ORIGINAL RESEARCH ARTICLE

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# Sense of coherence and self-reported health among Roma people in Sweden – a pilot study

Sven Hassler* and Leena Eklund

Department of Health and Culture, University West, Trollhättan, Sweden

***Objectives.*** The Roma people have been known in Europe for a 1000 years, during which they have usually been the subject of discrimination and oppression leading to isolation, powerlessness and poor health. The objective of this study is to investigate the sense of coherence (SOC) in relation to self-reported health among a group of Roma people in southwest Sweden.
***Study design.*** A cross-sectional, quantitative pilot study.
***Methods.*** A questionnaire was constructed based on the Short-Form Health Survey (SF-12) and Antonovsky's Sense of Coherence Scale (SOC-13) and was distributed among Roma people in southwest Sweden (n = 102). Self-reported health was summarised in a physical score (PCS) and a mental score (MCS). Comparisons were made with a general Swedish majority population and a Sami population.
***Results.*** The health scores were significantly lower among the Roma people compared to Swedes – PCS: Roma 46.0 (Swedes 52.0) and MCS: Roma 47.5 (Swedes 52.6). The SOC score for the Roma people (54.4) was significantly lower than that of the Swedes (65.2) and Sami (65.0).
***Conclusions.*** The low SOC with the Swedish majority society is a strong indication of the marginalisation and exclusion of the Roma people from mainstream society. Low scores in self-reported health among the Roma people also establishes the serious health risks the Roma people are experiencing through their present life situation.

Keywords: *Roma people*; *SOC*; *sense of coherence*; *health*; *Sweden*; *discrimination*

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The Roma people have been known in Europe for nearly a 1000 years, and for a great deal of this time, they have been the subject of discrimination and oppression, leading to isolation and powerlessness (1). These characteristics also influence the development of the Roma community as a whole and its participation in the working and social life of society. They also affect the Roma people's health, well-being and coping abilities. According to the available evidence, the Roma people have unequal access to health services (2–6), high morbidity especially regarding infectious diseases, culture-related difficulties with health service providers, worse health status, risky lifestyles, mental and reproductive problems and inadequate immunization compared with the general population (7–10).

It has been estimated that 50,000–60,000 Roma live in Sweden (9). The Swedish authorities divide the Roma into 5 groups according to their time of arrival in Sweden: the Travellers (arriving in the 16th century), the Finnish Roma (in the 17th century, the Roma were forced to move further to Finland, which was part of Sweden at the time), the Swedish Roma (coming from Hungary and Romania at the end of 19th century), the Non-Nordic Roma (immigrating from Poland and Eastern Europe in the 1960s) and the Newly arrived Roma (arriving from the former Yugoslavia, in the 1990s). The Roma are 1 of 5 national minorities in Sweden. As such, their culture is acknowledged as part of the common Swedish heritage, which therefore entitles them to special rights in mainly 3 respects: protection, strengthening of their influence and participation in society and support for and keeping alive of their own culture and languages. According to the Swedish Delegation for Roma Issues (9), the Roma people are the most exposed group when it comes to discrimination, in Sweden as well as in Europe. The delegation concludes that the Roma people are almost completely excluded from mainstream society through a solid pattern of social, economic and political marginalisation (9):





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a picture of vulnerability confirmed by other investigations describing the structural discrimination of the Roma (11). That the total entry ban of Roma people to Sweden was repealed as late as 1954 is only 1 example of the particularly long lived and strong structural discrimination of the Roma (11). As for general attitudes, they also adopt a structural appearance as the situation of the Roma by many is understood as natural and inevitable rather than having social, political or historical causes (12). A recent survey (2003) demonstrated that 90% of the Roma respondents consider Sweden to be a racist country hostile to Roma people (13).

As a predictor of the ability to maintain good health and cope with daily life, the sense of coherence (SOC) score has been proven to be of great value (14). For a community as well as individually, taking control of one's own health is seen as the means to improve health (15). Participation of people in their own society is therefore considered crucial to the strengthening of health in a society (16). In the long run, strengthened empowerment and self-organisation among marginalised groups will contribute to the democratic process of the society as a whole (17).

Cognition of, and reaction to environment are essential to individual health and well-being. Someone who finds life meaningful and comprehensible, and is able to cope with problems that might occur, is more likely to experience good health. It is for this reason that SOC, originally launched by Antonovsky at the end of 1970s (18), has become an important concept with regard to health. Antonovsky considers health to be the ability to resist physical, mental and social stresses and strains. Prevention of these stresses can lead to enhanced, life spans, functioning and well-being. He further emphasises the dual character of health, with the opposites ease (health) and dis-ease (illness) at the end points of a continuum. An individual's health is influenced by one's attitudes about the world and his or her own life. Antonovsky called this attitude the SOC. If an individual has a high SOC, this person should theoretically also be healthier in general, and, when ill, should be able to recover more quickly. Life experiences form one's SOC. A strong SOC requires life experiences that create what Antonovsky called general resistance resources, such as physical factors, intelligence, coping strategies, social support, financial power and cultural factors. Tension can be reduced by resistance resources, which in turn positively affect the state of health on the ease/dis-ease continuum.

Although it has been shown that the Roma people have poorer health than the mainstream population in medical or epidemiological terms, their perception of their own health reveals a somewhat different picture (10,12,19,20). In an European survey, 68% of Roma people consider their health to be good or very good, compared to 66% of the EU-27 population (10). There is a lack of studies on the Roma people from a salutogenic perspective. Such studies are needed to provide a comprehensive view of the human being, encompassing the whole life situation of people and not only their medical states. The objective of this study is to investigate SOC in relation to different aspects of self-reported health among a group of Roma people in southwest Sweden.

In the fall of 2010, an EU Social Fund-financed project (21) was initiated with the objective to strengthen the health and well-being of the Roma people in southwest Sweden. The project has a participatory approach and aims at changing the participants' sense of powerlessness and promote increased self-confidence and self-efficacy, mobilise the local community for health-promotive action and provide training for the local authorities in issues defined as important by the Roma people.

## Material and methods

In the planning phase of the Roma empowerment project mentioned above, a pilot survey of the self-reported health and SOC among the Roma was conducted. A questionnaire was constructed based mainly on the 12-Item Short-Form Health Survey (SF-12) and the 13-item version of Antonovsky's Sense of Coherence Scale (SOC-13) (22). In order to ensure validity and a representative sample of the Roma people, the questionnaire was written in 8 languages: Swedish, Finnish, English and Croatian, as well as the 4 Romani dialects of Kelderash, Kaale, Lovari and Arli. The questionnaire was distributed among and through Roma people with connections to the Agnesberg Folk High School, the Roma residential college for adult education located in Gothenburg, southwest Sweden. The majority of the students as well as the teaching and administrative staff of the School are Roma People and the catchment area of the School is the region of Västra Götaland (southwestern part of Sweden). The questionnaire was distributed personally by Roma people involved in the project acting as gate-keepers to a sample of staff and students at the School and their relatives and friends using a pragmatic snow-ball type of selection (23). The gate-keepers distributed the questionnaires personally and were also present during their completion, helping out if there were any questions. A total of 150 questionnaires were distributed. The material was analysed using statistical software (SPSS).

The self-reported health was summarised in a physical score (Physical Component Summary; PCS) and a mental score (Mental Component Summary; MCS) (24). The SOC of the Roma cohort was assessed using the SOC-13, with a 7-point Likert scale format with 2 anchoring responses, ''never'' and ''very often.'' All items were then summarised according to the instructions to create a total SOC score, which ranged from 13 to 91



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(25). How the Roma sensed their belonging to different social groups was estimated by using a 5-point Likert scale format with 2 anchoring responses, "very strong" and "none." The SOC scores of the Roma cohort were compared to those from a sample of 43,598 randomly selected Swedes living in 5 central counties of Sweden (Uppsala, Sörmland, Västmanland, Värmland and Örebro) (26). For the self-reported health measures (MCS and PCS), the comparison was made with a sample of 4,386 Swedes used in a health survey to validate the SF-12 (27). A comparison was also done with SOC scores and self-reported health measures from a group of reindeer-breeding Sami, representing another of the 5 national minorities in Sweden (28). The SOC, PCS and MCS scores of the Sami were adjusted for age, gender and level of education and the Swedish SOC scores for age and gender. For statistical comparison of means, t-tests were used, and to test correlation between scale variables, Pearson's test for correlation was used ($p < 0.05$ was considered significant).

## Results

A total of 102 questionnaires were returned out of which 3 considered themselves as not being Roma and, therefore, were excluded from the analysis. Of the remaining respondents, 53 were men and 46 women. The mean age for both men and women was 31 years (Table I).

The largest group represented in the study population was the Newly arrived Roma (60% of the men and 65% of the women). The second largest group was the Finnish Roma (13% of the men and 10% of the women) (Table I). One-third of the respondents (34% of the men and 33% of the women) stated that they had lived in Sweden most of their life, one-third (28% of the men and 37% of the women) more than 10 years and one-third (38% of the men and 30% of the women) less than 10 years. On the question of education level, a total of 65% (56% of the men and 74% of the women) answered that their highest level was elementary school (up to 9 years) and 24% (30% of the men and 17% of the women) high school (up to 12 years) (Table I).

The self-reported health summarised as PCS and MCS scores were significantly lower among the Roma people compared to a standard population of Swedes (Table II). In comparison to the reindeer-breeding Sami, the Roma scored significantly lower on the physical measure (PCS) whereas no statistical difference was observed for the mental score (MCS) (Table II).

The SOC score for the Roma people was significantly lower than that of a standard population of Swedes as well as a sample of Sami (Fig. 1). Roma men had a score of 53.5 (Sweden: 66.1; Sami: 68.8) and Roma women 55.5 (Sweden: 64.0; Sami: 60.7).

The correlation between the SOC and the PCS and MCS scores was tested (Pearson correlation) and revealed a significant correlation between SOC and PCS ($r = 0.40$; $p < 0.001$) as well as between SOC and MCS ($r = 0.66$; $p < 0.001$).

*Table I.* Sociodemographic characteristics of the study population

| | Men (n = 53) | Women (n = 46) |
|---|---|---|
| Age, years (mean ± SD) | 31 ± 11 | 31 ± 10 |
| Age, range (years) | 14–53 | 15–50 |
| Level of education | | |
| No education | 7 (13%) | 6 (13%) |
| Compulsory (6–9 years) | 23 (43%) | 28 (61%) |
| Upper secondary (10–12 years) | 16 (30%) | 8 (17%) |
| University (≥13 years) | 2 (4%) | 2 (4%) |
| Unknown | 5 (9%) | 2 (4%) |
| Roma group | | |
| Newly arrived Roma (Balkan) | 32 (60%) | 30 (65%) |
| Swedish Roma | 3 (6%) | 3 (7%) |
| Finnish Roma | 13 (25%) | 10 (22%) |
| Non-Nordic Roma (Eastern Europe) | 1 (2%) | 0 |
| Travellers | 4 (7%) | 3 (7%) |
| *I do not see myself as Roma* | *3*[a] *(5%)* | *0 (0%)* |
| Length of time in Sweden | | |
| Less than 2 years | 3 (6%) | 0 |
| 3–9 years | 17 (32%) | 14 (30%) |
| More than 10 years | 15 (28%) | 17 (37%) |
| Most of my life | 18 (34%) | 15 (33%) |

[a]These individuals were excluded from the study population.

The sense of belonging of the Roma people was estimated through the ranking of rate of belonging to certain defined groups: Europeans, close friends, Roma people, people in general, family, Swedes, immigrants and workmates (Fig. 2). The Roma people felt closest to the "family" group and then, in descending order, "Roma people," "close friends," "people in general," "Swedes," "workmates," "immigrants" and finally the "Europeans" group, which they ranked being the least close to. The sense of belonging to the family and the Roma people was the only group belongings that significantly differed from all the other groups (paired sample t-test; $p > 0.05$).

## Discussion

The marginalisation and exclusion of the Roma people from mainstream society, evident from several previous investigations and studies is confirmed by their low SOC with Swedish society shown in the present study (Fig. 1). Although they comprise a small sample, the group of Roma people in this study also score significantly low on self-reported physical health compared to mainstream society, represented by a general Swedish population sample, as well as to a sample of reindeer-breeding Sami

*Table II.* Self-reported physical and mental health among Roma people shown as means of compressed scores (PCS and MCS) and the corresponding p-value analysed with t-test. Comparison made with a population of reindeer herding Sami and a Swedish standard population.

| Group | Age | N | PCS | p-value | MCS | p-value |
|---|---|---|---|---|---|---|
| Roma | 14–51 | *74*[a] | 46.0 | | 47.5 | |
| *Sami*[b] | *18–76* | *87*[c] | *52.5* | ***0.000*** | *49.6* | *0.156* |
| *Sweden*[d] | *18–44* | *4,386* | *52.0* | ***0.000*** | *52.6* | ***0.000*** |

[a]74 of 99, resulting in a 75% response rate for the PCS and MCS scores.
[b]Adjusted for gender, age and level of education.
[c]n = 87 for PCS and n = 95 for MCS.
[d]Gandek et al. (27).

(Table II). Although alarming, this is consistent with previous reports of the Roma people's health conditions measured in epidemiological terms and reflects their vulnerable situation in society (9,10). However, the results of the qualitative studies by Eklund et al. (12) and FSG (10) indicate that Roma perceive their health as good when directly asked in an interview. The explanation for this might be found in the strong social ties of the Roma people with their core and extended family members (Fig. 2), which seem to function as a resource for general resistance to stress and difficulties in life (18). When these ties function well and relationships within the family are supportive and in order, the Roma regard themselves as healthy.

It has been concluded that the health situation of the Roma people is an effect of their life situation, which is characterised by high unemployment rates, exclusion from mainstream society, powerlessness and discrimination. These are conditions that further contribute to the exposure of unhealthy risk factors such as a high degree of alcohol consumption among men and youth, an increase in addictive gambling and drug use, together with physical inactivity and a diet containing a high

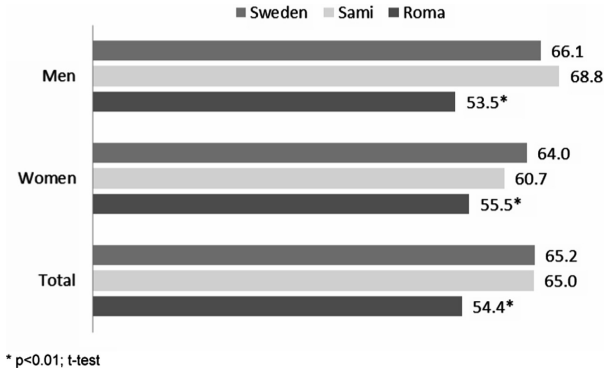


*Fig. 1.* Scores of sense of coherence among Roma, Sami and a Swedish standard population presented as means by gender.

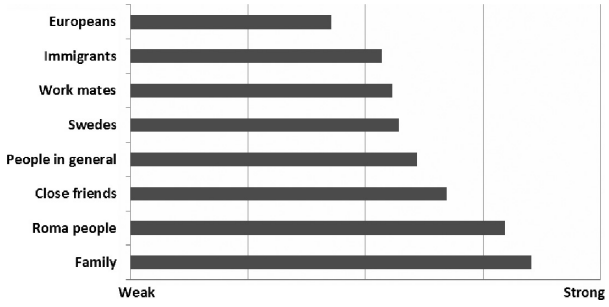


*Fig. 2.* Sense of belonging among Roma people.

degree of fat (20). That SOC is strongly related to health, especially mental health, has been established in several studies and is also shown in the present study (29). The situation of the Roma people serves as a convincing example of the relationship between SOC and health and confirms the conclusion that although it is not to be equated with health, SOC is still an important capacity determinant for the development and maintenance of health (20,29).

That the feeling of detachment from society is associated with low scores for self-reported health is alarming but not surprising (Table II). This study establishes the serious health risks the Roma people are experiencing through their present life situation. That the Roma and the Sami in this study share similar low levels on the MCS compared to the general Swedish population is in line with what has previously been reported regarding the psychosocial health situation of the reindeer-herding Sami (28,30). Although their status and situation as National minorities is not strictly comparable, they share a similar experience of a structural discrimination of the Swedish society that should be taken into consideration when addressing the issue of the mental health situation of the Roma as well as the Sami (11). In a previous Lithuanian study, long-term unemployment was shown to have a significant effect on the experience of low SOC (31), suggesting that the high degree of unemployment among the Roma people is an important factor for their low SOC. In the same study, it was also shown that the factors among the unemployed having the greatest negative influence on SOC were depression, suicidal intentions, intense alcohol consumption and feelings of loneliness and shame, making SOC close to actually being a measure of mental health, an observation that is acknowledged in several studies on SOC (32). For the purpose of supporting the empowerment process of the Roma people, a salutogenic approach is desirable, describing SOC not merely as an indicator of health status but as a resource for good health, a strength of coping (29). Furthermore, some earlier studies on Roma suggest that a participatory research approach could increase trust between the investigators and the research


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subjects and consequently improve research on minority health (33).

The strong sense of belonging to other Roma people and to their family could suggest a coherence of a different nature in the Roma in our study population, possibly not captured in all respects by SOC but with the potential of being a resource for good health (Fig. 2). Griffiths et al. (34), for example, do not see SOC as an overall adaptive capacity measure but suggest that SOC strength for concrete problems and relationship-oriented problems be viewed and understood as separate capacities. In a previous Swedish survey of the health situation of the Roma people (20), it was evident that they view their health as a collective quality, reflecting their strong cohesion within the group; the health of the individual is the health of the group. This collective, relationship-oriented identification of health could be a starting point for uncovering the coping strategies from which a stronger SOC among the Roma people can develop.

It is also evident that the coping strategies of the Roma people do not form the single road to solution for improving their health conditions. For the Roma people to improve their SOC, it is also necessary to include aspects of the Roma environment in mainstream society to a greater extent than what has been the case historically.

### *Methodological considerations*

The questionnaire used in this study is mainly based on 2 standard questionnaires – the SF-12 and the SOC-13. Although they have been tested and validated in many countries and in many different populations (14,35), one can argue that some of the questions have an orientation towards a Western lifestyle. For instance, examples of exercises in the SF-12 include bowling and playing golf, while the type of self-reflections requested in the SOC-13 can be considered to be characterized by Western culture. When formulated in English and Swedish, these types of questions can be expected to make sense to most fluent readers of these languages, but their translation into languages with a somewhat different cultural setting might cause misunderstanding or even bewilderment among readers. This is a condition that can affect the reliability of the questionnaire and thus also influence the validity of the study. With this in mind, the figures and scores should be interpreted somewhat cautiously.

Approaching a marginalised group like the Roma is associated with several ethical considerations and challenges. A true participatory perspective is essential (e.g. 33,36), and methods and scientific routines must be adapted to the context in which they are to serve. The distribution of the questionnaire therefore needed to be handled pragmatically through channels of Roma people who could be described as "gate-keepers." The gate-keepers distributed the questionnaires personally and were also present during their completion, helping out if there were any questions. The influence on the result of this course of action could and should be discussed and considered. It is difficult to judge whether this has caused a 1-way bias or a more general uncertainty regarding the accuracy of the results. The right approach is most likely to regard this study as a pilot study and to view the results as indications of certain health conditions that should be further analysed and valued in forthcoming studies.

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## Conflict of interest and funding

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***Sven Hassler**
Department of Health and Culture
University West
Gustava Melinsgata 2
SE-461 86 Trollhättan
Sweden
Email: sven.hassler@hv.se



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