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The stories of women who are transferred due to threat of preterm birth

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ABSTRACT

Background: Women at risk of preterm birth before 32 weeks gestation are routinely transferred to facilitate birth at a hospital that has Neonatal Intensive Care. The clinical outcomes of being 'in-born" improves newborn and neonatal outcomes is well documented. However little is known about the women's experiences when such a complication occurs.
Method: Using the NSW Agency for Clinical Innovation Patient and Carer stories method, 10 women were purposively invited and consented to tell their stories. Semi-structured interviews were undertaken during their inpatient stay and then again, by telephone in the months following their baby's due date. Themes were identified, illustrated by exemplars.
Results: All women were multiparous. Without exception, the women said that having the support of their family was the most important factor in coping with their unexpected hospitalisation and the anxiety of having to deal with the uncertainty of their pregnancy outcome. The most difficult aspect of their experience was the distress of being separated from their children and families and undue stress and distress from their partners. Other issues they identified were: physical difficulties during transfer; information overload as they sought to understand their changing circumstances; accommodation issues; and financial stress resulting from their relocation.
Conclusions: All women perceived their midwifery, obstetric and neonatal care to be exceptional and their neonatal outcomes were positive. Improvements may be made by facilitating family contact allowing flexible visiting, assisting with partner/family accommodation, providing women with their basic needs during transport and providing assistance to relieve financial strain.

Statement of significance

Issue

There is limited research into the experiences of women who transfer away from home due to threatened preterm labour.

What is already known

There are improved outcomes for preterm babies that are "in-born" and a proportion of women transferred will not give birth to a preterm baby.

What this paper adds

Insights into the clinical, emotional and financial challenges of the women and the impact of this on their families.

1. Introduction

Many women in Australia with pregnancy complications are required to be transferred to a hospital that has a Neonatal Intensive Care Unit (NICU). Women are transferred if they are less than 32 weeks gestation and are at real or perceived risk of delivering their baby prematurely as these babies may require respiratory support in an NICU. Evidence suggests that neonatal outcomes are significantly improved for premature babies before 28 weeks who have immediate NICU admission. Being an "inborn"

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Table 1
Number of babies born by gestation, place of birth.

Gestation at birth Weeks	Before admission	During initial admission	During readmission	After readmission at another hospital
<28 weeks	1	1		
28–29 + 6		1		
30–31 + 6				1
32–33 + 6		3		1
34–38 + 6			1	
>38			1	

birth provides significant advantages that allow for high technological clinical management of physiological parameters that is likely to benefit the woman and her baby.[1] While the clinical outcomes for the women and babies are well documented little is known about the human story behind what can be and usually is, a family crisis.

In New South Wales (NSW) the Perinatal Services Network (PSN) provides clinical advice and logistical support for clinicians who are caring for these complex women at such a critical time. PSN aims to ensure "each women births in the most appropriate setting, with the most appropriate care provider and within the most appropriate time frame" (p.1). PSN hosts a website which shows the availability of neonatal cots and maternity beds in each of the tertiary facilities and is accessed when the usual referral hospital does not have capacity to accept the transfer. PSN also operating the Perinatal Advice Line (PAL) providing midwifery and obstetric advice and support 24 h a day to clinicians caring for these complex women. When a woman needs to be transferred, the hospitals with available beds are contacted and an inter-hospital transfer is arranged. Depending on clinical need, women are transported by air or road ambulance and may be escorted by a midwife.[2] The outcomes for the babies are collected routinely via a centralised database, the Neonatal Intensive Care Units' Data Collection — NICUS. Established outreach and outpatient services monitor long-term outcomes for the babies.[3]

The PSN on-call obstetric consultants and the Perinatal Advice Line (PAL) midwives provide advice regarding the assessment and triaging and are able when required, to assist in negotiating the logistics of the transfer. Midwives caring for this high-risk group of women and/or babies are well aware of the difficulties posed. The women are often far from home, in unfamiliar environments and facing an uncertain outcome. The timing of delivery, condition of their baby at birth and ultimate neonatal outcomes can be uncertain. In New South Wales and the Australian Capital Territory one study reported that 40% of women delivered at the receiving hospital however up to 45% were discharge or transferred undelivered.[4] Similar findings were found in Queensland[5] where 40% of women delivered within 24 h and nearly 30% delivered after seven days in hospital or delivered elsewhere. However, to date, there has been exploration of the experiences of the women in such circumstances. The aim of this qualitative patient story project is to explore the experiences of a small cohort of women during and following their transfer for higher level pregnancy and neonatal care. Understanding of the issues that face women and their families will inform service providers to better meet their needs and promote a positive patient journey.

2. Methods

This study uses the New South Wales Agency of Clinical Innovation (NSW ACI), Patient and Carer's stories method. This method explores patient and carer's perceptions and experiences of their care and aims to illuminate to health care providers where improvements in patients experiences can be made. Specific "Patient Story" resources from the NSW ACI website including patient information sheets and consent forms were adapted for use.[6] Ethical approval was obtained from the LHD's Human Research Ethics Committee (Ref no LNR/14/POWH/180).

2.1. Recruitment, data collection and analysis

- An opportunistic purposive sample was sought for women meeting the eligibility criteria:
  - They were not residents of the Referral Hospital's, geographical Local Health District (LHD) or booked for care with other hospitals within LHD. The women came from regional and coastal areas of NSW including the south and central coast, central western and north western regions of NSW.
- At the time of consent and interview were:
  - An inpatient at the referral hospital
  - Less 32 completed weeks gestation

Women were not eligible if:

- They were seriously ill
- They were in labour or had signs of pre-labour
- had infants who are seriously unwell (only one woman had delivered at the time of the first interview and her baby was stable in the NICU)

Antenatal ward midwives identified the appropriateness and eligibility of admitted women. Eligible women were approached by the research midwife who discussed the study, gave an information sheet and consent form for their consideration. The research midwife was not engaged in the care of the women and had no prior knowledge of their clinical or life situation, however she had previous extensive experience in caring for women similar to those interviewed. The women consented to being interviewed twice, at two time frames and to their real first names being used. A face-to-face interview was undertaken during the women's current admission within the clinical ward and then a second interview by telephone in the month following the baby's due date. The timing for the first interview allowed for the woman to withdraw her consent if so desired. The research midwife arranged interview times at a time convenient to the woman and her family. Semi-structured interviews were used to explore the experiences of the women. The women were asked to describe their pregnancy, the events that brought them into the hospital and the circumstances surrounding these events. Included was what was problematic for them and finally what were the positive aspects of their pregnancy and neonatal care. During interview the women were encouraged to tell their story, taking as much time as they need. The interviewer took field notes for analysis. Following each interview, the notes were written up and key themes identified. All interview information was analyzed thematically over three coding sessions by the chief investigator. Field notes were referred

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