Zdravstvena pismenost i rijetke bolesti; preliminarno istraživanje

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Uvod

Zdravstvena pismenost (ZP) je izrazito bitna za održavanje zdravstvenog stanja i zdravih životnih navika. Očekivano je da će pojedinci ili roditelji pojedinaca s rijetkim bolestima imati odgovarajuće razine ZP jer se informiraju o posljedicama i tretmanu bolesti, a kako bi održali zdravstveni status na odgovarajućoj razini.

Cilj

Istraživanje je imalo za cilj ispitati razine ZP roditelja/staratelja pojedinaca s rijetkim bolestima.

Ispitanici i metode: Uzorak ispitanika je sačinjavao 43 roditelja/staratelja (42,74±9,51 godina) djece oboljele od različitih rijetkih bolesti (17,81±24,53 godina) na području Splitsko-dalmatinske županije. Za određivanje razina ZP koristio se upitnik European Health Literacy Survey Questionnaire (HLS-EU-Q), uz prikaz kategorizacije prema rezultatima u slijedeće kategorije: neadekvatna ZP (0-25), problematična ZP (26-33), dostatna ZP (34-42) i odlična ZP (43-50). Za prikaz stanja ZP korištena je deskriptivna statistika uključujući aritmetičke sredine, standardne devijacije te postotke.

Rezultati

Srednja vrijednost razine ZP je 26,35±9,32, što ukazuje na neadekvatnu do problematičnu ZP. Preciznije, rezultati pokazuju kako 39,53% roditelja/staratelja ima neadekvatnu, 34,88% problematičnu, 23,25% dostatnu te 2,33% odličnu razinu ZP.

Zaključak

Roditelji/staratelji osoba s rijetkim bolestima imaju niske razine ZP, što je suprotno očekivanom. Rezultati ovog istraživanja ukazuju na važnost edukacije roditelja i povećavanja njihove ZP, kako bi pojedincima s rijetkim bolestima mogli pružiti adekvatan i pravovremen zdravstveni tretman. Potrebno je naglasiti kako u tom procesu ključnu ulogu ima zavod za javno zdravstvo koji bi trebao pružiti adekvatnu edukaciju roditeljima osoba s rijetkim bolestima.

Ključne riječi: zdravlje; bolesti; znanje; javno zdravstvo

Health literacy and rare diseases; preliminary research

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Introduction

Health literacy (HL) is extremely important for maintaining health and healthy lifestyle habits. It is expected that individuals or parents of individuals with rare diseases will have adequate levels of HL because they are informed about the consequences and treatment of the disease, and in order to maintain their health status at an appropriate level.

Aim

The aim of the research was to examine the HL levels of parents/guardians of individuals with rare diseases.

Materials and Methods

The sample of respondents consisted of 43 parents/guardians (42,74±9,51 years) children suffering from various rare diseases (17,81±24,53 years) in Split-Dalmatia County. To determine the levels of HL we used the questionnaire *European Health Literacy Survey Questionnaire (HLS-EU-Q)*, with the presentation of the results according to the following categories: inadequate HL (0-25), problematic HL (26-33), sufficient HL (34-42) i excellent HL (43-50). Descriptive statistics, including arithmetic means, standard deviations and percentages, were used to display the state of HL.

Results

The mean value of the HL level is 26.35±9.32, which indicates an inadequate to problematic HL. More precisely, the results show that 39.53% of parents/guardians have inadequate, 34.88% problematic, 23.25% sufficient and 2.33% excellent level of HL.

Conclusion

Parents/guardians of people with rare diseases have low levels of HL, which is contrary to expectations. The results of this research indicate the importance of educating parents and increasing their HL, so that individuals with rare diseases can be provided with adequate and timely health treatment. It should be emphasized that the Institut of public health plays a key role in this process, which should provide adequate education to parents of people with rare diseases.