

Supporting patients with Female Genital Mutilation (FGM) in primary care: English GPs perspectives.

Abstract:

Background:

FGM includes all procedures which intentionally harm or alter female genitalia for non-medical reasons. In 2015, reporting duties were introduced, applicable to English GPs including a mandatory reporting duty, and FGM Enhanced Dataset. Our PPI work identified exploring the potential impacts of these duties as a research priority.

Aim:

To explore English GPs' perspectives on potential challenges and resource needs when supporting women and families affected by FGM.

Design and Setting:

Qualitative study with GPs working in England.

Method:

Semi-structured interviews focussed around a scenario about managing FGM in primary care. We spoke to 17 GPs from five English cities, including those who saw FGM often, rarely or never. Interviews were audio-recorded and transcribed verbatim for thematic analysis. We drew on Lipsky's theory of street-level bureaucracy to support analysis.

Results:

Managing women with FGM was experienced as complex. Challenges included knowing how and when to speak about FGM, balancing caring for women and their family's potential safeguarding needs and managing the mandated reporting and recording requirements. GPs described strategies to manage these tensions which helped them balance maintaining patient-doctor relationships with reporting requirements. This was facilitated by access to holistic services.

Conclusion:

FGM reporting requirements complicate consultations. The potential consequences for trust between women affected by FGM and their GP are clear. The tensions that GPs experience in supporting women affected by FGM can be understood through the theoretical lens of street-level bureaucracy. This is likely to be relevant to other areas of proposed mandated reporting.

Keywords:

Qualitative research, FGM, GPs, Mandatory reporting, Street-level bureaucracy, Trust

How this fits in:

We are not aware of any previous work considering GPs' perspectives on supporting women with FGM in primary care, including the impacts of recent English policy. GPs described tensions between their caring role and the policy requirements placed upon them. The provision of specialist support, and holistic education could support GPs when caring for communities affected by FGM.

Introduction:

Female genital mutilation (FGM) is defined by the World Health Organisation as "all procedures that involve partial or total removal of the external female genitalia, or other injury to the female genital organs for non-medical reasons". FGM has no known health benefits, and many documented harms¹ Potential harms include immediate risks such as haemorrhage, infection and death and enduring risks, including obstetric complications, menstrual and urinary problems, and psychological impacts including anxiety, depression and post-traumatic stress disorder². An estimated 200 million women and girls in 30 countries are living with the consequences of FGM³. Global migration from areas where FGM is traditionally practiced means that FGM is a worldwide health concern.

Using household survey data about FGM prevalence in countries where FGM is traditionally practiced, and UK 2011 census data, MacFarlane et al estimated that approximately 137,000 women and girls born in countries where FGM is traditionally practiced were permanently resident in England and Wales. Although there was significantly higher prevalence in urban areas, it was estimated that there would be no local authority areas without any women affected by FGM⁴. It therefore seems likely that many English general practitioners (GPs) will have clinical encounters with women and families potentially affected by FGM.

Understanding how to support affected families and meet their care needs is vital, and the recent increase in service provision recognising the needs of women and communities affected by FGM⁵ is timely and welcome.

FGM is an ancient cultural practice which has been the focus of recent education, safeguarding and policy focus.

In July 2014, the UK government hosted the first Girl Summit, in partnership with UNICEF, at which they pledged to mobilise domestic and international efforts to eliminate FGM within a generation⁶. The Prime Minister announced a raft of measures including legislative changes, a £ 1.4 million FGM prevention programme with NHS England, and training for professionals⁶.

Policy introduced following this included a mandatory reporting duty, requiring all registered professionals in England and Wales to report cases of FGM in under 18s directly

to the police, where FGM was identified on examination, or through a first-hand disclosure. The consequences for not doing so include professional sanctions⁷. There was also introduction of an FGM Enhanced Dataset (applicable in England) requiring submission of quarterly data returns including personally identifiable data (including name, date of birth, and NHS number) to NHS Digital from all NHS acute trusts and GP practices. The stated aim of the FGM Enhanced Dataset is to inform service provision. Consent for data sharing is not required, however fair processing requires clinicians to explain the dataset to their patients⁸. Concerns about the potential impacts of these two policies have been raised by both professionals and community members⁹⁻¹⁴. In the most recent data report for the FGM Enhanced Dataset, only 64 GP practices (out of an estimated 6867¹⁵) in England submitted data returns in 2018-2019¹⁶.

A patient and public involvement project to understand research priorities highlighted questions about how this legislation might affect trust in healthcare interactions¹⁷. There is very little research with GPs about their role in supporting women with FGM¹⁸. We are aware of no published research considering English GPs perspectives in the context of recent policy.

Street level bureaucracy is a sociological theory advanced by Michael Lipsky which seeks to explain how public servants think and act when they are delivering public policy in the course of their work on the service front line. Lipsky found professionals typically face constraints (such as excessive workloads, or limited time and resources) which limit their ability to respond to (all) of their individual clients' needs. Professionals therefore tend to develop routines of practice which inevitably influence outcomes. Lipsky described professionals working in this way as "street-level bureaucrats". Exercising professional discretion is central to the work of street-level bureaucrats, who face what Lipsky describes as an "essential paradox"¹⁹:

*"on the one hand, the work is highly scripted to achieve policy objectives that have their origins in the political process. On the other hand, the work requires improvisation and responsiveness to the individual case"*²⁰.

It has been suggested that Lipsky's observations apply to the work of GPs who are faced with enacting policy while trying to maintain a trusting therapeutic relationship with their patients²¹⁻²³. We draw on Lipsky's theory to explore the perspectives of GPs on supporting patients who may be affected by FGM.

Method

Study Design:

A qualitative study, using semi-structured telephone interviews based around a fictional scenario (BOX 1) about a woman presenting to primary care seeking support for her FGM. The scenario was piloted with two GPs and designed to resonate with scenarios likely to be

encountered in FGM related education. Ethical approval was granted by Oxford University and HRA (R46851/RE001, IRAS number 238807).

Sampling and recruitment:

GP practices in 8 English cities in the Southeast, Southwest, Midlands and Northwest regions were contacted once by email with information about the study. Using the published list of FGM specialist clinics from NHS England at the time of study recruitment, we chose cities which had a local specialist clinic and those that did not. Aiming to speak to GPs with different levels of exposure to FGM, we utilised published local maps of demographics and ethnicity to select areas likely to have practice populations with different prevalence of FGM. In addition, where possible, we approached by e-mail the named GP in these cities to ask whether they would consider sharing the study information through their local networks. Recruitment was enhanced through snowballing.

Seventeen GPs (16 women, 1 man) from five cities, with a range of experience and with varying access to a local specialist clinic, participated in the study.

Data collection and analysis:

semi-structured telephone interviews were conducted by SD (a GP and NIHR In-Practice fellow) between March and November 2018.

We used the fictional scenario to help create a neutral space for GPs to consider possible responses to issues they might face when seeing women affected by FGM, and strategies or resources that might help²⁴⁻²⁵. GPs were then invited to reflect on communicating about, and managing the requirements of the FGM reporting requirements.

With consent, the interviews were audio-recorded and transcribed verbatim for thematic analysis. A coding framework was developed (by SD and SZ). Transcripts were checked and coding was iteratively developed²⁶ to incorporate emergent as well as expected themes. The analysis was supported using Nvivo QSR Version 11. Lipsky's theory of street level bureaucracy was drawn on to help shape and interpret the findings.

Results:

GPs reflections on the fictional scenario included descriptions of how they would respond to the scenario presented, their wider reflections on potential issues and challenges they might encounter when supporting 'Samara' and what they thought might help. Key themes are discussed below, including responses to specifics of the consultation with 'Samara' about FGM, as well as the broader considerations and challenges of talking about FGM, managing FGM policy requirements, and what might help. We discuss these themes in relation to Lipsky's theory. The key findings are presented in Figure 1.

1: FGM is complex, potentially stressful and relatively unfamiliar

For many GPs, a consultation about a consultation about FGM is relatively uncommon and unfamiliar:

While the recent focus on FGM and safeguarding was helpful in raising awareness, it was only a relatively recent part of formal education, as noted by GP15, who had considerable experience of primary care.

"We didn't talk about it; Didn't receive any education pretty much until quite recently, maybe in the last 5 years, and that really stemmed from being safeguarding I think, not really from general practice education, but from being safeguarding" (GP15)

GP3 explained that their experience of scenario-based educational discussions about FGM helped them feel "moderately comfortable" about approaching our scenario.

Others noted that seeing a patient with FGM could be both complex and stressful. Towards the end of the interview, GP4 reflected that they would be '*really worried*' and '*really anxious about how to take it*', while some, including GP2, weren't sure they would recognize '*smaller forms of FGM*'

Considerations on talking about FGM:

GPs often expressed concerns about how, when and with whom they should raise the topic of FGM. This included uncertainty about what words they should or could use when talking about FGM, with some wanting guidance on what terminology would be acceptable to women and families. We heard concerns about the risks of offending women, breaching cultural sensitivities, or raising memories of a potentially traumatic experience.

"I think I'd be worried about sort of cultural sensitivities around it and using the right terminology and, you know, you wouldn't want to put your foot in it if you want to get a full history from somebody" (GP6)

In the scenario, the topic of FGM was introduced by 'Samara'. We asked GPs whether or how they might have approached talking about FGM had she not raised it. Some said they thought it was more acceptable to ask about FGM in the context of a potentially related clinical problem (e.g. wanting to get pregnant, recurrent urinary tract infections) or where the woman asked for an intervention or support.

"I don't think it would necessarily be a routine question for most GPs unless it.. There was a reason for it, you know period problems, that kind of thing"(GP16, experienced in the field)

"So if her agenda is already I've got a problem with my urinary tract then it eases you into asking those questions a lot more easily, a lot more naturally than just out of the blue. Coming up with "well have you had FGM then?" so it would just be bizarre" (GP10, experienced in the field)

While 'Samara' spoke good English, several GPs reflected on the additional challenges that using interpreters could bring to the consultation. Such consultations were likely to be complex and require more than ten minutes. An important consideration before commencing the conversation was who else was in the room.

"I think I wouldn't feel happy raising it in front of her partner or even probably her mother" (GP17)

"if she's with family then obviously that might coerce her into saying or doing things that she didn't feel comfortable" (GP4)

Balancing the needs of the woman in the room, and the potential needs of her extended family:

A consideration raised by many GPs was that the patient who presents may have other family members also registered with the GP practice. Therefore, seeing a woman who is affected by FGM may necessitate consideration of the potential clinical and safeguarding needs in her wider family. This could include working out how to assess potential safeguarding risks and needs in the family, considerations about how to assess, contact or review other family members, and potential reporting implications within the family. The impact of these considerations on the primary care relationship with the presenting patient was a concern. It was not always clear how to approach and manage these dual responsibilities.

"if it's just a case of managing that particular woman and her gynaecological problems, ..I mean I think that's fine you know, but it's the whole sort of expanded risk scenario which is.. So that can balloon out of proportion and just not be manageable really" (GP14, relatively inexperienced in the field)

"so I'd be thinking about the safeguarding side of things but also the legal side of things but equally my heart would be sinking because in a family you probably know the mother as well and you'll probably be thinking "Oh no, what have I done, what have I missed?" (GP13, experienced in the field)

The recording and reporting requirements add complications:

GPs reflected on coding FGM into the medical record, and how the FGM mandatory reporting and FGM Enhanced Dataset might affect patient-GP relationships.

The ability to exercise discretion is central to Lipsky's theory of street-level bureaucracy: *"because the accepted definitions of their tasks call for sensitive observation and judgement, which are not reducible to programmed formats"*²⁷. This resonates with the disquiet expressed by a number of GPs who talked about managing the inflexible reporting and recording FGM policy requirements, including coding into the medical record.

While GPs could see advantages of coding FGM to support professional communication about safeguarding or clinical needs and avoid repeated questioning, there were evident tensions between coding for internal clinician purposes and coding for other agencies, or when records are available to patients on-line.

“the whole online records and person record is being pushed from people with long-term conditions and it’s a very different issue and subset, and I think having somewhere safe to write notes for yourself and write notes for legal reasons is.. and then having to think about someone else looking at them makes it incredibly difficult.” (GP11)

Some expressed uncertainty about coding a mothers’ history of FGM into their children’s notes, raising questions about understanding of who was ‘at risk’ and the confidentiality implications of coding the mother’s history onto the computer. GPs from areas with different prevalence of FGM had similar concerns about the consequences and difficulties of labelling a child as ‘at risk of FGM’ if her mother was adamant that she would never subject her child to FGM.

“it feels a bit uncomfortable if you’ve had a frank discussion with the woman and she’s sort of said, you know, actually it’s not her belief and this would never happen”(GP9, inexperienced in the field)

“I wouldn’t want to label that child at being high risk if the mum had been dead against it, and was an advocate of not to have it, and then you put a label”(GP17 experienced in the field)

Some GPs reflected that the Enhanced Dataset could reinforce the need for service provision:

“I think in these days where they’re looking at how to allocate money, it would be hard if the data that you collect because people are opting out suggests that there isn’t the need for a service when there is, and therefore I would sell it to individuals that it’s held very securely and it’s not going to be released to third parties” (GP6, inexperienced in the field)

However, we also heard GPs concerns about the necessity or usefulness of the dataset collection or whether it constitutes a privacy breach, questioning the legitimacy of service norms, where they conflict with professional discretion:

“if it’s a safeguarding issue it’s a safeguarding issue and I’ll deal with that appropriately. But I don’t think sending all my women’s personal information somewhere is actually helping that at all really” (GP13)

“I’ve got severe reservations about the necessity for that information to go, and the breach of confidentiality which I fear it may be”(GP1)

Advocacy and making patients’ needs primary are explicitly required in medical ethics and professional guidance. Lipsky writes that this may be experienced as *“incompatible with their need to judge and control clients for bureaucratic purposes”*²⁸. We consider that this tension resonates with these GPs concerns that the Enhanced Dataset could complicate or deter conversations about FGM.

“I think it complicates the matter in terms of, you know, when you’ve got a woman who’s presented with what is a , you know very sensitive issue, and one that she’s potentially spent a lot of time umming and aching over whether to disclose it or not, to then have to [...], do all of that consultation and then go “well actually, just to let you know we do have to report this information” and how that might then make her feel” (GP8)

GPs' accounts highlighted tensions between appearing to be a "law-keeper" (GP10) in addition to their caring role, describing concerns about the potential impact on doctor-patient relationships.

"there have been sort of mixed messages I think for some of the patients about [...] our role as GPs to support them, but the sort of requirements on us also to be scrutineers..." (GP5)

"you want to be able to have a confidential relationship with your patient unless there's a really threatening thing like you're getting involved with and your hands are tied about whether you can do that or not. And so, I think that certainly it has the potential to risk the doctor/patient relationship because they came to you in confidence and that hasn't necessarily been how it's ended up" (GP10)

2. Strategies and resources to support women with FGM

Continuity of relationship:

Embedded within GPs descriptions of how they would approach Samara's scenario were accounts of what they valued as core components of being a GP. The GP should be the "first port of call" (GP13), know the wider family, and the locality, and offer on-going relationships and support. While FGM might be relatively unfamiliar, this experienced GPs noted that patient-centred consulting skills would be transferable.

"this feels like a scenario that has to be handled very carefully, but it's not...that's our sort of bread and butter as GPs, and just going with the patient and moving things forward at their pace, that's what we do" (GP7)

Developing trusting relationships could provide a framework that would support the opportunity to both care for the woman and safeguard her and her family. GPs voiced concern that mandated reporting could adversely impact on these relationships.

"it would just be building a relationship... and they would trust you. And then they'd also tell you the truth. You can only go on what someone tells you, and if they don't trust you and say "No, no" but then they disappear off. You've kind of blown it, and you've blown an opportunity" (GP17, experienced in the field)

"you want to maintain your relationship with her in order to have her best interests at heart, but also you want to do a risk assessment in terms of her sister as well [] You know there's that mutual trust thing that is quite difficult to maintain if you're suddenly going to start talking about reporting and involving other members of the family" (GP12, experienced in the field)

Embedding conversations about recording and reporting within these relationships:

GPs described how they would endeavour to make the policy requirements seem acceptable to Samara. This resonates with Lipsky's observations that *"One important way in which street-level bureaucrats' experience their work is in their struggle to make it more consistent with their strong commitment to public service and the high expectations they*

have for their chosen careers²⁹”, and “they believe themselves to be doing the best they can under adverse circumstances, and they develop techniques to salvage service and decision-making values within the limits imposed upon them³⁰”

Strategies suggested by GPs included framing the discussion in the context of their safeguarding duties, showing documents to prove that the reporting was not their idea or decision, or explaining that providing data will help ensure the provision of services.

“you lay on the table what your duties are and why, that it’s for the good of society in the population at large and it’s to protect people and it’s the idea of collecting data to look at incidence” (GP3, experienced in the field)

Another strategy was embedding required conversations within established patient-doctor relationships.

“I think that would happen at a time at which I’d felt that trust had been established that we could have an open conversation without jeopardising other aspects of the doctor/patient relationship” (GP5)

Being able to offer services that support women and meet their holistic care needs:

We asked GPs what services they thought would support them when they were caring for women and families who may be affected by FGM. They described wanting access to culturally sensitive services which would offer support care across the woman’s and her family’s life-course, including safeguarding, physical, and mental health. GPs with experience of working in areas with access to services described the difference that knowing there was a pathway through which the woman’s needs would be met could make to their confidence in raising the subject of FGM.

“because of the exposure and knowledge that we’ve got support there, it’s much easier to bring up. I suspect if I had less awareness and I wasn’t sure what there was to support somebody, it would be a really challenging issue to raise with all the associated potential distress and fallout, yet not have anywhere to go with that”(GP5)

Figure 1:

Discussion:

Summary:

FGM is experienced as complex to manage in primary care, with challenges including considering how and when to talk about FGM and how to meet the potential needs of both the woman who presents and her family. Managing FGM reporting and recording brings additional tensions into the consultation. Access to-specialist services and education about more than safeguarding were identified as important resources to support GPs when they care for patients with FGM.

Strengths and limitations:

As far as we are aware, this is the first study of the issues GPs consider when managing FGM in primary care. It contributes the perspectives of frontline clinicians on the policies of mandatory reporting and the Enhanced Dataset. Using a qualitative approach and a fictional scenario, we sought to create an open space for GPs' thoughts and reflections. We spoke to GPs with a range of exposure to FGM, including those who had experienced seeing women with FGM never, rarely, and often. Our study included GPs who were safeguarding leads, and others who were not, in five cities, two of which had a local specialist clinic.

All 17 GPs were interested in participating in a conversation about managing FGM, all but one were women. We therefore cannot (and do not) suggest that these findings are numerically representative, but we did achieve considerable variation of experience and views in the sample. We heard about a range of issues that GPs confront which Lipsky's social theory helps us understand as reflecting a wider issue in the tensions that GPs experience in relation to mandatory reporting.

Comparison with existing literature:

We are not aware of any previous work considering GPs' perspectives on supporting women with FGM in primary care, including the impacts of recent English policy. The existing FGM literature derives predominantly from obstetric and maternity settings. Some of our findings resonate with these accounts, for example the challenges in talking about FGM including the use of interpreters³¹⁻³⁴, but we also heard about issues specific to primary care. In maternity care, asking about FGM will usually be immediately relevant to the woman's current clinical care needs, and in the context of a clinical relationship that rarely outlasts the duration of pregnancy. In contrast, in primary care there is value in developing and maintaining on-going relationships over the life-course, and a requirement to balance the needs of the woman and her wider family, if registered at the same practice. GPs utilising trusting relationships with families within a strategy to facilitate care and safeguarding has been previously described³⁵.

Although well established, street level bureaucracy is an under-used theoretical model in general practice²¹. Previous work has used this theory to understand primary care responses to National Service Frameworks²³ and policies to reduce unscheduled care²². Our analysis is supported by its resonance with Lipsky's theory, notably the disquiet described at the removal of professional discretion.

Our central findings are the tensions expressed by GPs who perceived that policy required them to act as "law-keepers" whilst also patient advocates, and GP concerns that these requirements could negatively impact on perceptions of trust, confidentiality and on patient-GP relationships. Evidence from community settings suggests these fears may be well-founded, with community research demonstrating that policies can deter members of FGM affected communities from accessing services^{13,14}. Concerns have been raised that the response to FGM is "disproportionate" in comparison with other safeguarding³⁶, and of the lack of evaluation for mandatory reporting for FGM³⁷. Mandatory reporting is being considered in other areas of safeguarding in the UK³⁸⁻³⁹.

Beyond FGM, policies that require data-sharing (or where there are fears that data-sharing will occur) can deter patients, notably vulnerable patients, from accessing care and services⁴⁰⁻⁴². As with the GPs in our study, doctors have voiced concerns about requirements

to enact policies that they consider compromise their professional ethos or relationships with their patients^{43,44} including through organisations like docsnotcops⁴⁵ and medact^{t46}.

Implications for research and practice:

Making clinics available wherever there is need should be a resource priority. With GP and community expertise, educational resources including holistic aspects of care and safeguarding could be developed for primary care.

There is a pressing need to develop understanding about how the management of mandated reporting and data-sharing impact on trust and communication in primary care. In the context of consultations on the extension of mandatory reporting, it is a research priority that such policies are adequately evaluated.

Box 1

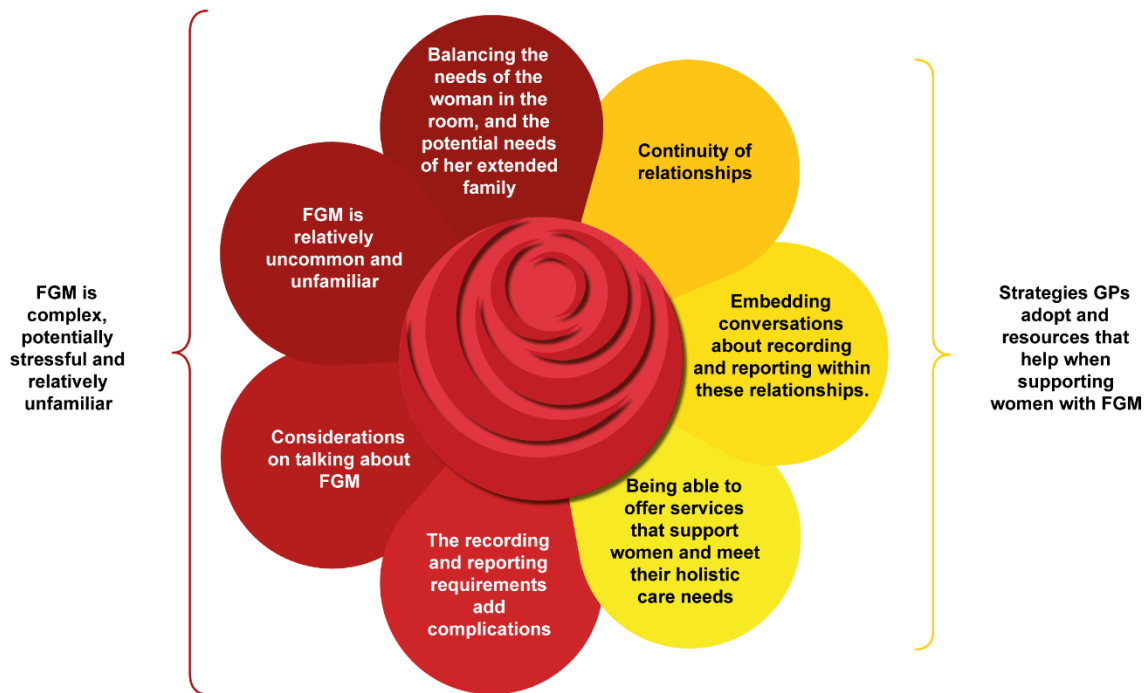
Box 1. Samara is a 22-year-old woman. Born in Somalia, she came to the UK 8 years ago with her parents, sister and brother. She finished her education in England and speaks good English.

She comes to see you because she is going to get married shortly and would like to be referred to be opened up before her marriage having been “closed” as a child in Somalia.

6 months later, she comes back to tell you she is now pregnant with her first child and would like to be referred for antenatal care.

Figure 1

Themes emerging through the lens of Lipsky's theory of street-level bureaucracy.



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