Predicting Cervical Screening and HPV Vaccination Attendance of Roma Women in Hungary: Community Nurse Contribution is Key

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Abstract

Background: HPV screening/vaccination has been observed lower for ethic minorities. Understanding factors that predict and can improve attendance is therefore key. Hence, the aim was to identify causes, especially concerning the quality of the patient-provider relationship, that predict past HPV screening and vaccination turnout of Roma women in Hungary.

Methods: Cross-sectional research design with self-developed, culturally sensitive questionnaire. A female Roma sample of 500 potential participants was randomly selected from census register. Community nurses contacted participants and distributed surveys. Surveys were mailed-in by participants. Bivariate logistic regression was used to predict former participation in HPV screening/vaccination.

Results: Of the total sample, 17.4% of women attended at least one cervical screening and HPV vaccination in the past. Past negative screening experience was negatively correlated to community nurses and positively to physicians. The odds of past attendance were 4.5 times greater if 'no negative earlier experience' occurred, 3.3 times likelier if community nurse performed screening/immunization and 1.6 times more probable if respondent felt 'no shame'. Evaluating the screening/vaccination process painful, being only financially motivated and attendance involving a lot of travel decreased the odds of 'no show' by 50%, 40% and 41%, respectively.

Conclusions: When considering the ratio of past cervical screening attendance, we conclude that our female Roma sample did not behave differently from the general population. We saw no evidence that racial mistreatment made any contribution to explaining cervical screening participation. Past positive screening experience and the quality of patient-provider relationship increased the odds of participation the most. Cancer of friends, pain, financial motivation and travel distance decreased odds of participation to a lesser extent. In order to improve future screening and immunization, community nurses should play more central and advanced role in the organization and implementation of such services specifically targeting Roma populations.

Introduction

As reported by the World Health Organization, Human papillomavirus (HPV) is a confirmed cause of cervical cancer and ranks # 4 globally of all cancers in women (WHO, 2020). Screening and vaccination are therefore key to prevent the disease. However, screening and vaccination participation remain a challenge, especially for women of ethnic minorities (Spencer et al., 2019). While ethnic groups were reported to have become more active in HPV vaccination uptake, they are still lagging behind in follow-through (Spencer et al., 2019). We also recognize that cultural HPV awareness and knowledge have a strong influence on vaccination attitudes and outcomes (Adjei Boakye et al., 2017, Marlow, 2011). Besides ethnic affiliation and personal knowledge, religious orientations were also identified as either constraints or enablers of vaccination (Chaparro et al., 2020, Shelton et al., 2013). Riza et al. (2020) confirmed that socio-economic background and education were important facilitators of Pap smear

testing and HPV vaccination. They argued that Roma ethnic origin was associated with misguided beliefs concerning cervical screening and the HPV vaccine. Jackson et al. (2016) went further to describe cultural aversion against HPV vaccination within travelling Roma communities which may also be part of a larger public mistrust (Karafillakis et al., 2019). A number of studies clearly stressed that concerns over vaccine safety was a major barrier of getting vaccinated (Hanson, et al., 2019, Jeudin et al., 2013, Marlow et al., 2009, Penhollow et al., 2019). Income (access to vaccine and healthcare) and actual logistics of obtaining the vaccine and seeing a healthcare professional similarly prevented seeking HPV vaccination (Jeudin et al., 2013). Getrich et al. (2014) reasoned that favorable healthcare provider attitudes were essential in the decision to get screened and immunized. However, when healthcare staff, particularly female healthcare professionals, were surveyed, lower than expected HPV vaccination alertness and patient immunization encouragement was discovered (Cheena Chawla et al., Burdette et al., 2017, 2016, Farazi et al., 2017). To achieve better screening and vaccination coverage, the quality of the human relationship between members of the Roma community and nurses and doctors was deemed critical for prevention and immunization success (Jackson et al., 2017). Why this relationship may be so critical was underscored by Ilisiu et al. (2019) who observed non-ethic women choosing hospital services for HPV screening whereas the majority of female Roma sought the attention of general practitioners. Finally, Vu et al. (2020) underlined that research should consider reflecting on healthcare practice and clinicians' views and actions towards both minorities and HPV testing and vaccination in order to help develop or improve culturally sensitive interventions.

In conclusion, while global HPV screening and vaccination have increased for ethnic groups, there are still barriers to fully utilizing preventive services. Obstacles have to do with cultural norms and expectations but are also related to socio-economic reasons. Research that accounts for the quality of interactions with health professionals and their impact have been emphasized. Therefore, this research aimed to explore causes that predict past HPV screening and vaccination attendance in Roma women in Hungary. Since cultural and healthcare provider contexts vary and may differ across countries, authors developed their own, culture specific instrument for the purposes of this research. Indicators revealed in the literature review informed and guided item development.

Methods

Research design was based on a cross-sectional survey with the intent to predict former participation in HPV screening/vaccination. Data was collected between July-September 2019. Potential participants received a mail contact and called researchers to indicate their willingness to join. Local community nurses were contacted and trained by the research team to identify participants using inclusion/exclusion criteria. The same nurses contacted participants, handed over the research instrument and supported subjects in responding to items if requested. To avoid respondent bias, nurses only explained all items but did not partake in responding. Participants forwarded surveys postal paid to the research team in sealed and unidentifiable envelopes. All methods were performed observing the relevant ethical guidelines.

Instrument

The research instrument was developed specifically for the purposes of the current research. Local community nurses with long personal experience working in Roma neighborhoods participated in the instrument development. Researchers also considered outcomes of prior local and international research, described in the introduction, published on the topic (Millei et al., 2015, Pakai et al., 2010, 2017, Vajda et al., 2013). Statements pertaining to health screening attitudes of Roma women obtained from previous research were organized into a survey form. Sample items include “I attend cervical screening/HPV vaccination because I care about my health”, “I attend screening/vaccination because my GP recommended to do so” and “I don’t attend cervical screening/HPV vaccination because it is too expensive”. The full scale comprised dimensions that tapped into behaviors concerning personal reasons, health reasons, influence of a healthcare personnel, influence of others, travel and time related difficulties, lack of incentives (financial), access to and availability of screening services and inconvenience of the screening procedure. Responses were recorded on a 5-point Likert scale (1 = absolutely disagree, 5 = absolutely agree). The final ‘scale’ included 17 items related to the dimensions above. Scale validity in this research was not tested and established. Authors refer here to content validity since actual community nurse expertise was used to cover all respective dimensions of the construct studied. Reliability, as measured by Cronbach’s alfa, was 0.88 for the full scale. Score range is between 17-85, greater scores indicating more potential for attending cervical screening/HPV vaccination. In terms of the logistic regression, individual items and not the aggregate scale was utilized.

Besides demographics, we asked respondents about their financial status (below average, average and above average), their current health (1 = very bad, 5 = excellent) and if they had ever been to cervical screening and received HPV vaccine at the same time (0 = no, 1 = yes).

Sample

The study sample was randomly selected from Roma women living in seven cities of Zala county with a total population of 282 thousand (KSH, 2011). Roma women were chosen as the target population because Roma represent the largest ethnic group in Hungary. Given that census data allows for identifing minorities, women with Roma origin and in the age range 25-65 years were selected and contacted by mail. A total of 500 potential participants were randomly selected from census who had initially been contacted. Acknowledging the difficulties referred to by Condon et al. (2019) and for ease of sampling and data collection, women only with a permanent address were recruited. A final sample of 411 participants consented to our research and 368 women provided complete data. Exclusion criteria were: 1) non-Roma origin; 2) inability to read and speak Hungarian; 3) outside of age range; 4) prior placenta removal or acute cervical cancer treatment; 5) survey form returned with missing data on key variables.

Ethics

The research was approved by the ethics committee of the Faculty of Health, University of Pécs before implementation (decision # ETKB/PTE-ETK/35-2019). Census data concerning minority status was

obtained by permission from the Bureau of Statistics. Participant list was cleared from records after making mail contact. Participation and final data collection were anonym and voluntary. All participants received and signed an informed consent. No monetary or other incentives were used to solicit responses. Survey forms were mailed in by participants pre-paid. Nurses received no compensation for research and participant support.

Statistics

Descriptive statistics was used to describe sample characteristics. One-sample Kolmogorov-Smirnov test was employed to evaluate normal distribution of main measures. In case of non-normal distribution, Spearman rank correlation coefficients were calculated to establish associations across main variables. Bivariate logistic regression analysis was used to predict actual screening participation and HPV vaccination. Outlier detection (standard residuals > ± 2.0) was performed and outliers outside the range of values were removed from final analysis. A priori sample size calculations (based on a one-tailed test with significance = 0.5; power = 0.8 and odds ratio = 2.0) indicated a total of 110 subjects required (Henrich Heine University, 2020). Missing data were excluded from analysis, no data replacement was performed. Actual past attendance of cervical screening was used as the dependent variable. One item representing each scale dimension described above was utilized as independent variables for the analysis.

Results

The average age of our sample was 36.4 years (SD 11.3). A total of 9% lived alone while 81% lived with some significant other (husband, relatives or children). In terms of education, 61.4% had less than or equal to primary school degree, 33.4% held high school degree and 5.2% graduate or postgraduate. Of the total sample, only 62.5% had active employment. As for financial status, 36.1% said their financial situation was below average, 62% thought they had average income, and 1.9% reported above average standards of living. Finally, 17.4% of women attended at least one cervical screening and HPV vaccination in the past. When asked about the first time it happened, the average age was 21.1 (SD 6.9) years, 14 years of age being the youngest and 54 the oldest.

Considering self-reported health of participants, average health rating (on a 5-point scale) was 2.96 (SD 0.96). The average score on the screening attitude scale was 47.0 (SD 7.49).

In terms of the association between self-reported health and employment, those actively employed enjoyed better health ($r = 0.18$, $p < 0.001$). Education was also positively associated with health, greater education was linked to better health ($r = 0.35$, $p < 0.001$). Income however did not correlate with past attendance of screening ($r = 0.84$, $p = 0.53$). Nor did self-reported health relate to past screening ($r = 0.14$, $p = 0.39$). Education, however, was positively associated with past attendance, greater education increased screening attendance ($r = 0.19$, $p < 0.001$). The fact that our respondent did not co-habit with someone had no influence on past screening attendance ($r = 0.44$, $p = 0.20$). As for the screening attitude measure, its total score was positively associated with income and education, more and income and

greater education increased the potential for attending future screening (r_{income} = 0.17, p < 0.001, $r_{education}$ = 0.19, p < 0.001).

Past negative screening experience was strongly correlated to doctors treating respondents racially unfair (r = 0.48, p < 0.001), the more unfair the personal conduct had been, the more past experience was appraised negatively. The opposite was true for community nurses (r = -0.27, p < 0.001), the more community nurses had been involved in screening, the less respondents reported negative experiences.

Finally, we preformed binary logistic regression predicting previous cervical screening attendance and HPV vaccination. The full model was significant (χ^2 = 121.96, p < 0.001, -2LL = 156.96) and resulted in an 87.9% correct classification and a good model fit. The model explained 44% of the variance in HPV screening/vaccination attendance. Table 1. presents outcomes of the logistic regression model. Variables that emerged significant were friends having cervical cancer, community nurse performing the check-up and vaccination, respondent feeling no shame, procedure being painful, respondent only financially motivated and had a negative prior experience, and less travel involved. In terms of the odds (Exp(B)) making the greatest contribution to having attended screening and vaccination before, negative experience, community nurse involvement and feeling shameful were key.

Discussion

The main objective of the current research was to predict past cervical screening attendance and HPV vaccination in a sample of Roma women. Past cervical screening attendance among Roma women was 17.4% which is not significantly lower compared to the general Hungarian female population (22.0-23.3%) (Boncz et al., 2007). However, when we compared our 3-year screening coverage to the general population, numbers fell unfavorably for our sample (7% vs 52.6%) (Boncz et al., 2007).

Using our descriptive measures, and according to expectations, we supported that self-reported health of respondents was positively correlated with greater income and education. We found income and health not linked to past screening attendance or HPV vaccination. Greater education, however, which we attribute to increased knowledge about health, was positively linked to past screening and vaccination. When the attitude scale total score was considered, both income and education was positive linked to screening attendance and vaccination (more income and better education increased turnout probability). These results are in support of Adjei Boakye et al. (2017), Jeudin et al. (2013), Marlow (2011) and Riza et al. (2020).

Concerning our logistic regression model, key variables predicted past screening and vaccination with greater precision (88% correct classification). The greatest odds of screening/vaccination show up was attributed to ‘no negative prior experience’, those who did not have such experience were 4.5 times more likely to seek screening/vaccination than those who had a negative past influence. In order of magnitude, community nurse performing the process was second. Those who favored the community nurse performing the check-up/vaccination were 3.3 times more probable to participate. The third most

influential variable was ‘feeling no shame’. Those who agreed to feeling no shame about the procedure were 60% more prone to attend screening/vaccination compared those who felt ashamed. All three findings confirm and support Getrich et al. (2014) and Vu et al. (2020) who argued the quality of the patient-provider relationship being a critical aspect of screening and immunization inclination.

Appraising the screening/vaccination process painful, being only financially motivated and attendance involving a lot of travel decreased the odds of ‘no show’ by 50%, 40% and 41%, respectively. When respondents’ friends suffered of cervical cancer, the odds of screening attendance/vaccination dropped by 53%. The result is opposite to expectations and authors have no immediate explanations for this outcome. More in depth research is suggested to explore the background of this behavior.

Note that while community nurse involvement was a significant determinant of HPV screening/vaccination, ‘doctors acting racially unfair’ as well as ‘sampling performed by the physician in his (GP) office’ did not make any contribution to explaining attendance. Same held true for ‘preventive reasons’ and ‘cancer in the family’, neither cervical cancer in the family nor preventing cancer reached significance in our model. These outcomes may have to do with cultural norms, but further research is required to verify the assumption.

Conclusion

When considering the ratio of past cervical screening attendance, we conclude that our female Roma sample did not behave differently from the general population. We saw no evidence that racial mistreatment made any contribution to explaining cervical screening/vaccination participation. Culturally similar to all females, ‘feeling no shame’ increased the odds of screening/vaccination participation. The positive role of the community nurse and her involvement in the procedure was highly emphasized by respondents. Having no negative prior experience with screening increased the odds of participation the most. Cervical cancer of friends, procedural pain, financial motivation and travel distance all decreased odds of participation to a much lesser extent.

In order to improve future screening and immunization, community nurses should play more central and advanced role in the organization and implementation of such services specifically targeting Roma populations.

Limitations

Only Roma women with permanent address were involved. Had women without a permanent address been selected as well, results may have been different from above. While only individual items were used for statistical analysis, and while we demonstrated sufficient reliability for the self-developed screening attitude scale, authors acknowledge that the instrument was not validated for this research.

Declarations

Ethics approval and consent to participate:

The research was approved by the ethics committee of the Faculty of Health, University of Pécs before implementation (decision # ETKB/PTE-ETK/35-2019). Subjects signed an informed consent before participation.

Consent for publication:

All authors have reviewed and approved the version submitted for publication.

Availability of data and materials:

The datasets used and/or analyzed during the current study are available from the corresponding author on reasonable request.

Competing interests:

Authors declare no conflict of interest.

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Author contributions:

AP – conception, data interpretation, drafting manuscript

RM-V – design, supporting data acquisition, data interpretation

ASÚ – conception, data interpretation, drafting manuscript

ZSKH – design, supporting data acquisition, manuscript revision

KSZG – data interpretation, manuscript revision

EBB – data interpretation, manuscript revision

MZ – data analysis and interpretation, drafting manuscript

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Tables

Table 1. Logistic regression model of screening/vaccination attendance

I attend cervical screening and HPV vaccination because…	B	S.E.	Wald	df	Sig.	Exp(B)
I care about my health	-0,408	0,240	2,885	1	0,089	0,665
of cervical cancer in my family	0,359	0,219	2,683	1	0,101	1,433
of cervical cancer in my friends	-0,750	0,239	9,830	1	**0,002**	0,472
I want to prevent cervical cancer	-0,116	0,244	0,226	1	0,634	0,890
my general practitioner told me to do so	-0,191	0,204	0,877	1	0,349	0,826
my community nurse will do sampling and vaccination	1,202	0,251	23,001	1	**< 0,001**	3,325
the doctor does not treat me racially unfair	0,270	0,211	1,627	1	0,202	1,309
sampling and vaccination will be done by the physician in his (GP) office	-0,013	0,187	0,005	1	0,944	0,987
I feel no shame	0,427	0,199	4,618	1	**0,043**	1,609
I had no negative experience before	1,505	0,382	15,514	1	**< 0,001**	4,503
I don't have to travel a lot	-0,524	0,208	6,339	1	**0,012**	0,592
it is organized by my workplace	-0,306	0,183	2,785	1	0,095	0,737
I don't attend screening/vaccination because it is too expensive.	-0,152	0,242	0,395	1	0,530	0,859
I don't attend screening/vaccination because it is too painful.	-0,675	0,259	6,807	1	**0,009**	0,509
I have no time for screening/vaccination because of family and other obligations.	-0,188	0,210	0,801	1	0,371	0,829
I can only financially be motivated to attend cervical screening/vaccination.	-0,507	0,244	4,335	1	**0,037**	0,602
I have no trust in cervical screening/vaccination.	0,039	0,211	0,034	1	0,854	1,040
Constant	7,095	2,027	12,250	1	0,000	1 205,580
Dependent variable: Have you ever attended cervical screening and received HPV vaccine? (yes/no)						