Premagovanje kulturnih razlik: Rezultati programa promocije zdravja v romski skupnosti

Overcoming cultural cleavages: results from a health promotion intervention among Roma

Avtor / Author

Erika Zelko[1], Igor Švab[2]

Ustanova / Institute

[1]Univerza v Mariboru, Medicinska Fakulteta, Katedra za družinsko medicino, Maribor, Slovenija; [2]Univerza v Ljubljani, Medicinska fakulteta, Katedra za družinsko medicine, Ljubljana, Slovenija

[1]University of Maribor, Faculty of Medicine,, Department of Family Medicine, Maribor, Slovenija; [2]University of Ljubljana, Medical Faculty, Department of Family Medicine, Ljubljana, Slovenija

Ključne besede:
promocija zdravja, intervencija, Romi.

Key words:
health promotion, intervention, Roma

Članek prispel / Received
28.02.2016
Članek sprejet / Accepted
29.03.2016

Naslov za dopisovanje / Correspondence
Erika Zelko
Univerza v Mariboru,
Medicinska fakulteta, Taborska ulica 8,
2000 Maribor
Telefon +386 31510496
E–pošta: zelko.e@siol.net

Izvleček

Namen: *Pilotni projekt SASTIPE je nastal na podlagi opažanja raziskovalcev, da se Romi niso udeleževali programov promicije zdravega življenja v lokalni skupnosti. Naraščajoče breme kroničnih obolenj in zavedanje Romov o pomenu zdravega načina življenja je botrovalo razvoju programa promocije zdravega življenjskega sloga za romsko skupnost, ki je bil izveden v romskih naseljih.*

Metode: *Program se je izvajal v 9 romskih naseljih od decembra do marca 2013. Za pripravo delavnic na temo sladkorne bolezni, KOPB, zdrave prehrane in visokega krvnega tlaka ter urgence smo uporabljali specifičen material, ki smo ga pripravili skupaj z Romi. Podatke smo zbirali s pomočjo prilagojenega in validiranega EUROPREV I n EuroQUoL vprašalnika pred in po intervenciji. Rezultate, dobljene po intervenciji, smo primerjali s kontrolno skupino,*

Abstract

Purpose: *The "SASTIPE" (health in Romani language) pilot project grew from the increasing awareness that the Roma generally have not participated in community-based healthy lifestyle promotion programs. The increasing burden of chronic disease and awareness of the need for a healthier lifestyle amongst the Roma have contributed to the development of an intervention program that was implemented in Roma settlements.*

Method: *The program took place in nine Roma settlements from December 2012 to March 2013. We provided workshops focused on diabetes, chronically pulmonary diseases (COPD), healthy foods and blood pressure, and emergency preparedness and used specific materials that were developed together with the Roma. Quantitative data was collected using the adapted and validated versions of the EUROPREV and EuroQol questionnaires before and*

v kateri ni bilo nobenih aktivnosti, in so nam služili za oceno učinkovitosti programa. Stopnja odzivnosti je bila v kontrolni skupini 74 % in v interventni 53 %.

Rezultat: *Interventni program je prispeval k statistično značilnemu povečanju znanja o nekaterih opazovanih medicinskih parametrih v interventni skupini ($p < 0.001$). Zaznali smo tudi spremembe v zavedanju o pomenu zdravega življenjskega sloga. Statistično več Romov iz interventnih naselij je začelo razmišljati o spremembi kadilskih navad ($p < 0.001$).*

Zaključek: *Dokazali smo, da je v sodelovanju s ciljno skupino možno razviti uspešen interventni program. Dosegli smo izboljšanje znanja, več Romov se je ob koncu intervencije v interventni skupini zavedalo pomena zdravega življenjskega sloga in potrebne spremembe kadilskih navad. Za oceno dolgoročnih sprememb življenjskega sloga so potrebne nadaljnje raziskave in dolgotrajnejše opazovanje.*

after the intervention. The assessment of the pilot project was made with data from the responders in the intervention group and the control group (response rates 53% and 74%, respectively), where the control group were populations that did not preform any other activities.

Results: *The program increased knowledge about some observed medical parameters in the intervention group ($p<0.001$), and we observed changes in the awareness of healthy lifestyles, especially smoking habits, which we noticed a significant difference between the control and intervention group in the pilot project ($p<0.001$).*

Conclusion: *We demonstrated that together with the target group it is possible to develop a successful intervention project. We achieved changes in medical knowledge and increased awareness of the need to change smoking habits and lifestyle within the intervention group. However, further research and longer observation times are needed to achieve a long-term change in lifestyle.*

INTRODUCTION

All ethnic groups have specific healthcare cultures that might be influenced by other neighboring cultures (1). In particular, the Roma face numerous obstacles in accessing healthcare services. These arise from poverty, low income (inability to pay for medical services), cultural features of the Roma, geographical isolation of Roma settlements, the uneven distribution of healthcare institutions and staff, and communication problems between the Roma and personnel at healthcare institutions (2–6). Previous studies carried out in Slovenia showed that healthy-lifestyle promotion measures and approaches that are generally successfully when applied in the general population are not effective in this community (7–9). Similar conclusions were drawn in a Hungarian study comparing the health status of the general population and the Roma community. A Slovakian study on metabolic syndromes in a Roma population and a Serbian study that examined sexually transmitted diseases identified the need for a public healthcare approach specific to the Roma community that includes health education and healthy lifestyle promotion (10–15). Additionally, Croatian researchers recommended planning public healthcare approaches specifically for socially marginalized and economically disadvantaged communities, such as the Roma (15).

Data on the appropriate development and implementation of public healthcare measures are lacking because of the problems researchers face when carrying out studies in Roma settlements. The Roma tend not to trust non-Roma researchers, fearing discrimination and exploitation, have problems talking with researchers and can be afraid of consequences they might face within and outside their community if they participate or do not participate in these studies (3, 10, 16, 17). Time- and financial-related challenges create additional obstacles to carrying out such studies. In addition, the poor health literacy of the Roma population can result in difficulties understanding and interpreting medical terminology. Consequently, only a few published studies have dealt with healthcare in Roma communities (3, 10, 17). Traditional mass-media methods of health education and public health

messaging usually reflect the dominant culture and not the norms or values of minority groups (18). This pattern occurred in the "Živimo Zdravo" program, as the Roma did not feel that it addressed their problems (7) and consequently did not participate in its activities. Later, their representatives requested that a program suited to their needs and culture should be organized (7). The project aims of this study were to demonstrate the effectiveness of the health promotion program developed and implemented with the help of the Roma people in Roma settlements.

METHODOLOGY

Type of study and settings

We provide an observational intervention study in Roma settlements, which includes eight interventional settlements and one control settlement.

Prekmurje Roma

The Roma in Prekmurje are a more organized group than other Roma in Slovenia and have their own association, Ciganje, which remains active to the present day (19, 20). Most of the Roma live in organized settlements near the major population centers. They are integrated into the community primarily through employment and education; Roma and non-Roma children attend the same schools. In general, the Roma have built good relationships with the non-Roma population while protecting and developing their cultural and ethnic identities. They have their own Roma-language radio and television programs and other publications that investigate the specific needs of the Roma population (1, 20, 21). The settlements that received intervention were Dolga vas, Trnje, Gomilica, Črenšovci, Krašči, Gornji Črnci, Serdica, and Pertoča and the control group was the settlement Pušča.

Participants

The pilot project "SASTIPE" took place in Roma settlements. The activities were prepared for all inhabitants, but the assessment of the project included only 200 adult Roma representatives in the control and intervention groups. The representative sample of 400 adults, 18–65 years old, was selected by random sampling of households in Roma settlements, with one adult selected at random per household, alternating men and women. Roma ethnicity was determined based on identification by the interviewed Roma themselves and by a member of the research team.

Data collection

The quantitative data was collected using the adapted and validated versions of the EUROPREV and EuroQol questionnaires, with some added questions about some demographical data (Table 1) and the normal value of medical determinants (blood pressure, body temperature, cholesterol and blood sugar). We defined normal values for blood pressure as 110–140/ 60–90, blood sugar between 5 and 6 mmol/l, cholesterol level as 4.5 mmol/l and body temperature between 36 and 37°C. Participants answered questions concerning demographic features (15 questions), health literacy (four questions), lifestyle (13 questions) and attitudes towards health protection and health changes (eight questions). Their health status was determined based on their answers to five questions from the EuroQol questionnaire. At the end of the pilot project we also added questions to the questionnaire about attending the project activities and awareness of the pilot project; these data are presented in Table 2. The data were collected with help from specially trained community nurses in the intervention and control groups before we started the workshops and 3 months after we finish the activities. In eight settlements we provided the intervention and one settlement was the control group without any activities. The control settlement was far away from the intervention settlements, so that visits and participation in the intervention program was minimal. To evaluate the effectiveness of the program we examined changes in knowledge about some medical determinants and changes in awareness of healthier lifestyles.

Description of the Interventions activities of the SASTIPE pilot project

The pilot project SASTIPE was conducted in nine Roma settlements from December 2012 to March 2013.

Table 1. *Socio-demographic profile and comparison of respondents in the SASTIPE pilot project.*

	Intervention group		Control group		p
	n=106	%	n=148	%	
Gender:					0.799
Male	42	39.6	61	41.2	
Female	64	60.4	87	58.8	
Marital status:					0.303
Married	83	78.3	100	67.6	
Single	16	15.1	34	23.0	
Divorced	3	2.8	5	3.4	
Widowed	4	3.8	9	6.1	
Educational attainment:					0.048
Unfinished basic school	34	32.1	37	25.0	
Basic school	56	52.8	64	43.2	
Vocational	10	9.4	31	20.9	
Secondary school	6	5.7	15	10.1	
Higher	0	0.0	1	0.7	
Employed status:					0.308
Employed	13	12.3	26	17.6	
Student	1	0.9	2	1.4	
Housekeeper	27	25.5	29	19.6	
Retired	5	4.7	15	10.1	
Unemployed	60	56.6	76	51.4	
Housing:					0.298
Wooden house	3	2.8	4	2.7	
Brick house	92	86.8	136	91.9	
At relatives	11	10.4	7	4.7	
Other	0	0.0	1	0.7	
Water in house	101	95.3	146	98.6	0.106
Electricity	102	96.2	140	94.6	0.546
Sewage	65	61.3	34	23.0	<0.001
Chosen general practitioner	103	97.2	143	96.6	

Table 2. *Awareness of the SASTIPE pilot project and participation in the activities in the intervention and control groups.*

	Both groups		Intervention group		Control group		p*
	n=254	%	n=106	%	n=148	%	
Aware of the project:							<0.001
Yes	117	46.1	101	95.3	16	10.8	
No	137	53.9	5	4.7	132	89.2	
Participate in the activities:							<0.001
Yes	64	25.2	59	55.7	5	3.4	
No	190	74.8	47	44.3	143	96.6	

**Fisher exact test*

Workshop

The basic activities in the Roma settlements were interactive workshops. After the results of the qualitative study and suggestions from Roma representatives we prepared four workshops for the intervention program (22–24). Each lasted 40 min and contained a practical part, like measuring blood pressure, blood sugar and cholesterol, practicing the handling of aerosol medications for lung diseases and learning basic first aid skills. We chose the additional topics, including diabetes mellitus, high blood pressure and healthy eating, emergency preparation and when to call the doctor, and COPD, the most common respiratory disease in this population. The lectures were prepared in a simple, understandable language and were also available as translations in Roma. We also heavily relied on the use of pictorial material and practical explanations.

Website

Most Roma have smart phones (80%), radio/TV (95%) and a lot of them own a computer (40%) according to the information of Roma representatives (25); therefore, we also created a website in an attempt to inform especially the young people about our project. The website was also used to inform the interested majority population about the project. The website (http://www.sastipe-zdravje.si/) contains information about the project and the incorporated Google program tools allowed us to measure use of the website.

TV and radio programs

The Prekmurje Roma have their own radio station and a channel on state TV with some hours of programming possibilities. At the start of the project we prepared one short introductory radio show for Roma listeners. Because we did not want to bias the research results, other shows on health topics that were suggested by the Roma representatives were prepared. These programs included topics such as diabetes mellitus, infectious diseases, healthy food, blood pressure and children's health. After finishing the pilot project these presentations were aired every week for 3 months.

Evaluating of the pilot project

A variety of methods were used to evaluate the SASTIPE project. Detailed documents regarding the work on the project were maintained, including notes and schedules of research group meetings and workshops, personnel records, meeting dates, health surveys, written materials and time spent designing the website and various data collection activities. All study activities in Roma settlements were also closely documented.

The most important aspect of the SASTIPE pilot project was to confirm the validity and reliability of the program. Needs assessments were conducted as part of the formative evaluation process during the regular meetings of the research group. The advisory group was responsible for ensuring that the program was culturally acceptable, well planned and capable of achieving its goals. For the intervention activities, it was extremely important to gain further insight from Roma settlements into their priorities. Informal feedback from the Roma representatives was sought and gained throughout the project.

Statistical analysis

Statistical analysis was performed using the SPSS 12 statistical program for Windows (SPSS, Chicago, IL, USA). Univariate, bivariate (Fisher's exact test, chi-square test and independent samples t-test) and multivariate analysis (logistic regression) methods were employed. Level of significance was set at $p < 0.05$.

RESULTS

Table 1 shows the characteristics of the control and intervention groups. Statistically significant differences in the two groups were noticed between the arrangement of the sewerage network ($p<0.001$) –better in the intervention group – and achieved educational status ($p=0.048$) – better in the control group.

The control group contained some subjects who were aware of the project, but there was a statistically significant difference in participation rates for the intervention group compared with the control group ($p=0.043$). Detailed results are presented in Table 2.

Change in knowledge after the SASTIPE pilot project

The results presented in Table 3 show the statistically significant improvements in knowledge about the normal value of some medical determinants in the intervention group compared with the control group. The best improvement was achieved in knowledge about body temperature (21.7%; from 23.2% to 44.9%). The improvement in knowledge about the normal value of cholesterol was minimal but still statistically significant (3.9%, from1.2% to 5.1%) in the intervention group compared with the control group.

DISCUSSION

Summary of the main findings

This study proved that a healthy-lifestyle education promotion program could be implemented in the Roma community with the participation of Roma representatives in all steps of the development process. The workshops, radio and televisions shows, written materials and children's playing cards were well accepted in the Roma communities. Because of low health literacy in the Roma community, we developed some simple and easily understandable materials with pictures to increase the understanding and support our activity in the settlements. This was also the suggestion of the Roma representatives included in the qualitative part of the research. The SASTIPE pilot project in the Roma settlements increased knowledge about some medical determinants (normal body temperature, cholesterol, blood pressure and blood sugar) and produced a noticeable increase in the awareness of healthy lifestyles, despite the fact that the educational status in the intervention group was significantly lower then in the control group. However, motivation to change risky behaviors was high only regarding smoking in the intervention group.

Table 3. *Changes in knowledge about the normal value of medical determinants after the SASTIPE pilot project.*

	Both groups n=254		Intervention group n=106		Control group n=148		p*
	n	%	n	%	n	%	
Blood pressure	+50	+19.7	+39	+36.8	+11	+7.4	<0.001
Blood sugar	+26	+10.2	+21	+19.8	+5	+3.4	<0.001
Cholesterol	+10	+3.9	+9	+8.5	+1	+0.7	0.002
Body temperature	+55	+21.7	+36	+34.0	+19	+12.8	<0.001

**Fisher exact test*

Intentions to change some health risk factors (EUROPREV Questionnaire)

At the end of the pilot project, 11.3% of participants in the intervention group considered that they should improve their eating habits, 14.2% expressed the need to normalize their body weight and 18.9% more of them believed that they were not moving enough. We also found a 9.4% increase in the number of participants in the intervention group who believed that changes in alcohol consumption were necessary. A statistically significant difference in attitudes toward intentions to change smoking habits we observed in the intervention group compared to the non-intervention group (chi-square=26,419; p<0,001).

The results of the EuroQol questionnaire are presented in the article "Quality of life and patient satisfaction with family practice in a Roma population with chronic conditions in northeast Slovenia" (26).

Comparison to other studies

Developing and implementing a healthy lifestyle intervention program requires a multi-faceted approach, which should address the target population by deploying multiple messages across multiple channels and products (27, 28). The program should address and provide solutions to the problems of the target population and test its ability to make lifestyle changes. Bar-

riers, beliefs, perceptions and cultural characteristics that might prevent acceptance of the program should be identified. The qualitative phase of this research and the inclusion of Roma representatives in all steps of the project were intended to meet this need. The program was based on suggestions from the Roma, which included having activities organized in Roma settlements, written materials prepared in the Roma language, and using many visual materials in the workshops carried out in the Roma settlements. In order for the content to clearly identify the benefits of the issues presented, for the message to be memorable and for attention to be given to the credibility of the sources (28, 29), health care practitioners who usually work in Roma settlements and know their culture were included in the implementation of the program. Feedback on activities was received at regular meetings of the advisory group. For successful implementation of the program, the involvement of influential Roma leaders who play key roles in their settlements was crucial. Their inclusion enabled the researchers to enter the communities and establish the minimum trust needed to work in the settlements.

Determining measurable goals and objectives to evaluate the outcome of a community intervention program is difficult (30, 31). Consequently, intervention programs frequently measure processes, not outcome variables (29). In this project, we attempted to measure changes in knowledge about important measurable outcome variables, such as understanding the normal values for body temperature, blood pressure, blood sugar and cholesterol. Statistically significant positive changes in post-intervention knowledge were observed. Additionally, the results of the EUROPREV questionnaire also contained positive changes in willingness to modify lifestyle.

Limitations of the study

The program was developed and implemented in Prekmurje and is not representative of all Roma in Slovenia, although similar approaches with some adaptations for local Roma communities can be used. The duration of the program evaluation was very short (3 months), preventing assessment of its long-term effectiveness. A longer time would be needed to observe actual changes in lifestyle, but we did document the intention to change some risk factors and improved awareness about healthier lifestyles. Bias from Roma representatives cannot be excluded because they were included in developing the program and participated in the qualitative research. The Roma representatives might have desired to please the research team and so given what they perceived as appropriative and expected answers.

CONCLUSION

Over the year that the program was developed, its acceptability and feasibility in the Roma community were demonstrated. In a very short time the intervention program raised the awareness and knowledge of the Roma community members regarding some health indicators. The execution of the intervention program in the Roma settlement enables a much more successful inclusion of the Roma people in the activities offered by this program. However, further research is needed to confirm its validity and reliability in Roma settlements and to test the completeness and transferability of the program.

Conflict of interest

The authors declare that no conflict of interest exist.

ACKNOWLEDGMENTS

The authors would like to thank the Roma participants in this study as well as the medical students and community nurses. Without them this work would not be possible.

REFERENCES

1. Zadravec J. The health culture of the Roma in Prekmurje. Murska Sobota: Pomurska Založba; 1989.
2. McKee M. The health of Gypsies. BMJ. 1997; 315: 1172–3.
3. Van Cleemput P. Gypsies and travellers accessing primary health care: interactions with health staff and requirements for 'culturally safe' services. J Res in Nurs. 2009; 14: 365–9.
4. Bodner A, Leninger M. Transcultural nursing care values, beliefs and practices of American (USA) Gypsies. J Transcultural Nurs. 1992; 4: 17–28.
5. Gaulet D, Walshok M. Values among underdeveloped marginals: the case of Spanish Gypsies. Comp Stud Soc Hist. 1971; 13: 451–72.
6. Colombini M, Rechel B, Mayhew HS. Access of Roma to sexual and reproductive health services: qualitative findings from Albania, Bulgaria and Macedonia. Glob Public Health. 2012; 7: 522–34.
7. Zelko E. Vrednotenje programa ukrepov za izboljšanje zdravja v lokalni skupnosti Beltinci [master's thesis]. Medicinska Fakulteta Ljubljana; 2007.
8. Belović B, Buzeti Verban Z, Copot M, Kranjc Nikolić T. Determinants affecting the health of Roma in Pomurje. Murska Sobota: Institute of Public Health; 2011.
9. Šimec V. Primerjava življenjskega sloga in zdravstvenega stanja med romsko populacijo in ostalim prebivalstvom v Beli krajini (specialistična naloga). Ljubljana: Medicinska Fakulteta, Katedra za Družinsko Medicino; 2013.
10. Kosa Z, Szeles G, Kordas S. A comparative health survey of the inhabitants of Roma settlements in Hungary. Americ J Public Health. 2007; 97: 853–9.
11. Voko Z, Csepe P, Nemeth R, Kosa K, Kosa Z, Szeles G et al. Does socioeconomic status fully mediate the effect of ethnicity on the health of Roma people in Hungary? J Epidem Comm Health. 2009; 63: 455–60.
12. Bogdanović D, Nikić D. Mortality of Roma population in Serbia, 2002–2005. Croat Med J. 2007; 48: 720–6.
13. Čvorović J. Sexual and reproductive strategies among Serbian Gypsies. Pop Environ. 2004; 25: 217–42.
14. Koupilová I, Epstein H, Holcík J, Hajioff S, McKee M. Health needs of the Roma population in the Czech and Slovak republics. Soc Sci Med. 2001; 53: 1191–204.
15. Posavec K. Sociokulturna obilježja Roma u Europi. Od izgona do integracije. Društvena iztraživanja. 2000; 9: 229–50.
16. Aniko J. Play in the ghetto: global entertainment and the European 'Roma problem'. Third Text. 2006; 20: 659–70.
17. Gabel-Gatenio S. The growing divide: the marginalisation of young Roma children in Bulgaria. Int J Soc Welf. 2009; 11: 67–75.
18. Bracht N, Kingsbury L. Community organization principles in health promotion: five stage model. In: Bracht N, editor. Health promotion at the community level. Los Angeles: Sage; 1990: 7-34.
19. Josipovič D, Repolusk P. Demographic characteristics of the Romany in Prekmurje. Acta Geographica Slovenica. 2003; 43: 127–40.
20. Statistični urad Republike Slovenije [Internet]. Available: 11 April 2012 from: http://www.stat.si/popis2002/si/rezultati_slovenija_prebivalstvo_dz.htm
21. Maksuti N. Samozdravljenje Romov v Prekmurju: specialistična naloga. Medicinska Fakulteta Ljubljana; 2009.
22. Zelko E, Švab I, Klemenc-Ketiš Z, Maksuti A. Attitudes of the Prekmurje Roma towards health and healthcare. WKW 2015; 127: 220-27.
23. Flick U, Kardorff EV, Steinke I. Qualitative content analysis. In: Steinke I, editor. A companion to qualitative research. London: Sage; 2004: 266–9.
24. Schreier M. Qualitative content analysis in practice. Los Angeles: Sage; 2012.
25. Zveza –Romov Slovenije [Internet]. Available: 28 April 2016 from: http://www.zveza-romov.si/Kdo_smo, 601,0.html
26. Zelko E, Švab I, Rotar Pavlič D. Quality of life and patient satisfaction with family practice care in a

Roma population with chronic conditions in north-east Slovenia. Zdrav Var 2015; 54: 336-44.
27. Nutbeam D. Health literacy as a public health goal: a challenge for contemporary health education and communication strategies into the 21st century. Health Promot Int. 2000; 15: 259–67.
28. Manoff R.K. Social marketing: new imperative for public health. New York: Praeger, 1985.
29. Brenner B. Implementing a community intervention program for health promotion. Soc Work Health Care. 2014; 1-2: 359–75.
30. Schooler C, Farquhar JW, Fortmann SP, Flora JA. Synthesis of findings and issues from community prevention trials. Annal Epidem. 1997; 7: 54–68.
31. Stone EJ, Pearson TA, Fortmann SP, McKinlay JB. Community-based prevention trials: challenges and directions for public health practice, policy, and research. Annal Epidem. 1997; 7: 113–20.