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LETTER TO THE EDITOR

What Roma nonadherence is likely and what drives it? Reply to Broz and Nunes

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We thank Broz and Nunes for appreciating our study on the drivers of nonadherence to medical recommendations among Roma in a segregated Roma settlement in Slovakia (Belak et al. 2018; Broz and Nunes 2019). In our reply, we first devote two sections to answer two general questions of the authors about Roma nonadherence. Next, we respond to their additional remarks and suggestions regarding related assessment tools. We close with a brief summary.

Do segregated Roma value their health less compared to poor non-Roma on average?

The segregated Roma we studied probably do value their health less than poor non-Roma. In two related previous studies (Belak et al. 2017, 2018), we found that the conviction among these Roma that adherence to medical recommendations is not appropriate for Roma, naturally and morally, contributed significantly to their nonadherence. We have already discussed in these papers that similar reasoning has been identified among other Central and East European (CEE) Roma, too.

Our studies show why, in regard to segregated Roma in the region, such findings also make very good sense historically. The identified Roma pro-nonadherence norms were directly inspired by racist views claiming that poorer health and lower socioeconomic position reflect specific natural incapacities of the Roma. These views are still common regarding Roma, whereas they have long become much less common regarding any CEE non-Roma (EUFRA 2018; Shmidt 2019).

However, our findings also show why such ethnically framed norms that support nonadherence still would not mean that being Roma equates to valuing adherence less. First, the identified pro-nonadherence norm itself did not apply to all Roma equally and did not regard all recommendations. Moreover, various Roma individuals tended to prefer and practice different mixes of adherence and nonadherence, with some persons consistently valuing adherence very much compared to local non-Roma standards.

Secondly, we found that the presence of the ethnically framed pro-nonadherence norm itself depended on several other social mechanisms that were primarily not controlled by the Roma in the settlement—including the above-mentioned prevailing anti-Roma ideologies among non-Roma. This means that such "Roma" pro-nonadherence norms are unlikely to affect numerous CEE Roma who are educated, employed, solvent and do not live in segregated enclaves with substandard infrastructure, surrounded by people and services holding racist anti-Roma views (EUFRA 2018).

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Do segregated Roma prefer non-medical concepts of health more often than poor non-Roma?

The segregated Roma we studied probably do not prefer non-medical concepts of health more often than poor non-Roma. Even the poorest, proudest and most nonadherent Roma would not choose this nonadherence due to favoring some alternative concepts of health or illness. Most Roma always tried to learn and to understand medical diagnoses and recommendations regarding their health problems and rarely expressed doubts about their relevance or effectiveness. Paradoxically, this high level of trust seems to have been supported by the same Roma adaptations to racist anti-Roma ideologies: most Roma were convinced that the non-Roma were naturally much more gifted for understanding "such complicated stuff".

We indeed found practices and utterances that could easily be misinterpreted as the Roma favouring some understandings of health and illness that deviate from the medical understandings. Firstly, we found that certain states of unwellness were understood and treated by the studied Roma as resulting from and requiring the intervention of magic (e.g., *z očí*, evil eye). Such phenomena were, nevertheless, viewed by the Roma as folk remedies compatible with medicine, adopted from local non-Roma traditions and practiced alike by the local non-Roma.

Secondly, some of the segregated Roma we studied would initially report fatalist views regarding health. However, most of them would later, after becoming personally closer with the first author, share their experiences of healthcare access barriers and their ethnically framed pro-nonadherence norms as the authentic reasons for nonadherence.

The Roma reported as the motive for their initial hesitance to share their authentic reasons that they expected such reasons to be viewed by a non-Roma as unjustifiable and irrational. This sheds new light on the common discrepancies between self-reported and assessed Roma health status mentioned by Broz and Nunes and also on common findings of traditional Roma fatalism regarding health (e.g., Petek et al. 2006). Such findings may also be partially due to the studies not sufficiently accounting for this kind of Roma social desirability vis-à-vis non-Roma researchers.

Assessing Roma nonadherence practically

Based on the above, we do agree with Broz and Nunes that quantitative assessments of differences in the valuing of medically defined health between various social groups can increase the understanding of respective health inequalities. However, based on the same, we also believe that acquiring adequate tools for such assessments regarding CEE-segregated Roma would require intense initial qualitative exploration and rigorous validation directly in the populations of interest, to account for likely significant discrepancies in semantics and interests between the researchers and those being researched (cf. Singer et al. 2016). To the best of our best knowledge, no such tools are available yet.

We did not identify alternative concepts of health and illness among the Roma studied, despite an initial ethnomedical focus based on the Kleinman's "explanatory models" approach that Broz and Nunes suggest to consider (see Belak et al. 2017). Nevertheless, our findings do show that appropriate use of such assessment approaches in the clinic (cf. Kleinman and Benson 2006) might indeed facilitate the identification of important social drivers behind an individual patient's nonadherence, including various structural vulnerabilities (cf. Bourgois et al. 2017).

Summary

Our findings do not confirm traditional Roma preferences, either for nonadherence or for alternative concepts of health. Instead, our findings point to another important pathway, via which Roma health status becomes adversely shaped by prevailing racist anti-Roma ideologies. They underline the need to equip epidemiologists, public health practitioners and clinicians with training and tools to more sensitively and effectively account for adverse structural and culture-bound influences on the health of the populations and individuals they focus on.

Compliance with ethical standards

Conflict of interest The authors declare that they have no conflict of interest.

Informed consent Informed consent was obtained from all individual participants included in the study.

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