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SOSYAL BELİRLEYİCİLERİN ROMAN KADINLARIN SAĞLIK ALGISI ÜZERİNE ETKİSİ: KALİTATİF ARAŞTIRMA

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Özet

Giriş: Sağlığın sosyal belirleyicileri açısından Romanlar diğer gruplara göre daha dezavantajlı durumdadır. **Yöntem:** Bu nitel çalışmanın verileri odak grup görüşmeleri ile toplanmıştır. Araştırmanın örneklemini araştırmaya katılmayı kabul eden 21 Roman kadın oluşturmuştur. **Bulgular:** Çalışmada Roman kadınların ekonomik yetersizlik, işsizlik, düşük eğitim yada eğitimden yoksun kalma, kötü barınma koşulları, sosyal destek yetersizliği, toplumsal cinsiyet eşitsizliği, dışlanma gibi birçok eşitsizliğe maruz kaldıkları sonucuna ulaşılmıştır. **Tartışma:** Roman kadınları ve Roman toplumu için sağlığı sosyal yönden etkileyen faktörlerin giderek daha sorunlu hale gelmeye devam ettiği, nesilden nesile aktarılan ve sürekli yenilenen bir kısır döngü içinde yaşanmaya maruz kalındığı düşünülmektedir. **Öneriler:** Toplum sağlığı hemşireleri eşitsizlikleri önlemek ve azaltmak için her türlü alanda yerel ve ulusal çalışmalara katılabilir ve aktif olarak savunuculuk rolü üstlenebilir.

Anahtar Kelimeler: Roman-Kadın, Algı, Sosyal Belirleyici, Sağlık, Niteliksel Araştırma, Hemşirelik.

THE IMPACT OF SOCIAL DETERMINANTS ON THE HEALTH PERCEPTIONS OF ROMANI WOMEN: A QUALITATIVE STUDY

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Abstract

Introduction: In terms of the social determinants of health the Romani population are more disadvantaged position than other groups. **Methodology:** This qualitative study data were collected in focus group discussions. The study sample consisted of 21 Romani women willing to participate in the research. **Results:** The study, it was concluded that Romani women are exposed to many inequalities such as economic inadequacy, unemployment, low education or lack of education, poor housing conditions, lack of social support, gender inequality, exclusion. **Discussion:** It is thought that the factors affecting health socially continue to become more and more problematic for Romani women and the Romani society and that they are exposed to a vicious circle that is passed on from generation to generation and is constantly renewed. **Conclusion:** Community health nurses can participate in local and national studies in all fields and actively take an advocacy role in order to prevent and reduce inequalities.

Keywords: Romani-Women, Perceptions Social Determinants, Of Health, Qualitative Research, Nurses.

Introduction

The social determinants of health are the foundation of health and refer to the conditions that affect our health and wellbeing. Poor conditions do not constitute a direct cause of illness, but they may signify the start of a string of factors that may lead to disease (Marmort & Bell, 2012). The World Health Organization (WHO) defines the social determinants of health as “conditions in which people are born, grow, live, work and age” that in turn shape the conditions of daily life. The organization also emphasizes that social determinants are influenced by policies, development plans, social norms and political systems (WHO, 2008; Marmort & Bell, 2012; Braveman & Gottlieb, 2014). An individual’s personal emotions, thoughts, preconceived notions and expectations regarding their own health is referred to as their “health perception.” It is important when evaluating an individual’s state of wellbeing to base the assessment not only on objective health data but also on how the person perceives their health (Bandura, 1999). Perceptions of health are formed under the influence of family, living conditions and the social environment (Diamond et al. 2007). The Romani community lives with poverty, inadequate education, unemployment, and unfavorable living and sheltering conditions. The community is unable to benefit sufficiently from healthcare services (Çetin, 2017; Ilhan & Firat, 2017). Studies have reported that the poor and the uneducated are more likely to have health problems compared to their wealthy and educated counterparts and that they die at earlier ages (Adler & Stewart, 2010; Parekh & Rose, 2011; Cook, Wayne, Valentine, Lessios & Yeh, 2013; Braveman & Gottlieb, 2014). To eliminate inequities in healthcare and ensure that public health is protected and improved, it is necessary to pinpoint the social mechanisms that define health. The social determinants of health are an important part of all disciplines, particularly in the context of public health nurses working in primary healthcare services (Marmort & Bell, 2012; Guney & Ulus, 2018). There is a steadily growing need to provide services that address social determinants in the effort to eliminate inequities in the provision of health services (Andermann, 2016). Romani women encounter inequities at a greater degree than women in other communities (Ravnbol, 2010; Cetin, 2017). There is only a limited number of studies that have explored how the social determinants of health have affected the lives of Romani women (Eskiocak & Akbasak, 2017). This study aimed to shed light on the health perceptions of Romani women and how these perceptions are formed by social determinants, exploring their viewpoints and experiences in a qualitative research design.

Method

Design

This qualitative study used the technique of conducting in-depth focus group discussions. Research questions in qualitative studies differ from those in quantitative studies where data is collected from a study sample and analyzed. The data collected from a qualitative design cannot be reduced to figures as in quantitative research. Instead, the main purpose of the research is to offer the reader comprehensive information about a realistic situation. In the discussion technique, participants offer their views and experiences as directly as possible (Streubert & Carpenter, 1999).

Sample and Setting

The study sample consisted of Romani women living in a crowded rural district of Istanbul. Using the purposive sampling method, 30 women consenting to participate who were between the ages of 18-65, married and who were parents were invited to take part in the research. Family nurses working in the family health centers in the same district were asked for their support in the sample selection. Since 9 of the women did not appear at the discussions on time, the study was ultimately carried on with 21 Romani women (Table 1).

Table 1. Descriptive Characteristics of the Women (N=21)

Table 1. Participants Characteristics (N=21)		
	N	%
Education		
Not literate	12	57.1
Literate	9	42.9
Working Status		
Working	3	14.3
Not working	18	85.7
Number of Children		
1-3	19	90,5
4 and above	2	0.95

Data Collection

The method of focus group discussions was used in the data collection. The questions in the discussions were derived through a scan of the literature and were decided upon after the opinions of two public health specialists were obtained so that the comprehensiveness and validity of the questions could be ascertained. A semi-structured discussion form was employed as a data collection instrument. Two female faculty members with doctorates from the Public Health Nursing Department conducted the data collection. The focus group discussions were held on a face-to-face basis at the Family Health Center with the support of the district family health nurse. The discussions took place in two groups of 10-11 individuals. The discussions were recorded. The researchers at the same time took notes on the body language of the participants. The information gathered at the discussions were kept confidential. Each discussion took approximately 90 minutes. After the discussions were completed, the researchers analyzed the voice recordings, combining these with their observational notes to obtain raw data.

The participants were asked the following questions:

1- What do you understand from the word “health”? How much can you benefit from health services? What are your opinions on this?

2- What difficulties do you experience in the matter of health? Can you say something about this?

3- Can you speak about the difficulties you faced in your children’s education, your own education? What can you say about the difficulties you experienced?

4- What do you think about the general effect on your health of living conditions, the environment you live in, your working conditions, education and the social support that you receive? Why is that?

Data Analysis

The raw data were transferred to the Windows Word program (Microsoft Office Professional Plus 2013). The data were read over repeatedly and then classified. The responses of the participants in the voice recording were analyzed in terms of their comments, the number of participants, the same type of comments, the meanings of the same words the participants used, and the originality of the answers. The answers the participants gave to each matter

discussed were evaluated one by one and grouped in terms of the similarity and difference between the responses. Each researcher read the raw data separately, coding and grouping the information into themes. The opinions of two specialists were obtained regarding the coding and themes (Kumbetoğlu, 2005; Streubert & Carpenter, 1999).

Ethical Considerations

Approval was received for the conduct of the study from Marmara University, Faculty of Health Sciences Ethics Committee (14.1 2019-23). The purpose of the research was explained to the participants and their written consent was received. In the analysis of the data, the participant's name was encoded with a letter and a number. The themes and sub-themes set out were shared with the participants and their verbal approval was obtained.

Results

Discussions were held in this study with 21 Romani women (Table 1). The mean age of the women was 29.6; their mean age when they were married was 16, and 57.1% had never attended school. It was found that 85.7% of the women were unemployed, and 90.5% had between 1-3 children. Content analysis was performed on the research data. Seven main themes and six sub-themes emerged from the study regarding the participants' perceptions of health and their thoughts and experiences about social determinants (Table 2).

Table 2. Main and Subthemes

Main Theme	Sub-Theme
1. Perceptions of the concept of “Health”	Health is being able to bring home the food Reaching health services is hard.
2. Unfavourable school climate	Lack of a role model in the family for continuing education the disadvantages of not being able to get an education
3. Difficulties with shelter and living conditions	You can’t even call what we live in a house
4. Social support	
5. The concept of a home	
6. Economic conditions	
7. Gender	Glorifying the Male

Theme 1. Perceptions of the concept of “Health”.

More than half of the participants defined health as being able to work, bring home the food and earn money. The women believed that health meant that their husbands could work and be bring home money. It was only when someone was too sick to work that they seriously considered the state of health. Very few defined health as being “the state of not being sick.” In short, the participants defined health as “bringing home the food and being well enough to earn money.”

Health means bringing home the food (P4). Otherwise, how can you live when you don’t work? Money can’t come in on its own. (P17). Thank God if you’re well enough to work so you go on working. Health means working. Our husbands need to be well to earn money and bring home the food so that we can be healthy (P6).

1.1 Health is being able to bring home the food.

More than half of the women in the study defined health as the ability to earn the money for food. Working to earn money and being able to use this money for their expenses, mostly for food, was what they perceived as being healthy.

Our people have this idea about health—first of all, it's economic, because you can't have health if you don't have money (P10). When you don't have money, you can't buy food, you can't buy fruit, when you don't have money, you can't get anything (P18). When you don't have money, you can't feed your kids. For me, health means money (P11).

1.2 Reaching health services is hard.

Almost all of the participants said they had difficulty reaching health services. They said this was because they lived far from the hospital, they could not get the medicines they needed because of high co-payments that had to be paid. They also stated that they could only get off-the-counter medicines from the pharmacies.

We go and have prescriptions made out for nothing. We can't get the medicines because they're too expensive (P2). It's very expensive when the state doesn't help pay for the medicines. There are baby formulas that they advise but we can't get them. We usually just take the kids to the hospital. The hospitals are too far away. (P7).

Theme 2: Unfavorable school climate.

The participants said that they could not sufficiently benefit from educational opportunities, either for their children or for themselves. This made them feel sad and hopeless. While regarding school as important, they emphasized that they did not want their children to be exposed to violence in school and that this was an important reason their children dropped out.

The kids are afraid, they don't go to school. They're afraid of being beaten up (P8). The other kids beat them up. We want the beatings to stop. We were never able to go to school. We want them to be educated. My child says, "Mom, I'm afraid, they beat me up and take my money." (P11).

2.1 Lack of a role model in the family for continuing education.

The participants said that their children didn't remain in school because their parents hadn't gone to school. They said that they felt they weren't good models for their children. The participants also stressed that going to school only brought deeper problems and their children were drop-out candidates because of their economic and social circumstances.

They don't go to school because there is no one in the family who has gone (P1). Our parents didn't send us to school. Our husbands never went either. People their age have already learned to read and write but they haven't. My children have been going to school for five years, but they haven't learned anything (P8). When the kids don't go to school, neither the teacher nor the school administration ever calls to find out why (P13).

2.2. The disadvantages of not being able to get an education.

Close to half of the participants had either dropped out of school or never gone to school at all. Dropping out of school due to marrying at a young age seems to be prevalent in the Romani community. The participants said that not having an education affected their daily lives—they had difficulty identifying which bus or other public vehicle to ride, they could not help their children with their schoolwork, and they experienced problems with finding a job.

We can't find a job because we don't have an education. Our children are going to be just like us (P11). Maybe, God forbid, they can even be worse than us (P14).

Theme 3: Difficulties with shelter and living conditions.

Almost all of the participants stated that they lived in a neighborhood that had unsanitary conditions due to economic reasons.

If I didn't have financial difficulties, if I had money, if I had a house, if I could get all my kids' lives together, I would say, OK, I'm saved. Everyone is miserable, the cold comes in through every crack in the house (P3).

3.1. *You can't even call what we live in a house.*

Almost all of the participants said that they didn't consider what they lived in to be a proper house. They confided that they were lacking in proper heating and didn't have basic conveniences like a bath or a toilet. They said they tried to keep warm by burning the garbage they collected off the streets.

We live in shacks. You can't call it a house. We don't have any firewood. I mean, the house is freezing. I'm sick (P5). When it's cold, we have to go under the blankets. The firewood is never enough. We burn the garbage we collect. We have 2 or 3 rooms in the house, but I can only heat up one of them. Sorry to disgust you, but we live together with the rats (P6). We don't have a water subscription because we don't have the money to pay for it. I make use of my neighbor's bath (P10).

Theme 4: Social support.

All of the participants said they received financial aid from the district mayorship or municipality. They believe however that the aid they get is not enough to meet their needs. Since their neighbors, friends and relatives have similar economic means, they said that no one is in any position to help anybody else out financially.

We get aid but it's not enough. I can't even pay for my kid's school fees (P14). You can see everyone's situation here. Which one of us can help anybody else? The situation at our parents' is even worse. We get a little bit of provisions from the Municipality (P17).

Theme 5: The concept of a home.

More than half of the participants said they had hope for their children and spouses in their family life. They stated that they felt more secure if they had their children and their spouses at home. They said they wanted to go out to earn money together with their children. This is another reason that Romani children tend to break off from their life at school. Although their living conditions may be bad, they feel it important that they can find shelter in their homes.

My family life revolves around the children. I want to find a job that I can do at home or find one that I can do with my children. My home means everything to me because of my children. We're thankful we have a roof over our heads and we're not in the streets (P9).

Theme 6: Economic conditions.

All of the participants said they were unemployed; some said they could not find a steady job. They said that due to economic uncertainties, their children in particular could not benefit from health services and they were sad because they couldn't provide their children with enough food.

My husband is very upset that he can't earn enough money, provide for us and bring home the food. So, what can we do? (P19) It's my husband who looks after me. I have an 18-year-old son but he doesn't have a job. If he had one, he'd support me. I have a daughter. The doctor says I have to look after her and protect her. The doctor says, take this, do that, but we can't get or do anything he prescribes. There are days when I just cry... (P3).

Theme 7: Gender.

More than half of the participants said that their husbands occupied a very important place in their lives. They stressed that there were groups of people in the Romani community who treated women differently. In some families, they said, the man took on the role of the head of the family and in some, the woman was forced to work in order to contribute to the household. The women said that if both genders brought home the food, this would mean that gender equality had been achieved.

Some men drink a lot and make their women work. Our husbands aren't like that, they want to support their wives. They support their wives, when the wife is sick, for instance. You'd want to go to work, he'll say don't go. And he'll care for you at home. Thank God, bless his heart (P16).

7.1. Glorifying the Male.

Different cultures set forth different ideas about gender roles and what is and what is not appropriate or suitable for a man and a woman. Close to half of the participants stated that they did not differentiate between their sons and daughters. They said however that although their husbands wanted to have a son, they did not assume a negative attitude toward their daughters. The women stressed that it was important for them to have a man at their side, whether they had a job or not, and that this was meaningful both for them and for their children.

It's meaningful for me because I married my husband out of love. Love should last forever. I have to admit I didn't love him at first but now I do. If I don't see him for 5 minutes, I feel I need to see him (P13).

Discussion

The social determinants of health are the conditions that affect health that we were born into, grew up in and now work in. These conditions may be the indirect, if not the direct, cause for the state of being healthy (Marmot & Bell, 2012; Aytac & KurtDas, 2015). This study explored the impact of the social determinants affecting the health perceptions and health of Romani women living in a rural area, while also determining their thoughts and experiences. Economic, social and environmental conditions are directly related to the factors that lead to inequalities in healthcare. Studies carried out in Turkey have indicated that the main issues Romani people face are social exclusion and economic difficulties (Akkan, & Deniz, 2011; Bingol & Buyukakin 2012; Tor, 2017; Cetin, 2017). Women and children are the ones to be most impacted by this (Akkan, & Deniz, 2011). Poverty and being deprived of the basic needs of shelter, food, health services and education have an adverse effect on the health perceptions and the quality of life of the Romani population (Koyun & Cicekoglu, 2011; Cubukcu, 2011; Tor, 2017; Hatipler, 2019). Studies conducted in locations in Turkey where the Romani population is more concentrated have shown that Romani children live in shack-like houses with no access to electricity or clean water (Balkiz. & Goktepe, 2014; Karan, 2017). Research carried out on the relationship between socioeconomic status and health has indicated that poor sheltering conditions and malnutrition are factors that increase mortality and the incidence of illnesses (Aytac & KurtDas, 2015). In the present study as well, it was similarly found that living with no water, the lack of baths and toilets, not having heat in the house and similar deprivations led to a heightened risk of infection and disease.

It was reported in a study carried out in Turkey with Romani people that their rate of unemployment was 80%-85% and the proportion of employed working under the social security system was 1%-2% (Alp & Tastan, 2011). This study emphasized that it was very important that the man in the household had a job, brought in some income and was able to meet the needs of the family. It was also noted however that income levels in Romani families were markedly inadequate. Only a small percentage of the women work and their economic contribution to the household is minimal. The Romani women said that they were forced to take their school-age children with them when they went to work or made them stay at home to take care of the younger children. This is an important factor that plays a role in their children's dropping out of school. At the same time, there is no action to resolve this issue on the part of schools and local administrations, which leads to a deepening of this deficiency in educational opportunities.

It has been shown that Romani women are farther behind in their education than Romani men (Gokce, 2019). In this study, more than half of the women (56%) had never attended school. The women do not want their children to go through what they have suffered due to a lack of education. On the other hand, they are not able to support or help their children in their education since they do not have the educational background nor the economic power to do so. The poverty among individuals in the Romani community, violence, exclusion, being forced to marry and/or work at young ages, and the inability to become a role model for the next generation are strong factors that prevent Romani children from getting an education (Tor, 2017). The inadequate system in place that does not help school administrators and teachers to follow up on absentee children, the system that requires fees for uniforms and for participation in various school activities are also elements that lead the children of economically disadvantaged families to leave school. There is in fact not enough data in Turkey on the school enrolment, late registration, absenteeism or dropout behavior of Romani children. The United Nations International Children's Emergency Fund (UNICEF), however, reports that Romani children exhibit the lowest school enrolment percentages (Karan, 2017). The results of our study indicate that there needs to be long-term studies conducted to expand efforts to satisfy the education, employment, health and shelter needs of this community at an optimum level. The literacy rate in the Romani community in Turkey is much lower than in the general population, with some regions exhibiting an illiteracy rate of 90 % (Koyun & Cicekoglu, 2011). Romani children are generally not a part of the educational system after primary school (Cook et al., 2013; Cetin, 2017). Romani women say that they face economic and social barriers when it comes to accessing health services because they live far away from the city center, out of the

locational range of hospitals. The fact that some health services have to be acquired for a fee, especially the requirement of paying a contributory fee for some medicines, cause the Romani people to terminate their treatment. In a study carried out in Edirne, a city where there is a concentration of Romani citizens, it was seen that despite the system of applying to family health centers, the Romani community is not fully able to benefit from health services because of the contributory payment requirement for medicines (Eskiocak & Akbasak, 2017).

Girls and boys are treated differently in the Romani community. In patriarchal societies, women are usually at a disadvantage compared to the men in the family (Cubukcu, 2011; Cetin, 2017; Gokce, 2019). The Romani people say they cannot send all of their children to school because of the conditions of poverty and they ultimately have to make a choice, which they exercise by sending their sons to school rather than their daughters. Besides destitution and discrimination, other factors that play a role in ending a girl's school life in this community is being assigned the responsibility of doing housework and taking care of the other children in the family. It was reported in a study conducted in districts of Istanbul where the Romani community lived that girls in the family were more disadvantaged and could not go to school because their parents would not allow them to, that they were forced to do housework, look after the other children or sell flowers on the street (Alp & Tastan, 2011).

Romani women's lives are stressful since they carry the responsibilities of housework, childcare and tending to the members of a crowded household. It can be said that women bear most of the burden of poverty in the family (Cubukcu, 2011). Men have been assigned the duty of working outside of the home and earning money. With the man outside of the home for most of the time, the woman is left to cope with the hardships of poverty and childcare, which can often lead to feelings of hopelessness and psychological stress. A study was conducted in the Slovak Republic on the correlation between mortality and the factors of education, unemployment and income. The results demonstrated that mortality rates for Romani men were higher than for women and that men died at earlier ages (Rosicova, et al. 2009). The study reported that the participants defined the concept of "health" as being well enough to bring home some income. For Romani women, being able to work and earning money is the most important definition of health. The participants look at health from a cultural viewpoint. Romani women believe that a husband and children are the fundamental elements of a family. In a study carried out in an area of Istanbul predominantly inhabited by Romanis, the marriage rate was found to be 90%, and the rate of being in a first marriage was 92.2% (Kolukirik, 2006). In this study, almost all of the Romani women stressed that they did not have adequate social support. In particular, the women voiced their interest in being able to benefit from public

resources. Most of the participants are able to benefit from the free services offered by the Social Security Administration. It has been noted that 35.6% of the Romani population however does not benefit from social security (Kolukirik,2006). It has been reported that unemployment, poverty and a lack of social security are major barriers in satisfying the needs of daily life and that the inadequacy of state systems leads to isolation (Hatipler,2019).

Conclusion

This study presented data on the viewpoints of Romani women living in a rural area of Istanbul regarding their health perceptions and the social determinants impacting health and other aspects of their lives. Our results showed that the factors that stood out the most in this context were poverty and inadequacies in education, shelter, access to health services, nutrition, social support and being deprived of social security. It can be seen from the results of our study of Romani women that the social determinants of health are at insufficient levels and continue to become progressively problematic, subjecting the Romani community to live in a constantly regenerating vicious circle of distress that is carried over from one generation to the next. In the context of the social determinants of health and the cycle of life, the Romani women predominantly perceive “health” to be “the state of being well enough to work.” Romani women and their families need to be included in national and localized programs designed to reduce the health inequities they suffer. Poverty, being deprived of educational opportunities, poor living conditions and the difficulties of accessing healthcare are risk factors that should be the target of interventions in an effort to bring these risks to a minimum. It has been shown once again that as a disadvantaged segment of the population, the Romani people represent a group that must be supported in terms of health and its social determinants. In the light of our results, our recommendations might be the following:

- In the awareness that healthcare is the primary right of every individual in the world and in Turkey, equitable, free, high quality health services should be provided to disadvantaged groups and policies should make these services readily available;
- Local administrations, civil organizations, educational institutions, university initiatives should collaborate in providing Romani woman and their children with education and other social and economic support in order to create sustainable systems;
- Vocational models should be made available;

- Efforts should be continued to prevent gender discrimination;
- Safe areas should be created and supported so that children have places to spend their after-school hours;
- Poverty should be addressed and barriers to benefiting from equal opportunities lifted so that illiteracy and lack of education are not transferred from generation to generation in the Romani community;
- New practices and studies should be carried out to enhance the impact of the efforts that are being implemented to eliminate inequities.

Disclosure Statement

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