Vitiligo and Quality of Life
A Comprehensive Review

A thesis submitted to the University of Arizona College of Medicine – Phoenix in partial fulfillment of the requirements for the degree of Doctor of Medicine

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Abstract

This comprehensive review will provide an overview of the current literature regarding vitiligo and its skin manifestations, as well as the stigma surrounding skin depigmentation diseases. We will also discuss measurement of quality of life. This comprehensive review will provide the background information necessary to understand the psychological impact of the disease vitiligo on global populations.
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Vitiligo – The Disease

Vitiligo is an acquired pigmentary disorder of unknown etiology. It is clinically characterized by development of white macules due to loss of melanocytes. Though the exact pathogenesis is still debated by experts, many believe it is caused by autoimmune destruction, oxidative stress, and/or sympathetic neurogenic dysfunction. (Alikhan) The lesions produce no symptoms, other than possible itching, so the main negative effects of the disease are cosmetic and psychological.

Epidemiologically, the prevalence of vitiligo in the United States is around 1%. This ranges from 0.1% to greater than 8% worldwide. (Alikhan) The reported prevalence of vitiligo worldwide has a large range, with some regions affected much more severely than others. Vitiligo can occur at any age, with some cases reported as early as 6 weeks after birth. About half of cases will initially present before the 20 years of age. There is no difference in prevalence between men and women, and no known difference based on skin tone.

The diagnosis of vitiligo is generally made clinically, with no special tests or biopsies necessary. The clinician will look for the uniformly white macules or patches on the skin with convex borders, surrounded by normal skin. The lesions are more likely to occur in areas where friction is more common such as the face, the dorsal hands, axillary and inguinal regions. There are typically more cases diagnosed in the spring and summer months. Vitiligo is divided into three categories: localized, generalized, or global. Each of these subtypes is generally progressive, as the lesions expand centrifugally or new lesions appear. Most lesions do not regress or disappear on their own.

Treatments involve corticosteroid cream and phototherapy to the affected areas. Repigmentation can occur in some cases, but is not guaranteed. New lesions could also appear even while treatment is being pursued. Vitiligo is a progressive disease that is difficult to treat, and this causes a great deal of distress to those it inflicts.
Cultural Stigma

The psychosocial impact of vitiligo is profound in some areas of the world. Cultural beliefs and biases shape what a population perceives about a person with vitiligo. Lack of vitiligo knowledge and awareness leads to stigmatization and alienation of those with the disease. Since vitiligo produces no physical health problems, this psychological aspect of the disease is the most detrimental.

In male-dominated cultures such as Saudi Arabia and India, vitiligo carries a heavy stigma. It is thought that the importance of marriage in these cultures contributes to the increased severity. Vitiligo patients can be seen as “unclean” or “unfit to marry” by some, which can isolate them from family and their community. A study in Saudi Arabia demonstrated that 56.1% of people would not consider marrying a person with vitiligo. (Firooz)

The long-term nature of the disease does not provide any optimism or hope for the future for these patients. Treatments are available, but they can be expensive, time consuming, or difficult to access for certain people. Even if treatment is started, the depigmentation will fail to resolve in some cases.

Also present in many cultures are the misconceptions about vitiligo due to lack of knowledge about the disease. It was found that 33.1% of people in Saudi Arabia thought vitiligo was contagious. (Firooz) Fallacies such as this are extremely harmful to the psyche of patients. Not only are they embarrassed by the depigmentation, they think they could possibly spread their disease to others. This leads to isolation and a large decrease in quality of life.
Measuring Quality of Life

One of the greatest hurdles overcome when studying the negative effects of vitiligo is to measure its impact objectively. Without question, quality of life is negatively affected in patients with vitiligo. The challenge is to create a way to examine the degree to which this occurs.

There are a number of scores created, but the most widely accepted standard measurement tool is the Dermatology Life Quality Index (DLQI). (Finlay) This is a 10 question survey meant to test how much of a patient's life is affected by their skin condition. The survey can be used for other conditions such as psoriasis or acne, but works very well for vitiligo since the main concern is psychosocial effects.

The survey attempts to inquire about each part of life and see the extent to which vitiligo negatively affects them. This includes questions about daily activities, leisure, work, school, personal relationships, symptoms, and treatments. The survey is simple enough for anyone to answer without difficulty, and gives Likert scale answers so that the data can be quantified. Scores range from 0 to 3 on each question, so that the minimum total score is 0 and the maximum is 30. Higher scores represent larger negative effects of vitiligo on the life of the patient. The “minimal clinically important difference” for the DLQI has been set at 4, meaning any score of 4 or above suggests quality of life is being affected.

This standardized survey and scoring system has been used in studies from around the world and has been translated in over 100 languages and even cartoon versions for those who cannot read. This allows for a unique objective view of how this disease affects different cultures.
DERMATOLOGY LIFE QUALITY INDEX

Hospital No:  Date:  Score:  
Name:  Diagnosis:  
Address:  

The aim of this questionnaire is to measure how much your skin problem has affected your life OVER THE LAST WEEK. Please tick one box for each question.

1. Over the last week, how itchy, sore, painful or stinging has your skin been?  
   Very much □  
   A lot □  
   A little □  
   Not at all □  

2. Over the last week, how embarrassed or self conscious have you been because of your skin?  
   Very much □  
   A lot □  
   A little □  
   Not at all □  

3. Over the last week, how much has your skin interfered with you going shopping or looking after your home or garden?  
   Very much □  
   A lot □  
   A little □  
   Not at all □  

4. Over the last week, how much has your skin influenced the clothes you wear?  
   Very much □  
   A lot □  
   A little □  
   Not at all □  

5. Over the last week, how much has your skin affected any social or leisure activities?  
   Very much □  
   A lot □  
   A little □  
   Not at all □  

6. Over the last week, how much has your skin made it difficult for you to do any sport?  
   Very much □  
   A lot □  
   A little □  
   Not at all □  

7. Over the last week, has your skin prevented you from working or studying?  
   Yes □  
   No □  
   Not relevant □  

   If "No", over the last week how much has your skin been a problem at work or studying?  
   Very much □  
   A lot □  
   A little □  
   Not at all □  

8. Over the last week, how much has your skin created problems with your partner or any of your close friends or relatives?  
   Very much □  
   A lot □  
   A little □  
   Not at all □  

9. Over the last week, how much has your skin caused any sexual difficulties?  
   Very much □  
   A lot □  
   A little □  
   Not at all □  

10. Over the last week, how much of a problem has the treatment for your skin been, for example by making your home messy, or by taking up time?  
    Very much □  
    A lot □  
    A little □  
    Not at all □  

Please check you have answered EVERY question. Thank you.

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References


Comparing Quality of Life in Global Vitiligo Patients

A thesis submitted to the University of Arizona College of Medicine – Phoenix in partial fulfillment of the requirements for the degree of Doctor of Medicine

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Abstract

This systematic review compares the quality of life of patients with vitiligo in different regions of the world. Multiple studies demonstrate that diseases that change the color of skin will have social and psychological impacts on those inflicted. Quality of life measurements can be objectively measured using the Dermatology Life Quality Index (DLQI), a ten-question survey given to vitiligo patients. Data from this survey has been compiled in many different countries, and have demonstrated major differences with high scores seen in Middle East and Southern Asia, and lower scores seen in Europe. These discrepancies present a serious global health problem.
List of Figures and Tables
Introduction

Skin pigmentation disorders, including vitiligo, are a major medical problem in all areas of the world. It has been estimated that 0.5 to 2 percent of the global population is affected by vitiligo alone (Kostopoulou et al. 2009). It is known by many names, including “sweta kustha” meaning "white leprosy.” (Parsad) While vitiligo does not cause physical impairment, its effect on the psychological state of the patient has been thoroughly examined. Studies from countries across the globe have gathered data on the quality of life of affected individuals, but there is a need to sift through this data to find trends. With a global focus, this study will examine this existing data and find similarities and differences between different cultures.

Vitiligo is a long-lasting disease, and its progression can be unpredictable. The specific cause of the disease is currently unknown, but it is brought about by the death of melanocytes in the skin, or the failure of living melanocytes to produce melanin (Matin 2015). Our current explanations for the cause of these problems are autoimmune attack, family history, or a trigger event such as a sunburn, stress, or chemical exposure.

While the exact etiology of the disease remains unknown, the information we do have should dispel many fictitious assertions about the cause. In societies where there is no baseline knowledge of the disease, affected individuals can be seen as cursed or unclean. In certain communities, this could cause those with vitiligo to be ostracized and looked down upon. This can have a profound effect on the quality of life of these individuals. Examining cultural differences and perceptions will be key in determining where this problem will be most prevalent.

An objective measure for studying quality of life is the Dermatology Life Quality Index (DLQI). (Finlay) This is a ten-question survey that is given for the purpose of discovering how significant an impact the patient’s disease has on their day-to-day life. It asks about all different parts of life, from the workplace to physical activity. Higher scores on this survey will demonstrate a more severe negative impact on the life of these patients. We will use this data to analyze the quality of life impact of vitiligo in various countries.
A recently published study described this Quality of Life impact on various populations. (Amer, A. A., Gao, X. 2016). Quality of life in patients with vitiligo: An analysis of the dermatology life quality index outcome over the past two decades) The aim of this systematic review is to focus on region-by-region analysis of this effect.

We will specifically examine the effect of baseline skin color in a population. Vitiligo is more noticeable on a darker skinned individual because of greater contrast (Sangma et al. 2015). It can be hypothesized that the cultural stigma of the disease will be worse in countries with a darker skinned population. Studies have been conducted in both regions with a predominantly light skinned population, and predominantly dark skinned population, so these results will be compared.
Methodological Approach

A systematic review will be conducted to find quality of life data of vitiligo patients around the world. The PubMed database was the primary engine used to find studies for inclusion. PubMed was last searched 7/25/17. Keywords for the search of these articles are “vitiligo + quality of life,” “vitiligo + DLQI,” and “vitiligo.”

Acceptance criteria include:

1. The article needs to be a primary research article with objective data that correlates to attitudes and perceptions toward those with vitiligo.
2. These articles will need to specify from which country the data was collected, so that they can be properly sorted.
3. The Dermatology Life Quality Index must be used.

Exclusion criteria include:

1. The article is not published in English, and no translation is available.
2. The article does not make use of the DLQI scale, and cannot then be compared to other studies.
3. The article was studying children rather than adults.

The literature search yielded 21 articles that span from African nations, to Asian nations, to European nations.
Literature Search:

*Database: PubMed*

Search: “Quality of Life”[Mesh] AND “Vitiligo”[Mesh]

87 results, 7 met criteria

Search: (“vitiligo”) AND “Quality of Life”[Mesh]

104 results, 8 met criteria


7 results, 3 met criteria
Records identified through database searching (n = 221)

Additional records identified through other sources (n = 0)

Records after duplicates removed (n = 198)

Records screened (n = 198) → Records excluded (n = 33)

Full-text articles assessed for eligibility (n = 165) → Full-text articles excluded, (n = 144)

Studies included in qualitative synthesis (n = 21)

Studies included in quantitative synthesis (meta-analysis) (n = 21)
Using the DLQI, it will be possible to determine the severity of negative impact on QOL. This is a 10 question survey meant to test how much of a patient’s life is affected by their skin condition. The survey can be used for other conditions such as psoriasis or acne, but works very well for vitiligo since the main concern is psychosocial effects.

Systematic review of the data will be performed to compare the results between the studies. The focus will be on DLQI differences in gender and location of the study.
# Dermatology Life Quality Index (DLQI)

<table>
<thead>
<tr>
<th>Hospital No:</th>
<th>Date:</th>
<th>Score:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Name:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Address:</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

The aim of this questionnaire is to measure how much your skin problem has affected your life OVER THE LAST WEEK. Please tick ☐ one box for each question.

1. Over the last week, how itchy, sore, painful or stinging has your skin been?
   - Very much ☐
   - A lot ☐
   - A little ☐
   - Not at all ☐

2. Over the last week, how embarrassed or self conscious have you been because of your skin?
   - Very much ☐
   - A lot ☐
   - A little ☐
   - Not at all ☐

3. Over the last week, how much has your skin interfered with you going shopping or looking after your home or garden?
   - Very much ☐
   - A lot ☐
   - A little ☐
   - Not at all ☐

4. Over the last week, how much has your skin influenced the clothes you wear?
   - Very much ☐
   - A lot ☐
   - A little ☐
   - Not at all ☐

5. Over the last week, how much has your skin affected any social or leisure activities?
   - Very much ☐
   - A lot ☐
   - A little ☐
   - Not at all ☐

6. Over the last week, how much has your skin made it difficult for you to do any sport?
   - Very much ☐
   - A lot ☐
   - A little ☐
   - Not at all ☐

7. Over the last week, has your skin prevented you from working or studying?
   - Yes ☐
   - No ☐
   - Not relevant ☐

   If 'No', over the last week how much has your skin been a problem at work or studying?
   - Very much ☐
   - A lot ☐
   - A little ☐
   - Not at all ☐

8. Over the last week, how much has your skin created problems with your partner or any of your close friends or relatives?
   - Very much ☐
   - A lot ☐
   - A little ☐
   - Not at all ☐

9. Over the last week, how much has your skin caused any sexual difficulties?
   - Very much ☐
   - A lot ☐
   - A little ☐
   - Not at all ☐

10. Over the last week, how much of a problem has the treatment for your skin been, for example by making your home messy, or by taking up time?
    - Very much ☐
    - A lot ☐
    - A little ☐
    - Not at all ☐

Please check you have answered EVERY question. Thank you.

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### Results

#### Table 1

<table>
<thead>
<tr>
<th>Author</th>
<th>Country</th>
<th>Year</th>
<th>Mean DLQI Score (SD) (UK=unknown)</th>
<th>Control Mean Age</th>
<th># of Patients (M=male, F=female)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Karelson et al</td>
<td>Estonia</td>
<td>2012</td>
<td>4.7 (UK) 0.6 (UK)</td>
<td>36.6</td>
<td>N=54, M=22 F=32</td>
</tr>
<tr>
<td>Ingordo et al</td>
<td>Italy</td>
<td>2014</td>
<td>4.3 (4.9)</td>
<td>41.1</td>
<td>N=161</td>
</tr>
<tr>
<td>Kostopoulou et al</td>
<td>France</td>
<td>2008</td>
<td>7.17 (4.9)</td>
<td>43.9</td>
<td>N=48, M=17 F=31</td>
</tr>
<tr>
<td>Ongenae et al</td>
<td>Belgium</td>
<td>2005</td>
<td>4.95 (UK)</td>
<td></td>
<td>N=119</td>
</tr>
<tr>
<td>Radtke M A et al</td>
<td>Germany</td>
<td>2008</td>
<td>7.0 (UK)</td>
<td>44.4</td>
<td>N=1023, M=292 F=731</td>
</tr>
<tr>
<td>Kent et al</td>
<td>United Kingdom</td>
<td>1996</td>
<td>4.82 (4.84)</td>
<td>46.6</td>
<td>N=614, M=150 F=464</td>
</tr>
<tr>
<td>Kiprono et al</td>
<td>Tanzania</td>
<td>2013</td>
<td>7.2 (4.8)</td>
<td>41.0</td>
<td>N=88, M=33 F=55</td>
</tr>
<tr>
<td>Mechri et al</td>
<td>Tunisia</td>
<td>2006</td>
<td>9.4 (17.1) 2.5 (UK)</td>
<td></td>
<td>N=60</td>
</tr>
<tr>
<td>Mishra et al</td>
<td>North India</td>
<td>2014</td>
<td>6.86 (UK)</td>
<td>29.36</td>
<td>N=100</td>
</tr>
<tr>
<td>Sangma et al</td>
<td>Northeast India</td>
<td>2013</td>
<td>9.08 (4.46) 1.04 (1.12)</td>
<td>29.72</td>
<td>N=100</td>
</tr>
<tr>
<td>Parsad et al</td>
<td>India</td>
<td>2003</td>
<td>10.67 (4.56)</td>
<td>33.6</td>
<td>N=150, M=67 F=83</td>
</tr>
<tr>
<td>Wong et al</td>
<td>Malaysia</td>
<td>2012</td>
<td>6.4 (5.17)</td>
<td>43.6</td>
<td>N=102, M=44 F=58</td>
</tr>
<tr>
<td>Wang et al</td>
<td>China</td>
<td>2010</td>
<td>8.41 (7.31)</td>
<td>30.83</td>
<td>N=101</td>
</tr>
<tr>
<td>Tanioka et al</td>
<td>Japan</td>
<td>2010</td>
<td>5.9 (UK)</td>
<td></td>
<td>N=144, M=75 F=69</td>
</tr>
<tr>
<td>Chan et al</td>
<td>Singapore</td>
<td>2013</td>
<td>4.0 (4.4)</td>
<td>48.4</td>
<td>N=222, M=105 F=117</td>
</tr>
<tr>
<td>Borimnejad et al</td>
<td>Iran</td>
<td>2006</td>
<td>10.59 (UK)</td>
<td>29.3</td>
<td>N=77, M=24 F=53</td>
</tr>
<tr>
<td>Aghaei et al</td>
<td>Iran</td>
<td>2004</td>
<td>7.05 (5.13)</td>
<td>28.3</td>
<td>N=70, M=27 F=43</td>
</tr>
<tr>
<td>Bin Saif et al</td>
<td>Saudi Arabia</td>
<td>2013</td>
<td>9.0 (UK)</td>
<td></td>
<td>N=127</td>
</tr>
<tr>
<td>Senol et al</td>
<td>Turkey</td>
<td>2012</td>
<td>15.0 (4.6)</td>
<td>36.2</td>
<td>N=178, M=87 F=96</td>
</tr>
<tr>
<td>Silverberg J</td>
<td>United States</td>
<td>2012</td>
<td>5.9 (5.5)</td>
<td>43.1</td>
<td>N=1541, M=433 F=1080</td>
</tr>
</tbody>
</table>
Figure 1
Discussion

The data suggest that there are indeed variations in quality of life in vitiligo patients from different regions of the world. Results are similar in countries that lie in geographical proximity to each other. For example, European countries tend to have lower DLQI scores. Estonia had an average score of 4.7, Italy had a score of 4.3, and France had a score of 7.2. (Karelson, Ingordo, Kostopoulou) Middle Eastern countries are on the other extreme, with very high scores on DLQI. Iran had an average of 8.82, and Saudi Arabia had an average of 11.86. The cause of these regional differences is most likely multifactorial, with influence from skin color, cultural stigmatization, and amount of disease education.

Average baseline skin color seems to be a factor, with darker baseline skin tones correlating with higher DLQI scores. In a study from the UK, scores from Caucasian and Non-Caucasian patients were compared. The Caucasian subgroup had a mean of 4.59, whereas the Non-Caucasian subgroup had a mean of 7.78. (Kent et al) In an individual with darker baseline skin tone, the vitiligo lesions will be more obviously observed, and will lead to more stigmatization. This would explain the rise in DLQI score in regions with generally dark skinned populations.

A major factor for higher DLQI scores in certain regions is the presence of arranged marriages. (Borimnejad, Parsad) This is commonplace in countries such as India and Iran, which both had high DLQI scores. Young women in these countries can be deemed “unfit to marry” by those in their community because of their disease. This has a lasting psychological impact. Even if a woman with vitiligo is able to marry, she will live in the constant fear that she will be divorced. Another misconception is that a woman affected with the disease can pass it to her offspring. (Borimnejad) This phenomenon is another reason that higher DLQI scores are seen in women.

There is no doubt vitiligo negatively affects Quality of Life, but each culture demonstrates unique reasons for this. The DLQI provides an objective, simplified measure of this effect, but cannot deeply describe the cause of the stigmatization in each culture. A study from India explains that other factors such as restlessness, teasing in schools, marriage prospects, and suicidal tendency are not included in the DLQI survey. (Narahari) Thus, the negative effect on Quality of Life could be even more severe than is suggested by the data we examined.
Future Directions

It is important to recognize that this poor quality of life is very severe in certain regions, and multiple efforts are underway to remedy this situation. For instance, a West African based organization called Vitiligo Support and Awareness Foundation (VITSAF) is spearheading efforts to improve disease education throughout the entire continent. (www.vitsaf.org) There are numerous similar organizations in India, such as Shweta Association, that serve the same purpose. (http://www.myshweta.org) Cultural stigmatization in these areas is severe, and those with vitiligo can be regarded as unclean or cursed. Since there is no known cure for vitiligo, the most powerful solution to this problem is education. The goal of this project was to identify what parts of the world are most affected by this issue. We will now have a more focused direction in which to aim a solution.
Conclusions

The major takeaway from this study is to recognize the regional differences in how vitiligo affects patients psychologically. From a global health perspective, cost and time are major factors when providing care. If an effort is to be made to solve this problem, it would be wise to begin in an area that is greatly affected. From the results of this study, it is clear that regions such as the Middle East and Southern Asia are highlighted as possible targets for intervention.
References


