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Using electronic maternity records to estimate female genital mutilation in Lothian from 2010 to 2013

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Background: Female genital mutilation (FGM) is most commonly encountered in Africa and the Middle East, with migration from FGM-practicing countries meaning it is increasingly seen in Europe. Addressing FGM requires accurate information on who is affected but ascertainment is notoriously difficult. This study estimated FGM prevalence in women presenting for maternity care in the Lothian region of Scotland and compared this with that expected by extrapolation of survey data from women's country of birth. **Methods:** Electronic clinical records were linked to birth registration data to estimate FGM in the obstetric patients in Lothian from 2010 to 2013. **Results:** Among all, 107 women affected by FGM were detected, at a rate of 2.8/1000 pregnancies. Of 487 women from UNICEF-recognized FGM-practicing countries who accessed care, 87 (18%) had documented evidence of FGM (three quarters of whom came from Nigeria, Sudan or The Gambia). The prevalence was 54% of the level expected from the extrapolation method. Country of birth had a sensitivity of 81% for FGM. **Conclusion:** Women from FGM-practicing countries commonly access maternity care in Lothian. This confirms the need for ongoing training and investment in identifying and managing FGM. Matching electronic clinical records with birth registration data was a useful methodology in estimating the level of FGM in the maternity population. In a European country like Scotland with modest migrant numbers, asking country of birth during pregnancy and making sensitive enquiries could detect 81% of women with FGM. Extrapolation from maternal country of birth surveys grossly overestimates the true prevalence.

Introduction

Worldwide, up to 140 million girls and women are estimated to have undergone female genital mutilation (FGM).[1,2] It is thought that FGM can have serious adverse effects on health, both at the time of cutting and later in life.[3,4] Obstetric and neonatal outcomes are not easily obtainable as most women with FGM live in settings with limited data collection, but a WHO study published in 2006 showed that women with FGM were significantly more likely to have a caesarean section, have greater blood loss and deliver babies more likely to require resuscitation.[5] While predominantly occurring in African and Middle Eastern countries, more international migration means that FGM is increasingly encountered in all countries around the world and it is essential that affected women are identified and offered appropriate care.[3,4,6–13] The period of time during pregnancy and delivery provides a unique opportunity for healthcare professionals to identify and communicate with women who may have undergone FGM. Better understanding of the number of women affected by FGM in a region or country will help to shape the development of local services that are tailored to their care.

Defining and mapping where FGM is practiced is complex. A UNICEF-compiled list of countries with a significant prevalence of FGM currently includes 30 countries.[1] They are Benin, Burkina Faso, Cameroon, Central African Republic, Chad, Cote D'Ivoire, Democratic Republic of Congo, Djibouti, Egypt, Eritrea, Ethiopia, The Gambia, Ghana, Guinea, Guinea Bissau, Iraq, Kenya, Liberia, Mali, Mauritania, Niger, Nigeria, Senegal, Sierra Leone, Somalia, Sudan, Tanzania, Togo, Uganda and Yemen. However, UNICEF also recognizes that FGM is reported elsewhere in the world (highlighting India, Malaysia, Oman, Saudi Arabia and the United Arab Emirates) but lacks evidence and data on prevalence in these other countries. These first 30 countries will be described as 'FGM-practicing countries' in this paper, in the absence of a better descriptor.

Efforts to develop appropriate services to identify and manage the needs of women with FGM in European countries are hampered by uncertainty around its epidemiology. Estimates of prevalence are either derived by extrapolation from country of origin figures, or by use of surveys within host countries. At its simplest, extrapolation assumes migrants have the same FGM prevalence as described in

national surveys of their home country.[14,15] These rates are projected onto the numbers of nationals from each country living in the host countries. Several European reports have used such methods, sometimes including consideration of specific characteristics of the migrants in their modelling. Scotland has published a national action plan on FGM with an approach combining prevention, protection and service provision.[16] This followed a 2014 Scottish Refugee Council report highlighting the increased evidence of FGM in Scotland and estimating that 23 979 people born in one of the FGM-practicing countries lived in Scotland.[17] However, clinically correlated data about FGM is currently very limited in Scotland, primarily because of the reliance on local paper-based maternity records. NHS Lothian serves a population of over 800 000 people in east central Scotland and has 10 000 deliveries per year in two maternity units. It was one of the first regions of Scotland to use electronic maternity records—maternity TRAK (mTRAK).

We used National Records of Scotland (NRS) country of maternal birth data for Lothian to focus analysis of mTRAK data to determine number of women affected by FGM.

This study aims to:

(1) Estimate the population of women in Lothian at heightened risk of FGM according to country of birth
(2) Determine the number of women with FGM recorded in their maternity records
(3) Discuss these data in the context of the total number of women delivering in Lothian
(4) Compare these data with prevalence estimated by other methods

Methods

Patients and setting

All women accessing maternity care in NHS Lothian between January 2010 and December 2013. They are the denominator.

Data sources

mTRAK and NRS birth registration data were interrogated in three stages.

Stage 1

NRS data are routinely provided to NHS Boards about their residents' births and this was examined to ascertain maternal country of birth for all registrations in Lothian from 2010 to 2013. Parental country of birth is not recorded on mTRAK. We identified women at heightened risk of FGM as those having their country of birth recorded as one of the 30 FGM-practicing countries recognized by UNICEF.[1]

Stage 2

All midwives should ask women presenting at their first visit in pregnancy if they have undergone genital cutting or piercing, and record this in a tick box field on mTRAK. Space for insertion of relevant free text comment is also available. Some women may not reveal information about FGM at their first visit and FGM may be discovered at a later stage of pregnancy. All information throughout pregnancy is documented and is entered onto mTRAK, including physical examination of FGM, when performed.

The mTRAK records from 2010 to 2013 were reviewed to find documented evidence of FGM.

This was either:

(i) Where the tickbox for 'genital cutting or piercing' was checked and where ethnicity was not recorded as White Scottish/ British/Irish/Northern Irish or Polish (as these women were assumed to have undergone piercing rather than FGM)

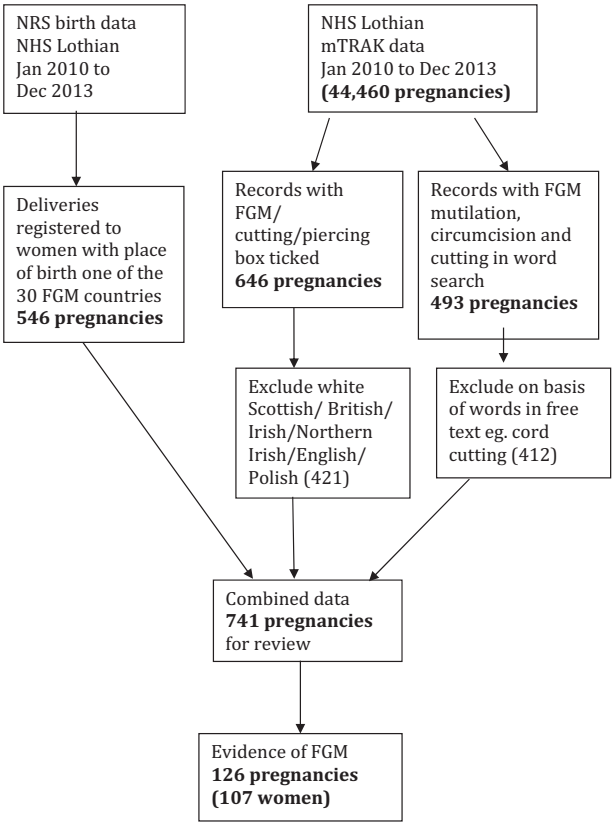

Figure 1 Algorithm. Methods for case detection

or

(ii) Where an electronic free text search of the entire record found the terms *FGM*, *circumcision, mutilation* or *cutting*. Records were then reviewed by clinical researchers (three midwives and two obstetricians familiar with the mTRAK database—CMF and KD) to exclude cases which did not refer to FGM, for example referring to male *circumcision* or umbilical cord *cutting*.

Stage 3

Where a woman was identified through mTRAK tick box or word search but her country of birth was unmatched, NRS conducted a search of their electronic records (using the unique hospital patient identifier, community health index, postcode and date of birth) to match these women and their country of birth. This search was necessary to identify women who lived in, or had registered the birth in, other Scottish NHS Board areas (as these data are not routinely supplied to NHS Lothian although they had maternity care in Lothian).

All eligible women, whether identified through NRS search or mTRAK review, were combined to create one group. (The different data sources were not mutually exclusive therefore the final number of women was from merging the three stages.) These steps are shown in the Algorithm (figure 1). The mTRAK records of each of these women were then individually reviewed to finally identify those with positive documented evidence of FGM.

Results

There were 44 460 registered pregnancies in Lothian in the 4-year period, from 2010 to 2013. Of these, 37 563 deliveries were recorded in Lothian mTRAK (others resulted in miscarriage or were delivered elsewhere).

- NRS searches found 487 women (with 546 pregnancies as some delivered more than once) who were born in FGM-practicing countries.
- mTRAK searches identified 1139 pregnancies positive for the genital cutting or piercing tick box or word search. Of these, 833 were excluded.
- In total 126 pregnancies to 107 women with evidence of FGM were identified. Of these women, 87 would have been identified by knowledge of their country of birth alone.
- The total number of women with FGM identified was 54% of that predicted by the extrapolation of country of birth survey data.

Country of birth

Women born in 23 of the 30 FGM-practicing countries accessed obstetric care in Lothian during 2010–13. Overall women from 15 separate countries were identified as having had FGM. Nine of these countries were on the UNICEF list of FGM-practicing countries (Nigeria, Sudan, The Gambia, Democratic Republic of Congo, Egypt, Iraq, Sierra Leone, Somalia and Tanzania) and six were not (Malaysia, India, Brunei, United Arab Emirates, Saudi Arabia and England). The majority of women with evidence of FGM were born in Nigeria, Sudan or The Gambia. For nine women, country of birth was unknown.

Women with FGM born in UNICEF-recognized countries: N = 87

Eighty-seven of the 487 women born in FGM-practicing countries from the UNICEF list had documented evidence of FGM.

Use of being 'born in a FGM-practicing country' as a screening tool for FGM in Lothian (and assuming that all instances of FGM are detected) is represented in table 1.

Sensitivity is 0.81, which suggests that this method could detect 81% of women with FGM.

The positive predictive value is 0.18, meaning that 18% of women from FGM-practicing countries have evidence of FGM.

The test is highly specific, meaning very few false positives would be generated—negative predictive value is 0.99. However, the test is only moderately sensitive, meaning that if the country of birth is not on UNICEF list it is still quite possible that they have FGM.

Table 2 shows country of birth and estimation of number of women affected from extrapolation of national surveys. The total from this would be 160 women, therefore our total is 54% of that estimate.

Table 1 Country of birth as diagnostic test

	FGM	No FGM
UNICEF list countries = 487	True positive = 87	False positive = 400
Not on UNICEF list of countries = 43 973	False negative = 20	True negative = 43 953

Women with FGM born in other countries: N = 11

Eleven women with FGM were born in six different countries where UNICEF does not have clear FGM prevalence data. These were Malaysia, India, Brunei, United Arab Emirates, Saudi Arabia and England.

Women with FGM with country of birth unidentified: N = 9

In nine instances, country of birth was unknown even after further NRS searches. This lack of information was explained from the review of mTRAK records: three women experienced miscarriages and another six had moved away from Scotland during the pregnancy therefore there was no registration of birth with NRS and country of birth was not otherwise documented.

All women identified with FGM: N = 107

In total, 107 different women with FGM were identified as accessing the Lothian maternity services over the four-year period, with 126 distinct pregnancies. Of these, 98 women delivered a total of 106 babies in Lothian. This means that approximately 2.8 per 1000 pregnancies in Lothian at that time were in women with FGM.

Country of birth was identified for all 98 women with FGM who delivered babies and 87 of them (89% of this total) were born in a known FGM-practicing country.

Discussion

Women from 23 of the 30 recognized FGM-practicing countries accessed maternity care in Lothian in the study period, totalling 546 pregnancies in 4 years. This number is 12/1000 pregnancies and equates to more than two women per week. This underlines the heterogeneous nature of the Lothian region.

We identified 107 women, born in 15 different countries, who had experienced FGM. While the proportion of women found with FGM is only 54% of that expected from direct extrapolation from surveys in country of origin, this lower level concurs with the findings of other similar European studies.[12,18] Other recent research also shows that using extrapolation of MICS and DCS data on FGM prevalence

Table 2 FGM identification by country of birth

Country of birth	Number of women who gave birth	Expected number of women with FGM in Lothian	Source of prevalence data and % with FGM aged 15–49[a]	Actual number of women with FGM (% of expected)
Nigeria	193	47.9	24.8% (DHS 2013)	31 (65%)
Sudan	54	46.8	86.6% (MICS 2014)	31 (66%)
The Gambia	28	21	74.9% (DHS 2013)	15 (71%)
Other	212[b]	44.1		10 (23%)[c]
Totals for FGM-practicing countries	487	159.8	–	87 (54%)
Women with FGM born in a country not on UNICEF 'list'	–	–	–	11[d]
Total women with FGM and identified country of birth	–	–	–	98
Women with FGM and unknown country of birth	–	–	–	9
Total number of women with FGM	–	–	–	**107**

a: Assorted MICS/DHS and a single WHO survey (DR Congo).
b: Total from 20 other countries where FGM is recognized—other than Nigeria, Sudan and The Gambia.
c: Actual from six other countries where FGM is recognized (DR Congo, Egypt, Iraq, Sierra Leone, Somalia and Tanzania).
d: Six countries not on recognized list (Malaysia, India, Brunei, United Arab Emirates, Saudi Arabia and England).

in individual countries tends to overestimate the extent of FGM in migrants.[17,19]

The vast majority of women with FGM in our study (72%) come from just three countries: Nigeria, Sudan and The Gambia. We found that 275 women from these three countries delivered in Lothian and that 77 (28%) of them had documented evidence of FGM. In these same countries, the number of women identified with FGM represented between 65% and 71% of that expected from simple extrapolation.

Several of the potential reasons for FGM prevalence being overestimated in other European countries would also apply in Scotland. Notably, there is the possibility that women who have migrated are from population groups within their home countries that have lower FGM prevalence. These could be particular tribal groups, more highly educated people or those coming from urban areas. Lothian is not a dispersal region for asylum seekers and refugees, but is more likely to be an attractive destination for migrant professionals to study or work, and this may be reflected in these findings. Although Lothian has a sizeable Sudanese population, there are relatively few residents from countries in the Horn of Africa where FGM is most prevalent and which make up large numbers of the affected populations seen in other parts of the UK.[17,20,21]

The sensitivity of country of birth for identifying women at risk of FGM was 81% in this study, or 89% of women who delivered and had country of birth registered. This was far more sensitive than using the 'genital cutting or piercing' question and tick box and underlines the importance of asking this discretionary question at booking and acting on the answer. The negative predictive value (probability of no FGM if not born in a country from the UNICEF list) is very high, at over 99%. However, we cannot recommend relying exclusively on this one, potentially culturally insensitive, question of country of birth as this might miss women from other countries not currently on the UNICEF list. Second-generation females, who over time will form a steadily larger group, would also be missed.

In an attempt to maximize FGM ascertainment, our methodology utilized multiple sources of data to help identify cases. While we were meticulous in examining the electronic records for any mention of FGM, we cannot be certain that healthcare workers always recorded when it was detected or that they used the terms included in our search. Also there may be women with apparently minor physical signs of FGM or previous deinfibulation who were not diagnosed, as described in other studies.[22] The extent of this is unknown but would inevitably lead to an underestimate rather than serve to inflate the true figure of women affected by FGM.

A national survey with FGM status ascertained accurately is the gold standard for determining the prevalence of women with FGM in a country. There have been efforts in several European countries, including innovative modelling to allow for how migrants might be different from the general population of their home country.[6,8,13] The methods chosen are largely determined by the population records and medical record-keeping systems existing in that particular country. To our knowledge this is the first report of linking birth registrations to clinical records to improve ascertainment of FGM cases.

Future steps

As almost all women having babies in Scotland use NHS services and register their births with NRS, we had access to records for virtually all births. The electronic mTRAK system facilitated data searches. Once all NHS Boards in Scotland use an electronic maternity record-keeping system, this method could be extended nationally. The principles could also be adapted for national data collection in future by utilizing the specialized FGM maternity services being developed in each NHS Board. Sensitive identification of FGM early in pregnancy allows specific care to be offered both during pregnancy or where women miscarry. In Lothian, prioritizing women from Nigeria, Sudan and The Gambia for more careful assessment would identify almost three quarters of women with FGM accessing maternity care.

Ethics

Caldicott approval was gained prior to undertaking the study.

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Conflicts of interest: None declared.

Key points

- With increasing international migration, FGM is an issue of high importance within the UK and other European countries.
- This study used electronic clinical records linked to national birth registration data to establish country of birth in women with evidence of FGM accessing maternity services in a 4-year period.
- A total of 126 pregnancies, or 2.8 per 1000, had evidence of FGM.
- Country of birth had a sensitivity of 81% for identifying women at risk of FGM, but there are probably more countries worldwide where FGM is practiced than previously confirmed. Positive predictive value of country of birth is only 18% overall, so there will be many false positives from country of birth alone. Negative predictive value is 99%.
- Extrapolating survey data on FGM prevalence from the countries of maternal birth tends to overestimate the extent of FGM in migrants.

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Short Report

Is food insecurity associated with maternal health among UK ethnic groups? An exploration of women in the BiB cohort

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Food insecurity is a determinant of maternal health; however, research on the health impact of food insecurity among mothers of varying ethnicities is under-developed. We assessed the association of food insecurity and health among white British and Pakistani mothers. Data from the Born in Bradford cohort were matched with data on food insecurity and self-reported health from the nested BiB1000 study ($N = 1280$). Food insecurity was associated with elevated odds of fair/poor health among white British mothers but not Pakistani mothers. Adjusting for financial security, the association between food insecurity and poor health was not significant among either white British or Pakistani mothers.

Introduction

Food insecurity among women during the postnatal period may have serious implications for the well-being of the mother and development of the child. Mothers in food insecure households often compromise their own intake to ensure their children have sufficient food.[1] Although this may attenuate the direct effect of food insecurity on children's consumption, it may not protect children from the wider effects of food insecurity, including strain in parent–child interactions and poor infant feeding practices.[1]

The strength of the association between food insecurity and poor maternal health may be dependent on ethnicity. In the UK, despite the consistent relative health disadvantage of Pakistani/Bangladeshi groups compared with the white ethnic majority, the degree to which ethnic inequalities in health are attributable to socioeconomic differences between and within ethnic groups is equivocal.[2] This may be to do with difficulties in measuring entrenched social disadvantage within and between ethnic minority groups,[2] racial discrimination and/or sociocultural factors, including social and familial networks and varying