



Heller, R., Purcell, C., Mackay, L., Caird, L., and Cameron, S.T. (2016) Barriers to accessing termination of pregnancy in a remote and rural setting: a qualitative study. *BJOG: An International Journal of Obstetrics and Gynaecology*, 123(10), pp. 1684-1691. (doi:[10.1111/1471-0528.14117](https://doi.org/10.1111/1471-0528.14117))

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**BARRIERS TO ACCESSING TERMINATION OF PREGNANCY IN A REMOTE AND RURAL SETTING: A
QUALITATIVE STUDY**

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Running title: Barriers to termination in the Scottish Highlands

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Word count: 3999 words

Barriers to accessing termination of pregnancy in a remote and rural setting: a qualitative study

Rebecca Heller, Carrie Purcell, Lynn Mackay, Lucy Caird, Sharon T Cameron

Abstract

Objective: To explore the experiences of women from a remote and rural setting who had a termination of pregnancy (TOP), in relation to any barriers they may have experienced trying to access TOP.

Design: Qualitative interview study.

Setting: Scottish Highlands and Western Isles

Population: Women who had undergone TOP in the Scottish Highlands National Health Service between October 2014 and May 2015

Methods: Sixteen semi-structured, audio-recorded telephone interviews were conducted by a researcher with women who had consented to be interviewed at their initial assessment. Six stages of thematic analysis were followed to explore themes in and across participant accounts.

Main outcome measures: Themes derived from interview transcripts.

Results: Four themes emerged relating to barriers to access and experience: (i) the impact of travel for TOP, (ii) temporal factors unique to this population and how they affected women, (iii) the attitude of health professionals, notably general practitioners, as a result of local culture, and (iv) stigma surrounding TOP and the expectation that abortion will be traumatizing.

Conclusions: Women in remote and rural areas experience barriers to accessing TOP. Prompt referrals, more providers of TOP and tackling stigma associated with TOP could make delivery of this service more equitable and improve women's journey through TOP.

Tweetable abstract: Women in remote and rural areas of Scotland face multiple barriers to accessing termination of pregnancy.

Keywords: Induced abortion, qualitative, rural health, travel, health services accessibility

1 Introduction

A lack of trained providers continues to be a significant barrier to accessing termination of pregnancy (TOP), even in resource-rich areas, as highlighted by the World Health Organisation (WHO). This problem is particularly acute in rural areas, where numbers of willing providers and distance to healthcare settings can impact on care even where safe and effective interventions exist.¹ In the United Kingdom (UK) TOP is regulated by the 1967 Abortion Act: TOP is legal only if two doctors agree that it is necessary.² (This law does not apply to Northern Ireland, where access remains severely restricted.) In 2008 the Scottish Government introduced a target that 70% of women seeking TOP should undergo the procedure <64 days gestation,³ a goal achieved in 2014 with 72.1% of 11,475 TOPs occurring <64 days.⁴ However only 67% of abortions in NHS Highland and 65.5% in NHS Western Isles occurred at <64 days in 2014.⁴ These regions experience healthcare challenges familiar in remote settings:⁵ populations are distributed over a wide area, with journeys necessitating multiple modes of transport, and particular access difficulties in winter.

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Numbers of TOPs in these areas are small, just 55 from the Western Isles in 2014, and 482 in the Highlands,⁴ making coordinated service provision and skills maintenance difficult. In Scotland TOP services are provided free of charge, almost always by the National Health Service (NHS), in contrast to England and Wales.⁴ The obstetrics and gynaecology department of Raigmore Hospital, a district general hospital in Inverness, provides the only TOP service for women in NHS Highland and NHS Western Isles (Figure 1).

Evidence from similar settings with legal TOP suggests that when seeking TOP, women living rurally are disadvantaged compared to urban women, due to lack of local services, judgemental service providers and long distance travel necessitating substantial financial outlay.⁶⁻⁹ Although women will travel long distances to undergo TOP,^{8,10-12} the greater the distance a woman lives from facilities, the less likely she is to use them.¹²⁻¹⁴ Little information is available about women's experiences of seeking TOP in this area. The aim of this qualitative study was to explore women's perceptions of their pathway to TOP and to examine any impact of delays in obtaining treatment.

2 Methods

2.1 Design

The study explored the experience of women receiving most or all of their TOP care at Raigmore Hospital, Inverness, Scotland. A qualitative research design was adopted to provide richly detailed, in-depth data on women's experiences of seeking and undergoing TOP in this specific setting. The multi-site study was granted ethical approval by the South East Scotland Research Ethics Committee 01.

2.2 Study Participants

Women were eligible if attending the TOP service at Raigmore Hospital for TOP under Ground C of the Abortion Act: a TOP under non-medical grounds.² Potential participants attending the clinic for the first time were approached by clinic nurses about participating in a confidential interview with the researcher (RH), either by telephone or face-to-face. If they agreed, informed consent was obtained and their details were forwarded to the researcher, who made contact 3-6 weeks later, in order to try and minimise recall bias. Interviews took place 5 weeks to 6 months after the procedure - with most taking place approximately 8 weeks after - as determined by the interviewee. 28 women consented to be interviewed. Of those, 11 were uncontactable and one explicitly withdrew. Interviews were completed with 16 women, all preferring to be interviewed by telephone. Participants constituted a convenience sample.¹⁵ Since the aim was to produce detailed, in-depth data, we initially aimed for a sample size of 20, a figure - similar to other studies in the field - judged likely to produce adequate data to address the research questions. Exclusion criteria were: if the woman spoke insufficient English to participate in an interview, was overtly distressed at the time of assessment, or was unable to provide informed consent. Participants were offered a £20 High Street voucher on completion of their interview as a thank you for their contribution.

2.3 Data Collection

Individual semi-structured interviews were conducted using a flexible topic guide, to allow for unanticipated issues to arise.¹⁶ The guide was informed by the literature on access to TOP in rural and urban settings, and by the clinical expertise of the authors. The topic guide addressed women's experiences of: their journey from first suspecting pregnancy to TOP; follow-up care; travel for TOP; (non) disclosure of TOP; community attitudes to TOP; and their views on TOP services in their area. Interviews lasted 25-90 minutes. All were digitally recorded, transcribed in full for analysis and anonymised. All interviews were conducted by RH. Analysis was iterative and began as soon as the first

interview was completed. Saturation was considered to have been reached when no new themes emerged from the data.

2.4 Analysis

Data were analysed thematically using systematic coding.¹⁷ This approach involved familiarisation with the data set by repeated re-reading of transcripts, and coding for emerging themes. Similar units were identified, regrouped and then categorised into broader themes, originally by RH. Themes and interpretations were discussed and compared between RH and CP following a review of selected transcripts – and the coding framework revised. RH then developed themes and conceptual linkages further. NVivo 10 qualitative data analysis software (QSR International) was used to manage and code data.

3 Results

Presented here are the key, interrelated themes which emerged from the interview data. Namely, these were: the impact of travel for TOP, temporal factors and how these were viewed by participants, the impact of the attitude of healthcare professionals, and the stigma surrounding TOP in this culture. Identifiers following quotes specify participant number; distance travelled to the TOP service (round trip in miles); approximate journey time; and mode of transport. Table 1 outlines the age, parity and gestation (by ultrasound scan) at initial presentation of participants. In order to maintain anonymity in a small geographical area these details are not linked to participant identifiers.

3.1 The impact of travel for appointments and procedures

Table 2 illustrates distances participants travelled and methods of transport used, Figure 1 shows the geographical area. Although not all participants travelled a substantial distance, those who did expressed their frustration at this. Participants were aware that they could access other healthcare services at local hospitals and did not understand why they were required to travel so far for TOP. They described the additional stress this created.

'It was really quite horrible. Like, if it had been here and I could have gone in and just taken the tablet, then gone home, and then just spent a few hours, and [the same] a couple of days later, it would have been so much easier and so much less stressful.' [B19, 224 miles, 9 hours 30m, plane/taxi]

The need to travel also affected the woman's ability to maintain privacy. Extended periods away from home necessitated disclosure of the procedure to individuals whom the woman would have preferred not to know. Childcare often had to be obtained for

several days, meaning, for example, that parents or ex-partners had to be given an explanation. Most participants in paid employment also felt obliged to disclose the TOP to their employer, to facilitate the necessary time off to attend appointments. Since local systems mean the procedure can require as many as three appointments, and potentially one or more overnight stays, women felt that they could not explain their absence without giving the reason.

'when I kind of decided that I was having a termination obviously I had to tell my boss at work because he'd be the one that I'd have to go to to ask for these so many days off, and I wanted him to know why I was having these days off [...] So it was a bit weird but I was obviously a bit nervous because I didn't know how he was going to react or anything like that.' [B9, 34 miles, 1 hour, car]

This was an additional burden, as most said they would have preferred to tell as few people as possible, either because they were worried about people's reactions or because they felt it was a private matter.

For some time the option has been available for women undergoing early medical TOP (≤ 9 weeks) to receive the first part of their treatment (mifepristone) at a local hospital (see Figure 1), although misoprostol is not currently provided there. Three women interviewed received mifepristone at this hospital, although one described a particularly difficult experience subsequently.

'Well, I actually had to travel to Inverness on my own [for misoprostol] because there was nobody available to come with me... So I had to drive on my own in quite a fair amount of pain. And as it turned out that halfway down the road, about an hour down, I actually – well, 'miscarried' is not quite the right word – but, you know, everything kind of came away on its own at that point. But I still had like an extra hour to drive whilst being in that situation. So that was quite nasty and not something I'd really want to happen to anybody else.' [B4, 208 miles, 4 hours 42m, car]

Although this participant's words minimise her experience ("quite a fair amount of pain"), there was a palpable sense that this had been extremely distressing. Other women spoke about the difficulty of flying or driving long distances with residual pain after procedures or tired after nights spent in hospital, and feeling that the length of travel had made the hours or days following the TOP more difficult.

3.2 Impact of temporal factors

Regardless of when and how they were referred, most women vividly described the time they waited before their initial assessment, which was typically ten days to three weeks. Many described this waiting period as the 'worst' part of the process. A considerable source of anxiety was not knowing the gestation of the pregnancy.

Although participants were not clear on gestational limits at which TOP could be performed, they were aware that gestational age could alter the care they received, and that beyond a certain gestation TOP is no longer available.

'And I was, you know, constantly at the calendar double-checking that I wasn't going to be too far on, you know, to do the procedure that I wanted to happen and stuff. And it didn't matter, you know, even though it was only the day after, I'd still go back to the calendar to make sure that I wouldn't be over, you know, six weeks, seven weeks, eight weeks.' [B18, 118 miles, 2 hours 36m, car]

Other sources of anxiety and distress included pregnancy-associated nausea, a wish to conceal the pregnancy, growing fear that the pregnancy would become evident to others in the woman's changing body shape, and concerns that they would be begin to 'bond' with the pregnancy, despite certainty in their decision to terminate. Almost all women said unequivocally that once they had made their decision they wanted to complete the procedure as soon as possible. Women described this waiting period with evocative language as 'incredibly stressful, 'horrendous', 'traumatic' and 'cruel'.

'It was just so stressful waiting, like, two weeks, I was just like crying the whole time, like I was so panicked!' [B19, 224 miles, 9 hours 30m, plane/taxi]

When asked what women would change about the TOP service, the wait between referral and assessment was identified by almost all participants as a key problem.

3.3 Healthcare professionals' attitudes and effect on women's experiences

A notable barrier that women encountered was at their General Practitioner (GP), who is typically the key gatekeeper to TOP services in the UK. Participants' experiences with referral are detailed in Table 3. Although the majority of GPs (and one midwife) did immediately refer participants on to the TOP service, this was not always the case. One woman was asked by her GP to self-refer to the TOP clinic and two were told they would be referred but no referral was made. This was explained to women by the GP practice as an administrative error, but there was speculation from participants as to whether GPs were being deliberately obstructive. A number of women were advised to return or conduct another pregnancy test one week later (see Table 3). One woman described the impact of being asked to send a urine test to the laboratory to confirm pregnancy and then return a week later for results.

'...I'd said stuff like "did they actually do this so that you don't go ahead with the operation, you know, so you've got time to think about it and stew over it?" It didn't feel like it was, you know, supportive in any way, it felt like it was just kind of like "oh, you shouldn't be doing it so we'll leave you

to decide and hopefully you'll change your mind." [B28, 6 miles, 16 mins, car]

Despite the fact that women expressed anger and disappointment, and all identified that lack of referral had made their experience more stressful and upsetting, there was little appetite for lodging a formal complaint. Three women voiced concerns about future care from the same GPs, were considering changing doctors, and/or "dreading" a return visit. One explicitly stated that she had not sought medical advice on heavy bleeding she experienced post-procedure as "they had put me off the first appointment" [B7]. However participants were at pains to minimise the impact that GPs' beliefs had on their ability to provide care.

"he is a very good doctor but I think that he just doesn't really want anything to do with [TOP]." [B7, 230 miles, 9 hours 38m, plane/taxi]

When probed further, participants speculated that their GP perhaps objected to TOP on religious grounds, and a number attributed GPs' apparent disapproval to local cultural factors.

'I think because the island is so small, and obviously religion is such a big part of it, it kind of dictates what happens on the island.' [B7, 230 miles, 9 hours 38m, plane/taxi]

Women's perceptions of local cultural attitudes towards TOP, as reflected in what they imagined GPs to be thinking, extended to speculation about other healthcare professionals' attitudes resulting in a lack of TOP services closer to home. A number of women - particularly those that had attended local services for other procedures - suspected limits to availability were a result of 'moral' objections to TOP.

'I had a very fine, very, very fine experience in Raigmore Hospital, I thought it was superb the way it was managed. However... I suspect, the reason terminations are not being carried out on these islands is for reasons of religion and whatever have you. That horrifies me. If that's the reason, and I don't know for sure it is, I just suspect... I don't think it's because we don't have the facilities here or the experienced staff, it's because over time and evolution they've opted out of this controversial procedure on ethical, moral, religious, whatever, grounds.' [B20, 244 miles, 10 hours, plane/taxi]

The conclusions drawn by women highlight the exceptionalism with which they felt TOP was treated in the organisation of local healthcare services.

3.4 Situating stigmatised experiences

Participants commonly situated their experiences in relation to how they expected others might fare in a similar position. Their accounts foregrounded factors that could make accessing TOP more difficult, such as youth, ability to negotiate time off work, support networks or, as noted above, reluctance to disclose due to the stigma associated with TOP. Almost all participants described their experiences as being more straightforward than they imagined other women's: they had overcome obstacles to treatment, but were concerned that others would not. This was common across the variety of ages and circumstances of participants. For example, many voiced concerns about how young women would access TOP.

'It just horrified me that... I'm lucky that I have a few quid in the bank and I could book a hotel if I needed to escape. I looked at private clinics on the mainland and all of that. But what if you couldn't? What if you were a young mum with, you know, toddlers and you had to go away and have that experience, you know?' [B20, 244 miles, 10 hours, plane/taxi]

'I think it's really quite a shame. Like because ...there's going to be a lot of people who are going to have to come up with ridiculous scenarios to tell their parents, to go away and that. And then like what if there was like people like in the school? Because they're going to be like "oh, I'm going to Inverness for a few days" and like where are you going to get the money for that?' [B19, 224 miles, 9 hrs 30m, plane/taxi]

Despite experiencing stress and anxiety relating to the cultural and temporal factors highlighted above, women still described a sense of relief and certainty that their decision had been the right one. However, they imagined that other women would feel 'traumatised' and conflicted about seeking TOP.

'I mean, like I don't know, like, I'm fine but most people like need to speak to people afterwards.' [B19, 224 miles, 9 hrs 30m, plane/taxi]

'I think I'm lucky in that I was so solid in my decision that I haven't needed any kind of aftercare.' [B28, 6 miles, 16m, car]

Our data shows that women assume that a TOP will necessarily be traumatic, but position this trauma in relation to other women, whilst simultaneously minimising the barriers they themselves faced.

4 Discussion

4.1 Main findings

The prompt for this research was that NHS Highland and NHS Western Isles have not met the Scottish Government target of 70% of TOPs occurring at <64 days gestation.^{3,4}

Our analysis demonstrates significant challenges to accessing TOP which could mean a higher proportion of TOP at later gestations, at greater risk to women and cost to the NHS. This issue is particularly pertinent in Scotland, where women seeking abortion under Ground C of the Abortion Act (non-medical grounds) over 20 weeks must travel to England for treatment.¹⁸

Our analysis highlights that women in this region's experiences of TOP were negatively framed by local cultural factors - including the attitudes held by healthcare professionals - and by the distance that many of them had to travel. Our work also foregrounds the anxiety that women experienced whilst waiting for TOP, paralleling other documented concerns.^{19,20} The stigma of abortion and the expectation that it will be traumatising is well documented,²¹⁻²⁴ and appears to have informed these women's interpretations of their experience.

4.2 Strengths and Limitations

As far as we are aware this is the first published qualitative research to specifically focus on women in this area of the UK and provide rich, detailed accounts of individuals' experiences.

The foremost limitation is that our sample does not include women for whom barriers to TOP were insurmountable. On the other hand, women who had a particularly challenging time attending clinic may have been more likely to consent to an interview compared to those whose experience was straightforward, particularly as the opportunity to improve services was a possible advantage of taking part. Due to a high clinical workload we do not have data on how many women were approached to be interviewed but declined to participate.

4.3 Interpretation (in light of other evidence)

An important perception of stigma centred around GP referral, which did not always meet RCOG guidelines regarding timely referral.²⁵ Our participants waited between ten days and three weeks for assessment and treatment. The Royal College of Obstetricians and Gynaecologists' Guidance recommends that referral to a TOP provider should be made within two working days, and providers must offer assessment within five working days of referral.²⁵

Our data suggest that aspects of local culture were perceived by women as contributing to delays and negatively impacting upon GP service provision. Existing research suggests around one in four GPs in England consider themselves broadly anti-abortion.²⁶ A 2011 study in the Republic of Ireland (where TOP is illegal under most

circumstances) found that GPs viewed waiting periods as desirable, giving women time to 'think over the decision'.²⁷ In contrast, evidence from women consistently shows that the vast majority have reached a decision before presenting at services.^{18,24,28} The assumption that more time is helpful for women contrasts significantly with how temporal factors emerged in our data, which suggested that the passing of time is experienced as highly uncomfortable – women feel they have no time and are anxious about each passing day. What might be explained as conflicting priorities or relevancies of time for women and health professionals were accompanied by stress. This mismatch is particularly pronounced in this population where the clinic is only weekly and journeys are likely to be lengthy and time consuming. Settings with mandatory "waiting periods" or other imposed delays create additional financial and logistical challenges,²⁹ and may result in higher numbers of TOPs at later gestations.^{30,31} A UK study found a significant fall in anxiety levels after TOP compared to before the procedure.¹⁹ Our findings suggest that more frequent services and prompt GP referrals could reduce women's anxieties and improve the accessibility of TOP.

Our data demonstrates that travelling long distances, particularly after taking mifepristone, can lead to highly distressing situations for women. Whilst the current interpretation of UK law does not allow for home administration of misoprostol,²⁵ evidence shows that it is safe and effective in a variety of settings.³²⁻³⁵ If women are not able to administer misoprostol at home, there are a number of healthcare centres and hospitals in the highland region that could improve access for women by providing misoprostol. As UK law mandates that two doctors certify that a woman has grounds for a TOP,² an absence of willing providers in a remote and rural setting creates a significant barrier to accessing essential healthcare provision.

In spite of what women experienced as judgemental GP attitudes and a burdensome amount of travel, women seemed reluctant to complain, despite some annoyance about the fact that TOP services were not available closer to them, and even a sense of discriminatory treatment, particularly where a connection was postulated between lack of services and moral or religious objections to TOP. It is possible that the stigmatisation of TOP, particularly in areas where provision is very limited, contributes towards a reluctance to both complain, and agitate for better service delivery.

Our analysis also highlights a significant amount of empathy towards imagined others who might have sought TOP but have greater difficulties overcoming barriers to access. Almost all participants discussed how much more challenging it could be for others in different circumstances. This diverges from research which found that women tended to

distance themselves from others seeking TOP, to present their own 'deserving' circumstances as the exception.³⁶ However, our data also reflects commonly held views about TOP, notably that it is 'difficult', 'traumatizing', and undergone by specific 'types' of women[39]. Although women of all ages access TOP,⁴ a cultural stereotype persists that it is primarily undergone by very young women,²³ which may explain our participants' focus on this age group. A causal link between TOP and poor mental health outcomes, including depression and suicide, has been disproved,³⁸⁻⁴⁰ and yet persists in highly negative public discourse and media portrayals in the UK and elsewhere.^{23,41} The well-documented stigma surrounding abortion^{21,22} is reflected in our data. Given the cultural invisibility of women who have undergone TOP, false perceptions persist even among women who themselves subvert them, leading them to interpret their own experience as exceptional. These misconceptions themselves constitute a significant barrier to access.

5 Conclusion

This study identified obstacles to TOP, explained by women in terms of local culture in their geographical area. We recommend increased resources to facilitate more clinics, and that telemedicine technologies are employed to reduce the number of visits required.⁴² It is a continuing challenge for all those involved in women's healthcare to challenge the ongoing stigma surrounding TOP and improve equity of access.

Acknowledgements

With special thanks to all the nurses in the TOP clinic in Raigmore for their assistance with recruitment. Further thanks to all the women who gave their time to participate.

Disclosure of interests

None of the authors have any competing interests in this field.

Contribution to authorship

RH designed the content of the research, conducted all interviews, carried out primary analysis and wrote the paper. CP read a selection of transcripts and revised the coding framework in discussion with RH, contributed to data analysis, drafting the paper and responding to reviewers' comments. LM led recruitment and recruited most participants, LC developed the initial idea in conjunction with SH, and fed back on the submission. SC conceived the initial idea for the paper, was the Chief Investigator on the project, and fed back on the submission.

Details of ethics approval

Ethical approval was granted by the South East Scotland Research Ethics Committee 01 on 3rd June 2014 (REC reference 14/SS/0076). A letter of permission was also granted by NHS Highland on 15th September. As this was deemed a multi-site study approval was also granted by National Research Scotland Permissions Coordinating Centre on 19th August 2014 (NRSPCC ID NRS14/SH09).

Funding

A small amount of funding came initially from the Sexual Health and Blood Borne Virus division of the Scottish Government. Further funding came from the Sexual Health Respect and Responsibility budget of NHS Highland. This funding paid for two trips for RH from Edinburgh to Inverness.

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Figure 1: Scotland. Area covered by Raigmore Hospital for termination of pregnancy (TOP) marked in blue.

RAIGMORE HOSPITAL: provision of assessment, mifepristone, misoprostol, manual vacuum aspiration (MVA) and surgical abortion

Caithness Hospital: provision of mifepristone

Other hospitals marked: no provision of TOP services