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

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Short title: Service users' experiences of in utero transfer

56 **Abstract**

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

60 **Design:** Qualitative descriptive study using semi-structured interviews

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

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

64 **Methods:** Audio-recorded individual or paired semi-structured interviews transcribed verbatim
65 and analysed thematically using Nvivo 9

66 **Main outcome measures:** Facilitators and barriers of the IUT experience

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

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

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

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83 **Introduction**

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

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

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

98 Current research in IUT for example, is dominated by quantitative studies focused on number of transfers,
99 pregnancy outcomes and service audits or evaluations.¹⁴⁻²¹ The efficacy of in-utero transfer versus ex-utero
100 transfer has also been debated²²⁻²³ and the obstetrician's perspective has been explored.²⁴⁻²⁵ However, the
101 experience of IUT and its impact on women and their families has largely been ignored.^{15,26} Those few studies
102 which do consider this population are quantitative in design and offer few experiential insights.^{6, 26}

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

109

110 **Methods**

111 A qualitative descriptive approach with phenomenological undertones²⁷⁻²⁸ was adopted. Generic qualitative
112 research takes a general approach towards clinical issues which is useful for understanding service users
113 perspectives of their health care.²⁹⁻³⁰ Data was collected via semi-structured interviews to facilitate the
114 gathering of information about knowledge, understanding, awareness and experiences of IUT.³¹ The interview

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

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

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

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

150 **Results**

151 A total of fifteen women, five men and two grandmothers were interviewed. All familial interviews were
152 conducted jointly with the women who had been transferred. The women ranged in age from 18 to 37 years,
153 13 were White European (87%) and 2 were Asian/Indian (13%), all were married/living with their partner. All
154 were single pregnancies and gestation at transfer ranged from 23 to 32 weeks. For eight of the women this
155 was their first pregnancy and for all 15, this was their first IUT experience. The transfer distance from
156 participant's home to the tertiary hospital ranged from 5 miles to 97 miles. Three of the women were
157 transferred due to lack of capacity (no beds or cots available) and 12 were transferred because a higher level
158 of care was required. Post transfer, seven women were discharged from the transfer hospital without having
159 given birth whilst eight delivered at the transfer hospital.

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

161 Theme 1- An acceptable experience

162 For most participants in this study, IUT was not a particularly adverse experience. All indicated that it would
163 not influence their decision to have more children in the future. Many felt that "*... it wasn't really terrible but
164 it wasn't good, it wasn't nice... it's something you have to put up with*" (P13). This was unexpected as service
165 users often react negatively when told they are going to be transferred to another obstetric centre. With
166 hindsight, many participants were able to acknowledge that the benefits of being transferred outweighed the
167 inconvenience of displacement and any initial negative reaction gave way to resigned acceptance that "*... if
168 you've got to be transferred, then that has to happen*" (P12). One woman explained: "*I was a bit angry, yeah,
169 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

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

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

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

178

179 Theme 2- An emotional experience

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

185 *I never expected it. I just thought God, they're going to transfer me somewhere really far away*
186 *[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*
187 *expect, to be honest. (P1)*

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

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

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

202 *Yeah, I just...it was just horrible, I just felt really on my own like and really scared, and didn't know*
203 *what was going to happen and whether I was going to have to...well, I was thinking I probably am*
204 *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*
205 *thinking I don't want to do that on my own and everything, but...which I did end up doing on my own*
206 *[laugh]. (P2)*

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

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

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

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

219

220 Theme 3 – A gendered experience

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

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

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

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

232

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

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

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

241

242 Theme 4 – A costly experience

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

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

254 Theme 5- Improving the experience of IUT

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

259 *...we didn't actually know anything about the hospital, we didn't know where the capps was, or*
260 *anything... (P6).*

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

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

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

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

274

275 **Discussion**

276 Main Findings

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

299

300 **Strengths and Limitations**

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

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

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

319 **Interpretation**

320 Qualitative thematic analysis highlighted that whilst participants demonstrated good understanding of the
321 reason for their transfer, most reported feeling "unprepared" for the experience. This may be linked to a lack
322 of knowledge and awareness of IUT and the circumstances that prompt the need for transfer. This knowledge
323 deficit can be addressed by providing pregnant women with information about IUT. Evidence shows that
324 information provision increases patients' satisfaction and their positive experiences of healthcare.³⁸ Being
325 forewarned about the possibility of IUT could potentially reduce stress levels and ensure expectant mothers
326 are better prepared for displacement. Such information could be included for example, in the Pregnancy
327 Book³⁹ given free to all expectant mothers in England.

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

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

337 IUT was a highly emotive experience for all patients in our study. Service users were shocked to hear they
338 needed to be transferred and many experienced high levels of anxiety. Both Steer² and Wilson et al²⁶
339 acknowledged that maternal transfer can be 'emotionally very stressful'. Given that IUT is usually triggered by
340 an adverse pregnancy event, the distress experienced is predictable. Women admitted in similar circumstances
341 (threatened pre-term birth) but not requiring IUT may have similar emotions and experiences and the current
342 study would have benefitted from having a comparison sample of non IUT patients to ascertain this. However
343 displacement to a different hospital and new medical team at such a vital point in pregnancy is likely to
344 exacerbate the prevailing distress. Further research is needed to ascertain the extent to which the IUT process
345 itself intensifies distress, with a view to developing strategies that minimise the negative emotional impact of
346 IUT and enhance a positive experience.

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

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

360 are transferred are not only emotionally affected but financially disadvantaged as well. Displacement incurs a
361 personal cost to service users, one that many find difficult to bear. Wilson et al²⁶ also contend that IUT results
362 in 'adverse socio-economic consequences' (p40). There is a need to counterbalance the negative fiscal impact
363 of IUT. One way to accomplish this is to transfer expectant women as close to home as possible. Furthermore,
364 when resource planning for maternity services, health care providers should consider the possibility of
365 subsidisation, providing financial help and free meals to compensate for expenses incurred as a consequence
366 of displacement.

367 **Conclusion**

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

377

378 **Disclosure of Interest**

379 No potential conflicts of interest

380 **Contribution to authorship**

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

383 **Details of Ethical Approval**

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

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