‘It’s something you have to put up with’: service users’ experiences of in utero transfer: a qualitative study

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Abstract

Objective: The purpose of this study was to gain in-depth insight and enhance understanding of service users' experiences of the in utero transfer (IUT) process, to inform policy and improve current service provision of maternal care.

Design: Qualitative descriptive study using semi-structured interviews

Setting: Participant's home or the hospital in the Midlands (UK)

Population: Fifteen women transferred in utero to a tertiary level maternity hospital; five male partners and two grandmothers

Methods: Audio-recorded individual or paired semi-structured interviews transcribed verbatium and analysed thematically using Nvivo 9

Main outcome measures: Facilitators and barriers of the IUT experience

Results: Findings suggest that IUT is an emotional experience that financially disadvantages patients and their families. Male partners were perceived to be most negatively affected by the experience. The quality of the IUT experience was influenced by a range of factors including the lack of proximity to home and the lack of information. Patients had little knowledge or awareness of IUT and most felt unprepared for displacement. Despite this, there was resigned acceptance that IUT was a necessary rather than adverse experience.

Conclusions: The experience of IUT for service users could be enhanced by ensuring they are better informed about the process and the circumstances that necessitate displacement, that they are better informed about the hospital to which they are being transferred and that they are transferred as close to home as possible. Efforts to minimise the emotional and socio-economic impact of IUT on women and their families also needs to be considered.

Key words: in utero transfer, qualitative research, experiences, families

Introduction

In-utero transfer (IUT), the transfer of expectant mothers before delivery, between hospitals for maternal care or predicted neonatal care is a necessary component of contemporary obstetrics; to ensure better health outcomes for mother and fetus. Although most transfers occur when specialist care is required, some are necessitated by a shortage of staff, cots or suitable facilities. Regardless of the reasons, IUT is known to be

stressful.[1-2] Evidence suggests that stress is an important predictor of adverse obstetric outcomes.[3-4] The unfamiliarity of new staff and surroundings, the lack of choice and control,[5] the absence of familial support and the domestic and logistical issues around child care, work commitments and finance make IUT a disruptive and anxiety-provoking experience.[6] A negative birth experience can affect emotional well–being, have life-long psychological effects and act as a barrier to future pregnancies.[7-9]

Given the significant impact of a negative birth experience, there is a need to ensure that current IUT provision engenders a positive one; the benefits of which are well documented. [8,10-12] Moreover, a positive service user maternal experience should be a strategic, commissioning and financial imperative for all NHS Trusts.[13] Whilst the importance of listening to women and families and using their experiences to influence maternity decisions has been widely advocated,[8-10] it remains relatively underdeveloped in maternity services.[13]

Current research in IUT for example, is dominated by quantitative studies focused on number of transfers, pregnancy outcomes and service audits or evaluations.[14-21] The efficacy of in-utero transfer versus ex-utero transfer has also been debated[22-23] and the obstetrician's perspective has been explored.[24-25] However, the experience of IUT and its impact on women and their families has largely been ignored.[15,26] Those few studies which do consider this population are quantitative in design and offer few experiential insights. [6, 26]

This research seeks to redress this experiential gap in the evidence base. The aim of this study, funded by The Staffordshire, Shropshire & Black Country Newborn Network, was to gain in-depth insight and understanding into service users' experience of IUT, to guide policy and practice decision-making, with a view to improving current provision of neonatal network services. Better understanding of how IUT is experienced from the service user perspective is of paramount importance, to ensure maternity services are relevant, responsive to need and engender a positive birth experience.

Methods

A qualitative descriptive approach with phenomenological undertones[27-28] was adopted. Generic qualitative research takes a general approach towards clinical issues which is useful for understanding service users perspectives of their health care.[29-30] Data was collected via semi-structured interviews to facilitate the gathering of information about knowledge, understanding, awareness and experiences of IUT.[31] The interview

guide consisted of a series of open-ended questions within 5 topic areas (see Box 1). The guide was informed by the literature on IUT and women's experiences of childbirth as well as the expertise of the IUT Research Group which was comprised of four consultant obstetricians, several midwives responsible for IUT in their units and network representatives. All the clinical staff was based in Level 3 obstetric units and had considerable IUT experience. Some demographic data was collected at the beginning of each interview as a means of establishing rapport. Standardised prompts and cures were used for probing and further clarification.

Ethical approval for this study was obtained from North Staffordshire Research Ethics Committee, University Hospital North Staffordshire Trust, Royal Wolverhampton Hospital NHS Trust and Liverpool John Moores University. Recruitment took place at two tertiary obstetric centres in the Midlands (UK). Purposive sampling was used. All expectant women (including any who had experienced a negative pregnancy outcome) who were transferred into the two tertiary obstetric centres between August 2010 and December 2011 were approached by a member of the clinical care team and provided with information about the study. Those who expressed interest after a 24 hour consideration period (N=25) were asked for written consent to extract minimal clinical information from their medical records and permission to be contacted by the lead researcher once discharged from the hospital.

Invitations to participate were sent by post within six weeks of discharge along with another copy of the participant information sheet. As the main service users, women were recruited as the primary participants of the research. However, other adult family members (fathers, grandparents) were encouraged to participate as well, either in a joint interview or on a one to one basis. Contact by phone, text message or email was made one week later and interviews were arranged for those interested in participating (N=15). Given that many of the participants had new-born babies, all interviews bar one were conducted in their own home. Formal written consent was obtained both prior to and at the conclusion of each interview. All interviews were carried out by the first author (LP) who is an experienced qualitative researcher. To encourage honest responses, confidentiality and anonymity were explicitly stressed and participants were made aware that the researcher was an academic not associated with the two tertiary obstetric centres involved in the study. Interviews were digitally recorded and lasted between 20 and 60 minutes.

All the interviews were fully transcribed and any identifiable data was anonymised. Data management and thematic analysis was done using QSR International's NVivo 9 qualitative data software. Data was analysed using the staged thematic analysis approach espoused by Burnard.[32-33] Transcripts were read several times to make sense of the data. Line by line coding was then undertaken. Similar meaning units were identified, recoded and then categorised into broader themes. Saturation was considered to be reached as no new codes were identified in the final transcripts analysed. To establish trustworthiness of the analysis, one quarter (n=4) of the transcripts were multiple coded by an independent researcher not affiliated with the study. This involved the cross checking of coding strategies and interpretation of data.[34]

Results

A total of fifteen women, five men and two grandmothers were interviewed. All familial interviews were conducted jointly with the women who had been transferred. The women ranged in age from 18 to 37 years, 13 were White European (87%) and 2 were Asian/Indian (13%), all were married/living with their partner. All were single pregnancies and gestation at transfer ranged from 23 to 32 weeks. For eight of the women this was their first pregnancy and for all 15, this was their first IUT experience. The transfer distance from participant's home to the tertiary hospital ranged from 5 miles to 97 miles. Three of the women were transferred due to lack of capacity (no beds or cots available) and 12 were transferred because a higher level of care was required. Post transfer, seven women were discharged from the transfer hospital without having given birth whilst eight delivered at the transfer hospital.

Several themes emerged as important determinants of the service user experience of IUT:

Theme 1- An acceptable experience

For most participants in this study, IUT was not a particularly adverse experience. All indicated that it would not influence their decision to have more children in the future. Many felt that "*… it wasn't really terrible but it wasn't good, it wasn't nice… it's something you have to put up with*" (P13). This was unexpected as service users often react negatively when told they are going to be transferred to another obstetric centre. With hindsight, many participants were able to acknowledge that the benefits of being transferred outweighed the inconvenience of displacement and any initial negative reaction gave way to resigned acceptance that *"… if you've got to be transferred, then that has to happen"* (P12). One woman explained: *"I was a bit angry, yeah, but you have to do what's best for the baby, don't you, and what's best for you*" (P2). Acceptance of IUT was

driven by the desire to do "*what's best"* to optimise positive health outcomes for their unborn babies. As one women stated, '*We wouldn't ever jeopardise, saying no, we're not going there just because I don't want to"* (P10).

However, for those few who were transferred as a result of lack of capacity, IUT was negatively perceived:

> *A nightmare [laugh]. Not something I'd like to relive. Because although there wasn't massive complications or anything, I got really stressed because I didn't know what was going to happen… And I think it's quite annoying, because I think me and my partner spent quite a lot of time getting annoyed, thinking why couldn't he have just stayed at XXX.* (P1)

Theme 2- An emotional experience

The process of being transferred from one hospital to another was a highly emotional experience for all participants. More than half were "*shocked*" when told they needed to be transferred. Almost all participants had no knowledge or awareness of IUT; only 2 had heard about it prior to their own experience. No one knew that IUT was a possible outcome for their own pregnancy. The fact that all the transfers were unanticipated meant that participants did not know what to expect and generally felt "*unprepared"* for displacement.

> *I never expected it. I just thought God, they're going to transfer me somewhere really far away [laugh] and I'm going to be all on my own. So it was quite a big shock and I didn't really know what to expect, to be honest. (P1)*

Many worried about the lack of familiarity with the transfer hospital, the lack of proximity to home, the increased travel time and the extra burden their displacement imposed on family members. Such issues added to the psychological distress that the women and their families were already experiencing as a result of pregnancy complications.

> *It just made me feel worse because of having to travel all that way and then the children not being able to come and see me and me not being able to see them and, you know, everybody having to sort it out. And then it was I was worrying about XXX because of him travelling quite a distance and he was tired. And then he was coming home and he was sorting things out, so I was worrying about that. (P3)*

More than half the women described their IUT experience as "*surreal*". Several mentioned being unable to process what was happening. Participants recalled "*feeling afraid*" and were concerned about "*being alone"* and "*isolated*" from family and friends. Many were *"anxious"* at not knowing what was going to happen. A few of the women experienced separation anxiety and "*panicked*" at the thought of being far away from children left at home.

> *Yeah, I just…it was just horrible, I just felt really on my own like and really scared, and didn't know what was going to happen and whether I was going to have to…well, I was thinking I probably am going to end up having a C section here, I was…that was in the back of my mind all the time. So I was thinking I don't want to do that on my own and everything, but…which I did end up doing on my own [laugh]. (P2)*

Family members in this study experienced similar negative emotions. Anxiety and fear for the fate of the expectant mother and her unborn baby were expressed. Family members were equally concerned about the unfamiliarity of the transfer hospital and the distance that the expectant women would be from home. Some were concerned that the birth would happen in their absence.

> *And my family, they was just in shock and they was upset because they was just worried about what was going to happen, being only 26 weeks pregnant and stuff, and worried about where I was going. (P6)*

The impact of IUT on children left at home was also highlighted by some participants. As transfers were generally implemented without warning, there was little time to prepare children for their mother's impending absence; some children found this distressing and difficult to understand.

> *It was just really hard on the children. I think it was…like for them, it was the worst because it was a long time that they were without me and that, so that was the hardest thing on them. (P2)*

Theme 3 – A gendered experience

There was consensus amongst the female participants in this study that their male partners were most negatively affected by the IUT experience. The general perception was that *"…although it was physically happening to me, the stress …of me being there was more on him…."* (P7). This was down to a range of factors

including the need to travel to and from the hospital, the need to be emotionally supportive in difficult circumstances, the need to manage logistic and domestic issues and competing priorities.

> *I think probably my partner suffered the most because he was having to go backwards and forwards, and look after my daughter and put up with her being sort of upset that I wasn't at home, and not understanding why. (P1)*

> *So it was a bit of a nightmare. And because my partner's been laid off, he had to go the Jobcentre and look for work and still sign on, because you can't just leave that, you know, you have to do it. And it was hectic, it was.* (P13)

Whilst the few male participants in this study did not overtly acknowledge the impact of IUT on themselves, they did highlight some of the physical (e.g. tiredness) and psychological implications of displacement.

> *…to me, it wasn't a problem, just keep going up and down, it was just time consuming, as I say and tiring. (MP7)*

> *I weren't…to be honest with you, I wasn't that bothered, as long as XXX and YYY was alright, you know, but I was just panicking just in case she had him over there and I weren't there and, you know, that was the only thing. And I mean I did hit some traffic as well, didn't I, and then I was panicking but tried to ring (MP3)*

Theme 4 – A costly experience

A significant detriment to the IUT experience was the personal cost accrued. The fiscal impact of displacement increased income pressures for many families. Participants cited time off work, travel costs for petrol, car parking charges and the cost of food and/or accommodation for family members as exceptional expenses triggered by the IUT process. Inflated phone bills, as a consequence of maintaining long distance contact with family and friends and/or to source information about the hospital (e.g. reputation, location and facilities) incurred further costs for patients.

It's the financial aspect of it, the financial aspect on XXX because he's having to take extra time, you know, off work, so there's that…. That's another thing as well, the feeding like I'm getting fed, what does XXX do? XXX's not at work, so he won't be getting paid….he's going over to the restaurant to get food, and it's not that expensive, but when you work it out for however long for the food that we've been here, it has got quite a bit. (P11)

Theme 5- Improving the experience of IUT

In response to a query on how to improve the IUT experience for future service users, suggestions centred around four main issues: information, subsidisation, location and visitation. Although most felt well informed about why they were transferred, many expressed concern about the lack of available information regarding the hospital to which they were being transferred:

….we didn't actually know anything about the hospital, we didn't know where the caffs was, or anything… (P6).

Many suggested that basic information such as an address, directions, visiting hours and available amenities was essential to an improved experience. Others recommended subsidisation of parking, meals and accommodation, to defray the financial impact of IUT:

I think they should give you like a parking permit or something, or give them reduced amounts, or something like that because it is a lot of money. (P2)

The location of the transfer hospital, away from family and friends was a significant issue for most, even those who were transferred less than 10 miles from home. IUT increased stress levels, caused logistical problems, had resource implications in terms of time and money. The lack of proximity was exacerbated by inflexible visiting hours and the inconvenience this caused to family and friends. Greater flexibility in visiting hours and transfers close to home were considered a good way to improve the IUT experience.

That was a problem. Like, you know, it's not that easy for somebody to just suddenly come two hours away. If it would have been near …, then lots of friends and family would have come and seen us. (P5)

Discussion

Main Findings

The central aim of this study was to explore service users' experience of IUT. For most participants in this study, IUT was not perceived to be an adverse experience. In line with previous quantitative research,[6,26] there was resigned acceptance from those transferred for a higher level of care that IUT was necessary to optimise the welfare of their unborn child. This may be a function of the "halo effect" whereby a positive outcome may make women less likely to be negative about their maternity experiences.[35] Despite this, findings demonstrated that prior to their own experience, service users had little knowledge or awareness of IUT and most felt unprepared for displacement. Male partners were perceived to be most negatively affected by the experience. For most, IUT was an emotionally, logistically and financially challenging experience, concurring with Wilson et al's Scottish audit.[26] Suggestions for improving the IUT experience included better provision of information, subsidization of meals, accommodation and parking, flexible visiting hours and being transferred as close to home as possible. Whilst these results are not unexpected and only generalisable locally, they do provide "confirmatory evidence" of what is known to be true anecdotally.[36] Findings are likely to reflect the national context of neonatal networks and thus may have wider relevance. The empirical evidence generated can be used by commissioners and providers of IUT services to make effective and efficient commissioning decisions. This is important given that IUT is a resource intensive practice with potentially long term implications.[15] Findings also serve as a reminder that the impact of IUT stretches far beyond the health needs of the expectant mother and fetus and need to be taken into account, to ensure a positive experience. Lastly, findings shed light on the impact that policies to centralise neonatal services have on families. There is a paradox in implementing a centralised neonatal network service to provide better resourced services and improve health outcomes which potentially exacerbates the factors that lead to a negative birth experience by transferring expectant women to unfamiliar obstetric centres, away from family, friends and support networks.

Strengths and Limitations

Our qualitative research contributes important experiential insights to a limited and primarily quantitative body of knowledge around service user's experiences of IUT. A particular strength of the study is that the emergent understanding is grounded in the perspectives of those most affected by the experience. It

emphasises what is important to women and their families and provides indicators of what works well and what needs improving in relation to IUT. Utilising this 'insider' knowledge to inform policy and practice not only fills an important gap in the evidence base but ensures that maternal service provision has relevancy for future service users. However, several limitations must be taken into account when interpreting the results. The study endeavoured to explore the familial experience of IUT however the experiences are limited to a small self-selected sample of families from one region in the UK and therefore cannot be generalised to all patients who have experienced IUT. The small proportion of immediate family members who took part (5 males and 2 grandmothers) also limits the transferability of the findings. Recruiting male participants is known to be difficult,[37] and given the focus of the current study, men may not have been interested or considered participation relevant. Moreover, most interviews were conducted during the day when many of them were at work.

The homogenous composition of the sample is another limitation of the current study. All the participants in this research had an initial positive outcome (either live birth or were discharged home). It can be surmised that families who experience a negative outcome following IUT would not only have a different experience but also different needs to address. Further research on a more diverse sample is recommended.

Interpretation

Qualitative thematic analysis highlighted that whilst participants demonstrated good understanding of the reason for their transfer, most reported feeling "unprepared" for the experience. This may be linked to a lack of knowledge and awareness of IUT and the circumstances that prompt the need for transfer. This knowledge deficit can be addressed by providing pregnant women with information about IUT. Evidence shows that information provision increases patients' satisfaction and their positive experiences of healthcare.[38] Being forewarned about the possibility of IUT could potentially reduce stress levels and ensure expectant mothers are better prepared for displacement. Such information could be included for example, in the Pregnancy Book[39] given free to all expectant mothers in England.

Family members in particular were hampered by a lack of information. Directions to and information about the transfer hospital were not always readily available which lead to distress, frustration and in some cases, confusion. Meeting service user's information needs is imperative to enhancing their experience. Leaflets with key information about the hospitals within the neonatal network should be made available. The

development of a national website or an 'app' which houses information about hospitals across the different neonatal networks (location, virtual tour including delivery room, amenities, visiting hours), information about local services (eating establishments, accommodation, transport links, shops) as well as information about pre-term babies and links to relevant organisations is recommended. Discussion is currently undeway regarding the development of such a website by the neonatal network, as means of improving current IUT provision.

IUT was a highly emotive experience for all patients in our study. Service users were shocked to hear they needed to be transferred and many experienced high levels of anxiety. Both Steer[2] and Wilson et al[26] acknowledged that maternal transfer can be 'emotionally very stressful'. Given that IUT is usually triggered by an adverse pregnancy event, the distress experienced is predictable. Women admitted in similar circumstances (threatened pre-term birth) but not requiring IUT may have similar emotions and experiences and the current study would have benefitted from having a comparison sample of non IUT patients to ascertain this. However displacement to a different hospital and new medical team at such a vital point in pregnancy is likely to exacerbate the prevailing distress. Further research is needed to ascertain the extent to which the IUT process itself intensifies distress, with a view to developing strategies that minimise the negative emotional impact of IUT and enhance a positive experience.

Contrary to expectation, the women in this study considered their partners to be most negatively affected by the IUT experience. Displacement meant that many male partners had to handle the 'triple shift' of paid work, childcare and domestic work and emotional work.[40] The women recognised that taking on multiple, traditionally female and potentially unfamiliar roles in critical circumstances proved difficult for many of their partners, heightening the distress they were already experiencing. This demonstrates that the impact of IUT is far-reaching and suggests that any measures to enhance the transfer experience must address the needs of the wider family as well. Given their vital role in the maternity journey, further research focussed exclusively on fathers/partners as service users in their own right is needed. [13]

Our results also suggest that IUT compromises social support which is known to be beneficial to psychological well-being.[41] Social support has been shown to reduce the psychological and physiological consequences of stress. At a time when expectant women are in greatest need of comfort, turning to family and friends may be hindered by the distance they have been transferred from home, the location of the transfer hospital and the limited visiting hours. Findings suggest that expectant women and their families, who

are transferred are not only emotionally affected but financially disadvantaged as well. Displacement incurs a personal cost to service users, one that many find difficult to bear. Wilson et al[26] also contend that IUT results in 'adverse socio-economic consequences' (p40). There is a need to counterbalance the negative fiscal impact of IUT. One way to accomplish this is to transfer expectant women as close to home as possible. Furthermore, when resource planning for maternity services, health care providers should consider the possibly of subsidisation, providing financial help and free meals to compensate for expenses incurred as a consequence of displacement.

Conclusion

IUT is a universally accepted method of ensuring expectant women receive the most appropriate care to optimise health outcomes. How this process impacts on service users remains an over-looked aspect of maternity service delivery despite the UK policy mandate for service user involvement in patient-focused healthcare. In our study, most service users had an acceptable IUT experience although displacement brought with it emotional, logistical and socio-economic impacts. Efforts to minimise these need to be considered. A number of areas for improvement around information, subsidisation, visitation and location were also identified**.** By giving voice to those most affected by antenatal transfer, greater understanding of how displacement impacts on women and their families not only addresses policy objectives but can lead to a more 'service user-friendly' IUT experience for women and their families.

Disclosure of Interest

No potential conflicts of interest

Contribution to authorship

LP, GM, FO, SJ, TV and KC conceived and designed the study. GM, FO, SJ, TV, KC and EP recruited participants to the study. LP conducted the study. All authors contributed to the writing of the article.

Details of Ethical Approval

Ethical approval for this study was obtained from North Staffordshire Research Ethics Committee, University Hospital North Staffordshire Trust, Royal Wolverhampton Hospital NHS Trust and Liverpool John Moores University.

Funding

This study was funded by the Staffordshire, Shropshire & Black Country Newborn Network.

Acknowledgements

The authors would like to thank the following people:

The women and their families who participated in this study

Patricia Rooney, Julia e and clinical staff who assisted with recruitment to the study

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