Accuracy of self-perceived risk perception of breast cancer development in Iranian women

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Research article

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Abstract

Background: The accuracy of subjective risk perception is a matter of concern in breast cancer development. The objective of this study was to evaluate the accuracy of self-perceived risk assessment compared to actual risk.

Methods: The demographic, clinical, and reproductive characteristics of 800 women aged 35-85 years were collected with an in-person interview. The self-perceived risk was assessed using the visual analog scale (VAS) and the actual risk was calculated from the Gail model. Gail’s cutoff of 1.66% risk was used to categorize the estimated 5-year actual risk as low/average risk (<1.66%) and high risk (≥1.66). In low/average risk, if the self-perceived risk> actual risk, then individuals were categorized as overestimating. Similarly, in high-risk women, if the perceived risk< actual risk, then, the subjects were labeled as under-estimate; otherwise, it was labeled as accurate. The Kappa statistics were used to determine the agreement between self-perceived risk and actual risk. ROC analysis was applied to determine the accuracy of self-perceived risk in the prediction of actual risk.

Results: The perceived risk was significantly higher than actual risk (p=0.001, 0.01 for 5-year and lifetime risk respectively). Both in low and high-risk groups about half of the women over-estimate and underestimate the risk by subjective risk perception. For a 5-year risk assessment, there was no agreement at all between perceived risk and actual risk (Kappa=0.00, p=0.98) but a very low agreement between them in lifetime risk assessment (Kappa=0.09, p=0.005). The performance of accuracy of risk perception versus actual risk was very low (AUC=0.53, 95%CI: 0.44-0.61 and AUC=0.58, 95%CI: 0.54-0.62 for the 5- year risk and lifetime risk respectively).

Conclusion: The clinical performance of risk perception based on VAS is very poor. Thus, the efforts of the public health education program should focus on the correct perception of breast cancer risk among Iranian women.

Background

Breast cancer (BC) is the most common cancer among women worldwide, and after lung cancer, the second leading cause of death among women worldwide. It is among the most costly cancers in the world with the annual financial burden of 88 billion dollars. In Iran BC is the most prevalent cancer among women and accounts for a quarter of all female malignancies. Also, the age of tribulation by BC in Iran is about ten years less than other developed countries. Incidence and mortality rates of BC are increasing in Iranian women. The increasing incidence in developing counties mainly attributed to
changes in lifestyles and reproductive behaviors. The majority of women with BC are diagnosed at a higher stage of the disease that is corresponded with a high mortality rate. To establish a preventive strategy for early detection, the risk assessment is primarily interested in BC from a public health perspective. Several methods of risk assessment of BC have been suggested. They can be categorized as objective risk assessment or actual risk and subjective risk perception. The Gail model was mainly adopted for quantitative assessment of BC development. It predicts the actual risk as an objective measure based on the profile of risk factors. The second method is the self-perceived risk perception that is based on the subjective matter on the visual analog scale (VAS). Another method of perceived risk assessment is the health belief model (HBM) scale to measure the perceived risk in different domains (susceptibility, seriousness, benefit, barriers, self-efficacy/confidence, and health motivation). The performance of HBM on screening behaviors has been acknowledged in several investigations.

The self-perceived risk perception based on the analog scale is a simple method that may use in clinical practices for purpose of screening. It can be motivates the women to undergo the screening program such as breast self-examination (BSE), breast clinical examination (BCE) and mammography. However, subjective risk perception is likely to be either optimistic or pessimistic. Thus, inaccurate risk perception may induce psychological symptoms, in particular in the case of over-estimate. It may concern that women either underestimate or overestimate their risk based on this subjective matter. Meanwhile, the subjective risk assessment depends on the culture and environmental conditions. Its accuracy is a matter of concern, and data in this regard is sparse in the Asian population, particularly in the Islamic Republic of Iran. This study aimed to evaluate the accuracy of self-perceived risk assessment compared to the objective risk and to identify characteristics of individuals who do not accurately perceive their risk of developing BC.

**Methods**

**Study Design and Subjects**

We reanalyzed the data of a cross-sectional study of risk assessment of breast cancer development that was conducted in Babol, northern Iran in 2018. A total of 800 women at age of 35-85 years participated in the study. In comparing between the mean of objective risk by Gail model and perceived risk by VAS scale in our pair samples, the allocated sample size could detect the effect size of 0.1 with 95% confidence interval and 80% power. A cluster sampling technique was used to recruit individuals in the study in the randomly selected community-based clusters and also the outpatient clinic. The details of sampling methods were described elsewhere. In brief, 20 randomly selected community-based clusters and 3 outpatient clinics in the major educational hospitals were used to select samples. Individuals with a previous history of a histologically confirmed diagnosis of breast cancer were excluded. The study protocol was approved by the institutional board of the National Institute of Medical Research Development (NIMAD), Tehran, Iran.
Data and Instruments

The data of demographic, clinical, and reproductive characteristics were collected with in-person interviews using a standard questionnaire. This questionnaire was adapted as breast cancer assessment tool that has been developed by US National Cancer Institute and it is included patient eligibility, demographic and para-clinical findings of biopsy and family history. More specifically, these data composed of age, the first menstrual age, age at first childbirth, family history of breast cancer in first-degree female relatives (mother, daughters, and sisters), history of taking a biopsy of the breast, number of biopsies, presence of dysplasia in the biopsy, educational level, marital status and occupation. We also used the Persian version of the breast cancer awareness measure (BCAM) questionnaire. This scale originally developed by UK cancer center and validated specific to BC awareness. The Persian version of this scale was investigated by Heidari and Feizi that showed a high test–retest reliability (ICC=0.84) and internal consistency (Cronbach's alpha=0.88). This scale composed of the knowledge of women in breast cancer risk factors and the sign and symptoms of breast cancer that included 14 items of multiple-choice scale to measure the awareness of risk factors and 8-item scale to assess the signs and symptoms with binary response. The score of both measures was categorized as low (≤ the average scale) and high (>average of scale). The self-perceived 5-year and lifetime risk were assessed using a visual analog scale (VAS) ranging from 0 to 100. The participants were asked to show the appropriate point in this scale for their risk perception of breast development for the next 5-years and also lifetime risk. Meanwhile, the objective risk/actual risk was calculated from the modified Gail's model. This model was automated with an interactive online program based on clinical and reproductive data of individuals' risk profiles that computes the actual 5-year and lifetime risk and also the average risk with similar age of individuals in the population of women. The details of this risk calculation were explained elsewhere.

Statistical Analysis

We used SPSS software version 18.0 for data analysis. The descriptive statistics for quantitative data of self-perceived and actual risk were shown as median and quartiles and for categorical data as frequencies and percentages. The Wilcoxon related sample test was used to compare the mean of perceived risk and actual risk. The Gail's cutoff criterion of 1.66% risk was used to categorize the estimated 5-year risk/actual risk of participants as low/average risk (<1.66%) and high risk (>=1.66). A similar classification was applied for lifetime risk at a cutoff point of 10% (<10% vs. >=10% risk). According to objective risk status (low/average and high risk), among the participants with low/average risk, if the self-perceived risk> actual risk, then the perceived risk was categorized as over-estimate. While among individuals with high actual risk, if the perceived risk<actual risk, then, the subjects were as under-estimate; otherwise, it was labeled as accurate. The frequencies and percentage of over-estimate and under-estimate of self-perceived risk was calculated according to actual risk status. The association of individuals' characteristics with over-estimate and under-estimate of self-perceived risk was determined by the cross-classification of data using the Chi-square test. Based on the categorization of both perceived risk and actual risk (cutoff value of 1.66% of the 5-year risk and 10% of lifetime risk), the Kappa statistics as an index of agreement and the p-value of McNemar test was calculated. Moreover, ROC
analysis was applied to identify the diagnostic value of perceived risk to classify correctly the actual risk based on the cutoff points of 1.66% and 10% for actual 5-year risk and actual lifetime risk respectively. The area under the curve and its p-value were calculated. All tests were two-sided and a p-value less than 0.05 was considered as significant level.

**Results**

The mean age (SD) of participants was 47.63 (10.46) years and the majority of individuals were at age 35-49 years (61.5%) and the minority (7.1%) was at age 65-85 and the rest were at age of 50-64 years. The majority of women were at an educational level of high school or higher (81.0%) and housewife (74.1%). A few participants (7%) had a family history of breast cancer in first-degree relatives. Almost, 84.9% were married and 6.6% single and the remainders were either divorced or widow (8.5%). About half of participants had a low level of knowledge of breast cancer risk factors and 34.8% had a low level of awareness of signs and symptoms of breast (Table 1). Table 2 shows that the mean of self-reported perceived 5-year risk and lifetime risk was significantly higher than actual risk (9.19±16.1 vs. 0.89±0.89, p=0.001, and 14.87±20.79 vs. 8.87±3.84 vs p=0.01 respectively). While the median of perceived risk was rather lower than actual risk (0% vs 0.7%, and 5.0% vs. 8.3%). But the third quartile (Q3) of perceived risk much greater than the actual risk for both 5-year and lifetime risk. Table 3 indicates that among participants with low or average 5-year risk for disease, roughly 45.7% of women, their perceived risk was over-estimated. While among high risk, 54.1% of participants under-estimated in their perceived risk. Based on the objective/actual 5-year risk assessment (Gail criteria) 61 women (7.5%) were at high risk. In contrast, for perceived risk with a similar cutoff value was 366 (45.8%). This also shows that higher level 5-year perceived risk compared to the actual risk for BC. The Kappa statistics across data in Table 3 show that there is no agreement between perceived risk and actual risk (Kappa=0.00, p=0.98).

Table 1. Characteristics of study subjects
| Characteristics                                      | N (%)       |
|------------------------------------------------------|-------------|
| Age (year)                                           |             |
| 35-49                                                | 492 (61.5)  |
| 50-64                                                | 251 (31.4)  |
| >=65                                                 | 57 (7.1)    |
| 1st menstrual age (year)                            |             |
| <12                                                  | 119 (15.1)  |
| >=12                                                 | 667 (84.9)  |
| Age at 1st birth (year)                              |             |
| <20                                                  | 249 (33.2)  |
| 20-24                                                | 317 (42.3)  |
| 25-29                                                | 141 (18.8)  |
| >=30                                                 | 43 (5.7)    |
| Breast cancer at 1st degree of relatives            |             |
| No                                                   | 742 (93.0)  |
| Yes                                                  | 58 (7.0)    |
| No of biopsy                                         |             |
| None/not applicable                                  | 744 (93.0)  |
| >=1                                                  | 56 (7.0)    |
| Education                                            |             |
| Illiterate                                           | 78 (9.8)    |
| Primary                                              | 154 (19.3)  |
| High school                                          | 393 (49.1)  |
| University                                           | 175 (21.9)  |
| Occupation                                           |             |
| Housewife                                            | 593 (74.0)  |
| Employee                                             | 175 (21.9)  |
| Retired                                              | 32 (4.0)    |
| Marital status                                       |             |
| Single                                               | 53 (6.6)    |
| Married                                              | 679 (84.9)  |
| Divorced/Widow                                       | 68 (8.5)    |
| Knowledge of risk factor                             |             |
| Low                                                  | 419 (52.6)  |
| High                                                 | 377 (47.4)  |
| Awareness of signs and symptoms of BC                |             |
| Low                                                  | 275 (34.8)  |
| High                                                 | 516 (65.2)  |

Table 2. The mean (SD) and the quartiles of self-perceived risk and estimated actual risk of women BC development in study sample

|                         | Perceived 5-year risk | Perceived lifetime risk | Actual 5-year risk | Actual lifetime risk |
|-------------------------|------------------------|-------------------------|--------------------|----------------------|
| Mean (SD) %             | 9.19 (16.1)            | 14.87 (20.79)           | 0.89 (0.89)        | 8.87 (3.84)          |
| Q1 %                    | 0.00                   | 0.00                    | 0.50               | 6.82                 |
| Q2 (Median) %           | 0.00                   | 5.00                    | 0.70               | 8.30                 |
| Q3 %                    | 10.00                  | 20.00                   | 1.10               | 10.30                |
Table 3. The self-perceived 5-year risk of BC development according to corresponded estimated actual 5-year risk

| Perceived 5-year risk | Actual 5-year risk | All       |
|-----------------------|--------------------|-----------|
|                       | <1.66% risk        | ≥1.66% risk|           |
| <1.66%                | 401 (54.3)         | 33 (54.1) | 434 (54.3) |
| ≥1.66%                | 338 (45.7)         | 28 (45.9) | 366 (45.8) |
| All                   | 739 (100)          | 61 (100)  | 800 (100)  |

Kappa=0.00; p=0.98

*The data show the frequencies and percentage in the parenthesis.*

Table 4 shows that women at high lifetime risk, 44.0% times under-estimated their risk while low or average-risk subjects, 45.0% of times over-estimated their risk in BC development. Based on actual lifetime risk, 225 (28.1%) subjects were labeled as high risk but this figure for perceived risk was 385 (48.1%) individuals. The Kappa statistics were 0.09 (p=0.005) which shows a low level of agreement between perceived risk and actual risk (Kappa=0.09, p=0.005).

Table 5 also presents that among women with low/average risk, the percentage of over-estimate of perceived risk was significantly higher among younger (p=0.05), the high level of knowledge of risk factors (p=0.002) and symptoms & signs (p=0.004) were associated with the higher education level (p=0.04). While in a high-risk group, the data did not show a clear pattern of under-estimate of perceived risk with individuals’ characteristics.

Table 4. The self-perceived lifetime risk of BC development according to corresponded estimated actual lifetime risk

| Perceived lifetime risk | Actual lifetime risk | All       |
|-------------------------|----------------------|-----------|
|                         | <10% risk            | ≥10% risk |           |
| <10%                    | 316 (55.0)           | 99 (44.0) | 415 (51.9) |
| ≥10%                    | 259 (45.0)           | 126 (56.0)| 385 (48.1) |
| All                     | 576(100)             | 225 (100) | 800 (100)  |

Kappa=0.09; p=0.005

*The data show the frequencies and percentage in the parenthesis.*

Table 5. The distribution of over-estimate and under-estimate with respect to individuals’ characteristics of women among low/average risk and high risk groups
### Table 1: Characteristics, Perceived, and Actual Risk

| Characteristics                  | Low/average risk (n=739) | High risk (n=61) | p-value | Low/average risk (n=739) | High risk (n=61) | p-value |
|----------------------------------|--------------------------|-----------------|---------|--------------------------|-----------------|---------|
|                                  | Accurate n (%) Over-estimate n (%) | Accurate n (%) Under-estimate n (%) |        | Accurate n (%) Over-estimate n (%) | Accurate n (%) Under-estimate n (%) |        |
| Age group (year)                 |                          |                 |         |                          |                 |         |
| 35-49                            | 241(49.9) 125(56.8) 24(66.7) | 242(50.1) 95(43.2) 12(33.3) | 0.05   | 3(33.3) 14(45.2) 11(52.4) | 6(66.7) 17(54.8) 10(47.6) | 0.63   |
| 50-64 relatives≥65               |                          |                 |         |                          |                 |         |
| Breast cancer at 1st degree relatives |                      |                 |         |                          |                 |         |
| None                             | 376(53.0) 14(48.3) | 334(47.0) 21(51.2) | 0.62   | 16(47.1) 12(44.1) | 18(52.9) 15(55.6) | 0.84   |
| Yes                              |                          |                 |         |                          |                 |         |
| No of biopsy                     |                          |                 |         |                          |                 |         |
| None                             | 370(53.0) 20(48.8) | 328(47.0) 21(51.2) | 0.59   | 20(45.5) 8(47.1) | 24(54.5) 9(52.9) | 0.91   |
| ≥1                               |                          |                 |         |                          |                 |         |
| Knowledge of risk factors        |                          |                 |         |                          |                 |         |
| Low                              | 221(58.3) 167(46.9) | 158(41.7) 189(53.1) | 0.002  | 20(50.0) 8(38.1) | 20(50.0) 13(61.9) | 0.37   |
| High                             |                          |                 |         |                          |                 |         |
| Knowledge of symptoms & signs    |                          |                 |         |                          |                 |         |
| Low                              | 155(59.8) 230(48.8) | 104(40.2) 241(51.2) | 0.004  | 5(31.2) 23(51.1) | 11(68.8) 22(48.9) | 0.17   |
| High                             |                          |                 |         |                          |                 |         |
| Education                        |                          |                 |         |                          |                 |         |
| Illiterate                       | 47(69.1) 78(53.1) 83(51.2) | 21(30.9) 69(46.9) 79(48.8) | 0.04   | 6(60.0) 2(28.6) 6(46.2) | 4(40.0) 5(71.4) 7(53.8) | 0.65   |
| Elementary                       |                          |                 |         |                          |                 |         |
| High school                      | 182(50.3) 180(49.7) | 79(48.8)       |         |                          |                 |         |
| University level                 | 83(51.2)              |                 |         |                          |                 |         |
| Occupation                       |                          |                 |         |                          |                 |         |
| Housewife                        | 292(52.7) 93(55.4) 5(29.4) | 292(47.3) 75(44.6) 12(70.6) | 0.12   | 18(46.2) 4(57.1) 6(40.0) | 21(53.8) 3(42.9) 9(60.0) | 0.75   |
| Employee                         |                          |                 |         |                          |                 |         |
| Retired                          | 93(55.4) 75(44.6) 12(70.6) | 75(44.6) 12(70.6) |         |                          |                 |         |
| 1st menstrual age                |                          |                 |         |                          |                 |         |
| <12 y                            | 48(45.3) 335(54.0) | 58(54.7) 285(46.0) | 0.09   | 7(53.8) 20(42.6) | 6(46.2) 27(57.4) | 0.47   |
| ≥12 y                            |                          |                 |         |                          |                 |         |

The p-values were calculated using Chi-square test.

Table 6 and Figure 1 in panel (a) and (b) display the corresponded accuracy and the location of ROC curves of perceiving risk in the prediction of actual 5-year and lifetime risk. The AUCs were 0.53 (95%CI: 0.44-0.61; p=0.47) and 0.58 (95%CI: 0.54-0.62, p=0.001) for perceived risk in prediction of actual 5-year risk and lifetime risk respectively. The perceived risk has appeared with very low sensitivity and specificity (Sen=45.9% and Sp=54.3% for 5-year risk and Sen=56%, Sp=55% for lifetime risk). These findings also show the low performance for accuracy of self-perceived risk on VAS in the prediction of the actual risk. Additionally, the perceived risk in VAS yielded low performance in positive predicted value (PPV) but relatively high in negative predicted value (NPV).
Table 6. The performance of accuracy of self-perceived risk in BC development compared with actual risk

| Perceived risk | AUC (95%CI) | p-value | Sen (%) | Sp (%) | PPV (%) | NPV (%) |
|---------------|-------------|---------|---------|--------|---------|---------|
| 5-year risk   | 0.53 (0.44-0.61) | 0.47    | 45.9    | 54.3   | 7.6     | 92.4    |
| Lifetime risk | 0.58(0.54-0.62)  | 0.005   | 56.0    | 55.0   | 32.7    | 76.1    |

AUC: area under the curve; Sen: sensitivity; Sp: specificity; PPV: positive predicted value; NPV: negative predicted value

Discussion

The study was conducted to assess the perceived risk of breast cancer compared to the actual risk in 800 Iranian women. Finding results showed that the perceived risk of breast cancer in low and high-risk women of breast cancer was significantly higher than the actual risk. In other words, study women overestimated of breast cancer risk than routine. This finding indicates a significant pessimism in breast cancer perception.

The results of the study were in line with the reports of Ceber and et al (2006)\(^{21}\), John and et al (2011)\(^{27}\), and Aduayi and et al (2015)\(^{28}\). Jones and colleagues found that the estimated risk among 3,000 Australian women was higher than the real risk\(^{22}\). However, the results of the study were inconsistent with the findings of studies by Chung and et al (2013)\(^{29}\) and Katapodi and et al (2010)\(^{30}\). A study by Chung et al found that most Korean women (51%) were optimistic about their relative risk of breast cancer and only 2.3% had pessimistic perception. In the study of Katapodi and et al, an optimistic and pessimistic perception of the risk of breast cancer was 40% and 10%, respectively\(^{29}\). Optimistic means that fewer negative events and more positive events happen to themselves than others\(^{20}\). This inconsistency may be some reasons. In this study, samples were selected from health centers. Whether the study sample is collected from the community or a healthcare setting, it plays a role in overestimation of breast cancer risk\(^{31}\). Selection of studies’ sample from a healthcare setting such as a primary care, a hospital, or a genetic counseling clinic may be pessimism bias of breast cancer perceived risk. However, studies also state an optimistic bias for the perceived risk had their samples from the community\(^{31}\). Health workers (physicians, midwives and nurses) that encountered with the reality of the deficiency of the pessimism opinion of the women in their daily practice can be effective to pessimism bias\(^{31}\). Future studies with comparative perceive risk of breast cancer in samples from community and health centers can be provide better information.

Also pessimism of breast cancer perceived risk can be attributed to the culture of the society\(^{20}\) and women worry and anxiety\(^{32}\). Researchers report that culture is an important factor in women’s perceptions of breast cancer risk\(^{20}\) as well as women worry and anxiety\(^{32}\). Additionally perceive measuring tools, and women's knowledge of breast cancer risk factors\(^{20}\) May also be
effective. Overestimated the risk of breast cancer can be a barrier to screening for health behaviors. According to theory and research, the probable justification for this approach can be that if the risk, (the perceived sensitivity), is high and the condition involved (breast cancer), is considered serious, the person will do less of the recommended interventions due to high fear. It is also possible to overestimate the risk of breast cancer in a person, leading to anxiety and it is followed by the barrier of mammography.

Perception of the risk of disease is the main stimulus of health behaviors to prevent, diagnose, and control cancer. Aligning a person's perceived and real risk of breast cancer leads to a more realistic understanding of risk. As a result, it can be a motivator for appropriate health behaviors. Women's optimism and pessimism about the risk of breast cancer make them evaluate their risks less and more and also it can prevent proper health behaviors.

The findings of the current study demonstrated that overestimated risk in younger and high education women was significantly higher than older women and lower levels of education. Jauns et al, in their study, illustrated that younger age and higher education in women are two predictive factors in the overestimate risk of breast cancer. Also in another study, women between the ages of 30 and 39 years estimated the risk of breast cancer significantly higher than women older than 40 years. More media focus on young women with breast cancer could be a possible reason for the increased perception of risk in this age group. Another possible justification is the high incidence of breast cancer in younger women in recent years. Breast cancer in younger women is associated with higher involvement and poor prognosis. The incidence of breast cancer in Iranian women is 10 years lower than developed countries. These factors can justify the overestimate of the risk of breast cancer in younger women. In contrary to our observations, David et al. and Cyrus-David et al. reported women with higher education compared to lower education, have a more accurate estimate of the risk of breast cancer. The same is expected. But sometimes maybe a high level of awareness about a disease can give the opposite result.

**Limitations**

This study has limitations. Our participants did not include women <35 years old; therefore, we cannot generalize our findings to this younger. The real risk was calculated based on the Gail model that the baseline risk was adopted from US women. Perhaps their breast cancer risk is higher than Iranian women. Furthermore, the self-report risk perception scale is a subjective measure that may be potentially susceptible to be more pessimistic culturally.

**Conclusion**
Women in the study overestimated their breast cancer risk higher than real risk. This finding illustrated a significant pessimism in breast cancer perception. Also, overestimated risk in younger and high education women was significantly higher than older women and lower levels of education. Women at low or average risk of breast cancer need to have an accurate perception of their risk to avoid unnecessary anxiety and treatment. Therefore, increasing women's knowledge to perception their true risk of breast cancer should be considered by health providers.

**Abbreviations**

BC: Breast cancer, VAS: Visual analog scale, HBM: Health belief model, AUC: area under the curve; Sen: sensitivity; Sp: specificity; PPV: positive predicted value; NPV: negative predicted value

**Declarations**

**Ethics approval and consent to participate**

The study protocol was approved by the Ethical Institutional Board of the National Institute for Medical Research Development (NIMAD), Tehran, Iran. All participants were informed about the purpose of the study and written informed consent was obtained from all participants before data collection.

**Consent to publication**

Not applicable.

**Availability of data and materials**

To keep patients' confidentiality, the raw data would not be shared. But, it is available from the corresponding author on reasonable request, and the summary data are available in the main document.

**Competing interests**

The authors declare that they have no competing interests.

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**Authors' Contributions**

Karimollah H and Maryam N have substantially contributed to the conception of study design, analysis, and drafting of the manuscript. Karimollah H and Maryam N have read and approved the final manuscript.
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