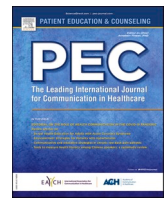


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Consent in pregnancy: A qualitative study of the experiences of ethnic minority women

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ABSTRACT

Objective: Consent in ante-natal and birthing contexts is often challenging, controversial and poorly understood. Increasing evidence indicates that ethnic minority women's overall experiences of ante-natal care are unsatisfactory, but little is known about their involvement in the consent process. This study aims to explore the views and experiences of ethnic minority women when making decisions requiring their consent.

Design: Qualitative interview study

Setting: A national study conducted in the UK

Sample: Seventeen self-selecting ethnic minority women who had given birth in a UK hospital in the previous 12 months.

Methods: In-depth telephone interviews with seventeen women. A thematic analysis was conducted with a focus on women's experiences of the consent process.

Results: Three themes were identified. 1. Compromised choice: women experienced limited choice; some women were not asked for their consent at all, or consent was presumed. 2. Pressured consent and silencing: women reported feeling undermined and 'othered' based on their ethnicity. 3. Impersonal consent: discussions were impersonal and not tailored to women as individuals; some women suggested that healthcare professionals ignored cultural concerns which were important to them.

Practice Implications: There is an urgent need for healthcare professionals to be supported in actively facilitating consent consultations which enable women from ethnic minority backgrounds to freely voice their concerns and priorities without censure.

Conclusions: This exploratory study is a first step towards understanding how consent is experienced by ethnic minority women. Many women's experiences reflected failure of healthcare professionals to support genuine choice-making which was perceived to be further undermined by negativity related to women's ethnicity and cultural identity. There is a need for further research focusing on the consent experiences of specific ethnic minority groups.

1. Introduction

The right of every woman to share in decision-making is central to person-centred maternity care. In the United Kingdom (UK) these rights are affirmed by professional guidance [1] and law with renewed attention following the landmark legal decision of *Montgomery v Lanarkshire Health Board* [2]. The case of *Montgomery* concerned a woman who was inadequately informed about the risks of vaginal birth. It established the requirement for 'material' risks to be defined through the lens of the patient and hence the decision in *Montgomery* and

subsequent cases [3–6] (underlined the centrality of a process of genuine dialogue in which a patient's role in decision-making is actively facilitated. Enacting such dialogues requires both a willingness to take whatever steps are necessary to understand what matters to an individual woman and the sensitivity to foster dialogues which enable a woman's participation whatever her circumstances or identity. The subjectivity of such dialogues has social and cultural implications which may significantly affect ethnic minority (EM) women's consent experience, especially if their personal or cultural priorities differ from those expected by the clinician.

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One in four women who give birth in the UK are from a minoritized ethnic background [7]. ‘Ethnic minority’ is a term that encompasses a heterogeneous population which, in the UK this includes anyone identifying with any ethnicity other than White British [8,9]. Black and Brown EM women face higher maternal mortality, and morbidity and report poorer experiences during pregnancy and childbirth in general, compared to their White counterparts [10–12]. Women from minority ethnic groups report feeling disrespected and uninvited to participate in shared-decision making [13]. Existing evidence suggests they are vulnerable to negative stereotyping and racism [11,14,15]. Reiterating these findings, in 2022 a large-scale inquiry into racial injustice and human rights in UK maternity care revealed that EM people often felt unsafe, were ignored and disbelieved, were not given a proper choice and were regularly dehumanised [11]. Consent in ante-natal care is problematic and limited existing evidence, mainly considering the consent experiences of women from the ethnic majority, indicates that women’s consent experiences often fall short of what the law requires [16–19]. Little is known about the specific experiences of EM women. This study aims to explore how consent is experienced by EM women.

2. Methods

2.1. Methodology and theoretical framework

Our methodology is both constructionist and constructivist grounded theory [20,21]. Constructivism allowed us to focus on the ways in which individuals constructed meaning and understood the treatment options and risks articulated by obstetricians and midwives during the consent process, and in so doing acknowledged the importance of subjectivities within the local world of women’s health care. Constructionism allowed us to situate these meanings within the broader cultural environment of women’s health and wider socio-political and discursive contexts. Women participated in in-depth interviews discussing their consent experience.

Our study design and analytic interpretation were underpinned by a medico-legal lens. Legal theory informed our considerations of the legal, moral and societal influences on matters of medicine and law. By legal theory we mean theory that is concerned with the practical problems of law, and approaches them from the outside, using the tools of other disciplines [22]. The study is reported with reference to the consolidated criteria for reporting qualitative research (COREQ) [23].

2.2. Participants and recruitment

Participants were identified through a **volunteer sampling approach** via a study recruitment advert on the social media channel of the human rights charity, Birthrights in June 2021 and subsequently via other relevant third sector organization websites including the Happy Baby Community, Birth Companions, Manor Gardens Centre, National Maternity Voices and Mumsnet.

Eligible women self-identified according to the following inclusion criteria:

- Had given birth in previous twelve months.
- Asked for written or verbal consent during their care.
- From a minoritised ethnicity.
- Able to understand written and spoken English.
- Age 18 + .

Women who met the inclusion criteria contacted the researcher by telephone or email, were provided with a Participant Information Sheet and invited to ask questions prior to providing audio-recorded verbal consent to take part in a telephone interview.

2.3. Data collection

The interview topic guide was developed and tested before use in a similar population by study team members experienced in qualitative

women’s healthcare research (AL & JN) and it was reviewed by the wider study team (ZK, KM, LH). Members of the study team (KM, LH, AL and JN) identify as White females and are all health care professionals trained in good clinical practice. JN is also a trained solicitor with experience in health law. Interviews were conducted by ZK a female medical student with dual British Bangladeshi and Pakistani heritage with experience of conversations with patients on sensitive topics, who had not met the women. Participants were asked about their experiences of consent (see Topic Guide, Table 1). Interviews were digitally recorded with field notes made during and immediately after the interview. Socio-demographic details including age; education level; parity; ethnicity and nationality were collected.

2.4. Data analysis

All interviews were transcribed for analysis. Braun & Clarke detail a six-step recursive process of thematic analysis [24] which can be used within different theoretical frameworks and methodologies. We selected this analytic approach. Transcripts were read and re-read for familiarisation. Initial codes were developed for the entire data set through a systematic and iterative approach by ZK with a random selection (N = 8) being coded independently by other members of the research team (JN & AL). The codes were discussed and refined by the multidisciplinary research team and synthesized into potential themes which were reviewed, refined and named in a final set of themes once data collection was complete [25]. Cross-checking between members of the research team maintained analytical rigour.

In accordance with our study design and purpose we used an inductive thematic process method to determine data saturation. We focused on reaching saturation at the level of analysis—i.e., in relation to the (non-) emergence of new codes and themes. At a later stage in our analysis, we considered saturation respecting the theoretical development and adequacy of our results addressing whether there was sufficient expansion of each thematic category to determine its characteristics – its dimensions, nuances, and meaning. Data collection continued until we had analysed 17 interviews and with those, we judged we had achieved conceptual depth and when there were no new emerging themes identified.

The influence of the research team member’s gender, ethnicity, profession, and personal and professional preconceptions of maternity care delivery with ethnic minority women were held in mind throughout the research. We acknowledged the advantages and potential biases our experiences brought to bear on the interview dynamic and the interpretation of data, and the impact of our expectations of what maternity care ‘should’ be [26].

3. Results

Seventeen EM women participated. One woman consented but for logistical reasons was unable to participate. Interviews lasted between 20–60 min. Demographic data are reported in Table 2.

All transcripts demonstrated that EM women’s experiences of consent discussions involved a multi-faceted interaction of clinical and socio-cultural issues. These were represented by three interrelating themes: compromised choice; pressured consent with silencing of women’s voices; impersonal consent with absent individualized dialogue.

3.1. Compromised choice

Some women underwent procedures without being asked for their consent at all. Most women reported that that they were not offered a real opportunity to choose whether to undergo procedures such as caesarean section (CS), induction of labour (IOL) or assisted vaginal delivery (VD).

Women reported a lack of time to consider their decision, and some

Table 1
Interview Guide.

Women’s involvement in decision making
(Can you tell me about any experience you have had about being asked to make decisions about your care?/Did you feel like you were involved in making decisions about your care? /Did you feel like this process supported you to explore the options for your care and make a decision about whether to agree or not to a particular procedure or course of action?/ Was the issue of consent raised with you? How?)
Information provision
(What information was given to you in relation to the decision you were being asked to give your consent for?/ Were risks discussed with you? How were they explained? Were benefits discussed? How were they explained?/ Were you given choices for any other alternatives to the proposed intervention?/ ‘Were you given any information sheets, websites, or other sources of information?)
Understanding women’s choices
(Did you feel that you understood the information to allow you to provide your consent? Did you ask any questions?/ Were you able to voice your concerns?/ If so, did you feel satisfied by the answers you received? If no, what stopped you from asking questions?)

Table 2
Participants’ demographic data.

	Number of participants (n = 17)
Age (median = 32.5)	
20-29	3
30-39	11
40-45	3
Ethnicity (self-defined)	
Asian/ Asian British	13
Black/ African Caribbean/ Black British	3
Other ethnic groups: Latin American	1
Highest Level of education	
Secondary Education	1
College/ Sixth form	4
Undergraduate degree	5
Postgraduate degree	6
Doctoral degree	1
Employment	
Employed	12
Unemployed	5
Parity	
1	9
> 1	8
Clinical characteristics	
Induction of Labour	9
Assisted Vaginal Delivery	7
Caesarean Section	7
Perineal tear repair	5

reported that healthcare professionals (HCPs) did not wait for them to agree before proceeding. Many women reported being asked for consent ‘at the last second.’

(British South Asian).

Women described feeling unsupported in decision making when patient-centred discussions were absent. Options were offered with little guidance and a lack of appropriate detail for them as individuals. For example, women who underwent instrumental delivery and needed an episiotomy reported that their consent for the latter was not sought or it was inadequately explained.

‘She used a ventouse, it still wasn’t working and they had to cut me. She explained that again. She didn’t really give me a chance to respond.’

(British Bangladeshi).

Women’s choices were limited in the way that they experienced pressure in explicit and implicit forms. HCPs took a dominant role in consent discussions with some women reporting that HCPs presumed they would comply with proposed procedures without consulting them. Some women highlighted that the language HCPs used in consent discussions was directive and lacked neutrality, so they felt forced to agree. Women reported being ‘told’ rather than ‘asked’ for their agreement prior to procedures.

‘But it is not really a question of ‘Do you want a scan at 36 weeks? Or do you want a growth scan?’ It’s ‘I’m booking you for (scan).’

(British South Asian).

Some women felt HCPs ‘manipulated’ (British Pakistani) their agreement by communicating an exaggerated sense of clinical urgency.

‘I had been frightened by doctors to think that if I don’t. have an induction now, my baby is going to be ill when she is going to be born’.

(British Pakistani).

Some women reported that risks involved with the proposed procedure were understated or ‘glazed over’ (British Bangladeshi) with emphasis being placed on the risks associated with declining the intervention. Women reflected that incomplete and imbalanced information provision persuaded their agreement to procedures including IOL and CS.

Women reported persistent, repeated pressure and scaremongering from HCPs. Decisions to refuse interventions were not always respected.

‘I didn’t want it... the midwife that was with me kind of kept saying ‘Have the epidural, have the epidural, get the epidural, get it now. If you don’t ... your contractions are going to be too strong and we are going to struggle to give it to you later ... so I ended up having it around 20 min after my contractions started, just because I got worried I wouldn’t be able to have it later on.’

(British Pakistani).

3.2. Pressured consent and silencing of women’s voices

Many women did not feel their preferences were listened to nor were they encouraged to voice them.

‘you don’t have anybody there that is backing you. Everybody there is a professional and everybody is there just to do their job. Nobody is there to like be there for you as an individual.’

(British Black Caribbean).

Most women reported asking questions which were summarily dismissed or met with hostility and condescension.

‘I kind of got a sense of ‘So do you think you know better now?’ and I was actually questioning because no I did not know any better, I’m questioning because no I do not understand and I don’t know how that translates to me being an African woman and I think if maybe if someone stopped and asked ‘Okay why do you actually feel that way? Why do you not want to even try it out?’

(British Zimbabwean).

Some women were deterred from asserting their choices, worried they would be treated differently as an EM woman and would be subjected to potentially severe repercussions if they declined to consent to procedures recommended by HCPs.

‘There is a fear of ‘What if they call safeguarding of me on something?’ Despite the fact that you have sound of mind and you have thought about it all... there can be fear of ...All sorts of negative repercussions happening if you speak up too much.’

(British South Asian).

Women did not always understand procedures, the risks involved and what they meant for them as individuals. Women reported that they felt treated differently because of their ethnicity, and it was this that impacted the exchange of information between women and HCPs. This subsequently hampered shared decision making during antenatal consent discussions regarding the potential need for assisted VD and CS.

Women carefully considered their refusal of interventions including IOL and epidurals because they perceived racial stigma would exacerbate the negative perceptions of their choices.

'It's different for us ethnic minorities when we are in hospital when we are giving birth. So, you don't really want to be the troublemaker when you already know that you are working from a disadvantaged point'.

(British Black African).

3.3. Impersonal consent: lack of individualized dialogue

Some women reported that information was not always forthcoming, so they had to probe HCPs for information regarding both risks and reasonable alternatives for CS and epidurals. In one example, HCPs failed to disclose risks associated with vaginal birth after Caesarean (VBAC), or what alternatives were available prior to the consequent rupture of her previous CS scar.

'I wasn't given a lot of information about the planned C section and how that would be and how that could have prevented what happened'.

(British Pakistani).

Women highlighted the impossibility of knowing to initiate these discussions unless initially raised by HCPs.

HCPs approach to consent to procedures lacked cultural sensitivity, according to several participants.

'I've always felt like (giving birth) is very cultural so to me I was always feeling like I am an African mum. But if I am now being asked to make decisions based on the western culture I just didn't know where I stood... sometimes you are then making decisions based on things that you don't even understand'.

(British Black African).

'it becomes difficult for me being an African British mother that still holds very much to my Zimbabwean values or my southern African values to then being a new mum in England where things are different'.

(British Black African).

'And even here it is something that I have never heard of so then sometimes you are then making decisions based on things that you don't even understand things that you haven't ever come across, so you don't know what the probability of that is for it to happen to your baby'.

(British Black African).

Finally, although some women highlighted a lack of respect from HCPs none of the women considered HCPs to be ill-intentioned towards them. Some women felt that the HCPs were overstretched by the demands placed on them leaving them unable to be responsive to EM women they perceived as 'different' to the norm.

4. Discussion and conclusions

4.1. Discussion

Consent and choice should be indisputable tenets of a woman's birth experience [27]. Yet our findings indicate that EM women's experiences of consent do not always align with legal and professional guidance. The ethnic minority women in this study did not perceive that they received

support and respect for their individual choice-making, were subject to unwanted pressure to conform and, rather than being enabled as autonomous partners in their care, struggled to be heard and believed.

Of obvious concern was that some women reported a complete absence of any consent process with the unsurprising effect of making women feel 'done to' and disregarded as individuals [2]. Although our study is the first to focus specifically on the consent experiences of EM women, our findings echo the results of a survey of a mixed demographic of 1100 women which reported that 12% had not been asked for their consent [15]. While issues of recall and the time-pressured nature of some obstetric decision-making may account in part for these findings, our data suggests a more fundamental compromise of adequate consent practice. This suggestion is reiterated by our parallel findings that participants felt their 'choice-making' was undermined in numerous ways apparently reflecting a perceived indifference by HCPs to women's views and a failure to foster women's involvement in genuine dialogue. These findings align with concerns around consent recently highlighted by a large-scale inquiry into racial injustice and human rights in UK maternity care [11]. Multiple factors may explain them. Perhaps most significant is a suggestion that an insidiously held assumption is that, compared to their White counterparts, EM women are less able or willing to make autonomous choices which are valid. This in turn hints at a perspective which, at some level, views EM women as fundamentally and negatively 'different' to the default White-centric norm. Echoing this, Bowler [28] in an ethnographic study of midwives' stereotypes of maternity patients, reported that a common theme in midwives' accounts of Black and Brown women was a perception that "they're not the same as us" and are bereft of "normal maternal instinct" due to their failure to conform to White-centric family norms. Although viewing EM women in this way may reflect a legacy of cultural ignorance that is, of course, no justification legally, ethically, or professionally for the sub-standard practice our findings point to.

It is a small step from perceiving women as 'other' to questioning their credibility as decision-makers or knowers of their own bodies in what might be described as a form of epistemic violence whereby individuals are disregarded as knowers of their own bodies, lives, and experiences, with others seeking to override the individual's knowledge with their own perceived expertise [29]. We were particularly concerned by women's reports of failures to respect their choice to decline interventions. Also troubling were reports in which consent was downplayed and women felt pressurised into acquiescing to an intervention desired by HCPs rather than supported in making a voluntary decision. The law unequivocally endorses a woman's right to make any decision, however unwise it may appear to others [30]. It has been noted that the rights of women of all ethnicities to refuse consent for interventions during childbirth are routinely undermined by HCPs who do not agree with or approve of the decision [31] and it has also been suggested that, compared to White women, EM women are especially vulnerable to being pressurised into accepting unwanted interventions [11]. Our findings give further credence to this view. Yet, voluntariness is central to lawful consent practice so why did so many EM women report experiences which failed in this respect?

There is a fine line to be drawn between an HCP who, in striving to discharge their professional duty to, 'do their best' for a patient, 'encourages' a particular decision and one who effectively overrides a patient's autonomy. Yet, although the use of implicit pressure is widely recognised as a pervasive and culturally normalised notion of paternalism within obstetrics [32,33] formal reports of explicitly pressurizing behaviour by HCP's, are largely confined to low- and middle-income countries [34,35].

In part, experiences of pressure may have been exacerbated by women's own perceptions that their ethnicity meant that HCPs viewed them as stereotypically 'different' or 'other.' This in turn meant that some EM women felt they were, 'working from a disadvantage point' resulting in them sometimes feeling pressured to agree to procedures which conformed with White sociocultural norms to secure 'approval' from their

HCP and 'earn' a right to be heard. It seems that awareness of being 'othered' may have served to undermine the epistemic agency of women by silencing their voices. Perceptions of being 'othered' have previously been suggested to adversely affect women's participation in choice-making [11,18,36] and our findings substantiate this assertion. Recognising the influence of perceived microaggressions and 'othering' on consent dialogues and addressing attitudes which view EM women as 'other' or lesser is a difficult challenge but a commitment to do so should be uncontroversial and is self-evidently an important first step towards the necessary development and implementation of practices and policies which address racial inequalities in maternity care.

Foundational to lawful patient-centred care are shared discussions in which patients are actively listened to and their views are both sought and taken seriously. Strikingly, women in our study reported a lack of any sense of real involvement in genuine dialogue with their HCP. We did not collect data concerning the nature of the relationship between each of the women and the HCP involved in the consent process. Our results would be less surprising if the HCPs were first introduced to the women at delivery, but it is an even greater concern if the HCPs had been attending them throughout their entire pregnancy. This perhaps reflects a toxic failure of communication emanating from harmful assumptions about a woman which simultaneously impugn her identity as a credible knower and give weight to negative assumptions about her ethnicity. Dotson [29] contends that such epistemic violence may be compounded by the effects of structural racism within maternity care and, although our findings do not explicitly address structural concerns, Dotson's assertion seems reasonable. But what is the way forward at the patient-professional interface?

Previous studies [11,16,18] of populations with mixed demographics have highlighted discrepancies in understanding from the perspectives of both women and their HCPs and providing values-driven dialogues is a professional challenge which applies to every choice-making dialogue. However, it is a challenge rendered more potent when, for whatever reason, facilitating a woman's engagement is not enacted or prioritised because of a failure to fully engage with an individual's identity and attendant socio-cultural factors. None of the women in our study indicated any malign intent on the part of HCPs but as Freedman et al. [37] note care can be experienced as disrespectful or abusive even if that was not the intention of the perpetrator. It has previously been noted that race is a key factor in determining trust between HCPs and patients and there is a high level of distrust in the maternity context between EM women and their HCPs due to "the impact of racial discrimination" and "past experiences. In summary at minimum, what our study suggests is a need for this dimension of the challenge of values-based healthcare to be explicitly addressed individually and systemically so that all women experience consent dialogues which are lawful, professional, and humane.

Our study included Black and Brown participants with different ethnic identities. While data saturation was achieved in this notoriously hard to reach demographic, we acknowledge that our sample is not fully representative of the EM population, and we may not have given full voice to the diversity of this population. Equally we did not explicitly ask participants whether their consent experience was in the context of them requiring emergency intervention although it seems likely that participants would have volunteered this when relaying their experience. All participants were self-selecting and while we used the superior consecutive non-probability sampling method to recruit participants there is likely sampling bias. For example, all participants were recruited via voluntary sector agencies that aim to give a voice to women and campaign for women's rights in maternity care. Arguably our sample of women recruited via these agencies is biased towards women with interests and experience in these matters. Also, participants were all able to speak English and further exploration of the experiences of women who cannot speak English is required.

4.2. Conclusions

Although informed consent is variably implemented for women of all ethnicities, our study reveals some particularly worrying dimensions experienced by EM women. The failure to enable and take seriously EM women's voices undermines lawful and professional consent practice and mandates action at all levels of service provision to prioritise and support individually and culturally sensitive care.

4.3. Practice implications

Healthcare professionals must actively facilitate consent consultations which are culturally sensitive to supporting individual women in voicing what really matters to them. They should routinely ask women about their specific concerns and facilitate conversations that not only 'enable' women from ethnic minority backgrounds to freely voice their concerns and priorities without censure but, importantly, actively endorse an ethnic minority woman as credible experts on their own lives and what matters to them. This necessitates the need for improvements in the development and dissemination of culturally sensitive training to guide HCPs engaged in consent consultations. Such training needs to explicitly draw attention to the potentially harmful effects of communicative practices that may tap into EM women's perceptions of being 'other'.

Ethical approval

This project was granted ethical approval by UCL Research Ethics Committee. The registration number for this is: Z6364106/2021/05/144.

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CRediT authorship contribution statement

jacqueline nicholls: Writing – review & editing, Supervision, Methodology, Conceptualization. **Zahra Khan:** Writing – original draft, Investigation, Formal analysis. **Anne Lanceley:** Writing – review & editing, Supervision, Methodology, Data curation, Conceptualization. **Katherine Maslowski:** Writing – review & editing, Supervision, Formal analysis. **Lily Hutton:** Investigation.

Declaration of Competing Interest

No conflict of interest.

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Contribution to authorship

The authors' contributions were as follows. AL and JN conceived the study and produced the initial interview guide for testing. ZK recruited the study participants, conducted the interviews with participants and transcribed interviews. JN, ZK, AL and LH conducted the qualitative analysis and JN and AL reviewed the codes. ZK drafted the manuscript, which was amended following comments from JN, AL, LH, and KM. All authors read and approved the submitted manuscript. All listed authors

meet the criteria for authorship and no individual meeting these criteria has been omitted.

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