



## Factors affecting Quality of Life in Children and Adolescents Vitiligo Patients at Dermatology and Venereology Polyclinic Bali Mandara Hospital : Cross Sectional Study based on VitiQol

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### ABSTRACT

**Introduction** : Vitiligo is a depigmentation disease of the skin, membranes mucosa and follicles hair that occurs due to the progressive loss of melanocytes cells. Vitiligo has impact on quality life of every affected individual. This cross-sectional study aims to identify factors affecting quality of life (QoL) in Children and Adolescents Vitiligo Patients at Dermatology and Venereology Polyclinic Bali Mandara Hospital.

**Methodology** : Cross-Sectional study was conducted with Vitiligo Quality of Life Index (VitiQol) questionnaire in children and adolescent vitiligo patients in range aged 5-24 years at Dermatology and Venereology Polyclinic Bali Mandara Hospital.

**Results** : Among 75 respondents participate in this study, which is from data analysis obtained that is no significant correlation based on sex ( $p = 0.528$ ) and long suffering of vitiligo ( $p = 1.000$ ) with VitiQol ( $p > 0.05$ ). Meanwhile from analysis results, there is significant correlation among age respondent with VitiQol that based on grouping age children and adolescents ( $p = 0.005$ ), as well based on grouping age respondents who had and hadn't puberty ( $p = 0.033$ ), between wide of the vitiligo lesion based on BSA (body surface area) in percent with quality life VitiQol vitiligo patients ( $p = 0.015$ ), and visibility location of lesion in visible areas with quality life patient VitiQol vitiligo patients ( $p = 0.016$ ).

**Conclusion** : This study shows that vitiligo has significant impact on quality of life patient with focus aspect are impacted dominantly environmental stigma on the children and adolescent. Counseling and supportive therapy is important key in the management of vitiligo.

**Keywords** : Vitiligo, VitiQol, quality of life, QoL.

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### INTRODUCTION

Vitiligo is a depigmentation disease of the skin, mucous membranes and hair follicles that occurs due to the progressive loss of melanocyte cells.<sup>1</sup> Vitiligo has characteristic skin lesions in the form of milky white macules which are referred to as depigmentation, with clear boundaries. Poliosis can also occur in hairy skin lesions.<sup>2</sup> Vitiligo is an autoimmune disease with an unclear cause. Although 15-20% of these diseases are inherited

or familial, many environmental factors play role in the pathogenesis of this disease. Until now there are still several hypotheses that explain the causes of this disease.<sup>3</sup> The prevalence of vitiligo is estimated globally around 0.5 - 1% of the entire population in the world.<sup>3</sup> Vitiligo affects individuals regardless of sex, both women and men, and varies in all age ranges, although 50% of the cases are more common in populations over



30 years old.<sup>3</sup> Although melanocyte cells are scattered in other organs such as the uveal tract, epithelial retinal pigment, the labyrinth of the ear, the heart and even the meninges lining the brain, in vitiligo melanocyte cells that occur depigmentation only occurs in hair follicles and skin.<sup>3</sup>

Vitiligo in several studies that have been conducted appears to have an impact on the quality of life of each affected individual.<sup>4</sup> Loss of pigmentation from the skin and significant discoloration occurs on several parts of the body, can cause significant psychological disorders due to the stigma in society. Considering that vitiligo sufferers amount to 0.5-1% worldwide which makes them part of the minority. Vitiligo is associated with low self-esteem. Depression, anxiety and stress are found in some of the vitiligo sufferers.<sup>5</sup>

Due to the characteristic of vitiligo disease in the form of different skin phenotype appearance in the general population, people with vitiligo can experience psychological and mental disorders which can eventually lead to depression. Depression itself can cause disruption to activities of daily living and become a challenge for growth in life. This can cause a decrease in learning and social achievement, especially for children and adolescents in productive age, even in one study it was found that the QOL (Quality of Life) of pediatric patients with vitiligo was lower than that of pediatric patients with atopic dermatitis.<sup>4</sup> Knowing the quality of life in people with vitiligo, especially in productive age, namely children and adolescents with an age limit of 5-24 years (based on WHO criteria) can provide holistic management. This holistic management help us to providing education to parents and encourage children to continue develop well even though

with a different skin appearance and also educate the signs of depression.

The aim of this cross-sectional study was to determine the factors that influence the quality of life of vitiligo patients, especially in the population of children and adolescents at Dermatology and Venereology Polyclinic, Bali Mandara Hospital. It is hoped that knowing the factors affecting the quality of life of children and adolescents with vitiligo patients can provide a better perception and management of therapy in the future.

## METHOD

This is a cross-sectional study using the Vitiligo Quality of Life Index (VitiQol) questionnaire instrument which is given to patients and assisted by parents in filling it out because the subjects of this study are targeted at the age group of children and adolescents based on WHO age group criteria (5-24 years) who visited the Dermatology and Venereology Polyclinic, Bali Mandara Hospital, Denpasar. This research was conducted on October 2022. The sampling method in this study used consecutive sampling where the minimum number of samples was calculated using the Lemeshow formula ( $n = 34$  samples). The inclusion criteria in this study were patients diagnosed with vitiligo with an age range of 5-24 years and voluntarily agreeing to participate in this study without any special interests or coercion. Exclusion criteria in this study were vitiligo patients who were outside the age range of inclusion criteria, refused to participate in this study, and diagnosed with other skin diseases other than vitiligo and other chronic diseases that could affect the quality of life of these patients.

The data that has been collected, then tabulated and processed using software IBM SPSS (Statistical Package for The Social Sciences)

Statistics v.25. Data analysis was performed using a non-parametric chi-square statistical test to see if there was a significant association between risk factors and quality of life for Vitiligo patients. In this study, the classification of age groups used WHO standards, namely children aged 5-12 years and adolescents aged 13-24 years.<sup>12</sup> Types of age groups based on puberty, namely in male patients are in the range above 16 years and in women are in the range above 14 years.<sup>12</sup> Also in this study, researchers divided the group of respondents to the wide of lesions in vitiligo patients into <9% and  $\geq$  9% based on the average value of VASI (Vitiligo Area Scoring Index) in vitiligo patients according to research conducted by Hedayat (2016).<sup>8</sup> In this study, the diagnosis of vitiligo was carried out by skin and genital specialists.

The Vitiligo Quality of Life Index (VitiQol) questionnaire is an instrument for assessing the quality of life for vitiligo patients that focuses on the clinical domain affected by vitiligo patients, where each questionnaire question has its own focus in the form of patient groups affected by limitations in participating in the social environment (question no. 3, 4, 6, 9, 10, 11, and 14), social environment stigma (questions no 1, 2, 5, 7, and 15), and changes in the patient's habitual behavior (questions no 8, 12, and 13).<sup>10</sup> The participation limitation domain is a domain of the obstacles or difficulties experienced by patients when participating in daily activities and social interactions. The stigma domain is the domain of perspective or giving negative attributes to individuals. The behaviour domain is a domain regarding individual reactions or responses to the surrounding circumstances.<sup>15</sup> The VitiQol questionnaire has 15 questions focusing on aspects of the quality of life of vitiligo patients and 1 question on the respondent perception of their skin lesions severity. VitiQol questions are rated on

a 7-point Likert scale (grades 0 to 6).<sup>8</sup> The highest point can vary from 0 to 96 where the higher the score indicates the lower the quality of life of the respondent. For each patient, the average score was calculated for each of the three domain groups that affected respondent's quality of life.

In the previous study by Giantoro et al (2022) a validity and reliability test was carried out on the VitiQol questionnaire research instrument in Indonesian language, which obtained a Cronbach's alpha value in the Indonesian language VitiQol reliability test is 0.924 and Cronbach's alpha value per item is lower than 0.924. Based on these results indicate that is significant consistency between each question and is believed to be reliable. Meanwhile, from the validity test, the results of the correlation coefficient on each question with a total value of VitiQol in Indonesian ranged from 0.549-0.894 with mean value of 0.683. Based on this, the correlation between each question and the total score of the VitiQol Indonesia language version is strong.<sup>6</sup>

## RESULTS

On this study, we had obtained 75 children and adolescents respondents in the Dermatology and Venereology Polyclinic, Bali Mandara Hospital. As for the distribution of the visibility of the lesion location, what can be seen are the lesions on the face, neck, forearms, fingers and various areas of the body that are not covered by clothes, while the areas that are not visible include parts of the body that are covered by clothes such as abdomen, chest, and the anal-genital area. In this study, the demographics of children and adolescent patients were 37 male respondents (49.3%) and 38 female respondents (50.7%). Based on the characteristics of the respondents in this study, it was found that the number of respondents who were adolescents (56%) was

more than the respondents who were children (44%). Based on the age classification of puberty, it was found that there were more respondents who had already puberty (52%) than respondents who had not yet gone through puberty (48%). In this study, the number of respondents with visible skin lesions (76%) was higher than respondents with invisible skin lesions (24%). In this study, the number of respondents who had vitiligo lesion areas <9% (64%) was greater than the respondents who had vitiligo lesion areas ≥9% (36%). Regarding the duration of patients diagnosed with vitiligo, they were grouped into less than 1 year and more than 1 year. Respondents who had or were diagnosed with vitiligo for less than 1 year (30.7%) were fewer than the respondents who had or were diagnosed with vitiligo for more than 1 year (69.3%). The distribution of respondents based on the focus on aspects of the affected domain, each in the form of a group of respondents affected in VitiQol is the most patients with a focus on stigma domains (48%), followed by changes in patient behavior habits (34.7%), and patients affected by limitations in participating in the social environment (17.3%).

Table 1. Characteristics of Respondents

| Characteristics             | Frequency (n) | Percentage (%) |
|-----------------------------|---------------|----------------|
| Age                         |               |                |
| Children                    | 33            | 44             |
| Adolescents                 | 42            | 56             |
| Puberty                     |               |                |
| Before Puberty              | 36            | 48             |
| Already Puberty             | 39            | 52             |
| Sex                         |               |                |
| Male                        | 37            | 49.3           |
| Female                      | 38            | 50.7           |
| Duration of diagnosis       |               |                |
| <1 year                     | 23            | 30.7           |
| ≥1 year                     | 52            | 69.3           |
| Wide lesion location        |               |                |
| <9%                         | 48            | 64             |
| ≥9%                         | 27            | 36             |
| Location of vitiligo lesion |               |                |
| Visible                     | 57            | 76             |
| Not Visible                 | 18            | 24             |

Table 2. Distribution of Respondents based on domain group affected by VitiQol

| VitiQol Domain           | Frequency (n) | Percentage (%) |
|--------------------------|---------------|----------------|
| Participation limitation | 13            | 17.3           |
| Stigma                   | 36            | 48             |
| Behavior                 | 26            | 34.7           |

*Table 3. Correlation between age, sex, wide lesion location, location of vitiligo, and duration of diagnosis with VitiQoI in Vitiligo Patients*

|                             | Vitiligo Quality of Life Index (VitiQoI) on Children and Adolescent Vitiligo patients. |      |        |      |          |      |         |  |  |  |
|-----------------------------|--|------|--------|------|----------|------|---------|--|--|--|
|                             | Participation limitation   |      | Stigma |      | Behavior |      | p-value |  |  |  |
|                             | n  | %    | n      | %    | n        | %    |         |  |  |  |
| Age                         |  |      |        |      |          |      |         |  |  |  |
| Children                    | 11   | 14.7 | 12     | 16.0 | 10       | 13.3 | 0.005   |  |  |  |
| Remaja                      | 2  | 2.7  | 24     | 32.0 | 16       | 21.3 |         |  |  |  |
| Puberty                     |  |      |        |      |          |      |         |  |  |  |
| Before Puberty              | 11   | 14.7 | 17     | 22.7 | 11       | 14.7 | 0.033   |  |  |  |
| After Puberty               | 2  | 2.7  | 19     | 25.3 | 15       | 20.0 |         |  |  |  |
| Sex                         |  |      |        |      |          |      |         |  |  |  |
| Male                        | 5  | 6.7  | 20     | 26.7 | 12       | 16.0 | 0.528   |  |  |  |
| Female                      | 8  | 10.7 | 16     | 21.3 | 14       | 18.7 |         |  |  |  |
| Duration of diagnosis       |  |      |        |      |          |      |         |  |  |  |
| <1 year                     | 4  | 5.3  | 11     | 14.7 | 8        | 10.7 | 1.000   |  |  |  |
| ≥1 year                     | 9  | 12.0 | 25     | 33.3 | 18       | 24.0 |         |  |  |  |
| Wide Lesion location        |  |      |        |      |          |      |         |  |  |  |
| <9%                         | 12   | 16.0 | 24     | 32.0 | 12       | 16.0 | 0.015   |  |  |  |
| ≥9%                         | 1  | 1.3  | 12     | 16.0 | 14       | 18.7 |         |  |  |  |
| Location of vitiligo lesion |  |      |        |      |          |      |         |  |  |  |
| Visible                     | 7  | 9.3  | 26     | 34.7 | 24       | 32.0 | 0.016   |  |  |  |
| Not Visible                 | 6  | 8.0  | 10     | 13.3 | 2        | 2.7  |         |  |  |  |

## DISCUSSION

From analysis obtained by the researchers, after analyzing several factors that affect the patient's quality of life using Chi-Square analysis. There was no significant correlation between sex ( $p = 0.528$ ) and the length of time diagnosed with vitiligo ( $p = 1.000$ ) with VitiQoI in Vitiligo patients ( $p > 0.05$ ). The results of this study are supported by Silpa-archa, et al. (2020) which stated that there was no significant correlation between sex with quality of life of vitiligo patients ( $p = 0.528$ ).<sup>7</sup> In this study, from the distribution of data, female children and adolescent patients were much more likely to

limit themselves in participating in the surrounding social environment because of their lack of self-confidence, which is also supported by the research of Hedayat et al. (2016).<sup>7, 8</sup>

Based on data analysis, the results also showed that there was no significant correlation between the duration of diagnosis and VitiQoI in vitiligo patients ( $p = 1,000$ ). These results are also consistent with research by Karmila et al. (2017) which stated that was no significant correlation between the long duration of being diagnosed vitiligo with the quality of life of Vitiligo patients.

Vitiligo is a chronic disease which requires a long duration of management with various results and response to therapy in each individual.<sup>5</sup>

In this study, the results showed a significant correlation between the age of the respondents and VitiQol, both based on the age grouping of children and adolescents ( $p = 0.005$ ) and based on the age grouping of respondents who had and had not yet reached puberty ( $p = 0.033$ ). In children and adolescents, the results on VitiQol showed that stigma towards the surrounding social environment was most dominant in patients, significant in both age groups. This is relate with study by Hedayat et al. (2016) who stated the same thing where vitiligo patients are vulnerable in their environment to discrimination and stigma.<sup>8</sup> This is also supported by research by Parsad et al (2003) which states that vitiligo is an important skin disease that has a major impact on the patients quality of life, they feels depressed and stigmatized by their condition.<sup>11</sup> Children and adolescents with emotional disorders due to vitiligo can be a long-term risk in their psychology and mental development. In accordance with previous studies by that in children with generalized vitiligo requiring comprehensive therapy showed improvement and increased quality of life in vitiligo patients.<sup>9</sup>

From the analysis of the wide of the lesion, a significant correlation was found between the wide of the lesion based on BSA (body surface area) in percent with the quality of life of VitiQol in vitiligo patients ( $p = 0.015$ ). These results are similar to the study by Hedayat et al. (2016), however it is also interesting from a study by Florez et al (2017) that state the size of the lesion has a much more significant effect on certain locations seen on the quality of life of vitiligo patients.<sup>13</sup> This also supports the results of this study which obtained the visibility of the lesion

location on the visible part of the body that had a significant correlation with the quality of life of vitiligo patients ( $p = 0.016$ ). Several studies have suggested the same thing, as in a study by Phinari et al (2022) which stated that this was caused by the location of the vitiligo that appeared to make vitiligo patients feel embarrassed and lack confidence in themselves and could cause feelings of disappointment in themselves. The same thing was also found in this study, especially in children and adolescents with vitiligo patients.<sup>14</sup> In a similar study, the results of logistic regression analysis using the DLQI showed that the visibility of the location of vitiligo has a significant effect on the quality of life of vitiligo patients (Sig. value = 0.03 with  $p \leq 0.05$ ).<sup>14</sup>

## CONCLUSION

Based on the data analysis, it was found that there was no significant correlation between gender and length of time diagnosed vitiligo with quality of life based on VitiQol in children and adolescents vitiligo patients. However, there was a significant correlation between age groups based on the classification of children and adolescents and based on puberty age, and also based on the wide of the lesion and also the visibility of the lesion location with the quality of life based on VitiQol in children and adolescent vitiligo patients. From the results of the data obtained from the focus on domain aspects in children and adolescent patients, it is more dominant in the social stigma so that there is a need for a holistic approach to patients and society that vitiligo is not a disease that deserves bad judgment in social life and interactions between individuals. This is necessary to improve the quality of life in patients, especially in children and adolescents. Counseling is an important key in the management of vitiligo which hopes to



improve the quality of life of vitiligo patients in children and adolescents..

## RESEARCH LIMITATIONS

In this study, because the respondents population in the range of children and adolescents age, so it cannot be studied regarding the specific socio-economic aspects of work and economic factors. Another limitation in this study was also due to the duration of the sampling time from the respondents which was carried out in a short time so that the amount of sample data obtained was still relatively minimal (n = 75). Suggestions for the future study, perhaps several other variables can be added such as their level of understanding of vitiligo, respondents' perceptions of therapy. The hope is that in future studies, these other variables can be included in future research analysis.

## RESEARCH ETHICS

This research has passed ethical clearance

## THE AUTHOR'S CONTRIBUTION

All researchers have the same contribution in terms of data collection, data analysis, reference review, and manuscript preparation and publication.

## CONFLICT OF INTEREST

There is no conflict of interest in this study.

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