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

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ABSTRACT

Problem/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.

Summary of Relevance:

Problem or issue

- Pregnancy and birth are unique and individual experiences for women and many birth preferences may fall outside of institutional policies. There is little guidance available to clinicians caring for women with such preferences.

What is already known

- Many clinicians face ethical turmoil, medico-legal concerns and feel professionally vulnerable when pregnant women decline recommended care. Accounts of disrespectful interactions and conflict are numerous, undermining women's rights to autonomy.

What this paper adds

- A structured documentation and communication process, available in one tertiary hospital, offered protection to clinicians and promoted respectful maternity care.

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1. Introduction

A competent adult's right to refuse recommended care is well established[1] and ethical and professional guidance for midwives and obstetricians emphasises informed consent and respect for patient autonomy.[2–4] Simultaneously however, there is growing emphasis on the use of evidence-based clinical guidelines to standardise practice.[5] 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.[6] In addition, the mechanistic application of clinical guidelines has been criticised as undermining maternal autonomy and being at odds with woman-centred care.[7,8]

Nonetheless, adherence to evidence-based clinical guidelines is often advocated as a route to reduced medico-legal risk,[9] and professional guidance is largely silent on the appropriate clinical response when women decline recommended care. In the maternity context, concerns about maternal and foetal safety can lead to conflict,[10] and in some contexts, judicial scrutiny.[11] 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.[12,13] Pregnant women may face difficulties finding clinicians willing to provide the care they prefer[14] 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.[15,16] 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.[17–23]

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.[24–26] Studies have found that women have limited involvement in decision-making and perceive that they are required to accept recommended care.[27,28] Other studies have found that routine care is rarely presented as a choice,[29,30] with examinations sometimes performed without seeking the woman's consent.[31,32] Even where consent is sought, in practice women are "obliged to choose what is set up as the most obvious and sensible option",[33] and power disparities between women and clinicians make it difficult to resist expectations of compliance.[34]

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.[35–37] 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.[38,39] One of those studies[38] found that Swedish midwives prioritised foetal wellbeing above respect for maternal autonomy and therefore sought to persuade women to accept recommended care. The second study[39] 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 UK,[40] 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.[41]

Women's voices are largely absent from the literature. Several studies have found that women who declined recommended care such as caesarean sections[42–44] and blood products,[44,45] had high rates of adverse clinical outcomes. However, the right to refuse recommended care is not diminished by the likelihood of adverse outcomes.[1] Three studies directly engaged women who had,[16,42] or intended to,[46] decline recommended care in a hospital setting. Ireland et al.,[16] 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[42,46] were conducted in Nigeria and focussed exclusively on caesarean section (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.[42] Both Ireland et al.,[16] and Chigbu and Iloabachie[42] 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,[47–49] only three described processes for discussing and providing care to women with a broader range of refusals.[50–52] Each of those processes retained the option of court intervention, two[50,51] 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.[42,53]

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 Fig. 1). 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.[54] 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.[54] This paper documents women's, midwives' and obstetricians' experiences of the MCP process.

2. Methods, participants and ethics

This qualitative, interpretive study involved in-depth semi-structured interviews with women, midwives and obstetricians.

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