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Exploring the needs and lived experiences of women hospitalised during pregnancy in the United Kingdom: A qualitative diary study

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Summary

There is a global call to optimise antenatal care experiences. Hospitalisation during pregnancy may have a significant impact upon the experience of care. Thus, the aim of this study was to explore the needs and lived experiences of those hospitalised during pregnancy.

A thematic analysis rooted in interpretive phenomenology was undertaken on the content of five written diaries produced by pregnant participants whilst hospitalised. Three themes were identified from the data; (1) 'Uncertainty'; (2) 'Loss of control'; (3) 'Vulnerability'. Study findings could usefully be translated into improvements for those hospitalised during the antenatal period.

Key words: Evidence Based Midwifery; pregnancy; antenatal care; prenatal care; diaries; qualitative research; autonomy; sleep; emotional support; hospitalisation

Introduction

A pivotal moment in the history of maternity services was the publication of the Peel report of 1971¹, which recommended that all women should birth in hospital. Hospitalisation in this report was recommended for a minimum of three days and thus it was recounted that the overt medicalisation of pregnancy overtook domiciliary midwifery care ².

Reasons for hospitalisations during pregnancy are varied³. Yet in many cases, it is reasonable to assume that hospitalisations during pregnancy will result in parents being separated from their children and have a significant impact upon the lives of those experiencing it. Consequently, the aim of this study was to explore the needs and lived experiences of women hospitalised during pregnancy in the United Kingdom (UK).

Methods

This study used interpretive phenomenology (IP), as described by Heidegger ⁴. Our sample was purposive. Recruitment began once ethical approval was granted. Those aged over 18 years who were able to write in English and currently hospitalised within a tertiary maternity unit for four days or more in the East Midlands area of the UK were invited to consent to participation. Participants were invited to write about their needs and experiences for the remaining duration of their hospitalisation. They were also asked to reflect upon whether their needs were being met.

Data collection

Our data consisted of participants' diarised needs and experiences, recorded during the Autumn of 2012. Brief demographic data was also collected upon recruitment. Diaries can offer participants greater scope to provide richer and more creative detail on the phenomenon of interest⁵. Diary lengths varied between 421 and 11676 words.

Data analysis

Data analysis was conducted by the lead author and focused on identifying shared needs and experiences through the process of colour blocking⁶, where common

phenomena were identified and then grouped into themes through an iterative process of refinement. Final themes were then triangulated with the wider research team.

Results

A total of five participants were included in this study, aged between 30 and 41 years (mean age: 34.8 years). The average length of hospitalisation for this participant group was 22.2 days. Baseline data collected at the recruitment stage is presented in table 1.

Table 1: Participant Baseline Data

Pseudonym	Nieve	Amanda	Lucy	Evangeline	Justina
Age	36	32	30	41	335
Partner	Υ	Υ	Υ	Υ	Υ
Gestation	31+4	34+3	33+3	35+1	29
Parity	G1P2	G5P4	G2P1	G5P3+1	G2P2
Admission	17	26	10	12	46
days					
Hospitalisation	Placenta	Pelvic	Placenta	Gestational	Dilated
rationale	Praevia and	girdle	Praevia,	diabetes	cervix
	Antepartum	pain	Sickle Cell	and Pelvic	
	haemorrhage		anaemia,	girdle pain	
			and		
			Antepartum		
			haemorrhage		
Number of	11676	622	421	1787	2982
diary words					
written					

Three themes were identified from the data; (1) 'Uncertainty'; (2) 'Loss of control'; (3) 'Vulnerability'. In line with the quality reporting of IP, participant quotes are embedded into a prosed representation of the accounts being presented with interpretation. Pseudonyms are used to maintain confidentiality.

Theme One: 'Uncertainty'

Within the diaries there was evidence of uncertainty, which in turn was seemingly accompanied by a need to understand the routine and culture of the antenatal ward in order to assume a compliant inpatient identity and role.

For Nieve, there was uncertainty associated with her 'high-risk' pregnancy in which she experienced persistent antepartum haemorrhages related to placenta praevia. These resulted in several "terrifying" transfers to Labour Ward for close monitoring of her baby's welfare, and a further degree of uncertainty in the accuracy of treatment. Similarly, Justina reflected on how due to "lots of admissions" and staff being "flat out" she had not "had a GTG performed." Justina went on to reflect how the CTG would have given her "that bit of reassurance" that she "wasn't getting any contractions or tightening's" and that baby was "still as OK".

Along with uncertainty, some diary entries seemingly reflect both confusion and maternal ambivalence. For example, Amanda "met this lovely girl" who "kept being told the same thing every day by the same doctor" so she "asked the midwife if she could see a different doctor" and the "midwife got really funny with her", which Amanda "thought was really bad because all she wanted to know is what was going on with her and her baby!"

Theme two: 'Loss of control'

In this theme, participants shared their need for autonomy and to develop a sense of identity and belonging and to regain control. For example, Nieve reflected her "joy" in discovery a when a midwife told her "about their ethnic menu" as "no-one had mentioned the existence of this amazing menu before". Here, seemingly as Nieve regained control over her food choices she describes how she "went from being totally miserable and at the end of my tether this morning to a satisfied, relaxed and relatively cheerful new woman this afternoon." Similarly, Justina wrote of her "absolute delight" when staff brought her alternative food from the canteen. The pleasures of this simple act opened up food choices for her and gave her a degree of ownership over her own nutrition.

Likewise, a loss of control was also identified in relation to the need for sleep, with Nieve reflecting on "feeling exhausted, desperate for sleep ", yet "being put between a loudly labouring woman and another new mum with a hungry new-born" where the "machines sounded like aircraft about to take off". Justine reflected on her need for sleep being left unmet as "everything in the world is easier to handle if you (I've) have had sleep, but those flipping doors! Have you ever noted how loud the crash of closing them is?". Seemingly, if sleep deprivation persists, everything can become "too much".

Empowerment and the regaining of control for participants seemingly came from supportive partners, and the positive attitudes of midwives. To "put a smile" on Amanda's face the "sister of a midwife" got her a wheelchair so she could "go of the hospital grounds" which made her "so happy." Participants appreciated staff that went the extra mile regarding very basic inpatient requirements, and food again played a large part in regaining control. For Nieve, 'food was "so important" as "there are no other possible pleasures. No glass of wine, no cigarettes, nothing indulgent". Consequently, Nieve describes how she couldn't "wait till all this is over" so that she might "have a bottle of wine and a fag." Such descriptions further reflect the need to regain control via one's bodily intake.

Theme three: 'Vulnerability'

The diary data featured in this third theme, revealed a strong sense of vulnerability, and the need for human connection. Some referred to the midwifery staff, one of whom had been "really good" at "cheering" Amanda "up", and another had sorted out "all issues" for Lucy. Justina reflected how', "visitors/family are trying to be kind when they say, 'there's not much going on out there, you're not missing much'" However, she reflected how they are "wrong" as she was "missing all of it". Yet Justina had really appreciated being given flexible visiting hours for her family and being able to see them during the day. She commented that this made time pass more quickly and allowed her to keep in touch with "the outside world". Evangeline wrote how she "needed some emotional support" from her husband. Yet this need for human connection with family was not always met due to restricted visiting hours. Justina also recounted a challenging visit from her children who "got really upset" by the prospect of enduring a further period of separation. Nevertheless, inside the antenatal ward, there was joy in seeing a new face with whom participants could spend time, after

such an encounter Justina reflected she "felt glad because someone had actually been able to sit with me for over half an hour to chat about things."

Anxiety and vulnerability remained evident throughout the diary data. Nieve and Lucy particularly expressed "panic" and "worry". Nieve catastrophized potential outcomes as being "horrific". Lucy wrote about her maternal ambivalence to an unexpected change with her inpatient scan appointment, which meant that her family missed out on the experience, and also left her "panicking that something was wrong". Such diary entries further highlighted participant's vulnerability and their need for support from family and staff, which was not always met.

Discussion

This study explored women's needs and lived experiences of hospitalisation. Three themes were identified from the data; (1) 'Uncertainty'; (2) 'Loss of control'; (3) 'Vulnerability'. In this context, the needs of participants in relation to autonomy, human connection, and sleep were not always met. The lived experience of hospitalisation carry significant contemporary relevance given the Covid-19 pandemic and associated restrictions on visitors ⁷. Findings presented here may also be used in practice to support recommendations for extended visiting times for those admitted for a prolonged periods of time.

Key global recommendations on antenatal care for achieving a positive pregnancy experience were published four years after this data was collected ⁸. Yet on a broader scale, the needs and experiences reported by this sample may still be relevant and remain unmet. For example, a recent study conducted in Australia identified how antenatal transfer is an extremely stressful experience for families ⁹. The fear of uncertainty presented more generally in theme one is also reflected in the more recent accounts of those hospitalised in one antenatal unit located in Jordan¹⁰. Therefore, it is suggested that the provision of high quality written, and verbal information may improve the experience of such hospitalisations in future.

Similarly, the sense of a loss of control reported in theme two has likewise been described in later research conducted in both Jordan¹⁰ and New Zealand¹¹, where participants reported feeling like prisoners with no control over their food, bodies, time, or decisions. The need for, but yet inability to sleep, described by participants in theme

two is also concerning given that maternal sleep has wide-ranging implications for maternal health and functioning¹². Yet others hospitalised more recently and elsewhere during the antenatal period also report this need for sleep being left unmet¹⁰. Interventions designed to target sleep-disturbing factors may improve maternal health in such contexts.

The findings presented in theme three depict a focus on the need for social and emotional support and connection. Those hospitalised in both Jordan¹⁰ and South Africa ¹³ during the antenatal period more recently have similarly expressed the need for social support and connection. Collectively, these findings suggest that whilst the need for support and connection may remain present, this need may also remain unmet for some. Future research could usefully identify how best to meet the individualised support needs of those hospitalised and explore how these may differ in relation to varied cultural, contextual, and geographical areas. Likewise, the anxiety recounted and presented in theme three has also been reported by a cohort more recently hospitalised during the antenatal period in New Zealand ¹⁴. To reduce such anxieties during this time, the use of home-based tele monitoring could be considered for those with high-risk pregnancies, as it has been in the Netherlands ¹⁵.

Limitations

Whilst our sample lacks diversity, small purposeful sample groups are characteristic of phenomenological approaches which seek in depth experiences from fewer participants¹⁶. Whilst our findings offer theoretical insights into the experiences of women in 2012, they may be less relevant in a contemporary context. Nevertheless, they may be useful when comparing changes in the experiences of care following the implementation of newer recommendations⁸ with more recent comparable data.

Conclusion

This cohort of childbearing women hospitalised in the UK during 2012 experienced 'Uncertainty' 'Loss of control' and 'Vulnerability', where their needs in relation to autonomy, human connection, and sleep were not always met. Considering that more recent evidence collected in other geographical areas has identified similar concerns, such findings may suggest a paucity of progress in improving women's experience of care in this context. Thus collectively, these findings could usefully be translated into

improvements for those hospitalised during the antenatal period through extended visiting times, wider food choices, high-quality written and verbal information, responsive antenatal monitoring and reduced sleep disturbances toward a more positive pregnancy experience for all.

Ethical approval was obtained via the University Ethics Committee and NHS Trust Ethics Committee, as well as from Leicester Central Research Ethics Committee (Ref 12/EM/0405).

References

- 1. Department of Health, Central Health Services Council. Domiciliary midwifery and maternity bed needs. report of a sub-committee of the standing maternity and midwifery advisory committee (peel report). 1970.
- 2. Al-Gailani S, Davis A. Introduction to "transforming pregnancy since 1900". *Stud Hist Philos Biol Biomed Sci.* 2014;47 Pt B:229-232.
- 3. Knight M, Bunch K, Tuffnell D. No title. *Saving Lives, Improving Mothers' Care: MBRRACE-UK Maternal Report 2018*. 2021.
- 4. Reiners GM. Understanding the differences between husserl's (descriptive) and heidegger's (interpretive) phenomenological research. *Journal of Nursing & Care*. 2012;1(5):1-3.
- 5. Snowden M. Use of diaries in research. Nursing Standard (2014). 2015;29(44):36.
- 6. King N, Horrocks C, Brooks J. Interviews in qualitative research. Sage; 2018.
- 7. Sanders J, Blaylock R. "Anxious and traumatised": Users' experiences of maternity care in the UK during the COVID-19 pandemic. *Midwifery*. 2021:103069.
- 8. World Health Organization. *WHO recommendations on antenatal care for a positive pregnancy experience.* World Health Organization; 2016.
- 9. Lewis M, Passant L, Cooke H, Challis D. Women's experiences of antenatal transfer for threatened premature labour in NSW: A qualitative study. *Women and Birth*. 2020;33(6):e535-e542.
- 10. Al-Maharma DY, Khalaf IA, Abu-Moghli F, Alhamory S. " Save my baby": The lived experience of hospitalized pregnant women with a threat of preterm birth. *The Qualitative Report*. 2020;25(4):1042-1059.
- 11. Lomax MJ. Doing time: The experiences of women hospitalised for an extended time in their pregnancy. *Doctoral dissertation, Auckland University of Technology*. 2019.

- 12. Christian LM, Carroll JE, Teti DM, Hall MH. Maternal sleep in pregnancy and postpartum part i: Mental, physical, and interpersonal consequences. *Curr Psychiatry Rep.* 2019;21(3):1-8.
- 13. Kent RA, Yazbek M, Heyns T, Coetzee I. The support needs of high-risk antenatal patients in prolonged hospitalisation. *Midwifery*. 2015;31(1):164-169.
- 14. Barber CC, Panettierre M, Starkey NJ. How am I, really? perceptions of health and distress by women and their midwives. *Journal of reproductive and infant psychology*. 2017;35(3):261-272.
- 15. Van Den Heuvel J, Teunis C, Franx A, Crombag N, Bekker M. Home-based telemonitoring versus hospital admission in high-risk pregnancies: A qualitative study on women's experiences. *BMC pregnancy and childbirth*. 2020;20(1):1-9.
- 16. Morris A. A practical introduction to in-depth interviewing. Sage; 2015.