The health of Roma and Primary Care

Position Paper of the European Forum for Primary Care

Summary

This paper describes successful approaches by practitioners, managers and policy makers to provide quality primary care to their Roma patients and communities.

For practitioners (GP's, nurses, social workers), tools exist to improve access to the consultation room and to develop an interaction with Roma patients that is effective in addressing the patient's complaints. Mutual understanding between patient and health care provider is a key element of quality care. For managers and policy makers examples show how access to health services in the community can be enhanced. Involving Roma organizations is key to this, including in further research on health needs and health services.

Introduction

The Roma population in Europe counts approximately 12 million and is the largest ethnic minority. Migration in ancient and recent times and the subsequent development of Roma communities in different societies have lead to various identities and characteristics. Indeed, many Roma are part of mainstream society. However, there is ample evidence of a particular low health status of many Roma communities and individuals and of particular high incidence and prevalence of a number of diseases. The age pyramid of Roma resembles the one of Low Income Countries. The causes are rooted in history and are multifactorial: exclusion, low level of education, low employment, low income level, etc. As a result, large gaps do exist in longevity and well-being of Roma, compared to the general populations of the different countries. Initiatives of Roma organisations, of national and local governments and of the EU, aiming at reducing exclusion and creating opportunities for Roma, vary in intensity and effectiveness.

While the health system cannot be expected to re-dress this situation entirely, the general question is whether health providers do the optimum to help improve the health of their Roma patients. In spite of all (international) efforts in policy, research and exchange of information and good practice, over the past years, many practitioners have insufficient knowledge, skills and tools to adequately address the health issues of their Roma patients and of the Roma communities under their care. Also, policymakers in the health system, in the communities and local organisations often do not know what approaches to take in improving access to health and of the health status of Roma.

This paper intends to describe the various approaches and experiences in policy and practice in primary care that have shown to be effective to improve the health of the Roma communities. We first turn to the concept of primary care and then move to the practice of
care delivery. Subsequently, we review the policies that strengthen the primary care capacity to deliver.

**Primary Care, especially for Roma?**

The concept of primary care 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. Primary care and its providers are expected to adjust their care and the way it is given to the composition of the patient population. The principles of primary care clarify what primary care aims to offer, see box 1\(^5\). It is especially expertise, skills and organisation of primary care providers that need adjustment to the sub-groups. Earlier, a paper of the European Forum for Primary Care discussed care for the elderly\(^6\), for example. Primary care for Roma is not different from other primary care, it just adjusts to specific Roma population characteristics. Because of the variation in Roma communities as mentioned above, this adjustment needs to be done at local or regional level, there is no overall model. At national and international level, measures can be taken to facilitate this local or regional adjustment.

**Box 1**

**List primary care characteristics**

Starting from these premises, we now turn to the characteristics of Roma communities to which primary care providers need to adjust. Obviously, the generalisations below need to be understood as intended in this paper and in no way mean to typify or stigmatise Roma and Roma communities. There is no template on the thinking or behaviour of a Roma based on his or her background. Further, a number of the generalisations below do apply to other population groups, among them recent migrants from other continents.

There is no generally accepted definition of who is a Roma. Features like genetic characteristics, social status, language and belonging to the group all have limited value and validity, for several reasons\(^7\). Attempts to determine the number of Roma population are not only less successful because of lack of clear criteria. Also, many Roma are reluctant to identify as such during a census, for fear of discrimination. Indeed, legislation in many countries in Europe does not allow for ethnic registration by authorities or health services. This limits the registration of health data and the development of consistent health statistics on Roma

**Characteristics of Roma and Roma communities**

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\(^8\). *Collectivism versus individualism* is one of the dimensions in which Roma differ from most of the surrounding populations: the group you belong to is more important than yourself. Family is playing a major role in decision making, the individual patient’s responsibility is limited. Check if other dimensions of Hofstede should be referred to here.

Language and literacy. Nearly 40 % of Roma speak one of the Romani dialects. The proportion that does not speak a second language is unknown. Language barriers are responsible for misunderstandings with negative impact on health and health care, such as non compliance or late admission. Even when language itself is no barrier, low literacy may
be. Low literacy or little to no schooling, often coincides with low health literacy, and is frequent among Roma communities. This has negative consequences for health. Patients might not understand medicine prescriptions and instructions, leaflets and explanations can be misunderstood or wrongly applied. Adherence to treatment, once symptoms have disappeared, is often not understood, and self management with chronic diseases such as diabetes can be a challenge. Many low literate people experience fear, uncertainty and shame about not being able to read or write. They often try to hide it by using excuses.

Expectations of the healthcare system. Related to (health) literacy, is the frequent lack of patient’s knowledge on the organization of the health care system. For instance the gatekeeper role of primary care often is not known. Opening hours of health centers or of a GP’s surgery are not understood or accepted. The expectation in many Roma communities is that health services should be available when they are needed, not when the system is ready to offer them.

Access to the health system. Thanks to dedicated efforts over the last decade in several countries, the proportion of Roma that has no identity papers or health insurance, has declined drastically. Still, up to XXX % of Roma do not possess a health insurance. In combination with the low economic status of many Roma, costs of health care often are prohibitive. Further, it has been demonstrated that the physical distance between Roma communities and health facilities is larger than for other population groups. Access to health care therefore is limited, leading to late consultation in case of serious health issues.

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 towards health and disease. However, some values like notions of purity and impurity are widespread among Roma communities. Further, individual communities do have strong beliefs and traditional knowledge concerning the causes of disease, healthy and unhealthy behaviour and the use of medicine and treatments. These influence health seeking behaviour and (non) acceptance of modern medicine. Knowledge and use of herbs for fever or minor ailments is part of this.

The factors mentioned above, in combination with the historic trajectory of Roma in Europe, which includes persecution and exclusion, in many cases have lead to a relationship of low trust between Roma and non-Roma health providers and health care that is not effective in adequately addressing Roma. At the level of primary care practice, one of the main challenges is to establish a relationship of acceptance and trust between patients and providers, leading to effective health care.

**The practice of primary care delivery.**

Mutual understanding between patient and health care provider is a key element of quality care. One of the key competences of primary care providers is to adequately assess their patient’s individual (health) literacy and to establish a relation of trust. Vintges suggests what signs may indicate the literacy level and what questions to ask.

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Beware of low literacy in the following cases of patients:
- Don’t show up on time or not at all
- Don’t take medication correctly, unable to name medication or why they are prescribed, unable to recall times of medicine taking
- Don’t fill out medical forms (excuses like forgetting of glasses)
* Difficulties in chronologically presenting their symptoms.
* Never ask questions

For health care professionals it can be a challenge to ask about literacy without embarrassing the patient. The following questions are helpful:
* How often do you have someone (like a family member, friend, or health worker) help you read hospital materials?
* How often do you have problems learning about your medical condition because of difficulty understanding written information?
* How confident are you filling out medical forms by yourself?

In case of language or literacy restrictions, the following approaches are helpful\textsuperscript{15}:

- **Warm greeting**: Greet patients with a smile and a welcoming attitude.
- **Eye contact**: Make appropriate eye contact throughout the interaction.
- **Plain, non-medical language**: Use common words when speaking to patients. Take note of the words they use to describe their illness and use the same words in your conversation.
- **Slow down**: Speak clearly and at a moderate pace.
- **Specific and concrete**: Be specific and concrete in your conversation.
- **Limit content**: Prioritize what needs to be discussed and limit information to the key points. Do not explain everything in detail.
- **Repeat key points**
- **Graphics**: Draw pictures, use illustrations, or demonstrate with 3-D models.
- **Patient participation**: Encourage patients to ask questions, to be involved in the conversation and to be proactive in their own health care.
- **Be positive and affirmative**
- **“Teach-back method”**: Check patient’s understanding by asking him or her to repeat your words. Make sure to ask this in a respectful way, for example ‘I want to be sure that I have explained you everything well’ instead of ‘I want to make sure that you understood me well’.
- **Don’t use idioms or sayings**

Trust in the provider-patient relationship is highly associated with patient satisfaction. When there is no shared language and cultural background, establishing a feeling of trust and understanding can be difficult. The most important cultural competences of caregivers when dealing with patients from different cultural background are openness and respectfulness and asking questions out of genuine curiosity. See Vintges\textsuperscript{16} suggestions in box 3.

**BOX 3**

- Communicate expectations and aims of the consultation, and reach consensus with your patient about this
- Always explain what you do and why
- Make sure patient and family members participate in decision-making
- Make in between summaries and check understanding, such as: Observation: ‘I see that….., is that correct? Interpretation: ‘I have the impression that….., correct? Conclusion: I think that……, correct?’
- Take time to find out patient’s thoughts, feelings and explanations of the symptoms, as well as those of the family members. Try to understand the world of your patient.
- Show empathy
- Be sensitive to cues of the patient, they might be non-verbal
- Show interests in patient’s family where appropriate. It often is highly appreciated.
- Do not be straightforward about sensitive cases
**Indirect asking can be useful in helping a patient to avoid speaking out, for example: “How in your culture a person with your symptoms (disease) would be helped? How is your family explaining your symptoms?”**

- Show interest and respect for patient’s own solutions or remedies
- Ask about cultural or religious customs or treatments in the home country
- Ask about consulting of traditional healers

The communication skills described above are generic: they are needed not only for Roma patients but for any patient in primary care. Understanding the views, needs and expectations of Roma patients also requires a relationship with the Roma communities and knowledge of living conditions and of the further context. Liaising with the community greatly enhances mutual trust, that plays out in the consultation room. Local or regional Roma organisations can be an effective channel to establish these relationships. **Box: examples of successfully establishing relationship between primary care (health centers) and Roma communities (Romania, Bulgaria, Slovenia, Spain, UK, other).**

In several countries (Romania, Bulgaria, Spain and others) there have been positive experiences with the Roma health mediator – a person from the Roma community (mostly female) who is trained to liaise and create understanding between the Roma and the (primary) health care services\(^\text{17}\). Similar experiences with mediators between health practitioners and Turkish/Moroccan and other minority populations in Western European countries have shown that this is a valid model to improve access to health care for minority populations\(^\text{18}\). Incomprehension between Roma and health staff is greatly reduced when communication channels function and both parties have opportunity to explain their views and wishes. Include description of the practice of the Roma health mediator.

As the previous paragraphs show, quality primary care does not start in the consultation room or at the level of the individual relationship provider-patient. Also, it helps to address financial and physical access barriers. **Examples of reducing financial and physical barriers in box.**

**Supporting and developing the practice of primary care delivery**

While the examples of adequate communication skills and approaches in the boxes above seem straightforward, in practice they are not. It needs genuine motivation and it needs training in the competence “communication”. Training in communication skills increasingly is part of the training curriculum of doctors and nurses in various countries\(^\text{19}\). The training of GP’s increasingly includes practical exercise in communication skills, through the use of a training lab\(^\text{19}\). Textbooks with case studies on effective communication are being used in several countries\(^\text{20}\). To expand this section with more examples, including CME. Especially CME is interesting for those GP’s and nurses who are already practising. Seek examples where doctors and nurses jointly are involved in a training programme.

The system of health mediators has shown to be effective\(^\text{21}\). Training curriculum, certification and conditions of work gradually have been optimized, supported by international studies and exchanges. A challenge remains the funding for this group of workers, since they are between the health system and community, and the final responsibility for their functioning...
and employment varies between and within countries. There are some signs that the current economic crisis affects their employment (check with Romania and Bulgaria).

**Box: 2 examples of employment and funding arrangements**

In case of very specific health needs among the population, primary care may need to develop special skills and approaches, like outreach. One of the great successes of developing trust and specific health services (counselling) was realised in Bulgaria. Although it started from the University Hospital in Sofia, after a number of years in played out in primary care as well.

**Box 200 words**

Other examples (TB, STD prevention)

**Identifying areas for further research.**

**Recommendations for policy measures on national and European level**

Currently we live in the "Roma decade of inclusion", from 2005 to 2015. In that context several health studies and projects have been undertaken. The EU has funded and is still funding projects for integration of Roma, of which health is a component.

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1 reference


3 *Left Out: Roma and Access to Health Care in Eastern and South Eastern Europe (2007)* Fact sheet from the OSI Roma Health Project outlining the main barriers for Roma in accessing appropriate and quality health care service.

The health status of Romani women in Bulgaria (2008); Teodora Krumova, Milena Ilieva; Center for Interethnic Dialogue and Tolerance “Amalipe”

Health and Roma community: analysis of the situation in Europe, transnational report I; (2006); Fundacion Secretariado Gitano Health Area. Raul Ruiz Villafranca


4 references
To include box 1

Several references

reference

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To include box 2

Box 3, Reference Vintges.

Same reference


reference

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Reference Slovenia and others

references