

The Influence of Ethnicity and Displacement on Quality of Antenatal Care: The Case of Roma, Ashkali, and Balkan Egyptian Communities in Kosovo

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Abstract

The conflict in Kosovo created mass displacement and a fractured health system. Roma, Ashkali, and Balkan Egyptian communities are particularly vulnerable to discrimination and exclusion from institutions. We aimed to examine Roma, Ashkali, and Balkan Egyptian disparities in quantity and quality of antenatal care received. We conducted a cross-sectional study in August 2012 with 603 women aged 15 or older who had given birth in the previous two years. We measured quantity of antenatal care using number of visits and quality of care using antenatal checklists. We used linear regression with interaction terms of displacement and type of health institution (for example, Serbian or Kosovar) to assess ethnic disparities in antenatal care. Women from Roma, Ashkali, and Balkan Egyptian communities received poorer quantity and quality of antenatal care compared to Kosovar Albanian and Serbian women. In adjusted models, Roma, Ashkali, and Balkan Egyptian women scored 3.5 points lower [95% CI (-5.2, -1.8)] on the checklists. Roma, Ashkali, and Balkan Egyptian women who were displaced received even poorer quality of care. Ethnic disparities exist in quality of antenatal care. Women from Roma, Ashkali, and Balkan Egyptian communities receive the poorest quality of services. As Kosovo strives to build a multiethnic health care system, a focus on equity is important to ensure the right to health for Roma, Ashkali, and Balkan Egyptian women.

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Background

Historical context

The countries of the former Yugoslavia faced extreme economic hardship, political instability, and social disconnectedness after the conflicts in the 1990s.¹ In Kosovo, the war created displacement and a refugee crisis of Kosovar Serbians, Kosovar Albanians, and Roma, Ashkali, and Balkan Egyptians.² Roma, Ashkali, and Balkan Egyptian communities in particular faced high levels of discrimination and prejudice during and after the conflict.³ A crisis of lead poisoning among Roma, Ashkali, and Balkan Egyptians during the United Nations Interim Administration Mission in Kosovo in UN refugee camps, and the failure of UN and Kosovar political leaders to respond, serves as a stark example of discrimination experienced by the community.⁴ More recently, segregation among ethnic groups in Kosovo, which was strongly present in the immediate years after the war, has decreased due to efforts by the international community, NGOs, and Kosovar government institutions. However, residential segregation remains in the municipality of Mitrovica where Kosovar Albanians and Kosovar Serbians live on opposite sides of the Ibar River.⁵

Who are Roma, Ashkali, and Balkan Egyptian communities?

Roma constitute Europe's largest ethnic minority with approximately 10–12 million Roma residing within European borders, of which the majority, 50–60%, reside in Central and Eastern Europe.⁶ In the context of Kosovar ethnic tensions, populations that had historically been labelled as Roma began to identify themselves as Ashkali and Balkan Egyptian, with their own respective cultural and social norms, and predominant use of the Albanian language.⁷ In the Kosovar context, the narratives and discourse of Roma, Ashkali, and Balkan Egyptian identities were complicated by the ethno-social and political environments during the time. Political forces at the time viewed Roma as more aligned to the Serbian cause, and deemed Ashkali and Balkan Egyptians as aligned with the Albanians during

and after the war. The political and institutional systems further exploited these identities and narratives for political leverage.⁸ In research of Roma, Ashkali, and Balkan Egyptian communities, the three ethnic groups are often considered together, although distinct, because of their socioeconomic position and health profiles relative to majority populations in the countries in which they live.⁹

Roma, Ashkali, and Balkan Egyptians have experienced oppressive disenfranchisement throughout Europe's history.¹⁰ They have experienced discrimination and persecution from state level actors, institutions, and society in general. Roma faced genocide during the Holocaust and Roma women have faced forced sterilization and removal of children. Roma, Ashkali, and Balkan Egyptians experienced suppression of language, identity, and culture, witnessed a rise in ethnic hate crimes post-Communism, and experienced high levels of forced displacement during the break-up of Yugoslavia and the ensuing wars in the 1990s.¹¹ Roma, Ashkali, and Balkan Egyptians continue to encounter discrimination, which has been identified as an important social determinant to health.¹²

Research comparing Roma, Ashkali, and Balkan Egyptians to other ethnic groups in their countries of residence indicates that they have poorer health-related outcomes.¹³ This extends to reproductive, maternal, and child health outcomes as well. A population-based study of 8,938 non-Roma and 1,388 Roma hospitalized singleton births in the north and southwest regions of the Czech Republic found that Roma women were 4.5 times more likely than non-Roma women to have a low birth weight baby.¹⁴ They were also 2.8 times more likely than non-Roma women to have a pre-term birth.¹⁵ Quality of care may also be poorer among Roma women. Qualitative research in the capitals of Serbia and Macedonia, and in settlements in southeast Slovenia with Roma, has shown lack of respect and poor quality of care in their experiences with reproductive health care services.¹⁶ In one study, Roma women stated they would like to receive more understandable information from their gynecologist and also discussed unease when accessing

gynecological care; this indicates that provider and patient communication and information sharing may be a barrier.¹⁷ A concern of the published literature is that Ashkali and Balkan Egyptians are often not the focus, while Roma receive particular attention, especially in European Union nations.

Health system in Kosovo

Since Kosovo declared independence in 2008, it has made substantial progress in reviving the post-war health system, but the system struggles from underfunding, slow progress of health care reform, limited availability of services, a growing private sector that operates with out-of-pocket payments, and limitations in access and utilization of health services by ethnic minorities.¹⁸

Unlike other post-Yugoslavia countries, Kosovo did not continue the social insurance system after the dissolution of Yugoslavia.¹⁹ A direct taxation system, without a purchaser-provider split, was established to enable basic financing of the health care system. This ensured an allocation of about 8–10% of the total Kosovo budget toward health care financing, which accounted for around 3% of Kosovo's GDP.²⁰

However, Roma, Ashkali, and Balkan Egyptian communities in particular have faced substantial barriers in access to health care services.²¹ In the creation of the new Kosovar state, the Kosovar government emphasized and enshrined in the constitution the creation of multiethnic state institutions and the protection of human and minority rights.²² But this has not been smooth and has been particularly problematic in the health care sector. In Serbian communities in North Mitrovica, the government of Serbia funds and operates parallel health care facilities.²³ According to a Kosovo Women's Network report, a majority of Kosovar Serbian women seek antenatal care services in a Serbian-managed health facility, and Roma, Ashkali, and Balkan Egyptian communities reported lower quality of the patient-provider relationship as compared to Kosovar Albanian and Kosovar Serbian women.²⁴

Quality of antenatal care

The World Health Organization (WHO) recommends a minimum of four antenatal care visits for women globally in order to ensure adequate antenatal care. Coverage or the proportion of women receiving four or more antenatal care visits has long been the predominant measure of antenatal care quality.²⁵ It was an indicator to measure progress in the Millennium Development Goals and for the United Nations Secretary General's Commission for women and children's health.²⁶ Although an important indicator, quantity of care does not capture the substance or content of the antenatal care visit. Research has shown that there is variation in practice quality, as measured by medical vignettes, clinical observations, and household reports, although patients may have higher frequency of doctor visits.²⁷ For example, research in two middle-income countries, Mexico and Indonesia, showed that patients in poorer areas received lower-quality antenatal care.²⁸ Das and Gertler also found that indigenous persons in Mexico received lower quality care in private sector settings and to a much lower extent in the public sector as well.²⁹ A 2009 UNICEF study showed that 81% of all women had blood pressure, urine, and blood samples taken during antenatal visits, while 71% of Roma, Ashkali, and Balkan Egyptian women had the same services provided.³⁰ However, these data only included findings primarily collected on Kosovar Albanian women; no information could be calculated for the Kosovar Serbian women because the sample size was not large enough for analytic purposes.

Displacement and health issues

Prior research has also shown that displaced and refugee women tend to receive poorer health care services in their countries of residence than non-displaced and non-refugee women.³¹ During and post-conflict, support systems, such as health care, kin, and support networks become destabilized and in some cases destroyed.³² The destabilization has long-term ramifications for the health of those displaced, particularly maternal and child health. In recent years, Western Euro-

pean governments have forcibly deported Roma, Ashkali, and Balkan Egyptian communities to Kosovo.³³ Displacement and movement, in tandem with a fractured health system, may further restrict ability to access antenatal care.

Objectives and aims

Historical contexts, pervasive institutional discrimination, and displacement during war all play important roles in disparities in maternal health care. The objectives of our study were to assess the interplay of ethnicity, displacement, and institutions and their influence on the quality of antenatal care among women of Roma, Ashkali, and Balkan Egyptian communities in post-conflict Kosovo. Our aims were to (1) examine differences in demographic and psychosocial characteristics by ethnicity among women in Kosovo; (2) explore differences in content of antenatal care services; (3) assess the interaction between ethnicity and displacement on antenatal care outcomes among women in Kosovo; and (4) investigate how ethnicity, displacement, and type of institution (Kosovar vs. Serbian government-run) all interplay to influence quality of antenatal care.

Methods

We conducted a survey in Kosovo to assess ethnic inequalities in access and quality of maternal health care. Fieldwork took place in August 2012. We approached women who had given birth in the previous two years and were 15 years of age or older in each of the three main ethnic groups of Kosovo to participate in the study.

We sampled Kosovar Albanian, Kosovar Serbian, and women from Roma, Ashkali, and Balkan Egyptian communities. We utilized multi-staged cluster random probability sampling, in combination with purposive and snowball sampling, which was informed by consultation with experts in the current location of Roma, Ashkali, and Balkan Egyptian and Kosovar Serbian populations. We enumerated the sample in three ways: (1) for the Kosovar Albanian sub-sample, the 2011 Kosovo census was used; (2) for the Kosovar Ser-

bian sub-sample, both the 2011 Kosovo census and estimates from the Kosovo Office of Statistics were used due to the fact that Kosovar Serbian populations in Northern Kosovo did not participate in the Kosovo census and; (3) the 2005 Organization for Cooperation Security in Europe (OSCE) municipal profiles were used to enumerate the Roma, Ashkali, and Balkan Egyptian population. We designed each sampling point in the Kosovar Albanian and Roma, Ashkali, and Balkan Egyptian sub-samples to have four effective interviews, and five effective interviews in the Kosovar Serbian sub-sample. The residential breakdown was 40% urban and 60% rural. In the urban areas, we first contacted the third house or address number from the starting point. In the rural areas, we utilized purposive sampling by contacting a knowledgeable person in the village (such as a village head or elderly woman) and then every *n*th household was selected (for example, if eight households were eligible and the number of effective interviews was four, then every second household was selected). If the rural sampling point could not be completed with the effective number of interviews required, a nearby village was selected and was clustered within the same sampling point. In the Roma, Ashkali, and Balkan Egyptian sample, this occurred in four sampling points, while in Kosovar Albanian and Kosovar Serbian communities, the rural sampling points were completed in one village. In the Kosovar Albanian sample, 9% of the sample was conducted via snowball sampling and 12% in the Kosovar Serbian sample. We conducted face-to-face paper and pencil interviews. Both the Kosovar Ministry of Health and the Rutgers Biomedical Health Sciences Institutional Review Board approved the project.

Variables

Predictor. The main predictor of interest was ethnicity, categorized as Kosovar Albanian, Kosovar Serbian, and the combined Roma, Ashkali, and Balkan Egyptian communities. In addition, we included displacement as an interaction variable to examine whether experiences of displacement varied by women in the various ethnic groups. Displacement was assessed using the question, “Have

you ever been displaced?” We also included type of institution (Serbian versus Kosovar-government run) as an additional interaction variable.

Outcome. For antenatal care visits, we operationalized adequate care as four or more antenatal care visits (yes vs. no). The quality of antenatal care variable was based on two guidelines. We based the physical health and examination content (for example, “Did you receive an ultrasound”) on WHO guidelines.³⁴ We created the content on communication (for example, “Did the doctor advise you about antenatal supplements?”) using the United States Centers for Disease Control and Prevention (CDC) Pregnancy Risk Factor Assessment Survey.³⁵ For quality of antenatal care, we summed responses to a list of 20 antenatal care services and communications received during antenatal care visits. The maximum score possible was 20. We then created a composite score that combined the services and communication scores. Higher scores indicated higher quality of antenatal care.

Statistical methods. We first conducted univariate analyses; we report means and standard deviations for continuous variables and frequencies and percentages for categorical variables. We used a chi-square measure of association for categorical bivariate analyses, t-tests for continuous variables, and analysis of variance (ANOVA) for analyses of continuous variables by categorical with three or more groups (such as ethnicity). For all findings, p-values are reported.

We performed unadjusted linear regression analyses on antenatal care quality by ethnicity. Then, we ran adjusted linear regression models of ethnicity while controlling for education and age at first birth. We included displacement and location of service in additional adjusted linear regression models. We also employed adjusted (for education and age of first birth) linear regression models with interaction variables of ethnicity and displacement, where non-displaced Kosovar Albanian women served as the referent category. We developed adjusted (for education and age of first birth) linear regression models with the three-way interaction of ethnicity, location of service, and displacement.

In these models, non-displaced Kosovar Albanian women receiving care in a Kosovar institution were the reference. In the Kosovar Serbian population, only two women had less than four antenatal care visits, thus we did not conduct regression models on this outcome. We report the regression coefficient and respective 95% confidence intervals. We used Stata 13 to analyze the data.³⁶

Results

Sampling outcomes

A total of 603 women participated in the study: 200 in the Kosovar Albanian sub-sample, 200 in the Kosovar Serbian sub-sample, and 203 in the Roma, Ashkali, and Balkan Egyptian sub-sample with an overall response rate of 93.3%. The response rate in the Kosovar Albanian sub-sample was 89.3%, in the Kosovar Serbian sub-sample, 92.2%, and in the Roma, Ashkali, and Balkan Egyptian sub-sample, 99%. The high response rate among the Roma, Ashkali, and Balkan Egyptian sub-sample is typical of community-based research we have conducted.³⁷ Of the 203 women in the Roma, Ashkali, and Balkan Egyptian sub-sample, 25% (n=50) identified themselves as Roma, 54% (n=111) as Ashkali, and 21% (n=42) as Balkan Egyptian.

Sample characteristics

Roma, Ashkali, and Balkan Egyptian women had the highest percentage of women with primary education or less (95%, n=191), as compared to 5% (n=10) of Kosovar Serbian, and 46% (n=92) of Kosovar Albanian women (Table 1). Kosovar Serbian women’s income was predominantly from salaries (87%, n=174), followed by Kosovar Albanian women (71%, n=141), while 45% (n=90) of Roma, Ashkali, and Balkan Egyptian women received social assistance as their main form of income. Kosovar Albanian women comprised the largest group of women displaced, 43% (n=87), followed by 33% (n=67) of Roma, Ashkali, and Balkan Egyptian women, and 18% (n=35) of Kosovar Serbian women. Lastly, the three communities live segregated from one another. Ninety six percent (n=176) of Kosovar Albanian women lived in

exclusively Albanian neighborhoods, 99% (n=179) of Kosovar Serbian women lived in exclusively Serbian neighborhoods, and 70% (n=122) of Roma, Ashkali, and Balkan Egyptian women lived within their own communities.

Pregnancy and antenatal care characteristics

Roma, Ashkali, and Balkan Egyptian women had the lowest average age of first birth, 20.3 years (standard deviation (SD)=4.7), compared to 23.6 years (SD=3.9) among Kosovar Serbian women, and 24.1 years (SD=4.6) among Kosovar Albanian women. Of all women (displaced and non-displaced) Roma, Ashkali, and Balkan Egyptian women had the highest percentage of women with less than four antenatal care visits; 19% (n=37); while 6% (n=11) of Kosovar Albanian and 1% (n=2) of Kosovar Serbian women received less than four antenatal care visits. Roma, Ashkali, and Balkan Egyptian women also had the lowest quality of antenatal care (Table 2). Out of a total possible score of 20, Roma, Ashkali, and Balkan Egyptian women had a mean content

score of 13.6 (SD=4.3), Kosovar Albanian women a mean score of 17.1 (SD=4.8), and Kosovar Serbian women a mean score of 18.4 (n=3.5). As seen in the figures, Roma, Ashkali, and Balkan Egyptian women had the lowest frequencies for receipt of various antenatal care services and communication around antenatal care issues (Figures 1 and 2).

Unadjusted analyses of antenatal care quality

In unadjusted analyses, Roma, Ashkali, and Balkan Egyptian women had received poorer antenatal care. Roma, Ashkali, and Balkan Egyptian women had a mean antenatal content score that was three [$\beta=-3.0$, CI (-3.8, -2.0)] points lower than Kosovar Albanian women’s mean score (Table 3). Kosovar Serbian women’s mean score was 1.5 [$\beta=1.5$, CI (0.7, 2.3)] points higher. Displaced women’s mean scores were 0.83 [$\beta=-0.83$, CI (-1.6, -0.4)] lower than non-displaced women (table not shown). In adjusted models, Roma, Ashkali, and Balkan Egyptian had scores that were two points lower [$\beta=-2.0$, CI (-3.0, -0.9)], while Kosovar Serbian women had

Table 1. Sample characteristics among mothers who gave birth in previous two years, Kosovo, all women, 2012

Variable	Kosovar Albanian	Kosovar Serbian	Women from Roma, Ashkali, Balkan Egyptian communities	
	N (%)	N (%)	N (%)	p-value
Education				<0.00
Primary or less	92 (45.8)	10 (5.0)	191 (95.0)	
Secondary	79 (39.3)	138 (69.0)	6 (3.0)	
University or higher	30 (14.9)	52 (26.0)	4 (2.0)	
Income source				<0.00
Salary/pension	141 (70.9)	174 (87.0)	32 (16.0)	
Social assistance	15 (8.0)	9 (4.5)	87 (45.0)	
Temporary employment	24 (12.1)	5 (2.5)	43 (21.5)	
Other	18 (9.1)	12 (6.0)	35 (17.5)	
Displacement				<0.00
Displaced	87 (43.3)	35 (17.5)	67 (33.2)	
Not displaced	114 (56.7)	165 (82.5)	134 (66.3)	
Inclusion in financial decisions				<0.00
Excluded	79 (44.4)	20 (10.5)	62 (38.8)	
Included	92 (51.7)	168 (87.9)	91 (56.9)	
Sole	7 (3.9)	3 (1.6)	7 (4.4)	
	Mean (standard deviation)	Mean (standard deviation)	Mean (standard deviation)	p-value
Age	29.0 (5.1)	27.5 (4.9)	27.2 (6.0)	<0.01
Age at first birth	24.1 (4.6)	23.6 (3.9)	20.3 (4.7)	<0.00

scores that were 1.3 points higher [$\beta=1.3$, CI (0.4, 2.1)]. In adjusted models (for education, age of first birth, displacement, and location of service), Roma, Ashkali, and Balkan Egyptian women's mean scores were 2.3 points lower [$\beta=-2.3$, CI (-3.5, -1.2)], as compared to Kosovar Albanian women.

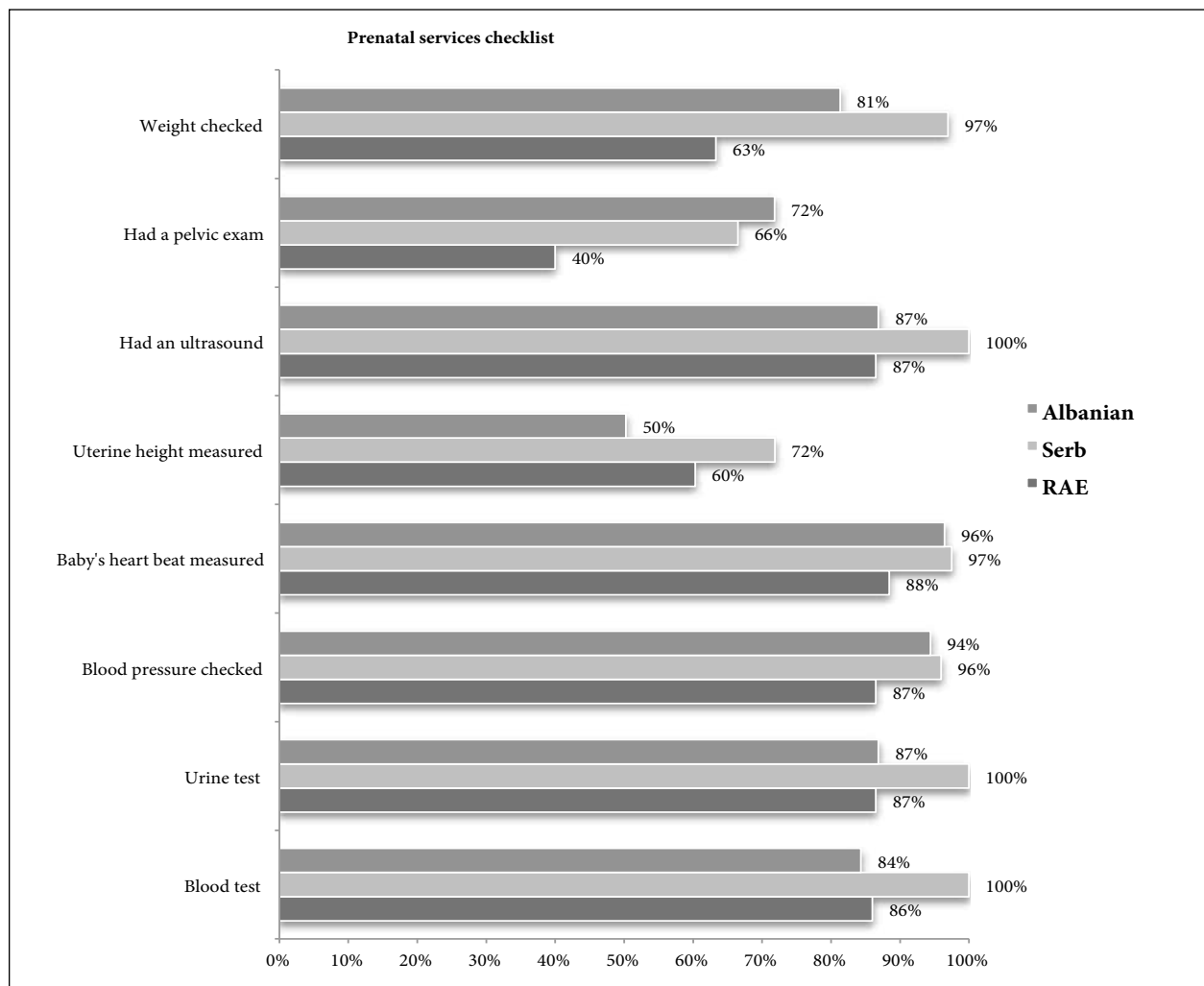
Adjusted interaction analyses of antenatal care quality

In the adjusted interaction model, non-displaced Roma, Ashkali, and Balkan Egyptian women's mean score was two points lower [$\beta=-2.1$, CI (-3.5, -0.7)], as compared to non-displaced Kosovar Albanian women. Non-displaced Kosovar Serbian women's mean score was 0.8 points higher [$\beta=0.8$, CI (-0.5, 2.1)], as compared to non-displaced Koso-

var Albanian women. In addition, displaced Roma, Ashkali, and Balkan Egyptian women had a mean score that was 2.4 points lower [$\beta=-2.4$, CI (-4.0, -0.90)], while displaced Kosovar Serbian women's mean scores were 1.7 points higher [$\beta=1.7$, CI (-0.1, 3.5)], although not significant.

In examination of location of service, Kosovar Albanian and Kosovar Serbian women overwhelmingly sought care in institutions within their own ethnic group. However, Roma, Ashkali and Balkan Egyptian women receiving care in Kosovar institutions had mean scores that were 2.4 points lower [$\beta=-2.4$, CI (-3.5, -1.3)], as compared to Kosovar Albanian women receiving care in Kosovar run institutions. Roma, Ashkali, and Balkan Egyptian women receiving care in Serbian-run institutions

Figure 1. Receipt of antenatal care examination services among women in Kosovo, all women, 2012



had mean scores that were not significant. Kosovar Serbian women receiving care in a Serbian-run institution had a mean score that was 0.8 points higher [$\beta=0.8$, CI (-0.09, 1.8)], as compared to Kosovar Albanian women receiving care in a Kosovar-run institution.

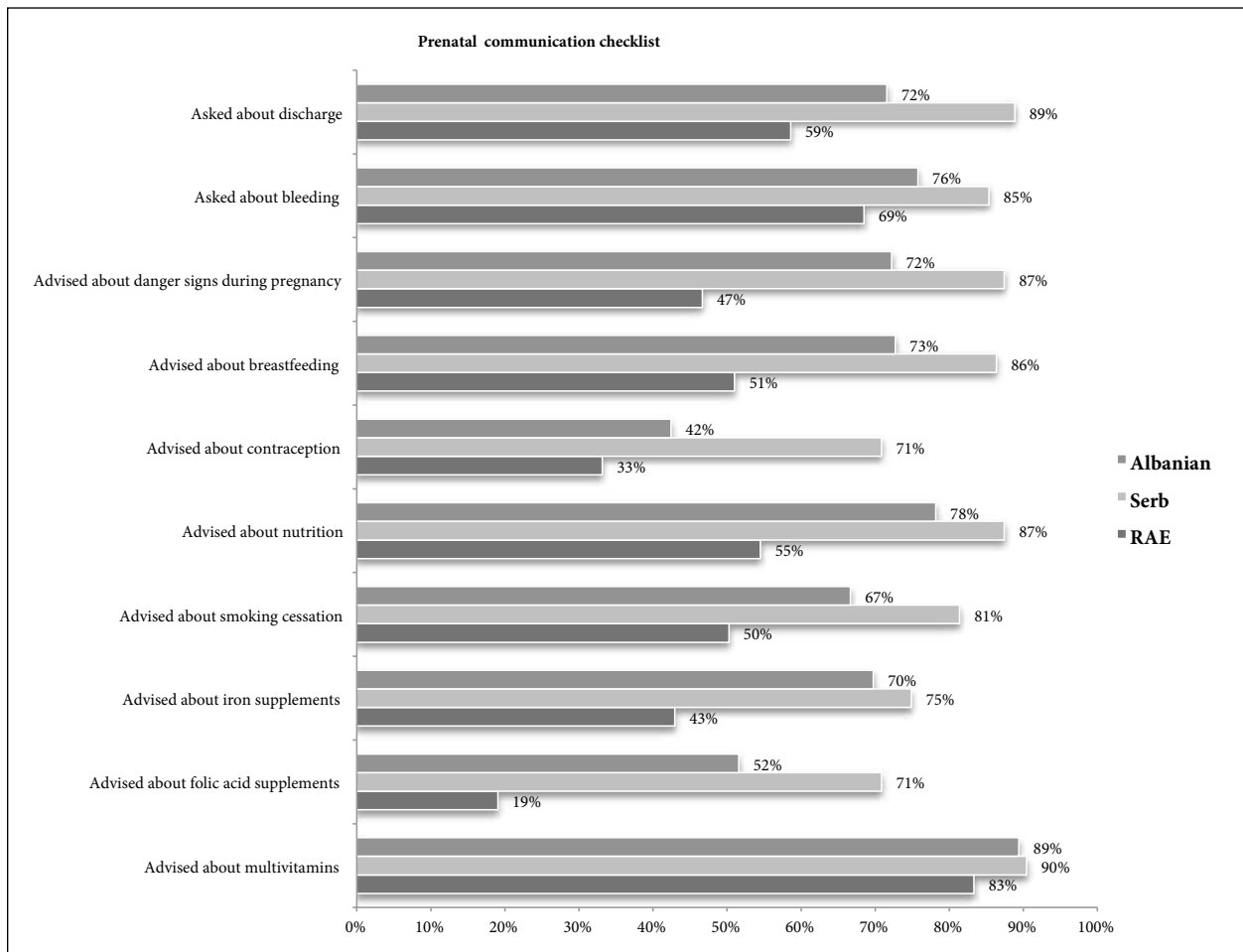
In the three-way interaction of ethnicity, displacement, and type of institution, Roma, Ashkali, and Balkan Egyptian women received the lowest quality of care regardless of the various interactions. Non-displaced Roma, Ashkali, and Balkan Egyptian women receiving care in a Kosovar-run institution had mean scores that were 2.1 points lower [$\beta=-2.1$, CI (-3.5, 0-0.8)], and non-displaced Roma, Ashkali, and Balkan Egyptian women receiving care in a Serbian-run institution had mean scores that were 3.3 points lower [$\beta=-3.3$, CI (-6.2, -0.4)]. Among displaced Roma, Ashkali, and Balkan Egyptian women

receiving care in Kosovar-run institutions, their mean score was three points lower [$\beta=-3.0$, CI (-4.6, -1.5)], while those receiving care in Serbian-run institutions saw no difference in their scores.

Discussion

We found ethnic inequities in the quality of antenatal care among women in Kosovo. Women from Roma, Ashkali, and Balkan Egyptian communities as compared to Kosovar Serbian and Kosovar Albanian women received poorer quality antenatal care as identified by the use of antenatal care checklists. Stratified analysis indicated that women from Roma, Ashkali, and Balkan Egyptian communities received fewer antenatal examinations and, to an even greater extent, poorer quality of communication regarding antenatal care. Women from Roma, Ashkali, and

Figure 2. Completion of essential checklist items that require communication, all women, 2012



Balkan Egyptian communities that had a history of displacement during and after the conflict received even poorer antenatal care services, especially those in the Kosovar-run institutions. These findings indicate that as Kosovo develops multiethnic state institutions, specifically the health care system, improvements are needed. Particular attention should be paid in development of communication guidelines. Communication guidelines can help providers working with ethnic communities to ensure cultural humility and sensitivity, which research has shown is necessary in ensuring the right to health for child-bearing women.³⁸

A previous UNICEF study called attention to the need for improved antenatal care in Kosovo.³⁹ However, these data may mask differences in quality of antenatal care services, as the findings do not analyze specific subgroups of Kosovar Albanian, Kosovar Serbian, and Roma, Ashkali, and Balkan Egyptian women. The outdated 2011 Kosovar census was largely used to develop the clusters from which women were sampled, indicating potential concerns about representation. In addition, data on Kosovar Serbian women could not be calculated due to the limited sample. It is important to ensure that subgroup analyses are incorporated because findings from the region show that Roma, Ashkali, and Balkan Egyptian women and lower socioeconomic status Roma, Ashkali, and Balkan Egyptian women have poorer birth outcomes.⁴⁰

Antenatal care is an important point of intervention to improve birth outcomes and child

health.⁴¹ Although most women in Kosovo deliver in hospitals, as our findings show, women from Roma, Ashkali, and Balkan Egyptian communities received poorer antenatal care services.⁴² Prior research has shown that discrimination is prevalent among Roma women (focus was explicitly on Roma, as Ashkali and Balkan Egyptian are a smaller group in Europe) seeking maternal health services across Europe encounter discrimination.⁴³ This discrimination creates demand-side concerns, where Roma women refuse to access care due to concerns of stigma or cultural and language barriers, thus limiting access to antenatal care. Furthermore, the discrimination Roma, Ashkali, and Balkan Egyptian women experience serves to exacerbate issues surrounding acceptable and quality antenatal health services.⁴⁴

Our findings suggest that displaced Roma, Ashkali, and Balkan Egyptian women who receive care in Kosovar institutions received the poorest-quality antenatal care. War and forced displacement disrupts the lives of those impacted, as well as all governmental systems including health and rule of law. One structural barrier for Roma, Ashkali, and Balkan Egyptian women is statelessness due to lack of government documentation.⁴⁵ Although we did not ask for documentation in our survey, it is possible that displaced Roma, Ashkali and Balkan Egyptian women were less likely to have identification documents, making it more difficult to access antenatal care. In addition, the fact that the quality of care received by Roma, Ashkali, and Balkan Egyptian women was lowest in

TABLE 2. Differences in antenatal care use and quality among women in Kosovo, all women, 2012

	Frequency of antenatal care visits			Antenatal content score	
	<4 visits	4+ visits	p-value	Mean score	
	N(%)	N(%)		Mean (standard deviation)	p-value
Variable					
Ethnicity			0.00		<0.00
Roma, Ashkali, Balkan Egyptian communities	37 (19.5)	153 (80.5)		13.6 (4.3)	
Kosovar Serbian	2 (1.1)	176 (98.9)		18.4 (3.5)	
Kosovar Albanian	11 (5.7)	183 (94.3)		17.1 (4.8)	
History of displacement			0.646		<0.04
Displaced	19 (10.4)	163 (89.6)		14.3 (4.1)	
Not displaced	31 (8.2)	348 (91.8)		15.1 (4.0)	

Kosovar institutions in particular could be due to barriers such as language and government policy. Roma tend to speak Romani or Serbian in Kosovo, while Ashkali and Balkan Egyptian generally speak Albanian. Because Kosovar institutions use the Albanian language, Serbian and Romani speakers may face language barriers in communicating with the health care staff. Furthermore, health insurance financing and ability to pay are different according to Kosovar and Serbian policies, which may alter how the institutions are run. Health insurance in Serbian-run institutions would follow Serbian law, which may allow Roma, Ashkali, and Balkan Egyptians access to health insurance by declaring they are part Roma, Ashkali,

or Balkan Egyptian.⁴⁶ However, Kosovar law doesn't guarantee health insurance rights via this avenue and no social insurance is provided, thus limiting the ability of Roma to pay for services, which could influence quality of care received. Finally, displaced Roma, Ashkali, and Balkan Egyptian communities may be more likely to live in isolated neighborhoods and have lower income levels, creating geographic and ability to pay variation in quality of care that could explain our findings. We were not able to test these hypotheses in this study, but the suggestion that formerly displaced Roma, Ashkali, and Balkan Egyptian women might be most vulnerable in accessing health care might be explored in further qualitative research and during

TABLE 3. Unadjusted and adjusted analyses of antenatal care quality among women in Kosovo, 2012

	Antenatal care content score	
	β	95% CI
Model 1 (n=455)		
Ethnicity		
Kosovar Albanian	Reference	
Roma, Ashkali, and Balkan Egyptian communities	-2.91	(-3.77, -2.05)
Kosovar Serbian	1.50	(0.72, 2.28)
Model 2 (n=452)		
Ethnicity		
Kosovar Albanian	Reference	
Roma, Ashkali, and Balkan Egyptian communities	-1.93	(-2.98, -0.88)
Kosovar Serbian	1.26	(0.41, 2.12)
Education		
Primary or less	Reference	
Secondary	0.81	(-0.23, 1.86)
University or greater	1.31	(0.11, 2.50)
Age of first birth	0.11	(0.03, 0.19)
Model 3 (n=405)		
Ethnicity		
Kosovar Albanian	Reference	
Roma, Ashkali, and Balkan Egyptian communities	-2.35	(-3.47, -1.22)
Kosovar Serbian	0.52	(-1.32, 2.36)
Education		
Primary or less	Reference	
Secondary	0.60	(-0.52, 1.72)
University or greater	1.26	(-0.02, 2.55)
Age of first birth	0.11	(0.03, 0.20)
Primary health clinic		
Kosovar Albanian institution	Reference	
Kosovar Serbian institution	0.37	(-1.26, 2.00)
Displacement		
Non-displaced	Reference	
Displaced	0.04	(-0.75, 0.83)

needs assessment activities.

This research study is particularly important as it could support existing efforts to address the needs of Roma, Ashkali, and Balkan Egyptians with regards to antenatal care. In April 2017, the Kosovar government approved a new national strategy for Roma, Ashkali, and Balkan Egyptian communities including a section on health and with an emphasis on maternal health.⁴⁷ Health care reform processes have been ongoing since 2011 with attempts to address many structural issues within the Kosovo health care system, such as access to care, financing, quality of care, and accountability of health professionals. The data from our study could help to inform these processes and provide an opportunity to address access issues of Roma, Ashkali, and Balkan Egyptian communities in antenatal care through development or adjustment of policies and guidelines, as well as strengthening of mechanisms for their implementation. Our findings also highlight the need for accountability during these processes, particularly for vulnerable populations, and that implementation should be monitored to ensure penetration of new guidelines among all population groups. Given that strategies are under way, the Kosovar Ministry of Health should work with community stakeholders to ensure that efforts meet the specific needs of women from Roma, Ashkali, and Balkan Egyptian communities. These findings should also prove useful as Kosovo continues to strive toward implementing WHO recommendations for maternal health care.⁴⁸ Numerous barriers exist in implementing the recommendations, including fragmentation of the health care system, an urban-rural division, and limited health care infrastructure due to conflict. Finally, this research could provide direction for international stakeholders (such as Lux Development, Swiss Development Cooperation, The World Bank, UNFPA, UNICEF) and the NGO sector in Kosovo, which is active in supporting the health care sector.

A few limitations of our study should be noted. First, the cross-sectional nature of the study limits the ability to determine causality. Women from Roma, Ashkali, and Balkan Egyptian communities

may have limited experiences with public services more generally, and patients from Roma, Ashkali, and Balkan Egyptian communities and the health care staff attending them may find effective communication a challenge. Other omitted variables may include low demand for health care services, which is a symptom of widespread societal and institutional discrimination, as has been shown in other research.⁴⁹ Second, we had to create a combined ethnic Roma, Ashkali, and Balkan Egyptian ethnic group in order to include all women in the analyses. However, the heterogeneity of these populations may also influence outcomes, particularly in regards to Ashkali, and to a lesser extent, Balkan Egyptians being viewed as “Albanized.” However, research among Roma, Ashkali, and Balkan Egyptian communities shows that each of the three representative groups face similar issues, such as discrimination, social exclusion, poverty, and poor health due to the ethno-politics of the country and greater region.⁵⁰ Another limitation is that our displacement measure might represent a different construct for different ethnic groups. Sources suggest that majority of Kosovar Albanians were displaced during the conflict, but also have returned to their original home voluntarily. In contrast, Roma, Ashkali, and Balkan Egyptian groups have been more likely to be permanently displaced to a new location and be forced to return to Kosovo, creating many barriers to protection of their rights and access to health.⁵¹ Self-report of antenatal care and clinical patient checklists could be another limitation, particularly for different ethnic groups across different socioeconomic indicators. A research study in Mozambique has shown that women are able to recall aspects of their care, but not all, and that socioeconomic factors are also at play.⁵² In addition, “yes or no” items on a clinical checklist tell us that woman received, for example, an ultrasound, but we don’t know what the ultrasound was looking for and if results were provided to women. Furthermore, the checklist assumes that providers communicate that services are being provided to their patient. However, a particular service could have been completed, but the woman never notified, further complicating issues of the right to

health. In order to improve upon our understanding of the acceptability and quality of care, patient-centered approaches and questions are needed. Items included in the WHO Responsiveness Model, such as respect, dignity, and shared decision-making may be particularly helpful in guideline development and future research efforts with Roma, Ashkali, and Balkan Egyptian communities.⁵³ Despite the limitations, the checklists in this study, particularly around issues of communication, are important additional pieces of information not normally included in international studies of antenatal care, and particularly among women in Roma, Ashkali, and Balkan Egyptian communities. Lastly, we do not have enough information to conjecture about why differences in quality of care exist for Roma, Ashkali, and Balkan Egyptian communities depending on the type of institution they visit (Kosovar versus Serbian-government run). The policies and guidelines in the Kosovar and Serbian institutions may be markedly different, with one following Serbian government regulations and the other the newly developed Kosovar regulations. In addition, the Kosovar health system has begun privatization, which has grown substantially over the years. As shown in prior research, greater levels of discrimination may exist in private health institutions.⁵⁴ Lastly, we understand that the use of ethnicity, particularly of Roma, Ashkali, and Balkan Egyptian communities, only serves as a proxy to the underlying and complex socio-political conditions they face in post-conflict Kosovo.

There are also many aspects of our study that lend to its credibility. We worked directly with Roma, Ashkali, and Balkan Egyptian communities and Kosovar Serbian based NGOs to ensure representation of the Roma, Ashkali, and Balkan Egyptian communities and Kosovar Serbian communities. We pilot tested the survey with women from NGOs representing Roma, Ashkali, and Balkan Egyptian communities to ensure cultural humility and sensitivity of the questions. We also conducted the study in the local languages of participants, and when possible, we completed questionnaires with women in privacy or with other women household members in attendance. We

also conducted regular site visits to monitor data collection quality and ensure sampling methods adhered to the protocol. In addition, our high response rates among women in all groups help to provide confidence in the findings.

As our findings show, the most vulnerable women in Kosovo, women from Roma, Ashkali, and Balkan Egyptian communities, and in particular women from Roma, Ashkali, and Balkan Egyptian communities who have been displaced, received the poorest antenatal care services in terms of quantity and quality. A focus on equity and inclusion is necessary to guarantee that policies and guidelines ensure all women in Kosovo receive equitable opportunities to access and receive appropriate high-quality care, and that their human rights are respected, protected, and fulfilled. As Kosovo moves forward with privatization and creation of a multicultural health care system, a human rights-based and patient-centered approach will be particularly important to ensure the right to health for all women.

Conclusions

Women from Roma, Ashkali, and Balkan Egyptian communities in Kosovo receive poorer care as compared to Kosovar Albanian and Kosovar Serbian women. Furthermore, a history of displacement and where they receive their services also play important roles in quality of antenatal care. As the Ministry of Health in Kosovo continues to embark upon improving maternal health care in the country, it is important that it incorporate equity, patient-centered care, and human rights-based frameworks to ensure all women in Kosovo receive equitable access and quality of services to improve child and maternal health outcomes.

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References

1. K. Desmet, M. Le Breton, I. Ortuno-Ortin, S. Weber, "The stability and breakup of nations: a quantitative analysis," *Journal of Economic Growth* 16 (2016), pp. 183-213.
2. Kondaj, R. Management of refugee crisis in Albania during the 1999 Kosovo conflict. *Croatian Medical Journal* 43 (2002), pp. 190-194.
3. T. Perič, M. Demirovski, "Unwanted: the exodus of Kosovo Roma (1998 - 2000)," *Cambridge Review of International Affairs* 13 (2000), pp. 83-96.
4. P.A. Wyman, C.H. Brown, M. LoMurray, et al. "An outcome evaluation of the sources of strength suicide prevention program delivered by adolescent peer leaders in high schools," *American Journal of Public Health* 100 (2010), pp. 1653-1661.
5. J.D. Bloom, I. Hoxha, D. Sambunjak, E. Sondorp, "Ethnic segregation in Kosovo's post-war health care system," *European Journal of Public Health* 17 (2007), pp. 430-436.
6. European Commission. *The social and economic integration of the Roma in Europe*. Available at: <http://eur-lex.europa.eu/legal-content/en/ALL/?uri=CELEX:52010DC0133>.
7. R. Zemon, *History of Ashkali Identity* (Strasbourg, France: Interculturalism and The Bologna Process, April 2010).
8. C. Lichnofsky, "Ashkali and Egyptians in Kosovo: New ethnic identifications as a result of exclusion during nationalist violence from 1990 till 2010," *Romani Studies* 23 (2013).
9. T. Vrenezi, *The Position of Roma, Ashkali, and Egyptian Communities in Kosovo*. (Prishtine, Kosovo: Kosovo Foundation for Open Society, 2009).
10. European Union Agency for Fundamental Rights. *Second European Union Minorities and Discrimination Survey Roma - Selected Findings*. (Luxembourg, Luxembourg: European Union, 2016)
11. D. Crowe, *A History of the Gypsies of Eastern Europe and Russia*. (New York: St. Martin's Press, 1995); Y. Matras, "Scholarship and the politics of Romani identity: strategic and conceptual issues," *European Yearbook of Minority Issues* 10 (2011), pp. 211-247; C. Donert, "Creating 'Citizens of Gypsy Origin': Ethnicity, Planning and Population Control in Socialist Czechoslovakia," In: *Zukunftsvorstellungen Und Staatliche Planung Im Sozialismus: Die Tschechoslowakei Im Ostmitteleuropaischen Kontext* (Munich: 2010), pp. 89-114.
12. T. Janevic, D. Gundersen, K. Stojanovski, et al. "Discrimination and Romani health: a validation study of discrimination scales among Romani women in Macedonia and Serbia," *International Journal of Public Health* 60 (2015), pp. 669-677; T. Janevic, T. Osypuk, K. Stojanovski, et al. "Associations between racial discrimination, smoking during pregnancy and low birthweight among Roma," *European Journal of Public Health* 27 (2017), pp. 410-415.
13. Z. Kósa, G. Széles, L. Kardos, et al. "A comparative health survey of the inhabitants of Roma settlements in Hungary," *American Journal of Public Health* 97 (2007), pp. 853-859; Matrix. *Report on the Health Status of the Roma Population in the EU and Monitoring Data Collection in the Area of Roma Health in the Member States*. (European Union, August 2014); D. Kaluski, K. Stojanovski, G. McWeeney, et al. "Health insurance and accessibility to health services among Roma in settlements in Belgrade, Serbia-the journey from data to policy making," *Health Policy and Planning* 30 (2014), pp. 976-984; K. Stojanovski, G. McWeeney, N. Emiroglu, et al. "Risk factors for low vaccination coverage among Roma children in disadvantaged settlements in Belgrade, Serbia," *Vaccine* 30 (2012), pp. 5459-5463; S. Stanković, S. Živić, A. Ignjatović, et al. "Comparison of weight and length at birth of non-Roma and Roma newborn in Serbia," *International Journal of Public Health* 61 (2016), pp. 69-73; P. Balázs, I. Rákóczi, A. Grenzler, K. Foley, "Risk factors of preterm birth and low birth weight babies among Roma and non-Roma mothers: A population-based study," *European Journal of Public Health* 23 (2013), pp. 480-485; S. Hajioff, M. Mckee, "The health of the Roma people: a review of the published literature," *Journal of Epidemiology and Community Health* 54 (2000), pp. 864-869.
14. M. Bobak, J. Dejmek, I. Solansky, RJ. Sram, "Unfavourable birth outcomes of the Roma women in the Czech Republic and the potential explanations: a population-based study," *BMC Public Health* 5 (2005).
15. Ibid.
16. T. Janevic, P. Sripad, E. Bradley, V. Dimitrievska, "'There's no kind of respect here' A qualitative study of racism and access to maternal health care among Romani women in the Balkans," *International Journal of Equity in Health* 10 (2011); M. Logar, D. Pavlič, A. Maksuti, "Standpoints of Roma women regarding reproductive health," *BMC Women's Health* 15 (2015).
17. Janevic (2011, see note 16).
18. Bloom (see note 5); S. Suisse, *A Proposal for a Health Insurance Plan: How Does It Affect Us?* (Prishtine, Kosovo: 2012); DI Consulting. *Barriers in Access to Primary Health Care*. (Prishtine, Kosovo: 2015).
19. M.S. Stanculescu, G. Neculau, *The Performance*

of Public Health-Care Systems in South-East Europe: A Comparative Qualitative Study (Belgrade, Serbia: Friedrich-Ebert-Stiftung, 2014).

20. Suisse (2012, see note 18).
21. DI Consulting (2015, see note 18).
22. Republic of Kosovo, Assembly of Kosovo. *The Kosovo Constitution*. (Prishtine, Kosovo: June 2008); A. Beha, "Minority Rights: An Opportunity for Adjustment of Ethnic Relations in Kosovo?," *Journal of Ethnopolitics and Minority Issues in Europe* 13 (2014), pp. 85-110.
23. Bloom (2007, see note 5).
24. Bloom (2007, see note 5); N. Farnsworth, K. Goebels, R. Ajeti, *Access to Healthcare in Kosovo* (Prishtina, Kosovo: Kosovo Women's Network, 2016). M. Telaku, R. Engel, E. Raunio, et al. *New National Health Insurance Will Save Lives Life Expectancy and Health in Kosovo's Roma, Ashkali and Egyptian Communities*. (Prishtine, Kosovo: Kosana, 2016).
25. S. Hodgins, A. D'Agostino, "The quality-coverage gap in antenatal care: toward better measurement of effective coverage," *Global Health Science and Practice* 2 (2014), pp. 173-181.
26. Ibid.
27. J. Das, P.J. Gertler, "Variations in practice quality in five low-income countries: A conceptual overview," *Health Affairs* 26 (2007), pp. 296-309.
28. Ibid.
29. Ibid.
30. Kosovo Agency of Statistics. *Kosovo Multiple Indicator Cluster Survey* (Prishtine, Kosovo: UNICEF, 2014).
31. T. Ejigu, M. Woldie, Y. Kifle, "Quality of antenatal care services at public health facilities of Bahir-Dar special zone, Northwest Ethiopia," *BMC Health Services Research* 13 (2013); E.T. Kibiribiri, D. Moodley, A.K. Groves, M.H. Sebitloane, "Exploring disparities in prenatal care between refugees and local South African women" *International Journal of Gynecology and Obstetrics* 132 (2016), pp. 151-155; C. Owens, J. Dandy, P. Hancock, "Perceptions of pregnancy experiences when using a community-based antenatal service: A qualitative study of refugee and migrant women in Perth, Western Australia," *Women and Birth* 29 (2016), pp. 128-137.
32. World Health Organization. *Reproductive Health during Conflict and Displacement*. (Geneva, Switzerland: 2000).
33. H. Castañeda, "European Mobilities or Poverty Migration? Discourses on Roma in Germany," *International Migration* 53 (2014).
34. J. Villar, H. Ba'aqeel, G. Piaggio, et al. "WHO antenatal care randomised trial for the evaluation of a new model of routine antenatal care," *Lancet* 357 (2001), pp. 1551-1564.
35. Centers for Disease Control and Prevention. *Pregnancy Risk Assessment Monitoring System*. (Atlanta, Georgia: 2012). Available at: <https://www.cdc.gov/prams/aboutprams.htm>.
36. StataCorp. *Stata Statistical Software* (College Station, TX: StataCorp LLC, 2013).
37. Stojanovski (2012, see note 13); Janevic (2015, see note 12).
38. E. Coast, E. Jones, A. Portela, S.R. Lattof, "Maternity care services and culture: A systematic global mapping of interventions," *PLoS One* 9 (2014), pp. 1-17.
39. Kosovo Agency for Statistics (2014, see note 30).
40. Vrenezi (2009, see note 9); Stojanovski (2012, see note 13); Janevic (2011, see note 16); B. Cook, G.F. Wayne, A. Valentine, et al. "Revisiting the evidence on health and health care disparities among the Roma: A systematic review 2003-2012," *International Journal of Public Health* 58 (2013), pp. 885-911.
41. Coast (2014, see note 38).
42. Kosovo Agency for Statistics (2014, see note 30).
43. H.L. Watson, S. Downe, "Discrimination against childbearing Romani women in maternity care in Europe: a mixed-methods systematic review," *Reproductive Health* 14 (2017).
44. Ibid.
45. W. Troszczyńska-van Genderen, *Rights Displaced Forced Returns of Roma, Ashkali, and Egyptians from Western Europe to Kosovo* (Human Rights Watch, 2010).
46. Kaluski (2014, see note 13).
47. E. Lantscher, "Protection of Minority Communities in Kosovo: Legally Ahead of European Standards - Practically Still a Long Way to Go," *Review of Central and East European Law* 33 (2008), pp. 451-490.
48. S.E. Straus, J.E. Moore, S. Uka, et al. "Determinants of uptake of maternal health guidelines in Kosovo: qualitative study," *Implement Science* (2013), pp. 1-34; J.E. Moore, S. Uka, J.P. Vogel, et al. "Navigating barriers: two-year follow up on recommendations to improve the use of maternal health guidelines in Kosovo," *BMC Public Health* 16 (2016).
49. Organization for Security and Cooperation in Europe (OSCE). *OSCE Mission supports policies for inclusion of vulnerable communities in Kosovo*. (2016). Available at: <http://www.osce.org/kosovo/281301>.
50. Janevic (2015, see note 12); Janevic (2017, see note 12).
51. Vrenezi (2009, see note 9).
52. C.K. Stanton, B. Rawlins, M. Drake, et al. "Measuring Coverage in MNCH: Testing the Validity of Women's Self-Report of Key Maternal and Newborn Health Interventions during the Peripartum Period in Mozambique," *PLoS One* 8 (2015).
53. M. Scheerhagen, H.F. van Stel, E. Birnie, et al. "Measuring Client Experiences in Maternity Care under Change: Development of a Questionnaire Based on the WHO Responsiveness Model," *PLoS One* 70 (2015), pp. 1-19.
54. Das (2007, see note 27).