

HEALTH LITERACY AND PATIENT RIGHTS AWARENESS IN ETHNIC HUNGARIAN MOTHERS IN EASTERN EUROPE

Renáta Erdei Jávorné¹, Melinda Nagy², Eszter Molnár³, Réka Zsuzsánna Máthé^{4,5}, Emese Emőke Tóth-Batizán⁴, Mária Konečná⁶, Mária Zahatňanská⁷, Marta Mydlárová Blaščáková⁶, Janka Poráčová⁶, Vincent Sedlák⁶, Ágnes Sántha⁴

¹Department of Health Methodology and Prevention, Faculty of Health Sciences, University of Debrecen, Nyíregyháza, Hungary

²Department of Biology, Faculty of Education, J. Selye University Komárno, Komárno, Slovak Republic

³Department of Engineering, Lancaster University, Lancaster, United Kingdom

⁴Department of Applied Social Sciences, Faculty of Technical and Human Sciences, Sapientia Hungarian University of Transylvania, Targu Mures, Romania

⁵University of Public Service, Europe Strategy Research Institute, Budapest, Hungary

⁶Department of Biology, Faculty of Humanities and Natural Sciences, University of Prešov, Prešov, Slovak Republic

⁷Institute of Pedagogy, Andragogy and Psychology, Faculty of Humanities and Natural Sciences, University of Prešov, Prešov, Slovak Republic

SUMMARY

Objectives: The paper proposes to identify the determinants of patients' rights awareness in mothers and to examine the relationship of health literacy with awareness of those rights.

Methods: Our results are based on data from a convenience sample of 894 non-health professional ethnic Hungarian mothers from Hungary, Romania and Slovakia. Health literacy is measured with the HLS-EU-16 questionnaire.

Results: Analysis of variance reveals a significant association of health literacy with patient rights awareness. Our results show that health literacy is the highest among patients who filed a complaint through formal channels and/or took legal measures to restore their rights upon violation. A logistic regression model is built to identify the likelihood of having high patient rights awareness, that is, acting formally for the restoration of rights upon infringement. The model controls for covariates. When controlled for covariates, the likelihood of having high patient rights awareness increases with age, and is higher for mothers with highest education, for inhabitants of larger towns, as well as for those with adequate health literacy.

Conclusions: The findings of our study have implications for health policy, as they reveal significant inequalities in patient rights culture.

Key words: health literacy, patient rights awareness, socioeconomic determinants

Address for correspondence: Á. Sántha, Department of Applied Social Sciences, Faculty of Technical and Human Sciences, Sapientia Hungarian University of Transylvania, 540486 Targu Mures O.P. 9, C.P. 4, Romania. E-mail: santhaagnes@ms.sapientia.ro

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INTRODUCTION

Increasing health literacy is recognised as a policy objective, as a means to overcome existing social determinants of health and to exercise agency over the health condition of patients. By the same token, patient rights awareness is a critical issue. Patient awareness is being acknowledged to reduce the pressure on healthcare system and professionals (1). Rights awareness empowers patients to make informed decisions about their health services. Contrary to this, unawareness contributes to increasing health inequalities and disempowers patients' control over their healthcare treatments (2).

In spite of these common features of the two notions, the explicit association between health literacy and patient rights awareness has only sporadically been studied. Schulz and Nakamoto (3) argue that the concepts are distinct, both conceptually and

empirically, but their impacts are deeply intertwined. An eventual asymmetry between the two would result in threats both to patients and to health systems. High levels of health literacy without high level of awareness creates an unnecessary dependence of patients on health professionals, whereas a high levels of patient empowerment eventually associated with inadequate health literacy might lead to dangerous health choices of patients (3).

In this paper, patients' rights awareness is understood as being one aspect of legal literacy. Legal literacy is defined as "the process of acquiring critical awareness about rights and the law, the ability to assert rights, and the capacity to mobilize for change" (4). Our analysis solely comprises the second of the three dimensions, that is, the ability of patients to assert their rights, hence the notion of patient rights awareness is being used as synonymous to the rights assertion capability dimension of legal literacy.

At the most basic level, acquiring legal literacy means to acquire some consciousness of one's legal rights, of how to appropriate those rights and to work to overcome any encountered barriers to care. Higher levels of legal literacy imply actively expressing agency in confronting issues, engaging and participating in one's own health care, exercising self-determination about one's own health care (5).

Patient rights are defined as the care, treatments, support, and services that the patient needs from the medical, social and regulatory environment in the process of treatment (2). Patient rights promote patient autonomy, empowerment, participation in the treatment process, and, globally, the health system reforms (6). Half of the eligible population in Western European countries claim not to have received care with respect to patients' rights (2, 7).

Legal awareness, in particular patient rights awareness is lower in the countries of Eastern Europe than in the Western societies with longer democratic past (1), mainly due to the paternalist legacy prevailing in these countries. In formal socialist countries, in spite of the formal adherence of legal systems to the Western ones (8), rights culture is unstable and not fully developed, entailing a range of emotions, and the public opinion shows a deep institutional scepticism (9).

In Eastern Europe, knowledge of patient rights is limited (10), and particularly low is the actual initiation of grievance redressal. Research in Greece found that one out of four patients would take no restorative action upon rights violation. Oral complaint forms are envisaged by about one in four patients, whereas written complaint submission by one in ten, and court appeal initiation only by one in thirty (11). Although studies are scarce on the topic, international research identifies some barriers to expressing dissatisfaction. These include the lack of health-related experience and reduced critical contemplation of patients, as well as their paternalistic preferences, as health literacy is linked to patient empowerment (12). Other barriers are the fear of consequences, feelings of dependency on medical staff, and feelings of powerlessness in the healthcare system. Further, the lack of a guiding framework is perceived as an obstacle in many developing countries. Patients often report perceptions of low medical literacy as a barrier to their restorative actions (13). This consideration justifies the need to further study the associations of health literacy and patient rights awareness, as proposed in this study.

Among possible determinants of high patient rights awareness, research identified high educational level and urban residency (14–16). Further, higher level of rights awareness was more typical for women than for men (15), and for younger adults compared to other age groups (15, 16). Awareness is increased by health literacy and healthcare services' duration (17), thus family health history is an antecedent of rights consciousness. Hardly any study addressed the issue of family size with respect to legal literacy, but the results of studies on rights perception reveal that in larger families children are less aware of their rights and perceive a lower level of respect for their rights from their parents, too (18).

This paper aims at examining the nature of the relationship of health literacy with rights awareness, as well as at identifying the determinants of the practice of patient rights in ethnic Hungarian mothers in Eastern Europe. For the purpose of this study, the indicator of patient rights awareness is the fact of having acted formally upon rights infringement in the healthcare system.

MATERIALS AND METHODS

Research Design and Data Collection

The data used in this study derives from a cross-sectional survey carried out at the end of 2020 by the Quality of Life Research Centre at the Sapientia Hungarian University of Transylvania, Romania. The study aimed at obtaining information from Hungarian-speaking mothers in Hungary, Slovakia and Romania, mothers to children aged up to 10 years. Starting from secondary school age, children are increasingly taking the responsibility for their own health and gradually make the transition to self-management, and care responsibilities are also transferred from parents to children (19). As children above 10 are already themselves highly involved in their medical self-care, the upper age limit of children was set at this age, until their caregivers' health literacy is decisive for their health outcomes (20).

Permission to conduct the survey was obtained from the research ethical body of the Sapientia Hungarian University of Transylvania. The survey was a joint effort of four researchers from the three countries involved, and considerable efforts were made to propagate participation. In all places involved, social media was called upon to help reach the target group. The questionnaire was made available for a period of two weeks in December 2020 to mothers who were members of closed social media groupings, where discussions on different childcare topics take place. These groups are generally countrywide or have at least a regional scope. Group moderators were approached in advance with the test questionnaire, being provided the ethical consent for the survey. Then, with the permission of the group moderators, the researchers were let in the closed group and were allowed to share the questionnaire. The target groups were encouraged twice to participate, and a reminder was also sent two days before the closing of the survey. Informed consent of respondents was obtained at the beginning of the questionnaire, and results were anonymized. Following the survey closure, due to the high interest of participants in the results, the descriptive statistics were also shared in the same groups.

As online surveys inevitably contain a selection bias due to the opt-in survey design (21), data was weighted on education and settlement type in order to increase the generalizability of results. Weights were computed to adjust proportions of our convenience sample to the real female population proportions according to two control variables using the rake extension in SPSS. The two weighting variables – education (low, middle, high) and settlement type (urban, rural) – were raked according to their female population marginal distributions in each of the three countries. Marginal control totals were known separately for the two variables but not the full joint distribution. Through weighted sampling with replacement, our data reflects the female population percentages for education and settlement type. Although census data is somewhat outdated to this point, as the latest available results date back as long as 2011 in the EU countries, from this adjustment procedure it is hoped that the sample approximates the real female population distribution existing in the three countries. Still, however, the sample remains unrepresentative, and the generalizability of results limited.

Instruments

Health literacy is assessed with one of the most widely used measures, the standardized questionnaire of the Health Literacy Europe research group called Health Literacy Survey (HLS-EU) (22). The conceptual model is an integrative approach with an up-to-date theoretical framework, elaborated for general populations. In this subjective measure, respondents judge their skills in the dimensions of accessing, understanding, appraising, and applying health-related information in the domains of health promotion, disease prevention and health care. The original longer version of the questionnaire has by now been shortened and validated to allow a more adequate and general usage and has by now a version consisting of 16 questions used on the European continent and beyond, which was validated in several languages, including Hungarian, and used on different samples of the Hungarian speaking general population (23, 24).

The questions inquire about the degree of ease or difficulty experienced by respondents in medical issues and settings. For all the 16 questions of the HLS-EU-16 measure, 5-point Likert-type answers were dichotomized into two scores, “easy” (“fairly” or “very” easy – 1) and “difficult” (“fairly” and “very” difficult – 0). The score was calculated by adding the non-weighted sub scores of each item and resulted in a scale ranging between 0 and 16, where higher scores signal better health literacy. For respondents who had had at least 14 valid answers, missing values or “I don’t know” answers were estimated with a maximum likelihood algorithm, whereas those who had missed two or more answers were excluded from the analysis, following standard procedure (25). Subsequently, the scale scores were recoded into three categories following standard procedure. As a result, inadequate (0–8 points), problematic (9–12 points) and adequate (13–16 points) levels of health literacy were identified (Fig. 1).

As reported in a previous study based on the same dataset (24), the HLS-EU-16 scale has good psychometric properties,

displaying acceptable internal consistency ($\alpha = 0.763$). When performing exploratory factor analysis with polychoric correlation, most items loaded high on a single factor consisting of all 16 questionnaire items. Scale validity was checked with confirmatory factor analysis and the model fit was found acceptable. The comparative fit index in R was higher than 0.95, RMCA lower than 0.05, and SRMR lower than 0.08.

The measure of patient rights awareness is more problematic. To date, one complex measure has been developed (2), which places to the forefront the factual knowledge and familiarity with social security rights, healthcare system rights and other rights. For our research question, however, it is not the knowledge aspect but much more the empowerment that is being sought, for two reasons. First, the concept of health literacy also entails this active engagement aspect, second, in order for patients to become conscious partners in the healthcare system, active engagement with patient rights is a first order imperative, much more than simply being knowledgeable of these rights. Accordingly, the indicator of patient rights awareness is whether the mother patient has taken any formal action to restore her rights upon infringement.

The questionnaire used for data collection contained a conditional question formulated by the authors on the type of action taken by the respondent in the case that she or her children’s patient rights were infringed in health care. The wording of the question was the following: “Have you ever had your or your child’s patient rights violated in health care during pregnancy, in the perinatal or postnatal period, or in child health care?” If the respondent answered yes, she was subsequently asked: “What have you done to restore your/your child’s rights?” The answer options were: “no action”, “internet forum complaint”, “printed media complaint (reader’s letter or comment)”, “written complaint to hospital management/patient rights representative”, or “initiation of a lawsuit”.

How easy or difficult is it for you to ...?

1. Find information on treatments of illnesses that concern you
2. Find out where to get professional help when you are ill
3. Understand what your doctor says to you
4. Understand your doctor’s or pharmacist’s instruction on how to take a prescribed medicine
5. Judge when you may need to get a second opinion from another doctor
6. Use information the doctor gives you to make decisions about your illness
7. Follow instructions from your doctor or pharmacist
8. Find information on how to manage mental health problems like stress or depression
9. Understand health warnings about behaviour such as smoking, low physical activity and drinking too much
10. Understand why you need health screenings
11. Judge if the information on health risks in the media is reliable
12. Decide how you can protect yourself from illness based on information in the media
13. Find out about activities that are good for your mental well-being
14. Understand advice on health from family members or friends
15. Understand information in the media on how to get healthier
16. Judge which everyday behaviour is related to your health

Answer options: “very easy”, “easy”, “difficult”, “very difficult”.

Fig. 1. Items of HLS-EU16 questionnaire.

Statistical Analysis

This study uses descriptive and multivariate analysis. Following the frequency analysis in experiencing patient rights violation and the restorative steps taken, a two-variable analysis (one-way analysis of variance) is performed to assess the association between patient rights awareness and health literacy. Here, awareness is a categorical variable with three values. The original answers obtained to the question on rights restoration types were recoded into the categories: the respondent may have taken “no measure”, “any informal measure” or “any formal measure” of those listed above. Tukey-Kramer HSD post hoc test is carried out to identify the significant differences between activity categories.

Thereafter, the determinants of patient rights awareness are searched for. The independent effects of socioeconomic variables, health literacy and family health history are assessed in a binary logistic regression model, with the aim of identifying those factors that contribute to the differences in the practice of patient rights. This time, the outcome variable is a dummy recoded from the previous three-value categorical variable: upon patient rights violation, the respondent either “took no formal measure” – 0 or “took any formal measure” – 1, the latter being considered the indicator of a high level of patient rights awareness.

The regression model contains independent explanatory variables which were identified by previous research from different regions as having an impact upon the outcome variable. These are four socioeconomic and demographic variables: educational attainment, age, residence, and household size, and two health-related variables: health literacy and family health history (13–18).

Further socioeconomic variables like subjective income and employment relation were not included among possible determinants due to their interdependence with educational at-

tainment, as their inclusion would have resulted in decreasing or even vanishing the explanatory power of education. The alleged explanatory variables are, first, the categorical variable – educational attainment with the values low, medium and high. Second, the settlement type is included with four values: rural, urban with less than 20,000 inhabitants, urban with 20,000–100,000 inhabitants, and urban with more than 100,000 inhabitants. Third, mothers’ age is included in the analysis as a scale level variable. Fourth, the number of people in the household is also a scale level variable. Health literacy is used as a categorical variable with the values inadequate, problematic and adequate, computed according to the standard procedure (25). Sixth and last, family health history is a categorical variable with two values: in the family of the respondent there is either nobody with a chronic condition, or at least one family member (or herself) suffers from a chronic illness.

The reference is in all cases the smallest value of the variable. Significant odds ratios (Exp(B) values) higher than 1 indicate a higher chance, whereas those lower than 1 point to a lower chance for appropriate patient rights awareness of that group category to the reference category, all other variables being controlled for. Confidence intervals of 95% are provided.

Sample Characteristics

The total case number was 1,014 initiated and 952 fully completed questionnaires. Out of them, 58 respondents were healthcare professionals who were excluded from this analysis. Consequently, this study draws on the answers of 894 women. All respondents are ethnic Hungarian women, mothers of children of up to 10 years of age (Table 1).

Table 1. Sample characteristics (N = 894)*

Variable	Hungary n = 317 (%)	Romania n = 341 (%)	Slovakia n = 236 (%)
Age (mean)	36.7	34.2	35.6
Average family size (mean)	3.9	3.8	3.9
Number of children (mean)	2.0	1.7	1.9
Marital status: single	4.5	4.3	4.2
Urban > 100,000 inhabitants	24.8	20.1	18.6
Urban 20,000–100,000 inhabitants	23.2	22.1	19.1
Urban < 20,000 inhabitants	11.9	15.5	17.9
Rural	40.1	42.3	44.4
Subjective SES (0–10, mean)	7.36	6.98	7.16
Low educational attainment	1.2	1.9	1.6
Middle educational attainment	25.3	26.9	26.4
High educational attainment	73.5	71.2	72.0
Employee	55.9	59.1	56.2
On maternity leave	36.7	32.9	36.1
In education	1.7	1.4	2.0
Unemployed	0.7	1.2	1.0
Housewife, full-time mother	5.0	5.4	4.7
Has a child with chronic illness	14.2	13.8	14.0

*This table is duplicated from a previous article based on the same dataset written by one of the authors (24).

The majority of respondents have a university degree, one in four has completed high school and only a small minority stopped after elementary education. Thus, our results allow for careful generalizations only. To diminish this bias, iterative proportional fitting was used.

The mean age of mothers, the number of children in the family and the average family size are similar to the trends in the countries of study.

The sample entails only very few single mothers. There are more town inhabitants than village inhabitants in the sample. With respect to family health history, one in three respondents have at least one close family member with at least one chronic condition, and about one in seven respondents is herself caregiver of a child suffering from some kind of chronic disease.

The three subsamples entailing ethnic Hungarian mothers in Hungary, Slovakia and Romania are very similar to each other with respect to socioeconomic features, as reported in a previous study (24), thus our sample allows for an analysis that treats this population segment as a unitary group. Further analysis might consider regional differences, too.

RESULTS

Our study aims at thematizing the association of health literacy and patient rights awareness in ethnic Hungarian mothers in Hungary, Slovakia and Romania, and at identifying the socioeconomic, demographic and health-related predictors of high patient right awareness.

To start with, out of the total sample of 894 respondents, 32.4% have reported experiencing a violation of their rights in healthcare during pregnancy, childbirth or childcare. As our research questions concern only those patients who have experienced rights

infringement, the analysis below focuses on this group of patients only ($n = 308$). Table 2 displays the actions mothers undertook upon the violation of their or their children's rights.

From those mothers who experienced rights infringement, the vast majority undertook no restorative action. Second in the row, about one in seven mothers let loose of their indignation on internet fora or social media groupings, some respondents turned to the printed media and issued a reader's letter or a comment. Third, some patients wrote a complaint to either the hospital patient rights representative or the management, or both. The number of those mothers is the smallest who filed a lawsuit to redress their grievance.

Among those who had reported an experience of having their patient rights infringed, the overwhelming majority took no action to restore their rights. Those who took any measure mostly chose to complain on internet community fora. Compared to these two groups, the rate of those who took formal measures is minimal. That is, only 18 respondents (5.8%) chose any formal restorative action, the rest either remained silent or, at most, turned to the media.

In the quest to identify the association of health literacy and the practice of patient rights in ethnic Hungarian mothers, a one-way analysis of variance is performed. The health literacy level of respondents is compared among the groups of those mothers who reacted to rights infringement in similar ways. Here, the previous actions "internet fora complaint" and "printed media complaint (reader's letter or comment)" are considered informal actions indicating a low level of rights awareness, whereas "written complaint to hospital management/patient rights representative" and "initiation of a lawsuit" are the indicators of a high level of rights awareness. It is assumed that those mothers who, upon violation of their rights in the healthcare system, took official steps to redress grievance, have better health literacy

Table 2. Respondents' reactions upon patient rights infringement ($N = 308$)

Type of reaction	Relative frequency of respondents' reaction n (%)
No action	256 (83.1)
Informal complaint on the internet/social media	42 (13.63)
Written complaint to hospital management/patient rights representative	11 (3.6)
Comment/letter in printed media	8 (2.6)
Lawsuit initiation	7 (2.3)

Table 3. Two-variable association of patient rights awareness and health literacy ($N = 308$)*

Action taken upon rights infringement	HLS-EU-16 score (0–16)	HLS-EU level
No action ($n = 256$)	11.98	Problematic
Informal action: internet fora/printed media complaint ($n = 50$)	9.58	Problematic
Formal action: written complaint to hospital management/patient rights representative, initiation of a lawsuit ($n = 18$)	15.26	Adequate
Eta Squared = 0.60, $F = 17.150$, $p < 0.001$		

*The cumulated number of cases at the three types of action is actually higher than the total number of respondents involved in the analysis ($N=308$), because some respondents took both formal and informal actions and are thus included in both categories.

than those who took no action at all or who chose an informal way of complaint.

A one-way ANOVA was performed to compare the health literacy scale scores across the three types of activities and results indicated a statistically significant difference in mean scores between at least two groups ($F = 17.150, p < 0.001$). The Levene statistics indicate the homogeneity of variance ($p = 0.412$). The Tukey-Kramer HSD test for multiple comparisons with unequal case numbers found that there is a statistically significant difference in the health literacy scores between those who took no action and those who raised an informal objection ($p < 0.001, 95\% \text{ CI: } 1.06\text{--}3.74$), between those who took no action and who initiated a formal complaint ($p < 0.001, 95\% \text{ CI: } -5.05, -1.49$), as well as between those who raised an informal objection and who initiated a formal complaint ($p < 0.001, 95\% \text{ CI: } -7.79, -3.56$).

As displayed in Table 3, there are huge differences among those with low and high levels of rights awareness. Most health literate are those mothers who undertook formal restorative actions. Although the group of those who chose to act via a formal channel is small, its average health literacy score almost gains up the theoretical maximum of 16 points.

Having acknowledged these differences, our aim is to assess the impact of health literacy upon rights awareness independently, controlled for other effects. At the same time, the effect of further plausible predictors of the practice of patient rights can be identified. In order to do so, a binary logistic regression model is constructed to measure the chance of formally acting upon patient rights infringement. Here, the outcome variable is whether

the respondent “took no formal measure” (value 0) or “took any formal measure” (value 1) for rights restoration.

Plausible determinants of patient rights practice are those features of respondents that had been identified as impactful by previous research: education, residence, age, number of people in the household, health literacy, and family health history (13–18).

Data introduced in the logistic regression equation is available for 308 persons, that is, to all those who had experienced patient rights infringement.

The cumulated explanatory power of the logistic regression model is significant. The most powerful determinant of patient rights awareness is educational attainment, more specifically high education. Table 4 reveals that compared to mothers with low educational attainment those with high education are almost eight times more likely ($\text{Exp(B)} = 7.719, 95\% \text{ CI: } 4.859\text{--}11.925$) to go for the restoration of their own or their children’s patient rights in cases of infringement. Medium educational level does not increase the likelihood of patient rights awareness in our sample.

Next, health literacy is a strong individual determinant of patient rights awareness. Here, compared to those with inadequate health competences, even a problematic level of health literacy makes it more likely ($\text{Exp(B)} = 3.047, 95\% \text{ CI: } 1.114\text{--}5.154$) for a mother to be knowledgeable of her rights and take action in order to probate them in cases where she faces their violation during the treatment process. As expected, adequate health literacy makes it four times as likely ($\text{Exp(B)} = 3.950, 95\% \text{ CI: } 1.257\text{--}6.587$) to have high rights awareness compared to the group with inadequate health competences.

Table 4. Determinants of patient rights awareness ($N = 308$)

Explanatory variables	B	p-value	Exp(B)	95% CI for Exp(B)	
				Lower	Upper
Educational attainment					
Low*					
Medium	-20.413	0.999	0.000	0.000	0.000
High	2.044	0.008	11.925	4.859	11.925
Residence					
Rural*					
Urban <20,000 inhabitants	-18.472	0.999	0.000	0.000	0.000
Urban 20,000–100,000 inhabitants	-18.650	0.998	0.000	0.000	0.000
Urban >100,000 inhabitants	1.069	0.001	2.746	1.878	3.387
Age	0.105	0.021	1.111	1.059	1.288
Number of people in the household	-0.333	0.196	0.717	0.050	1.660
Health literacy (HLS-EU-16)					
Inadequate*					
Problematic	1.114	0.045	3.047	1.114	5.154
Adequate	1.374	0.004	3.950	1.257	6.587
Family health history: family member with chronic disease					
No*					
Yes	0.124	0.759	1.132	0.352	5.147
Constant	5.820	0.001	0.003		

*Reference category; binary logistic regression model; outcome variable: respondent has not vs. has taken any formal measure; $-2 \log\text{-likelihood} = 177.305$; $\chi^2 = 25.77$; $df = 6$; $p = 0.001$; Nagelkerke R-square = 0.176. Numbers in bold indicate statistically significant values.

Independently of educational attainment, settlement size itself is a predictor of the practice of patient rights. Mothers residing in larger towns with more than 100,000 inhabitants display a higher chance of acting formally for patient rights restoration compared to the inhabitants of rural settlements (Exp(B) = 2.746, 95% CI: 1.878–3.387).

Last, among the socioeconomic and demographic features that have proven to contribute to better patient rights awareness, the age of the mother has a significant effect. This seems to be a moderate effect, however, with the increase of age difference compared to the youngest respondent, this effect also cumulates.

DISCUSSION

The focus of this paper is the association of health literacy and patient rights awareness. To date, there is scarce evidence on the relationship between the two. The vast and fast growing literature on parental health literacy and information source types mostly focus on child health indicators and chronic disease prevention and management (20).

As the association of health literacy and legal literacy has insufficiently been researched, the path to patient rights awareness among mothers is provided by the literature on the use of information sources in health issues. Here, too, formal and informal information sources are being distinguished and linked to health literacy levels. Research reveals that health literacy is associated to the type of information sources used by mothers. For instance, high-risk pregnant women with adequate health literacy were more likely to make an informed choice with respect to screening types available to them, based on the formal counselling by healthcare specialists, and informed choice was associated with less decisional conflict and less anxiety (26). Mothers with adequate health literacy tended to use more formal information sources than did mothers with low health literacy (27). Recent research on a sample of patients with chronic illnesses from Israel found that information source credibility and patients' rights awareness is directly and positively associated (2). Formal information from public health sources such as healthcare workers are viewed as more trustworthy because they are considered authoritative in the field of health care (28).

With respect to patient rights awareness, our results recall the same dichotomy of formal and informal channels. The two-variable analysis reveals the significant association of health literacy and patient rights awareness. When it comes to the infringement of their rights as patients or as caregivers, those mothers who took legal measures or turned to formal institutions in attempt to restore their violated rights, displayed significantly higher health literacy levels than did their fellows who rather chose informal channels to let loose their indignation, but took no legal measure. This shows that enhanced patient rights awareness and activity go hand in hand with adequate health literacy, which is the second most powerful determinant of the practice of patient rights, being preceded solely by educational attainment. It is most interesting to find out that the lowest health literacy scores are reached not by passive respondents but by those who let loose of their indignation on informal channels. Other than citizen passivity typical for the Eastern European civic culture (12), expressing dissatisfaction via informal channels may lay in the feeling of powerlessness

in front of official bodies, or/and in the lack of knowledge and competences for initiating a formal complaint (13), which goes in hand with low educational attainment. This crucial finding should be further addressed with qualitative methods suitable to find out underlying reasons of choices.

The individual impact of education in the logistic regression model comes as no surprise, as it has been equivocally found to be a determinant of patient rights awareness in other research, too (14–16). Our results indicate that controlled for other effects, especially for that of the level of education, health literacy is a powerful determinant of rights awareness in mothers. This finding is crucial for designing targeted interventions for this population, as health literacy can be improved in adulthood, by existing educational attainment, and its improvement would presumably contribute to the enhancement of patient rights awareness, too.

In the scarce research available, the place of residence was in most cases found to be associated with patient rights consciousness, even though this evidence originates from developing countries (14, 15). Here, patients from urban settlements were more familiar with their rights. With respect to the knowledge of a specific patient right, namely the right to request the diagnostic opinion of another doctor, Krzych and Ratajczyk (29) found in Poland, a Central European country with similar history and culture to those studied, that inhabitants of smaller settlements had better knowledge on this specific right. Nevertheless, this finding applied to familiarity with the rights rather than to acting for rights restoration.

In our study, the controlled effect of the place of residence on patient rights awareness is reported to be significant for the largest towns and cities compared to village dwellers (Exp(B)=2.746, 95% CI: 0.098–7.547). Most probably, the reason for this excess of chance for the benefit of city dwellers originates in the larger number of experiences with the healthcare system. Larger towns and cities have hospitals with a range of specialized institutions, more easily accessible to their inhabitants, which could increase the number of encounters of these patients with the healthcare system on the whole. Further, population attitude differences resulting from different residence types may also underlie this result. That is, in larger towns, a higher legal consciousness in general, irrespectively of high educational attainment, might be associated with more courage and determination to act for rights restoration. However, our study did not have in its focus those experiences and encounters that could have led to such differences, and the number of healthcare experiences was also not assessed. These considerations call for further research on intertwining of the place of residence with the practice of patient rights.

Last but not least, existing literature provides controversial evidence on the association of age and patient rights awareness. In developing countries, these two correlated inversely, younger adults displaying better results (15, 16, 30). However, in a study on patient rights knowledge conducted in Poland, younger persons were more knowledgeable about some specific topics like discharge on request, whereas for others, such as the right to additional nursing care, it was the older respondents who knew them better (29). For the ethnic Hungarian mothers in Eastern Europe, our findings reveal that patient rights awareness increases with age. This novel finding echoes some previous results from the same population segment, as a similar positive impact of age was found for health literacy, as well (24). The fact that older mothers

are more likely to act formally in order to redress their healthcare grievances needs to be further explored.

Limitations of the Study

In spite of the new finding of this paper, some shortcomings must be briefly addressed.

First, due to the study design and the online data collection procedure, our sample is biased with respect to socioeconomic characteristics, including more women with high educational attainment than would a representative sample. This limitation was to some extent ameliorated with a raking procedure which adjusted the sample's distributions to the female populations' real proportions with respect to educational attainment and settlement type in all three countries. Nevertheless, the generalizability of the results is limited.

Second, our survey only targeted Hungarian speaking mothers in Eastern Europe. Ethnic Hungarians in Romania and Slovakia are minorities in their home countries whose rights are assured by law, however, they might experience discrimination in health care, and possible linguistic barriers in health care may contribute to their encounters of patient rights violations. Thus, in spite of the similarities of the subsamples, healthcare experiences might differ across them. Further, rights awareness, as well as patient empowerment to act for rights restoration could possibly be impacted by linguistic competences, too. As the survey focused on mothers' health literacy, this study could not address these underlying questions in detail, and in order to do so, it should be complemented by contextual analysis.

Third, due to the length of the survey instrument, patient rights awareness was assessed with only one standardized question formulated by the researchers and does not yet allow for comparison over time and space. Legal systems and cultures of the three countries, as well as eventual differences in addressing patient rights restoration measures must not be overlooked by future studies.

Fourth, in this study the formal action for rights restoration is equated with the concept of patient rights awareness. The explanation for this decision is the aspect of citizen empowerment present in the current interpretations of awareness and literacy. However, in a broader view, awareness entails not only activity but also factual knowledge, which – for the reasons mentioned above – did not fit in the framework of this study.

CONCLUSIONS

The findings of this study are relevant for the design of health interventions and patient education, and for increasing overall civic engagement in the Eastern European region.

Our results, drawing on a convenience sample of ethnic Hungarian mothers, reveal the strong association of health literacy and patient rights awareness in a region with relatively low legal consciousness (Hungary, Slovakia and Romania). In this study the formal act for patient rights restoration was considered an indicator of high rights awareness.

Every third mother had experienced her or her children's rights infringement in health care during pregnancy, in the perinatal and postnatal period, or in child health care. However, the majority of them took no measures to restore their rights, or a few chose

informal channels to complain, such as internet fora or social media sites. These mothers display significantly lower health literacy scores than do their fellows who acted for the restoration of their rights via formal channels.

When controlled for other effects, health literacy, following educational attainment, remains a strong predictor of patient rights awareness. Older mothers and those living in bigger towns are more prone to act formally upon the infringement of their or their children's rights in the healthcare system.

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Conflicts of Interest

None declared

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