

Quality of Life Impairment in Children and Adults with Vitiligo: A Cross-Sectional Study Based on Dermatology-Specific and Disease-Specific Quality of Life Instruments

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Key Words

Quality of life · Vitiligo · Pigmentation disorders · Lifestyle

Abstract

Background: Vitiligo can negatively affect a patient's quality of life (QoL). A specific questionnaire has been developed and validated in the English language: the vitiligo-specific quality-of-life instrument (VitiQoL). The instrument was translated, culturally adapted and validated into Brazilian Portuguese (VitiQoL-PB). **Objective:** The aim of this study was to assess the QoL in adult patients through the VitiQoL and Dermatology Life Quality Index (DLQI) and in pediatric patients through the Children's Dermatology Life Quality Index (CDLQI) in a sample of patients with vitiligo. **Methods:** Subjects were selected from a dermatological outpatient clinic and from a private practice in Porto Alegre. The QoL of pediatric patients was evaluated using the CDLQI questionnaire. In adult patients we used the VitiQoL-PB and the DLQI. **Results:** A strong correlation between the scores of the total VitiQoL and DLQI was observed ($r = 0.81$; $p < 0.001$). The factor that most contributed to the final score of VitiQoL was stigma. In our sample, women had higher scores than men ($p < 0.05$). Psychiatric problems were associated with lower

QoL. In the pediatric population, the median score of the CDLQI was 3 (interquartile range 1.3–7.3). There was a statistically significant correlation between the child's age and the CDLQI score ($r_s = 0.41$, $p = 0.044$). **Conclusion:** This study confirms that the VitiQoL is easy to administer and adds important information about the impact of vitiligo on a South American population. Stigmatization is very present in the disease. There are groups of patients that are more vulnerable, like women, patients with psychiatric diseases and adolescents.

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Background

Vitiligo is a common skin disease which has been reported to affect approximately 1% of the population worldwide. It affects people of any age or ethnicity, more than half of whom develop it before the age of 20 years. Vitiligo is clinically characterized by the development of white macules due to the loss of functioning melanocytes in the skin, hair, or both. The cause of this condition is uncertain but seems to be dependent on the interaction of genetic, immunological and neurogenic factors [1, 2].

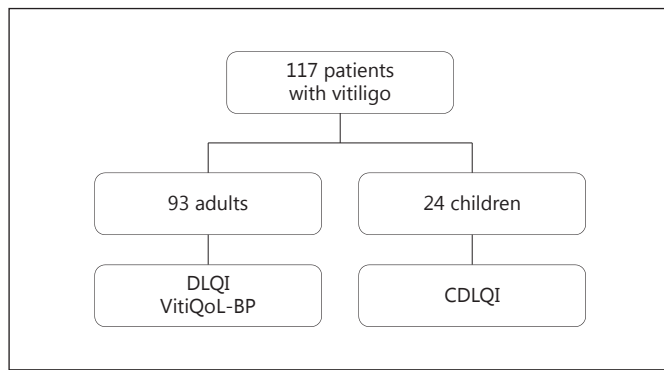


Fig. 1. Flowchart of the Methods.

Chronic skin conditions can impact a patient's quality of life (QoL) beyond the skin. Vitiligo can negatively affect a patient's QoL, the disorder can be psychologically devastating and stigmatizing. Patients with vitiligo are mostly affected by their psychosocial well-being, whereas patients with other chronic skin conditions such as psoriasis and atopic dermatitis are affected by both physical and psychosocial well-being [3–7].

A disease-specific questionnaire for vitiligo has been developed and validated in the English language: the vitiligo-specific quality-of-life instrument (VitiQoL) [4]. The VitiQoL is a questionnaire of 15 items, with item scores from 0 (never) to 6 (all the time). It yields a total score from 0 to 90. The 16th question of the VitiQoL questionnaire is a self-reported severity scale ranging from 0 (no skin involvement) to 6 (severest case).

The questionnaire proved to be a promising clinical and epidemiological study instrument, and a powerful marker of the treatment outcome. An exploratory factor analysis with oblique rotation yielded 3 factors: participation limitation, stigma, and behavior. The instrument was translated, culturally adapted and validated into Brazilian Portuguese (VitiQoL-PB) [8].

As the disease usually begins in childhood or young adulthood, pediatric patients are also affected, and the repercussions of the disease in the pediatric population have also been studied quite extensively [9, 10]. The most widely used questionnaire is the Children's Dermatology Life Quality Index (CDLQI), which is a questionnaire of 10 items that can be used on children and adolescents from 5 to 16 years old. The score ranges from 0 to 30, and the higher the score, the worse the QoL.

The measurements of QoL have a lot of importance in dermatology. Skin diseases, in the vast majority of cases, do not imply a life's risk, however, strongly influence pa-

tients' emotional state, social relations and daily activities. Many times, evaluating the influence of the disease differs between the patient and the doctor, which can interfere directly in the management of the disorder. The analysis of responses to questionnaires on QoL allows us to establish the relationship between the disease and the overall impact on the patient's life and, thereby, analyze more satisfactory indications and the result of certain treatments [11–13].

The Dermatology Life Quality Index (DLQI) was developed in 1994 and was the first QoL assessment tool in dermatology. It is a dermatology-specific questionnaire of 10 items, and the scores range from 0 to 30; the higher the score, the worse the QoL [14].

The relationship between QoL and treatment is also well established for other diseases, such as psoriasis [15]. There are few publications that specifically address clinical and epidemiological characteristics with QoL in different age groups. Besides that, till today in Brazil, there's no available data about the aspects of QoL using a disease-specific questionnaire for vitiligo. Dermatology-specific instruments are useful and allow comparisons with other dermatoses; however, it is recognized that disease-specific instruments for each disease are more sensitive.

Therefore, this study was undertaken to assess clinical and sociodemographic characteristics that adversely affect the QoL in different age groups of patients with vitiligo so that these variables could be considered in their treatment and care.

Objective

The aim of this study was to assess the QoL in adult patients through VitiQoL-PB and DLQI and pediatric patients through CDLQI in a sample of patients with vitiligo in southern Brazil, and its relation with demographic data and clinical characteristics.

Methods

For further details, see the supplementary materials (for all on-line suppl. material, see www.karger.com/doi/10.1159/000448656) [4, 8, 16] (fig. 1).

Results

We included a total of 117 patients, 93 adults and 24 children. Table 1 shows the clinical and demographic data of patients.

Table 1. Clinical and demographic data

	Adults (n = 93)	Children (n = 24)	p
Female sex	63 (67.7)	12 (50.0)	0.169
Age, years	45.7±16.9	10.04±4.102	<0.001
Civil state: married	36 (38.7)	–	0.001
Education			<0.001
<12 years	32 (34.4)	21 (87.5)	
High school graduate	35 (37.6)	3 (12.5)	
Graduate, professional school or postgraduate	26 (28.0)	1 (4.2)	
Income/by month			0.362
<USD 250	28 (30.8)	9 (37.5)	
USD 250–750	44 (48.4)	13 (54.2)	
>USD 750	19 (20.9)	2 (8.3)	
Duration of vitiligo, years	13.9±12.82	3.98±3.164	<0.001
Age at onset, years	31.81±20.48	5.96±3.873	<0.001
Family history	20 (22.7)	4 (18.2)	0.778
Triggering event	65 (69.9)	10 (41.7)	0.020
Symptoms	40 (43.0)	12 (50.0)	0.701
KP	44 (47.3)	9 (37.5)	0.492
Disease activity			0.509
Stable	26 (28)	9 (37.5)	
Affected area			
Head	79 (84.9)	19 (79.2)	0.538
Trunk	64 (68.8)	9 (37.5)	0.010
Arms	48 (51.6)	12 (50.0)	0.999
Legs	57 (61.3)	13 (54.2)	0.688
Hand and foot	65 (69.9)	7 (29.2)	0.001
Involvement			0.079
Unilateral	9 (9.7)	6 (25.0)	
Bilateral	84 (90.3)	18 (75.0)	
Classification			0.999
Segmental	8 (8.6)	2 (8.3)	
Nonsegmental	85 (91.4)	22 (91.7)	
Areas not covered by clothes	84 (90.3)	20 (83.3)	0.464
Phototype			0.581
II	26 (28.0)	9 (37.5)	
III	35 (37.6)	9 (37.5)	
IV	27 (29.0)	4 (16.7)	
V	5 (5.4)	2 (8.3)	

Categorical variables described by numbers with percentages in parentheses and quantitative variables as means ± standard deviation.

The most common triggering events reported by children and adults were death of a close relative or friend and fights or disagreements. Regarding the Koebner phenomenon (KP), in 23 (24.7%) the diagnosis was based on history and 21 (22.6%) had KP on examination. In children, 5 (20.8%) had a history of KP, and in 4 (16.7) it was observed on examination.

Table 2. Descriptive table of scores in the adult sample

	Median	Interquartile range	Minimum	Maximum
VitiQoL total	37.00	17.00–61.50	0.00	90.00
Participation limitation	14.23	3.00–22.50	0.00	42.00
Stigma	16.75	7.00–26.50	0.00	30.00
Behavior	9.15	5.00–14.00	0.00	18.00
VitiQoL 16	3.6	2.00–5.00	0.00	6.00
DLQI	3.00	1.00–6.50	0.00	29.00

Data presented as medians and interquartile ranges (25th percentile to 75th percentile).

Table 3. Scores between adult men and women

	Men (n = 30)	Women (n = 63)	p
VitiQoL total	27.0 (11.8–49.5)	41.0 (22.0–66.0)	0.011
Participation limitation	7.0 (1.8–16.0)	13.0 (5.0–26.0)	0.029
Stigma	15.5 (4.8–23.3)	20.0 (10.0–29.0)	0.043
Behavior	6.0 (2.5–10.3)	11.0 (6.0–16.0)	0.001
VitiQoL 16	3.0 (1.0–4.3)	4.0 (3.0–6.0)	0.023
DLQI	2.0 (0–5.3)	3.0 (2.0–8.0)	0.041

Data presented as medians with interquartile ranges in parentheses.

Table 4. Scores between patients with and without psychiatric illness

	With psychiatric illness (n = 49)	Without psychiatric illness (n = 44)	p
VitiQoL total	47.0 (23.5–76.0)	28.5 (14.25–50.5)	0.011
Participation limitation	13.0 (4.5–33.5)	7.5 (2.0–17.8)	0.009
Stigma	22.0 (10.0–29.5)	14.0 (6.3–24.0)	0.016
Behavior	11.0 (5.0–16.5)	6.5 (4.3–12.0)	0.061
VitiQoL 16	4.0 (3.0–6.0)	3.0 (2.0–5.0)	0.011
DLQI	3.0 (1.5–8.5)	2.5 (1.0–5.0)	0.151

Data presented as medians with interquartile ranges in parentheses.

Table 2 describes the scores of QoL questionnaires in adults. The factor that had higher scores was stigma (median = 18). A correlation was observed between total VitiQoL score and participation limitation ($r_s = 0.94$; $p < 0.001$), stigma ($r_s = 0.94$; $p < 0.001$) and behavior ($r = 0.80$; $p < 0.001$).

A strong correlation between the scores of the total VitiQoL and DLQI was observed ($r = 0.81$; $p < 0.001$), as

Table 5. Impact of vitiligo on individual aspects of lifestyle and QoL in adults, children and adolescents: correlation of DLQI and CDLQI headings with the total score of each instrument

DLQI headings	Questions	Adults r_s	CDLQI headings	Questions	Children r_s
Symptoms and feelings	Q1 Scratchy/sore/painful skin Q2 Self-conscious about lesions	0.76 (<0.001)	Symptoms and feelings	Q1 Scratchy/sore/painful skin Q2 Self-conscious about lesions	0.68 (<0.001)
Leisure	Q5 Social/leisure activities Q6 Sports	0.84 (<0.001)	Leisure	Q4 Clothing decisions Q5 Going out/playing hobbies Q6 Sports	0.74 (<0.001)
Work and school	Q7 Schoolwork	0.39 (<0.001)	School or holidays	Q7 Schoolwork	0.43 (0.036)
Personal relationships	Q8 Partner/close friends/relatives Q9 Sexual	0.66 (<0.001)	Personal relationships	Q3 Friendships Q8 Teasing and bullying	0.73 (<0.001)
Daily activities	Q3 Shopping/home/garden Q4 Clothing decisions	0.76 (<0.001)	Sleep	Q9 Sleep	0.06 (0.765)
Treatment	Q10 Treatment	0.36 (<0.001)	Treatment	Q10 Treatment	0.16 (0.469)

r_s = Spearman correlation coefficient; p values indicated in parentheses.

well as their specific areas of participation limitation ($r_s = 0.70$; $p < 0.001$), stigma ($r_s = 0.80$; $p < 0.001$) and behavior ($r_s = 0.66$; $p < 0.001$). A correlation was also observed between the total VitiQoL and the self-reported severity of the VitiQoL item 16 ($r_s = 0.70$; $p < 0.001$).

In our sample, women had higher scores than men, with a statistically significant difference, as can be seen in table 3.

Regarding the previous diagnosis of psychiatric illness, higher scores of the total VitiQoL were observed in patients with psychiatric illness, as it can be seen in table 4. There was no statistical difference in DLQI and in the question 16 of the VitiQoL regarding psychiatric illness.

When performing multiple linear regression, the relationship between women and psychiatric disease remained as significant independent predictors of VitiQoL ($p < 0.05$). VitiQoL item 16 was also correlated with the percentage of the total affected area of the body ($p = 0.016$). There was no correlation between QoL scores in adults and some variables such as age, marital status, education, income, vitiligo classification, areas covered by clothes, phototype and disease activity.

In the pediatric population, the average CDLQI for children was 3, with an interquartile range of 1.3–7.3. There was a statistically significant correlation between

the child's age and the score on the CDLQI ($r_s = 0.41$; $p = 0.044$). The median CDLQI score found in the present study was significantly higher in adolescents aged 15 years and older (median = 11, interquartile range = 4.75–14.25, $p = 0.04$). There was no difference between boys and girls ($p = 0.219$), and no relationship between CDLQI and the affected area of the body or the extent of the disease either ($p > 0.005$). The impact of vitiligo on different aspects of QoL in children and adolescents is presented in table 5. Table 5 describes the correlation of DLQI and CDLQI headings with the total score of each instrument.

The questions with highest average scores among adults and children were questions 2 and 4. Question 2 is about self-consciousness about lesions and question 4 about decision of which clothes to wear in both instruments.

Discussion

The VitiQoL score in our sample was similar to that found in the original study [4]. Our study did not find any difference in the scores between the areas covered and not covered either, even taking into consideration that the majority of the patients in our sample (over 90%) showed

lesions in visible areas. Although some studies have found an association between lower QoL and involvement of visible areas such as the face, neck and hands [17, 18], others did not observe such findings [19].

The most important factor that contributed to the total score of VitiQoL was stigma. We had already found a similar result when we validated the VitiQoL to Brazilian Portuguese [8], because, in both studies, as well as in the original VitiQoL study [4], the single item that most contributed to the total score was related to the frustration about the skin condition (question 2). This aspect is quite important, since it has already been observed that self-esteem of patients is greatly affected and that stigmatization is very present in the disease, as already assessed in previous studies [20, 21].

Several studies indicated a greater impairment of QoL in women [22, 23]. It is interesting to consider also that, despite the fact that vitiligo affects both sexes, women seek medical care more often than men due to a great concern about skin appearance and the related psychosocial effects [24]. Regarding vitiligo-specific questionnaires, the Vitiligo Impact Scale-22 [25] also showed higher scores in females. Nevertheless, there are also studies that did not observe any differences between the sexes regarding the QoL in vitiligo [26].

As in previous studies with VitiQoL, there was a correlation between the VitiQoL and the DLQI and the individual patient's assessment of the severity of the disease [4, 8]. Similarly, other specific questionnaires for vitiligo had shown a correlation with the DLQI [25, 27, 28].

A very important aspect of vitiligo is the high prevalence of psychiatric disorders in these patients. It has been observed that the presence of psychiatric illness is related to a higher incidence of QoL impairment [29]. In our study it was also shown that patients who spontaneously reported a previous psychiatric diagnosis also had higher VitiQoL scores. A similar relation was demonstrated in other dermatological diseases when evaluated by a disease-specific questionnaire, as in melasma [30].

Vitiligo affects significantly also multiple aspects of the QoL of children and adolescents [31]. The average CDLQI was 3, similar to the data from other studies, both international [32], as well as those that were carried out in Brazil [33]. There was a statistically significant correlation between the child's age and the score on the CDLQI. This aspect is present in other studies, and the reason for this association may be the fact that the QoL impairment usually occurs when children develop a sense of competence and socialization in school as well as self-identity [32]. A limitation to our study is the relatively small sample size

of children and adolescents, and the calculated sample size for adults was 99 but we included 93 adult patients.

Besides the QoL, some clinical features are present in adults and children, and should be taken into consideration in the management of the disease. A triggering factor is very common in the history of patients, once they correlate the appearance of the lesions with some notable event of their lives [34]. Another interesting aspect is that, despite the vitiligo being considered asymptomatic, 43% of adult patients and 50% of pediatric ones reported associated symptoms. Previous studies demonstrated that itching and burning skin occurs in one third of patients [9]. Discussed potential mechanisms for such skin symptoms include higher-grade inflammation, higher sensitivity to sunburns and also possibly the adverse effects of some treatments, like phototherapy and the use of calcineurin inhibitors.

The KP is very common in vitiligo patients. Type 1 KP is defined as the diagnosis of KP made on the basis of history. Type 2A KP is based on evidence of trauma-induced depigmentation on physical examination and type 2B KP by linear streaks of depigmentation on examination. A recent study reported that KP was seen in 130 of 202 patients (64.4%) [35]. In this study the majority of diagnoses was based on physical examination (type 2A), but in our study, many patients were also diagnosed by previous history taking (type 1).

Although the DLQI and CDLQI are not directly comparable, most of the questions are the same, as well as the headings. The main heading item in adults influenced by disease was leisure, followed by symptoms and feelings and daily activities ($p < 0.001$), which is in agreement with Ongenaes et al. [36] and Wang et al. [12]. In children, the main heading item influenced by disease was also leisure, and vitiligo had a highly significant impact on personal relationships; the item includes questions about friendships, teasing and bullying.

Vitiligo seems to have less influence on activities such as going to work and school, and this is in agreement with the results of other studies [12, 18, 22]. Leisure, social activities and sports seem to have a higher impact on QoL, and it may be related to self-consciousness about lesions and clothing decisions, since those were the questions that had higher scores in the DLQI and also in the CDLQI. Unlike other studies [37], treatment does not seem to have such an impact on QoL, in both adults and children, in our sample.

When comparing the dermatology-specific with the disease-specific questionnaire, it is observed that there are more questions in VitiQoL related to stigmatization

of the disease, which is a very important aspect of vitiligo. Feelings such as frustration, embarrassment/self-consciousness and concern about the reaction of what other people may think about the patient are better explored in the VitiQoL. As in dermatology-specific questionnaires (DLQI and CDLQI), daily activities seem to be less affected than leisure and social activities. And the decision of the clothes to wear is also a concern in the disease-specific instrument.

The use of disease-specific instruments to assess QoL helps in the management of patients. The present study showed how much stigma is present in the lives of patients with vitiligo. Besides that assessment of QoL provides relevant information about treatment benefits, the importance of early treatment and understanding of the profound psychosocial effect of vitiligo correlate with positive QoL outcomes and prevent social and emotion-

al limitations that can result from the disease [7, 10]. Patients may benefit from referrals for psychological intervention and early treatment [9]. Finally, this study contributes to gather evidence on the Brazilian Portuguese version of the VitiQoL, encouraging other groups to develop more studies about QoL in larger populations.

Statement of Ethics

The study was approved by the ethical committee of our institution.

Disclosure Statement

The authors have no conflicts of interest to declare.

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