Health surveys and health promotion activities in vulnerable populations especially in the Roma popultion

PhD Thesis

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Budapest
2010

Introduction, historical overview

Vulnerable populations are significantly different from the average of the majority population in terms of somatic and mental health status, behavior and/or socio-economic conditions associated with disadvantaged situation. Examples of vulnerable populations are impoverished people, unemployed persons, certain ethnic minorities, homo- and bisexual males, sex-workers and other groups suffering from discrimination and segregation. Their disadvantaged situation may lead to negative health consequences and they may face various barriers to reaching health care services.

1. Aims

This paper summarizes the methods and findings of several studies concerning the health behavior of vulnerable populations in order to improve health education and promotion programs. Specifically it seeks:

1.1. To study health behavior of vulnerable groups, namely Roma, men having sex with men (MSM) and female sex workers considering their cultural characteristics, using methods of epidemiology, sociology and cultural anthropology.

1.2. To establish community based health promotion model programs for Roma populations aiming at primary prevention of HIV/AIDS, cardiovascular and non-infection diseases, in addition to secondary prevention of oral cancer.

1.3. To monitor and evaluate the above programs and to suggest recommendations for sustainability and extension.

3. Methods and Study Designs

3.1. Health behavior surveys in vulnerable populations

3.1.1. HIV/AIDS related knowledge, attitude and behavior (KAB) survey in low class sex workers (1993).

Two hundred self-administered KAB questionnaires were distributed to sex workers in the streets of 8th district of Budapest by social workers. Questionnaires were sent back anonymously (n = 78). Participants were asked about their age and education level, HIV/AIDS-related knowledge, for example, transmission of the virus, first signs and symptoms of the disease and possibilities of prevention. Other questions in connection with high-risk HIV/AIDS behavior asked about drug use and sharing needles, alcohol consumption, numbers of clients, frequency of condom use and lubricants. Descriptive analyses were performed to calculate frequencies, means, and medians. Data were compared to qualitative observations (interviews and participant observations) made by social workers.

3.1.2. High-risk HIV/AIDS behavior of MSM in Budapest (2001).

Participants of the study (n=469) were men who reported a history of sex with other men. They were surveyed in gay community venues in the city. Descriptive analyses were performed to calculate frequencies, means, medians and standard deviations. To explore factors related to high-risk behavior, univariate analyses were performed. T-tests were used to compare groups on continuous variables that were normally distributed, Mann-Whitney U-tests for variables that had skewed distributions and chi-square tests for dichotomous variables. Multivariable logistic regression analysis was used to determine the predictors of high-risk behavior, namely having engaged in anal intercourse without using a condom.

3.1.3. Association between ethnicity and high-risk behavior and health status in the Roma population (2004).

Comparative health interview surveys were performed in 2003-2004 on representative samples of the Hungarian population (n=4121) and inhabitants of Roma settlements (n=931). Health status was described with self-rated health and functionality while surrogates of health behavior were smoking, consumption of fresh fruits and vegetables and types of fat used for cooking. Logistic regression models were applied to determine whether Roma ethnicity modifies the association between socioeconomic status and health (including health behavior). Dependent variables in the logistic models were self-reported health, functional limitation, smoking habits, consumption of fresh fruits and vegetables, and using only lard as fat for cooking and living in Roma settlement as independent variable corrected for age and gender. Next we added income, education and employment in each model one by one. Wald-test was applied to test the hypotheses of no interaction, $p<0.01$ was considered statistically significant.

3.2. Programs to improve the health status of Roma population – a critical overview

3.2.1.Model program for prevention of HIV/AIDS in a Roma community (2002).

Roma groups for the program were selected by participant observation at community meeting points. Ten social networks were involved altogether with 80 participants. The networks' structure and leaders were identified using the sociometry method suggested by Moreno. We surveyed AIDS-related knowledge, attitude and behavior and conducted in-depth interviews. Answers were used to elaborate training program for leaders. Leaders were required to transmit AIDS-related knowledge to their peers and influence the attitudes related to high-risk behavior.

Leaders participated in a training program consisting of six sessions. In addition to improving their communication skills, they got appropriate information on HIV/AIDS and risk factors. They learned how

to change their peers' high-risk behavior. Three month later changes in AIDS-related knowledge, attitude and sexual behavior in the group were measured.

3.2.2. Health promotion club (HPC) network for elderly Roma individuals in three counties of Western-Hungary (2003)

Sixty-six health promotion clubs were established for more than 2000 elderly Roma people in three counties of Western-Hungary as part of a compensation program because of atrocities in the 2nd World War. The main objective of the project was to improve the unfavorable health and social status of the Roma population by providing medical, lifestyle, social and legal assistance and helping them to use health care facilities and social services, in addition to improve doctor-patient relationship. Cardiovascular and respiratory diseases and cancer are the most important causes of death in Hungary, especially among disadvantaged populations; hence the objective was the primary prevention and early detection of these diseases and their risk factors. Prevention of infectious diseases with improving environmental and personal hygiene) was also an important target of the project.

We collaborated with governmental, local governmental and non-governmental organizations, health care workers and leaders and members of Roma communities. We contacted all beneficiaries (n=2053) and health care providers (n=400) first through a letter and then in person to explain the aim of the program and the importance of their participation. Questionnaire survey was administered in order to estimate the most important health problems and needs, risk factors like blood pressure, smoking, alcohol consumption and unfavorable nutrition. Standardized baseline data collection including BMI, blood pressure, testing of respiratory function and health related knowledge, attitude and behavior were conducted by trained Roma field staff. Data were used to improve project performance. Basic needs of the target population were also studied. Our elaborate incentive system (distributing food-tickets) not only facilitated participation but also contributed to covering their basic needs. Roma mediators played a central role in assisting Roma people with ele-

vated blood pressure, respiratory and other diseases to establish good relationship with their family doctor. Individuals who were not able to attend the club meetings were visited at home.

3.2.3. Screening for oral cancer – a model program in Roma population (2005)

The aim of the project was to set up a model program for early diagnosis of oral cancer in a high risk (Roma) population. Collaboration among dentists, public health physicians and local Roma community were established. The number of participants was 1200 in four Hungarian towns. Roma individuals were informed about the objective, place and time of screening with the help of Roma mediators. Participants filled out a questionnaire about risk factors before an oral examination. Patient with oral cancer or suspicious lesions were referred to a specialist.

4. Results

4.1. Health behavior surveys in specific vulnerable populations

4.1.1. HIV/AIDS related knowledge, attitude and behavior (KAB) survey of low class female sex workers (1993).

The response rate was 39%. More than three quarter of responses about HIV transmission were correct, however the role of oral and anal intercourse was less known. False knowledge occurred like “AIDS is a disease of homosexual males”, “the infection can be prevented with oral anti-conceptive or vaccination”. One woman was drug user, 50% of the responders consumed alcohol regularly. Sixty-six percent of them had been treated for sexually transmitted infections, 27% had been tested for HIV, none of them was positive. Although 84 % of responders knew that HIV infection can be prevented by using condom, condom was used only in 47% of the sexual intercourses. If the client did not want to use condom, less than half

of prostitutes asked them to use it. According to observations of social workers alcohol consumption was more frequent and condom use was less frequent than reported in the self-reported survey.

4.1.2. High-risk HIV/AIDS behavior of MSM in Budapest (2001).

The mean age of men in the sample was 29.2 years, 44% had completed high school and 40% had completed post-secondary education. All men in the sample reported having sex with a man at some point in their lives, 75% of respondents described their sexual orientation as homosexual, 24% as bisexual, and 1% as heterosexual. The mean number of partners was 39 during the past three months. Half of them reported engaging at least once in UAI during the past three months; condoms were not used in approximately 50% of AI acts. Seventeen percent of participants reported selling sex to get money or valuables, and similar proportion of respondents said they were buying sex. More than 77% of participants had sex with female partners at some point in their lives. Condom use by bisexual men with their female partners was only 23%. Approximately 19% of men in the sample reported that they had been treated in the past for STD. Seventy-three percent of men said that they had an HIV test in the past; 97% of them reported the result as negative. Approximately 20% of participants reported the use of illicit drugs during the past three months, most commonly marijuana. Participants correctly answered an average of 75% of the questions assessing practical knowledge about HIV risk, however approximately 52% of them did not know that condoms should not be lubricated with oil or Vaseline. Thirty-seven percent of respondents believed that washing carefully after sex helps to protect one from HIV. Twenty-three percent of participants believed that one can tell from a person's appearance if he is HIV-positive, and about 31% felt they did not have to follow safer sex guidelines if their partners said he was HIV negative. Men who engaged in unprotected sex had lower AIDS risk behavior knowledge ($p=0.05$), held weaker intentions to change risk behavior ($p<0.001$), had more negative condom and safer sex attitudes

(p<0.001), were less likely to perceived norms as supportive of condom use and safer sex (p<0.001), and were lower in risk reduction self-efficacy (p<0.001) than men who refrained from high-risk sexual behavior. Men who had engaged in any UAI had different levels of condom access, experience, and perceived importance. Men in the high-risk group more often said that they did not have enough money to buy condoms (p=0.005), less regularly bought condoms and had not them available when they were needed (p<0.001), did not like condoms or did not consider them important (p<0.001), and knew less about how to use condoms (p=0.01). In addition, men who engaged in high-risk behavior were less likely to report having ever had an HIV test (p=0.05).

Megjegyzés [IM1]: ez itt tul sok adat, egyszeruen omesztve, nem tul elegans

4.1.3. Association between ethnicity and risky health behavior and health status in the Roma population.

The odds of reporting very bad or bad health was 2.2 (95% confidence interval (CI: 1.8-2.7) times higher among people who lived in Roma settlements than in the general population. This difference gradually disappeared after adjustment for income and education. The relationship between Roma ethnicity and functional limitation was similar the effect almost entirely disappeared after adjustment for income. Just like health status, health behavior was also strongly related to socioeconomic factors. The odds of daily smoking, consuming fresh fruits less than weekly and using only lard as fat for cooking were much higher among those who lived in Roma settlements. The odds ratios were reduced, but remained statistically significant after adjustment for income, education and employment. We found that the associations between socioeconomic factors and health were modified by Roma ethnicity. Income had a very strong negative association with daily smoking and non-consumption of fresh fruits and vegetables among people living in Roma settlements. A 40€ increase in the household equivalent monthly income reduced the odds of daily smoking by 6% in the general population, and by 16% among people living in Roma settlements, odds ratio (OR) 0.94 (95% CI 0.92-0.97) and 0.84 (95% CI 0.76-0.92). Similarly, a 40€ increase in the household equivalent monthly income reduced the

odds of consuming fresh fruits or vegetables less than weekly by 5% in the general population and by 22% among people living in Roma settlements; OR=0.95 (95% CI 0.87-1.03) and 0.78 (95% CI 0.69-0.88).

4.2. Programs to improve the health status of Roma population – a critical overview

4.2.1. Model program for prevention of HIV/AIDS in a Roma community (2002)

Social network leaders participated in all training sessions. They paid attention to the information on HIV/AIDS. During the training their knowledge about prevention of HIV infection increased. Communication training helped them to improve ability for making relationships. They became able to transfer their knowledge and positively influence the attitude of their peers. The network leaders reported about their activity by phone and also by writing a diary. They spoke with their peers about HIV infection and prevention 1-2times per week and by phone 2-3 times per week. In-depth interviews were conducted in three month. The communication about HIV infection and prevention continued for a while, however, less frequently.

4.2.2.Health promotion club (HPC) network for elderly Roma people in three counties of Western-Hungary (2003)

Three interactive lectures were presented in club meetings on cardiovascular diseases, malignances, musculoskeletal disorders and risk factors like smoking, nutrition and alcohol consumption. Family doctors were the lecturers so these meetings improved doctor-patient relationship. Physicians received specific training before the lectures. Participants received an illustrated information booklet. An overwhelming majority of invited Roma people (altogether about 2,000 people in 66 setting) participated in these meetings. Social and legal issues, such as marital problems, divorce, child protection, violence in the family, social security, social support and tax problems and compensation for atrocities against Roma people in the 2nd

World War also emerged frequently. Assistance was provided in matters related to administrative difficulties. We tried to help participants deal with problems caused by discrimination and segregation. Distribution of food vouchers motivated Roma individuals to participate in the meetings and improved their nutrition. Roma mediators secured temporary jobs and could use their experience in similar projects. Qualitative analysis of mediator's reports showed that participants enjoyed the lectures and they were active. They met frequently after the meetings, so social support increased. Roma people visited family doctors regularly. A focus group was organized one year later for Roma mediators, formal and informal leaders. Their opinion was favorable on the program. Doctor-patient relationship generally improved. The group hoped to continue the program.

4.2.3. Screening for oral cancer – a model program in the Roma population

Oral cancer screening was performed in four sites for 1146 persons. Mean age of the participants as 40 years, 75% had 8 or less years of schooling. Half of them did not brush their teeth regularly, 75% were smokers, and 45% consumed alcohol regularly. Accordingly, they had high baseline risk. Eighty-four percent had oral or dental complaints.
Oral lesions were found in 18 or 1,6% of the respondents, leukoplakia in 15 or 1,6% while 12 or 1% have lesions which appeared malignant. Half of the participants did not attend dentist regularly, this rate was 93% in people screened for any kind of lesions.

5. Discussion

Health and health care problems can be interpreted and solved only in connection with social, economic, political, biological, genetic and environmental factors. The epidemiological approach to examine cause and therapy of an illness (especially in vulnerable populations) is disease-oriented, while the cultural context frequently has not been taken into consideration. There are limitations in methodology e.g. sampling problems, involving subjects and assuring continuous participation in the study. Medical anthropology with holistic-

humanistic approach focuses on cultural and social contexts of the diseases in prevention and curing them. The number of participants in anthropological studies is usually low, the results are mainly qualitative. Studies based on methods of epidemiology or cultural anthropology alone can not give a full picture about risk factors and health status of disadvantaged population. Each by itself is not suitable for planning, accomplishing and evaluating health promotion programs. Hence both methodology of epidemiology and cultural anthropology was used in our studies. Data can be used for program planning, monitoring and evaluation. Analysis of relationship between health and ethnicity helps to elaborate health promotion programs for Roma communities.

Based on our research we demonstrated the well-known fact that health status and health behavior of vulnerable populations are unfavorable and access to health care services is difficult. Primary and secondary prevention programs are cost-effective in vulnerable populations since the burden of diseases is great. Before organizing health promotion programs, health behavior and health status surveys should be conducted in order to estimate needs. Survey subjects should be convinced that the study has not only scientific importance but can also improve their health status in short run. Participation can be motivated with financial means . In order to establish health promotion programs in line with needs and wish of the given population health behavior and health status should be surveyed. Surveys provide data for monitoring and evaluation of the programs. Examining the influence of ethnicity on health behavior and health status helps to plan Roma health programs. Accordingly, health surveys should be followed by health promotion programs and health promotion programs should be evaluated using the same health surveys.

The study of health behavior of vulnerable populations is associated with methodological problems. Special characteristics of these groups should be taken into consideration when compiling and editing questionnaires and in communications with them avoiding the use of difficult to understand style and unusual words. Cultural adaptation of questionnaires is important, Representative sampling

usually is not possible mainly because the exact size and structure of these populations are not known. To categorize certain individuals into certain groups is problematic too, as definitions are not accurate and group members frequently hide their identity. Even experts of this topic have not reached a consensus about classification of Roma people. Self-identification is not always acceptable, and identification by others can cause ethical and legal problems. The surveys are typically conducted in sites like Roma colonies, remote neighborhoods or in pubs and other venues frequently visited by disadvantaged groups. Consequently the assistance of peers and intermediaries of studied population is needed. Street prostitutes are not ready to answer questions even for well trained interviewers if the interviewers are not known or trusted. Survey in gay bars could not been conducted without the help of gay organizations. The assistance of Roma mediators was necessary for surveying Roma health and high-risk behavior and organizing health promotion programs.

The results of questionnaire surveys should be analyzed with caution, especially in the case of questions about sexual behavior and alcohol or drug consumption as the responders want to be in line with social norms and expectations. In certain cases honest responses and identification of the respondents may have criminal consequences (e.g. drug-use, illegal prostitution). These difficulties can be decreased with appropriate preparation, knowing the specific population well, maintaining strict confidentiality or anonymity, and using methods of epidemiology, sociology and anthropology in integrated way.

Basic condition of success of these prevention programs is the collaboration with the community which can form after a long-term relationship. Many health promotion programs were organized on the same site before the HIV prevention model experiment and the oral screening program. The health club program started with mediator training (establishing good working relationship) with formal and informal leaders of the local Roma community before beginning the study.
Based on our experiences we emphasize again the importance of collaboration of epidemiology, sociology, cultural anthropology,

psychology for improving of health status of vulnerable populations. Health promotion programs should be elaborated with cooperation of the given population using the results of former projects.

Usually the deprived socio-economic conditions contribute to the unfavorable health status of vulnerable groups. A program should follow the hierarchy of needs beginning with basic biological needs before improving complex psychological motivations. The later ones become important only if basic needs are satisfied. Standard of living, quality of life and health status should be improved step by step. Education and health care without discrimination can interrupt the development the disadvantaged situation. Health status and accessibility to health care system should be improved even if the socioeconomic status does not change in short run.

Equality in the society and in the health care connects with each other closely. To achieve equality in health status and health care it is not enough to improve the financial situation, but skills to solve conflict and to communicate efficiently also need to develop. The role of continuous learning should be emphasized moreover it is important to reduce dependency, helplessness and chronic stress. Community-based health promotion projects, especially programs involving community opinion leaders, should be a priority. Social support is protective, therefore it should be strengthened too. Empathy is fundamental, as *Spinoza* said:"Do not weep. Do not wax indignant. Understand"

Publications

Publications connected to the thesis

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