

PRIMARY CARE FOR THE ROMA IN EUROPE: POSITION PAPER OF THE EUROPEAN FORUM FOR PRIMARY CARE OSNOVNO ZDRAVSTVENO VARSTVO ZA ROMSKO PREBIVALSTVO V EVROPI: AKTUALNO STALIŠČE EVROPSKEGA FORUMA O OSNOVNEM ZDRAVSTVENEM VARSTVU

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ABSTRACT

Roma populations' low health status and limited access to health services, including primary care, has been documented in many European countries, and warrants specific health policies and practices.

Keywords:

primary care, primary health care, the Roma people, the Roma people's health mediators

A variety of experiences shows how primary care can adjust its practices to reduce the barriers to primary care for Roma populations.

At local level, establishing collaboration with Roma organisations helps primary care to improve mutual relations and quality of care. Mediation has proved to be an effective tool.

Skills training of primary care practitioners may enhance their individual competences.

Research and international sharing of experiences are further tools to improve primary care for the Roma people.

IZVLEČEK

Slabo zdravstveno stanje romskega prebivalstva ter omejen dostop do zdravstvenih storitev, kar vključuje tudi osnovno zdravstveno stanje, je zabeleženo v več evropskih državah in potrjuje določena zdravstvena načela in dejavnosti.

Ključne besede:

osnovno zdravstveno varstvo, Romi, romski zdravstveni posredniki

Različne izkušnje prikazujejo načine, kako se lahko osnovno zdravstveno varstvo prilagodi dejavnostim za zmanjšanje ovir med osnovnim zdravstvenim varstvom in romskim prebivalstvom.

Vzpostavljane sodelovanja z romskimi organizacijami na lokalni ravni lahko pripomore k skupnim povezavam in kakovostni oskrbi na področju osnovnega zdravstvenega varstva. Posredovanje se je izkazalo za učinkovito orodje.

Usposabljanje izvajalcev osnovnega zdravstvenega varstva lahko izboljša zmožnosti posameznika.

Orodja za izboljšanje osnovnega zdravstvenega varstva za romsko prebivalstvo so nadaljnje raziskave in primerjanje izkušenj na mednarodni ravni.

1 INTRODUCTION

The 12 million Roma population in Europe constitutes its largest ethnic minority (1). A history of migration and exclusion in ancient and recent times has led to their dispersion over many countries and a wide variety of identities and characteristics. Many Roma people are a part of mainstream society with a health status that is comparable to that of the general population but, in contrast to the general population, low levels of education and illiteracy, low employment and a low income level are also frequent features of many Roma communities. This has resulted in a particularly low health status and high incidence and prevalence of a number of diseases among the Roma population (1-3).

This position paper is exploratory in character. Selected experts and practitioners contributed to it. The procedure to collect information on what was actually happening on the primary care level was through workshops at various conferences in Barcelona, Vienna and Istanbul. During workshops, drafts of the paper were discussed, which led to content additions and revisions. Representatives from Slovenia, Bulgaria and Belgium have presented several research projects and examples of good practices in the field of health care of the Roma. Experts received comments from the National Roma Agencies as well. In addition, authors did a PubMed survey to have relevant background information; The European Forum for Primary Care's Executive Committee endorsed the final version in accordance with its procedures.

The key objective of this paper is to assist practitioners, policymakers and researchers in Primary Care (PC), by providing information on health needs of the Roma people and on the research, policies and practices that intend to overcome the barriers to the delivery of effective Primary Care to the Roma.

This paper describes specific needs of the Roma and the barriers to good PC for them. It discusses the current context in which health care for the Roma population functions, and shows various approaches in the policy, practice and research intended to improve PC for Roma communities. A number of suggestions are offered to strengthen the skills of practitioners.

2 THE ROMA POPULATION

This paper makes generalisations about the Roma population. Yet, in no way do we intend to stigmatise the Roma and Roma communities in this paper. Further, some of the generalisations below also apply to other population groups, among them recent migrants from other continents.

The largest Roma populations are to be found in the Central and Eastern European states, such as Bulgaria, the Former Yugoslav Republic of Macedonia, Slovakia, Romania, Serbia and Hungary. In these countries, the Roma people make up between 7 and 12 per cent of the total population. In most other states, the Roma make up around one per cent, or much less, of the population (4).

2.1 Health Status

In line with the low socio-economic status of Roma communities, many health indicators are unfavourable for the Roma. Specific patterns of morbidity and mortality in Roma communities obviously vary with the composition and location of the community and with the precise socio-economic characteristics. A recent EU report, reviewing health status of Roma communities, highlights a higher incidence of major chronic diseases in the Roma community compared to the general population (4). As it could be expected, a frequently high TB prevalence is a major issue, in addition to sexual and reproductive health, including the early age at first pregnancy, abortion rate and unmet contraceptive needs. Indeed, Roma women are generally in worse health and more disadvantaged than Roma men and non-Roma people. Poor maternal health is a particular risk for Roma women.

As a consequence of isolation across generations, in some Roma communities in Eastern Europe, hereditary diseases are highly prevalent; several of them are unique to the Roma: hereditary motor sensory neuropathy type Lom, congenital myasthenic syndrome and several others. Other disorders, like G6PD deficiency, are not specific for the Roma, but in certain sub-groups they are highly prevalent (5). Due to the migration in recent years, families and individuals with these traits are now living in other regions of the world as well.

2.2 Access to Health Care

Various barriers limit the Roma people to access the health care system. Supply side and demand side barriers have been described in a number of reports and publications (6-8). The examples below illustrate the most common barriers. A major supply side barrier is a large distance to health services, including PC, for Roma communities. This influences the access to services because transport time and costs are prohibitive.

Affordability refers to the costs and prices of services. In view of the low economic status of many Roma people, this is an obvious supply side barrier. Health insurance takes this barrier largely away. However, the Roma are significantly less likely to have insurance coverage in countries of Central and Eastern Europe, except in Slovakia and Serbia, and this gap remains when adjusting for socio-economic differences between the Roma and non-Roma

populations (9). The reasons include the lack of identity papers, non-qualification for health insurance because of income or employment status, or lack of knowledge as how to access health insurance. Thanks to dedicated efforts over the last decade, in several countries the proportion of the Roma that has no identity papers or health insurance has declined drastically. Still, as late as in 2012, up to 26% of the Roma in Romania did not possess health insurance, and currently the numbers of non-insured Roma people in Bulgaria are increasing (10). In emergency situations, people do have the right to access health services without health insurance, but family planning and antenatal care are not included in the medical package for the uninsured in several countries. This results in low accessibility of antenatal care and a higher risk of complications during pregnancy, as well as high rates of low birth weight (4, 11, 12).

Acceptability is a supply side barrier when health staff attitudes express lack of respect or empathy. An overwhelming amount of personal accounts of Roma patients point at a condescending or hostile attitude of their primary care provider(s). Prejudice and lack of trust easily become reciprocal and are often fed by the Roma's distrust in public services (13-16). Fortunately, also the contrary has been documented: primary care providers committed to their Roma patients without hesitation.

On the demand side, several factors play into the actual use of health services. Language and literacy are among them. Nearly 40% of the Roma speak one of the Romani dialects. The proportion that does not speak a second language is unknown. Language barriers are responsible for misunderstandings, having a negative impact on health and health care, such as non-compliance with a prescribed treatment or late admission.

Many Roma people regard health care institutions as distressing places. They are alien spaces in which everything is different and where the established norms are, not only strange, but in many cases, at variance with their own (17). Related to (health) literacy is a frequent lack of Roma people's knowledge about the organisation of the health care system. For instance, the gatekeeping role of primary care often is not known. Opening hours of health centres or of a GP's surgery, and the purpose of diagnostic and therapeutic procedures are not understood or accepted. The purpose and timing of childhood immunisation is often not known.

Health seeking behaviour is also influenced by concepts of health and disease. Following from the large diversity of Roma communities and subcultures, there is no single, well defined set of concepts, beliefs and attitudes of the Roma towards health, health behaviour and disease. However, some values, like notions of purity and impurity,

are widespread among the Roma, and may explain the avoidance of contact with particular materials or individuals.

The place where we grew up shapes the way we think, feel, and act. Hofstede's theory of cultural dimensions describes the effects of a society's culture on the values of its members, and how these values relate to behaviour (18). Collectivism versus individualism is one of the dimensions Hofstede has identified in which Roma differ from most of the surrounding populations: the group you belong to is more important than yourself. Individuals feel complete only within a group of peers. Family is playing a major role in decision making; an individual patient's responsibility is limited. This explains the strong wish of Roma patients to be accompanied by members of the group during consultation and hospitalisation. This easily leads to controversy with staff and other patients, when these feel overwhelmed and do not understand the importance of the group being together.

2.3 The Current Policy Context Concerning the Roma People

Of relevance for the delivery of primary care to the Roma people are the current local, national and international policy initiatives that attempt to break the social barriers and widespread discrimination of the Roma. The main international initiatives are briefly reviewed below.

One of the main initiatives is the "Decade of Roma inclusion 2005-2015". Currently, 13 countries in the Central and Eastern Europe participate as members or observers, plus Spain, Norway and the United States. Four priority areas have been defined, namely: housing, education, employment and health (36). While some successes can be claimed, in early 2014, the members of the Roma decade concluded that the ultimate aims by far had not been achieved and that the Decade needs to be followed up by similar actions (19).

The EU Fundamental Rights Agency was established in 2007 as an agency with the specific task of providing independent, evidence-based advice on fundamental rights. It is EU's channel for many of its Roma policies. The "EU Framework for National Roma Integration Strategies up to 2020" has been established in 2011, which focuses on the same four priorities as the Roma Decade. Member states have to develop a National Roma Integration Strategy, and the European Commission provides an annual report to the European Parliament on the progress made regarding Roma integration (20).

The Council of Europe adds its voice and moral as well as practical guidance through another four distinct approaches, namely: (1) Effective monitoring and evaluation of the implementation of national strategies

for Roma; (2) From targeting to mainstreaming policies for Roma; (3) Ensure Roma and Travellers participation in the political process; (4) Strengthen co-operation between all stakeholders (21).

The Regional Office for Europe of the WHO supported the development of the WHO Collaborating Centre on Social Inclusion and Health in Alicante, Spain. The Centre runs a programme dedicated to the health of the Roma. It publishes a quarterly electronic "Roma health newsletter" and supports initiatives, like a symposium in Hungary on healthy ageing of the Roma in late 2014 (22).

All the above initiatives emphasise the importance of the collection and use of specific data on Roma health, and of the participation of the Roma in defining, implementing and monitoring the policies that aim to help the Roma people to integrate and eliminate exclusion.

3 PRIMARY CARE DELIVERY: ESTABLISHING AN EFFECTIVE RELATIONSHIP WITH ROMA COMMUNITIES AND PATIENTS

The concept of PC includes the notion that it adequately addresses the needs of all patients for which it is responsible, irrespective of age, gender, creed and ethnic background (23).

From the above follows that strong PC adjusts the expertise, skills and organisation of its providers to the sub-groups in the population. Therefore, we consider that PC is universal. PC for the Roma is no different from other PC, but it adapts to specific Roma population characteristics. Because of the variation in Roma communities, this adjustment needs to be done at the local or regional level. At the national and international level, measures can be taken to facilitate this local or regional adjustment.

3.1 Generic Competences

Effective communication between health care providers and patients is of key importance. Primary care providers have to be competent communicators. Effective communication skills come with knowledge and genuine motivation (24).

As described above, collectivity is a very important dimension of Roma culture. The Roma people often come in groups to emergency services or primary care consultations, which is an expression of group solidarity. The acceptance of this culture and behaviour reflects competences of health care providers. Making practical arrangements, like creating the necessary space in waiting rooms or consultation rooms when that is possible, is part of the acceptance.

3.2 Specific Competences

Language is often one of the obstacles that need to be overcome. The practice of involving family members to translate between patient and care provider has several negative effects, and guidelines have been developed to support the practice of translation. The current European RESTORE project aims to investigate the implementation of guidelines and training initiatives that support communication in cross-cultural general practice consultations. In several countries, a telephone Romani translation service is available (25).

Local or regional Roma organisations can be effective partners to establish such relationships. In Romania, a guide for General Practitioners on Roma culture was developed through an intensive consultative process between health providers and the Roma community (26). In Spain, a handbook for health providers was developed as well (27). Local studies on Roma health status, lifestyle and health (seeking) behaviour may have the double benefit of establishing relationships through the studies and of providing knowledge to primary care practitioners. Below, several examples of local, regional and national initiatives are given.

In 2013, a cervix cancer screening programme among Roma women in Oradea, Romania, gradually gained more acceptance. GPs took the responsibility for the programme and careful explanations to both the male and female population; the acceptance of the programme was ensured with the help of a Roma Health Mediator (see below). Practical obstacles, like distance and travel expenses, however, were difficult to overcome. Yet, when the funding dried up after one year, the service stopped running. This affected trust, since earlier promises to the Roma target group could not be kept. The lesson learned here is that we need continuity in (funding) policies and services.

3.3 Research and Dissemination

In a number of countries, GPs and local health services conduct research. A major point to emphasize is a close collaboration between the academia, local primary care providers and Roma organisations, which help to implement the research and may by itself contribute to trust-building. In addition, researchers may reach out to their professional peers and demonstrate as well as advocate Roma oriented research.

3.4 Slovenia

The Universities of Ljubljana and Maribor have undertaken a research programme, three outcomes of which are highlighted below. A study on smoking and smoking behaviour among the Roma showed a strong

cultural dimension of smoking. Traditional strategies for smoking cessation are largely ineffective among the Roma. Therefore, innovative and culturally acceptable methods need to be developed (28). The “Health beliefs and practices among Slovenian Roma in response to febrile illnesses” study concludes that Roma generally do not use a thermometer, but instead define health or illness according to their general wellbeing (29). The Roma frequently use traditional folk medicine (teas, compresses) to treat fever. They only see a doctor if their health problems last more than 3 days. This knowledge helps GPs in advising their Roma patients. In Goričko region, the University of Maribor supports local primary care by helping to organise education workshops for groups of Roma patients. Topics are asthma, blood pressure, diabetes mellitus and emergency.

In 2012, a new edition of the textbook on Family Medicine included a chapter on anthropology, and in 2014, a module was added to the 3-year training of GPs, which provides GPs with information on the specificity of the Roma population, their usual way of visiting primary care doctors, and recommendations on how family doctors should communicate with Roma patients.

3.5 Belgium

In Ghent, with a population of 5000 Roma, a group of primary health care centres has been strongly oriented towards community care for many years. In 2014, the city of Ghent, in collaboration with Ghent University, conducted research on the experiences of the Roma population with regard to (the access to) healthcare. The main objectives were: (1) to gain insight into the barriers that are experienced by the Roma-population; (2) to explore how the Roma experience their health; (3) to identify the factors which contribute to mutual relations of trust and respect between patients and healthcare providers. Results indicate that the Roma population in Ghent is encountering similar barriers as the Roma in other European countries. The most prominent barrier is finances. As in other countries, the Roma often have trouble to pay for health services. Language and transport also seem to be important barriers. In addition to these more practical aspects, the Roma also tend to foster distrust towards the mainstream society. In order to establish a relationship of trust between the Roma and health care providers, some specific measures can be taken, like translating services. Longer consultation times are also mentioned as being important. Lastly, the collaboration between health care providers and health care and welfare professionals, as well as the centralisation of care mean that patients can rely on one or two providers that are familiar with their background and situation, instead of having many different professionals with whom they have not established personal relationships (30).

3.6 Bulgaria

During the 1990s, alerted by the diseases of a number of their Roma patients, neurologists from the Sofia University Hospital explored the prevalence and clinical manifestations of a range of neuro-muscular conditions among the Roma in almost all Roma communities in the country. Through many visits over the years, they identified a number of rare hereditary neuro-muscular diseases, some of which had not been described before in other population groups. By quietly and respectfully explaining the symptoms and heredity, they succeeded in gaining the trust of the Roma communities, in spite of the sensitivity of the subject. Gradually, the visits developed into counselling sessions, whereby couples could discuss family planning and risk of hereditary diseases among their offspring. The good practice here is to gradually develop a relationship of trust. This practice does not originate in primary care, but rather serves to inspire primary care practitioners.

3.7 Multi-country Study

The European Centre for Disease Prevention and Control studied how the uptake of vaccinations can be improved. It concluded that one of the top interventions is to invest in education for physicians and nurses to communicate more efficiently and emphatically. It has published short guides for health staff in various languages (Let’s talk about protection) (31).

3.8 Mediation between Primary Care and Roma Communities and Patients

In several countries, there have been positive experiences with the Roma Health Mediator (RHM): a person from a Roma community, mostly female, who is trained to liaise and create an understanding between the Roma and (primary) health care services. The report, “Roma Health Mediators, successes and challenges”, reviews the experiences (32). Official RHM job descriptions vary little by country, although the actual work may vary.

In general, for the RHM, training curriculum, certification and conditions of work have gradually been optimized, supported by international studies and exchanges. The funding for this group of workers remains a challenge, since they are between the health system and community, and the final responsibility for their functioning and employment varies between and within countries. In Romania, the RHM was initially employed by an NGO and the Ministry of Health, but currently the municipalities are taking over the responsibility for their employment, emphasising that the RHM is not a health professional, but a member of a Roma community. After more than 10 years of experience with the RHM, a number of lessons learned are worthwhile to quote:

Mediators can be ineffectual if health professionals have an unclear understanding of the mediator's functions, and when they are:

- delegating all the weight of the intervention to the mediator,
- delegating all activities that healthcare professionals dislike, i.e. community interventions, to the mediator,
- using the mediator's service exclusively in situations of conflict.

Therefore, a number of prerequisites should inform the actions of mediators, namely:

- a clear definition of their role and functions;
- an adequate training;
- a coordination of their work with healthcare professionals.

In no country the number of RHMs is sufficient yet to cover at least all larger Roma communities.

4 PERSPECTIVES AND RECOMMENDATIONS FOR THE POLICY AND PRACTICE ON LOCAL, NATIONAL AND EUROPEAN LEVELS

Local primary care organisations and staff are encouraged to establish long-term cooperation with local Roma organisations because it shows, time and again, that a mutually beneficial relationship can be developed. Ultimately, this helps to improve the access to care and the quality of care for the Roma population.

Programmes and projects oriented towards improving Primary Care for the Roma, like, for example, training programmes for primary care providers and screening programmes, need time to be prepared, implemented and institutionalised, also in the financial sense. Therefore, funding should be long-term and not limited to a short-term action.

One main recommendation resulting from many reviews and analyses is to sustain and expand the funding for the RHM.

Communication skills, in general, and knowledge about Roma health and culture should be built in the training curriculum and Continuous Medical Education of Primary Care providers in settings with a high proportion of Roma population.

International organisations, like the European Forum for Primary Care and the European Public Health Association, may continue to organise meetings and workshops on Roma health. In several countries, the size of the Roma population is small, and it may be difficult to offer Roma-specific information and training to health professionals. They would benefit, in particular, from these international opportunities to advance their knowledge and skills.

The unavailability of the data on health of the Roma population in most countries has led to suggestions in the last years to start a collection of health data based on ethnicity. With safeguards on the use of data and a climate of trust, the fear of stigmatisation may diminish. National legislations and regulations, including the creation of ethical committees to assess research plans, are required to establish research activities that are unchallenged and productive.

Amongst others, research should collect information on cultural and other characteristics of local Roma communities and include a process of establishing a stable relationship between the researchers and the population to be studied. Since the research necessarily takes place at the local level and on the small scale, primary care practitioners need to be actively involved, if not themselves leading the research.

CONFLICTS OF INTEREST

The authors declare that no conflict of interest exists.

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ETHICAL APPROVAL

Not required.

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