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# Health literacy in patients with epidermolysis bullosa in Iran

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## Abstract:

**INTRODUCTION:** Health literacy is a set of different skills, including reading, listening, analyzing, deciding, and applying these skills related to health status. Epidermolysis bullosa (EB) is a rare hereditary genetic disease which affects several aspects of the life of patients and their families. The aim of this study was to assess the health literacy of patients with EB in Iran.

**MATERIALS AND METHODS:** Thirty-three patients from Iran with EB, aged above 15 years-old, were enrolled in the study. Iranian Health Literacy Questionnaire, which measures health literacy in five domains including reading, access, perception, assessment, and decision-making skills, was used for collecting the data. SPSS analytical software, version 22, was used for statistical analysis.

**RESULTS:** In total, 19 (57.6%) patients were male and 14 (42.4%) female with an age range of 15-41 years. Nineteen (57.6%) patients had inadequate health literacy in reading skills. One-third of patients had enough health literacy in the realm of access, and two-thirds were excellent in perception. Overall, there was no significant correlation between the level of health literacy with age ( $P = 0.92$ ), sex ( $P = 0.55$ ), race ( $P = 0.58$ ), and educational level ( $P = 0.51$ ) of the patients.

**CONCLUSION:** The majority of the patients had inadequate health literacy in reading skills while these patients had acceptable health literacy in perception, assessment, and decision-making skills. Improvement of health literacy of these patients should be a priority for health policy makers with the aim of increasing their quality of life and decreasing their personal and social problems.

## Keywords:

Epidermolysis bullosa, health literacy, Iran

## Introduction

Epidermolysis bullosa (EB) is a rare inherited genetic disease in which the skin and mucous membrane begin to blister even with minor rubbing and injury, so blisters and open wounds appear. In healthy people, who do not suffer from EB, two layers of skin, epidermis, and dermis are held together so that they do not move independently. In contrast, in people with EB, these two layers can move independently so that any friction between them causes blisters or wounds that is similar to the third-degree burns.<sup>[1-3]</sup> According to the reports of 1986–1990, the overall prevalence of the EB in the

USA is 8 in every 1,000,000 people and its incidence is 19 in every 1,000,000 live birth.<sup>[4,5]</sup> Furthermore, the prevalence rate is similar for both men and women. Based on Debra institute reports, the prevalence of EB was 3.5 million from 2007 to 2011.<sup>[6]</sup>

EB as a hereditary disease usually occurs at birth or shortly after it while the nonhereditary type usually occurs in adulthood.<sup>[1]</sup> Types of hereditary EB are defined by the depth of blister location within the skin layers, including simplex, junctional, dystrophic, and kindler.<sup>[7]</sup> EB patients experience a different set of symptoms, but blisters and pain are common symptoms in all the three types so that in patients with simplex EB, the

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blisters cover all parts of the body and they need further medical care. About half of junctional EB patients will die before the age of three due to malnutrition and anemia which is the result of deep blisters in the throat and esophagus, but the rest can live freely with no restriction.<sup>[1,3,8,9]</sup> Although there is no cure for EB, the symptoms can be controlled or minimized by preventing infection, protecting the skin against injury, considering food deficiencies and diet side effects, and minimizing abnormalities. Therefore, considering the patients' limitations, such as traveling, sports, and leisure activities, they need to be taught about their personal care and improving health literacy.<sup>[1,10]</sup> Investigations revealed that the patients with poor health literacy are less aware of health, receive less preventive health-care services, and have difficulty controlling their chronic diseases; consequently, they will have poor mental and physical performance.<sup>[11,12]</sup>

Health literacy is a collection of various skills including reading, listening, analyzing, decision-making, and applying these skills to the situations related to health;<sup>[11,13]</sup> the WHO considers health literacy as an important matter and one of the greatest determinants of health; hence, it suggests monitoring and coordination for strategic plans in terms of health promotion in various societies.<sup>[14]</sup> Based on the studies conducted by the USA Center for Health Care Strategies, people with limited health literacy are less likely to perceive written and verbal information provided by health experts and so have a poor health condition.<sup>[15]</sup> Several studies reveal that the hospitalization rate and referral to the doctor have increased in people with weak health literacy, especially in patients with chronic diseases such as diabetes, dementia, chronic heart disease, stroke, asthma and chronic obstructive pulmonary disease as well as people with physical disabilities; consequently, they are faced with higher health-care costs.<sup>[16,17]</sup> Considering the importance of EB and its rarity, weak health literacy and self-care lead to the acceleration of side effects, such as isolation, bedridden state, and social anxiety disorder.<sup>[18,19]</sup>

Although it is not still clear to what extent health literacy influences the health outcomes, there is lots of evidence that most of the unpleasant health results are due to inadequate health literacy.<sup>[20]</sup> Considering the fact that there is no investigation on EB patients' health literacy in Iran, the present study aimed to investigate the health literacy and life quality of EB patients in Iran and also to identify their weak and strong points, providing proper approaches, promoting interventions, thereby reducing the patients pains and suffering, and preventing the disease side effects and the patients' death.

## Materials and Methods

### Design of the study and ethics statements

This is the first cross-sectional study on health literacy of EB patients from Iran. The Ethics Committee of Shiraz University of Medical Sciences approved the protocol. All patients were adult (above 15 years-old) and were aware of the concept of the study. Verbal informed consent was obtained from all participants before filling the questionnaires out and patients were free to withdraw from the project. Writing names on the questionnaires was optional for all patients.

### Sample size and study population

This study was conducted on EB patients above 15 years from September 2015 to September 2016; the patients under study were selected using the patients' registered information at Iran EB Home (the first and only established center for EB disease inaugurated on July, 2015, in Tehran), snowball sampling, and identifying new cases to increase the sample size. Given that there is no accurate statistics about Iranian EB patients, the samples were considered as representative of total EB patients. The inclusion criteria of the study were all EB patients aged 15 and over, and the exclusion criterion was also the patient's dissatisfaction to participate in the study and the unavailability of him/her.

### Data collection

Data collection was done in two parts; the first part included demographic information such as age, sex, ethnicity, number of people with EB in the family, place of residence, and the parents' marriage with a cousin. The second part also included the health literacy questionnaire of Montazeri *et al.*, with the reliability confirmed by Cronbach's alpha coefficient 0.72–0.89 and also validity confirmed by experts according to an original paper. The questionnaire was used to measure the reading ability and health-related concepts and evaluate the health literacy of the community members in five areas including comprehension (questions 1–6), reading skills (questions 7–10), evaluation of health-related topics (questions 11–17), accessing,<sup>[18-21]</sup> and health-related factors decision-making (questions 22–33). The Likert scale was used to score the questions from 1 to 5, so the total score would be 33 (minimum)–165 (maximum); the scores were also evaluated based on the average and levels of health literacy. The score below 50% indicates inadequate literacy level, 50.1–66 indicates not quite enough literacy level, 66.1–84 indicates adequate literacy level, and 84.1–100 indicates excellent literacy level.<sup>[11]</sup>

To fill out the questionnaire, the patients were invited to attend a predetermined place and asked if they agree to participate. Otherwise, the questionnaire was sent to patients through E-mail or using a phone call for

those who could not be present at the appointed place. A presentation was also made on the importance and goals of this research before the distribution of the questionnaires.

### Data analysis

SPSS analytical software, version 22 (IBM Corporation, Armonk, NY, USA), was used for the statistical data analysis; for the qualitative data analysis, the frequency and percentage were used. Furthermore, for the quantitative data analysis, central tendency and index of dispersion, including mean and standard deviation, were used. Due to the low sample size, the nonparametric tests of Mann–Whitney, Kruskal–Wallis, and chi-square were used for comparisons.

## Results

The study involved 33 participants as follows: 19 males (57.6%) with a mean age of  $25.89 \pm 5.85$  and 14 females with a mean age of  $26.14 \pm 9.03$ . There were no significant statistical differences in age, indicating the uniform distribution for both sexes ( $P = 0.58$ ). The minimum age was 15 and the maximum 41; 28 patients (82.4%) in our study suffered dystrophic EB, and 23 (69.7%) of them were the only EB patient in their family. Parents of 16 families (48.5%) were first cousin marriages, eight families (24.2%) were second cousin marriages, four families (12.1%) were third cousin marriages, and only the parents of five families (15.2%) had no blood relation or consanguinity [Table 1].

Table 1 shows that the average health literacy of patients had no significant statistical differences in the types of disease ( $P = 0.58$ ), number of patients with EB in the family ( $P = 0.69$ ), parents' cousin marriages ( $P = 0.80$ ), ethnicity (0.75), patients' educational level (0.57), and the family income (0.26). Most participants (36.6%) were Persian origin. Most of them were from Tehran province (30.3%) and Fars province (15.2%). 30.3% of the patients had high school diploma, 4 patients had a M.A degree (12.1%), and only 1 patient had a PhD (3%). Table 2 also shows various aspects of health literacy level.

Findings revealed that there were no significant statistical differences in every investigated area for both male and female patients in terms of health literacy level: reading ability ( $P = 0.91$ ), accessing ( $P = 0.53$ ), comprehension ( $P = 0.11$ ), evaluation of health-related topics ( $P = 0.43$ ), and health-related factors' decision-making ( $P = 0.75$ ). Men, actually, had higher reading, comprehension, and decision-making level abilities than women; however, women had higher abilities in accessing and evaluating health-related factors than men. The overall average of health literacy for both men and women was almost the same [Table 3].

## Discussion

This research showed low health literacy level (57.6%) and inadequate health literacy level (15.2%) among the EB patients. There are variations in health literacy level according to the type of disease and the geographic region, etc. In a systematic review in US, the prevalence of inadequate health literacy was estimated to be 26%;<sup>[21]</sup> furthermore, inadequate or marginal health literacy level was 11.4 % in England.<sup>[22]</sup>

Based on an investigation conducted in 2012, the health literacy level of 525 adults (above 18 years-old), referred to Isfahan clinics, was inadequate.<sup>[23]</sup> Another research in Isfahan also showed that the average score of the health literacy in participants was just a bit more than average, and most of them had inadequate health literacy.<sup>[24]</sup> A study on 1086 adults in five cities and five villages in provinces of Bushehr, Mazandaran, Kermanshah, Qazvin, and Tehran showed 56.6% inadequate health literacy.<sup>[25]</sup>

More than 70% of EB patients had inadequate health literacy in reading skills which may imply educational deprivation in this group; thus, providing appropriate educational conditions may improve the overall level of health literacy; most of these groups could not attain a high school diploma and this influenced the level of health literacy. Score of health literacy showed no significant difference in different educational groups; probably, low level for reading ability is compensated by the increase in other areas or the other members of family have a better literacy level than the patients; this compensates for their low level of ability. However, there was a relationship between health literacy and educational level. Health literacy level increases with higher educational attainment, and low literacy level is in direct relationship with aging.<sup>[21,22,26]</sup> Paasche-Orlow *et al.* also found the results in line with this study, which indicated no relationship between gender and low health literacy level.<sup>[21]</sup>

There was no significant difference between health literacy level of different ethnic and income groups. This may be due to the limited sample size or inaccurate self-stated income level. Moreover, EB imposes high costs on the patients' families and puts them below the poverty line, whatever their income is.<sup>[19]</sup>

According to this study, EB patients had a high level of health literacy in terms of source accessing, comprehension, evaluation, and decision-making; this may be due to more efforts by patients and their families to reach more educational aids to understand and evaluate the factors associated with the disease despite their low reading reading ability. Probable causes for

**Table 1: Demographic characteristics of the participants**

| Independent variables                  | Frequency (%) | Mean±SD of health literacy level | P    |      |
|--|---------------|----------------------------------|------|------|
| Sex                                    |               |                                  |      |      |
| Male                                   | 19 (57.6)     | 70.92±13.69                      | 0.55 |      |
| Female                                 | 14 (42.4)     | 70.92±11.51                      |      |      |
| Total                                  | 33            |                                  |      |      |
| Age; years old (mean±SD)               |               |                                  |      |      |
| Age in Males                           | 25.89±5.85    |                                  | 0.92 |      |
| Age in Females                         | 26.14±9.03    |                                  |      |      |
| Type of disease                        |               |                                  |      |      |
| RDEB                                   | 28 (82.4)     | 70.36±13.03                      | 0.57 |      |
| Kindler                                | 5 (14.7)      | 66.96±11.36                      |      |      |
| Number of EB patient in family         |               |                                  |      |      |
| One patient                            | 23 (69.7)     | 69.27±12.15                      | 0.83 |      |
| Two patients                           | 10 (30.3)     | 71.19±14.43                      |      |      |
| Consanguinity of the patients' parents |               |                                  |      |      |
| First degree                           | 16 (48.5)     | 70.63±14.69                      | 0.86 |      |
| Second degree                          | 8 (24.2)      | 67.27±11.44                      |      |      |
| Third degree                           | 4 (12.1)      | 74.47±13.61                      |      |      |
| No relation                            | 5 (15.2)      | 69.85±12.68                      |      |      |
| Ethnicity of the patients              |               |                                  |      |      |
| Fars                                   | 21 (36.6)     | 71.15±12.74                      | 0.58 |      |
| Turk                                   | 8 (24.2)      | 67.52±15.10                      |      |      |
| Lor                                    | 4 (12.1)      | 67.67±8.34                       |      |      |
| Province                               |               |                                  |      |      |
| Alborz                                 | 1 (3)         |                                  |      |      |
| Lorestan                               | 1 (3)         |                                  |      |      |
| Tehran                                 | 10 (30.3)     |                                  |      |      |
| Zanjan                                 | 2 (6.1)       |                                  |      |      |
| Khorasan                               | 2 (6.1)       |                                  |      |      |
| Markazi                                | 1 (3)         |                                  |      |      |
| Ardebil                                | 2 (6.1)       |                                  |      |      |
| Khouzestan                             | 2 (6.1)       |                                  |      |      |
| Gilan                                  | 2 (6.1)       |                                  |      |      |
| Fars                                   | 5 (15.2)      |                                  |      |      |
| West azarbaijan                        | 1 (3)         |                                  |      |      |
| Sistan - baloochestan                  | 1 (3)         |                                  |      |      |
| Semnan                                 | 1 (3)         |                                  |      |      |
| Mazandaran                             | 1 (3)         |                                  |      |      |
| Gazvin                                 | 1 (3)         |                                  |      |      |
| Educational level of the patients      |               |                                  |      |      |
| Under-diploma                          | 9 (27.3)      | 67.66±13.70                      |      | 0.51 |
| Diploma                                | 10 (30.3)     | 70.89±10.87                      |      |      |
| Bachelor's degree                      | 9 (27.3)      | 68.80±17.27                      |      |      |
| Master's degree                        | 4 (12.1)      | 69.39±12.47                      |      |      |
| Doctorate                              | 1 (3)         | 90.41                            |      |      |
| Level of income                        |               |                                  |      |      |
| <10 million rials per month            | 18 (54.1)     |                                  | 0.38 |      |
| 10-20 million rials per month          | 9 (27.3)      | 69.91±12.20                      |      |      |
| >20 million rials per month            | 3 (9.1)       | 89.81±12.76                      |      |      |
| Missing                                | 3 (9.1)       | 82.24±7.15                       |      |      |

RDEB=Recessive dystrophic, SD=Standard deviation, EB=Epidermolysis bullosa

higher skills of comprehension and decision-making in EB patients in this study needs further investigation.

Therefore, using educational aids, such as pamphlets, training videos, and other modern electronic devices, can

improve the patients' health literacy level. Cyberspace and distance learning and internet and intranet networks can also be used to facilitate continuing education in these patients. Moreover, employing tutors is also an effective way which needs the support of the Ministry of

**Table 2: Health literacy in patients with epidermolysis bullosa**

| Level of health literacy | Skills    |           |            |            |                 | According to sum of skills scores |
|--------------------------|-----------|-----------|------------|------------|-----------------|-----------------------------------|
|                          | Reading   | Access    | Perception | Assessment | Decision-making |                                   |
| Inadequate, n (%)        | 19 (57.6) | 4 (12.1)  | 0 (0)      | 7 (21.2)   | 2 (6.1)         | 2 (6.1)                           |
| Not quite enough, n (%)  | 5 (15.2)  | 6 (18.2)  | 4 (12.1)   | 6 (18.2)   | 12 (36.4)       | 12 (36.4)                         |
| Enough, n (%)            | 4 (12.1)  | 11 (48.5) | 7 (21.2)   | 9 (27.3)   | 13 (39.4)       | 15 (45.5)                         |
| Excellent, n (%)         | 5 (15.2)  | 7 (21.2)  | 22 (66.7)  | 11 (33.3)  | 6 (18.2)        | 4 (12.1)                          |

**Table 3: Association between sex and level of health literacy**

| Skills                   | Gender      |             | P    |
|--------------------------|-------------|-------------|------|
|                          | Male        | Female      |      |
| Reading                  | 52.30±27.41 | 51.33±20.53 | 0.91 |
| Access                   | 71.05±18.50 | 75.00±15.37 | 0.53 |
| Perception               | 88.72±13.05 | 81.12±13.46 | 0.11 |
| Assessment               | 19.35±22.13 | 66.96±23.94 | 0.43 |
| Decision-making          | 69.18±12.29 | 67.55±17.11 | 0.75 |
| Level of health literacy | 70.92±13.69 | 70.92±11.51 | 0.58 |

Education and Welfare and other organization to cover the costs. Psychological counseling can also help improve the patient's motivations.<sup>[27]</sup>

There was no difference in health literacy level between men and women; however, men got a higher level than women in terms of reading, comprehension, and decision-making. Women obtained higher scores than men in terms of accessing and evaluating health-related factors. Although it is indicated that women have better health literacy than men, conflicting results have also been observed in some studies.<sup>[22,23]</sup>

Although it is not clear yet to what extent health literacy can affect health outcome, evidence shows that the unpleasant health outcomes and more probability of being evaluated in a weak health condition is the result of low health literacy level.<sup>[26,28]</sup> Health literacy measurement could be a helpful tool in health promotion plans of Iran, since it could facilitate the patients' access to the health knowledge and increase effective application of health knowledge. Effective collaboration between different sectors such as mass media and the health system of the country should not only provide a comprehensive plan to improve health literacy level but also prepare simple and understandable educational media for those with low health literacy level. There are some sample techniques such as using simple and clear language, allocating more time for teaching and training, and participation of important family members in the discussions.<sup>[25]</sup> One of the most important aspects of information transmission is its emphasis on principles of human relations, effective communication in medical education, and improvement of medical response capacity.

This is the first study which considers EB patients' health literacy in Iran, despite the difficulties in access to

participants due to geographic dispersion of the EB patients. However, the authors hope that the small sample size of the study will be justified in further studies; although there are no accurate statistics in terms of the number of patients in Iran, the current EB Home of Iran data shows that there are eight patients in every one million people. Therefore, most of Iranian EB patients over 15 years-old till September 2016 were included in this study.

## Conclusion

Based on this research, most patients' health literacy ranged from not enough up to inadequate levels. This study shows that the patients had both acceptable and not acceptable health literacy levels in some skills. Hence, it is recommended that the patients should be evaluated individually; then, the patients with low health literacy level should receive appropriate education to improve their health literacy which in turn increases their life qualities.

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## Conflicts of interest

There are no conflicts of interest.

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