Original Article

Health Literacy of Parents/Caregivers of Paediatric Surgical Patients: A Study on 1000 Individuals

Georgios Kampouroglou, Venetia-Sofia Velonaki[1], Ioanna D. Pavlopoulou[2], Marinos Kosmopoulos[1], Nikos Kouvas[1], Eleni Drakou[1], Nikolaos Skoutelis[1], Dimitrios Spinos[1], Stavros Tsagkaris[1], Konstantinos Tsoumakas[2]

Department of Pediatric Surgery, Agia Sofia Children's Hospital, [1]Department of Nursing, School of Health Sciences, National and Kapodistrian University of Athens, [2]Department of Nursing, Pediatric Clinic, 'P. and A. Kyriakou' Children's Hospital, School of Health Sciences, National and Kapodistrian University of Athens, Athens, Greece

Abstract

Purpose: There is a paucity of studies concerning health literacy (HL) of parents/guardians of patients in paediatric surgery. The purpose of our study is to measure HL levels of parents/guardians of paediatric surgery patients and to explore the determinants of low HL levels in this population. **Materials and Methods:** We conducted a cross-sectional study from December 2016 to July 2018 through in-person interviews of parents/guardians of paediatric surgical patients. Sociodemographic and clinical data were recorded, and HL levels were calculated using a validated tool (HLS-EU-Q16). In order to examine the impact of various sociodemographic variables and clinical data on HL, a multivariate regression model was run. **Results:** A total of 1000 participants were recruited (recruitment rate 93.5%). Slightly less than half (44.2%) presented problematic or inadequate HL levels. The results of the regression analysis showed that nationality other than Greek ($\beta = -2.180$, $P < 0.001$) and lower health insurance status ($\beta = -0.461$, $P < 0.05$) were associated with lower HL levels. HL was found positively associated with the educational level of the parent ($\beta = -0.775$, $P < 0.001$) and being a health professional ($\beta = 1.791$, $P < 0.001$). **Conclusion:** The prevalence of low HL levels in the parents/guardians of paediatric surgical patients is high and should not be neglected both in the pre-operative and post-operative setting. Communication should be tailored to the specific needs of each individual to achieve better engagement and quality of care.

Keywords: Demographics, health literacy, parents, paediatric surgery

Introduction

In recent years, the concept of health literacy (HL) has been very popular in medical research.[1] It is defined as 'the knowledge, motivation and competences to access, understand, appraise and apply health information in order to make judgements and take decisions in everyday life concerning health care, disease prevention and health promotion to maintain or improve quality of life throughout the course of life'.[2]

In relevant studies, up to 50% of parents have been found with low HL levels.[3] This phenomenon, which is most of the time neglected in daily practice, has potentially serious complications in child health.[3,4] Especially in paediatric surgery, HL levels of parents or guardians are of utmost importance on the comprehension of surgical pathologies, risks and benefits of surgical procedures and implementation of instructions in the pre-operative and post-operative periods.[5,6] It has also been found to be associated with anxiety levels during surgical consultations and the quality of informed consent provided preoperatively.[7]

Given the paucity of studies on HL in the paediatric surgical setting,[6] our study aims to analyse HL levels of parents/guardians of children hospitalised in the paediatric surgery department or being examined at the outpatient clinic and to explore potential determinants of adequate HL.

Address for correspondence: Dr. Georgios Kampouroglou, Department of Pediatric Surgery, Agia Sofia Children's Hospital, Thivon and Levadeias, 115 27, Athens, Greece.
E-mail: gkampouroglou@gmail.com

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Materials and Methods

Study design and participants

The presented analyses are part of a cross-sectional study, which was carried out in the Department of Pediatric Surgery, 'Agia Sofia' Children's hospital in Athens in Greece, through a period of 20 months from December 2016 to July 2018. Using convenience sampling, we recruited parents and guardians of children aged 0–16 years, waiting for their appointment at the outpatient clinic or being hospitalised for elective or emergency surgery in the department of paediatric surgery. The survey was conducted through in-person interviews in Greek. The interview consisted in completing an anonymous standardised questionnaire after providing informed consent. Exclusion criteria were the failure to comprehend the Greek language both in writing and speaking or the willingness to participate in the study. The participants had the opportunity to quit at any point during the interview. The study received institutional review board approval (ID: 23473/12-16).

Variables and measures

Sociodemographic data

The questionnaire included questions on sociodemographic data and a tool of HL measurement. The socioeconomic information of the participants was self-reported and included age, sex, nationality, educational level, employment status, health insurance status, household region, being a health professional, having previous experience of surgery or caring for other people with severe health problems. In addition, we enquired about the number and of children under their jurisdiction, as well as possible morbidities in the household. The surgical condition of their child, previous surgery and number and age of siblings were also recorded. The surgical pathologies of the child were classified as ones needing conservative treatment (zero severity cases) and those who required surgical interventions as minor 1 surgical procedures (e.g., skin biopsy, skin abscess drainage etc.), minor 2 surgeries (e.g., circumcision), intermediate-severity surgeries (e.g., orchiopexy, inguinal hernia surgery), major surgeries (e.g., incisional hernia repair, branchial cleft cyst removal) and complex 1 surgeries (e.g., laparoscopic cholecystectomy, pyeloplasty and hypospadias reconstruction surgery) and complex 2 surgeries (e.g., Hirschsprung disease surgeries and anorectal malformation surgeries).

Health literacy assessment

To access the participants' HL levels, the Greek short version of the European HL Survey (HLS-EU-Q16) was used. It consists of 16 questions with answers on a 4-point Likert-scale (1 = 'very difficult', 2 = 'fairly difficult', 3 = 'fairly easy' and 4 = 'very easy'). The answers were dichotomised for each item: 'fairly easy' and 'very easy' (1 point) and 'fairly difficult' and 'very difficult' (0 points). A sum score (0–16 points) was calculated for those who have answered 14 or more of the 16 questions. Participants were assigned to HL categories according to their score: scoring 13 or more points on the HLS-EU-Q16 scale suggests adequate HL. Persons with 9–12 points show problematic HL, and ones with 8 or fewer points are assigned to the group of inadequate HL.

Data were tested for normality using the Kolmogorov–Smirnov test and Q-Q plots. They were analysed descriptively using counts, mean and standard deviation for normally distributed data and median and interquartile range for non-normally distributed data. Correlation analysis between HL and various variables of interest was done with independent sample *t*-test, one-way analysis of variance with *post hoc* Tukey honestly significant difference test and Pearson's and Spearman's correlation coefficient, where appropriate. In order to examine the impact of various sociodemographic variables to HL levels of the studied population, a multivariate regression model (ENTER method) was run. For all analyses, significance was accepted at $P < 0.05$. Statistical analyses were performed using SPSS Statistics (Version 24.0. IBM Corp., Armonk, NY, USA).

The internal consistency reliability of the scales was assessed by calculating Cronbach's alpha, thus ensuring the inter-relatedness of the items within each scale. Reliability was considered acceptable when Cronbach's alpha values were ≥0.7.

Results

During the study period, 1000 parents/caregivers were recruited (recruitment rate 93.5%) [Figure 1]. The age of the participants was 38.93 ± 7 years, while the majority was female (62.9%). Only 6.5% of the participants were not Greeks and 10.2% had not completed upper secondary education. Details about the descriptive sociodemographic data of the sample are presented in Table 1. Almost half of the participants presented problematic or inadequate HL (44.2%). The results of HL evaluation are shown in Figure 2. The calculated Cronbach's alpha value of the HLS-EU-Q16 was 0.84.

Concerning subdimensions of HL, as represented in the HLS-EU-Q16 scale, almost half of the participants (48.2%) answered that finding information on how to manage mental

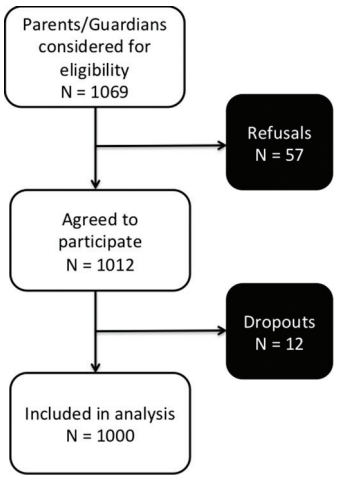

Figure 1: Flow diagram showing the study recruitment process

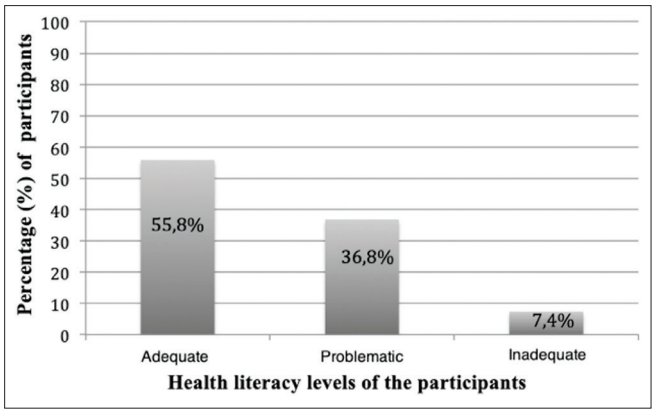

Figure 2: Health literacy levels of participants (n = 1000) according to HLS-EU-Q16 results

Table 1: Demographic characteristics of the sample

Variable	Total (n=1000)
Age of guardian (years), mean±SD	38.93±7
Age of child (months), median (IQR)	60 (95)
Number of children, *n* (%)	
1	302 (30.2)
2	514 (51.4)
More than 2	184 (18.4)
Gender, *n* (%)	
Male/female	371/629 (37.1/62.9)
Nationality, *n* (%)	
Greek/other	935 (93.5)/65 (6.5)
Severity of surgical pathology, *n* (%)	
Conservative treatment	75 (7.5)
Low	211 (21.1)
Medium	564 (56.4)
High	150 (15)
Educational level, *n* (%)	
< High school	102 (10.2)
High school	419 (41.9)
Bachelor degree	359 (35.9)
Postgraduate studies	120 (12)
Insurance type, *n* (%)	
Public	778 (77.8)
Private	181 (18.1)
No insurance	41 (4.1)
Place of residence, *n* (%)	
Urban/non-urban	861 (86.1)/139 (13.9)
Previous surgical experience or caring for people with severe health problems, *n* (%)	481 (48.1)
Health professionals, *n* (%)	84 (8.4)

SD: Standard deviation

health problems such as stress or depression is fairly or very difficult. Moreover, the participants seemed sceptical about information on the media regarding health in general and also disease prevention. Judging when to get a second opinion from another doctor also appeared to be problematic, as almost 30% of the participants regarded it as fairly or very difficult. The results are shown in detail in Table 2.

Table 2: Results of the comparison and correlation analysis between health literacy score and various variables of interest

Comparison analysis	HL score (mean; SD)	Test (P)
Sex		
Male	12.57 (2.78)	−0.852[a] (0.394)
Female	12.73 (2.70)	
Nationality		
Greek	12.83 (2.68)	6.41[a] (<0.001)**
Other	10.85 (2.68)	
Job status		
Other	12.84 (2.64)	−3.414[a] (<0.001)**
Employed	12.17 (2.94)	
Insurance status		
Public	12.75 (2.63)	13.719[b] (<0.001)**
Private	12.81 (2.78)	
No	10.51 (3.44)	
Health professional		
No	12.50 (2.75)	−6.283[a] (<0.001)**
Yes	14.43 (1.69)	
Previous surgical experience or caring for people with severe health problems		
No	12.48 (2.67)	2.069[a] (0.039)*
Yes	12.84 (2.78)	
Correlation analysis of the HL score with		
Age of parent/guardian		0.046[c] (0.1430)
Educational level		0.269[d] (<0.001)**
Age of child		−0.25[d] (0.421)
Number of children		−0.038[d] (0.236)

Independent samples *t*-test, [b]One-way analysis of variance, Tukey's *post hoc* correction, [c]Pearson's r correlation coefficient, [d]Spearman's rho correlation coefficient, *Statistically significant result, P<0.05, **Statistically significant result, P<0.001. SD: Standard deviation, HL: Health Literacy

Table 3: Multiple regression analysis results with Health Literacy Survey-Europe-16 Questions score as a dependant variable (R^2=0.181)

Independent variables	*B* coefficient	*P*	95% CI
Parent/guardian age	−0.006	0.724	−0.026- 0.038
Educational level	0.775	0.000**	0.510- 1.041
Previous surgery or caring for people with severe health problems	−0.418	0.052	−0.84- 0.004
Nationality	−2.180	0.000**	−3.047- −1.314
Employment	0.219	0.380	1.129- 2.454
Health professional	1.791	0.000**	0.774- 1.040
Number of children	−0.017	0.902	−0.289- 0.255
Health insurance	−0.461	0.016*	−0.837- −0.086

*P<0.05, **P<0.001. CI: Confidence interval

Correlational analysis showed that HL is associated with nationality (P < 0.001), educational level of the parent (P < 0.001), job status (P < 0.001), insurance

status ($P < 0.001$), being a health professional ($P < 0.001$) and previous surgical experience or caring for people with severe health problems ($P < 0.05$). The other clinical data and sociodemographic factors, which were tested, were not found to be statistically significantly correlated with the HL levels of the participants. The results are shown in detail in Table 2.

A multiple regression analysis was calculated to determine HL predictors in this specific population, taking into consideration sociodemographic factors and clinical data of the participants. The results show that HL is negatively associated with nationality ($\beta = -2.180$, $P < 0.001$) and health insurance status ($\beta = -0.461$, $P < 0.05$) and positively associated with the educational level of the parent ($\beta = -0.775$, $P < 0.001$) and being a health professional ($\beta = 1.791$, $P < 0.001$) [Table 3].

Discussion

The results of our study show that almost half of the participants (44.2%) presented problematic or inadequate levels of HL. In detail, 7.4% of the parents/guardians were found to have inadequate and 36.8% problematic HL levels, whereas 55.8% presented adequate HL levels. These results are comparable to the ones reported from the European HL Survey for Greece (55.2% adequate HL and 44.8% problematic and inadequate HL levels).[8] In the systematic review by Roy *et al*., pooled estimate of limited HL among surgical patients was 31.7%. The difference could be explained due to the different tools used in order to measure HL in the studies included (19 different tools overall).[9] In the study of Otal *et al*., 29% of parents/guardians of children who presented in paediatric surgical consultations in Canada had inadequate HL.[10] This percentage is even smaller than ours, probably because they report a selection bias, excluding parents from a region with expected low HL levels.

Interestingly, very high percentages of judging as difficult were found concerning questions about information and disease prevention from the media, a finding that is in accordance with those of the general population.[11] The highest percentage was noted at the question regarding finding information on how to manage mental health problems such as stress or depression (48.2%), while in the general population the percentage was 33%. This difference could be probably explained by the special population of our study.[11]

Compared to those with adequate HL, parents/guardians with problematic or inadequate HL were found to be non-Greeks, with fewer years of education, less likely to be employed, and more likely to be uninsured. Being a health professional and previous surgical experience were predictors for adequate HL. The socioeconomic profile of patients with limited HL in our study matches that of other studies in parents,[10,12,13] surgical patients[14-16] and the general population.[11,17-19]

As it has been previously illustrated, lower HL is associated with higher levels of stress, especially in the context of pre-operative consultations and consent process.[7] Although assessing HL levels in day-to-day clinical practice may prove difficult, it is important to have in mind that almost half of the parents experience difficulties during medical consultations because of their low HL levels. Rapid screening tools that can be implemented in clinical practice could be of great aid in this direction and guide appropriate interventions aiming to minimise all the aforementioned problems in the surgeon–parent relationship.

Concerning the limitations of our study, persons not speaking Greek language were excluded. They represent individuals at high risk of low HL, and this could have led to an underestimation of low health literate parents/guardians in our sample. Added to this, the tool used to measure HL levels is based on self-reporting, raising the possibility of bias in some of the answers.

Conclusion

HL is an important factor in the paediatric surgical setting and should not be neglected during pre-operative consultations and treatment of children. Almost half of the parents/guardians presented problematic or inadequate HL levels. As a result, paediatric surgeons should adapt communication to the specific needs of parents/guardians of paediatric surgical patients by avoiding using technical medical terminology, confirming patient understanding, patient engagement and quality of care.

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Conflicts of interest

There are no conflicts of interest.

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