



## Original Research Article

## Impact on quality of life in family members of patients suffering from vitiligo

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## ABSTRACT

**Introduction:** Vitiligo affects patients profoundly as onlookers tend to stare at individuals with Vitiligo which impacts social life of patients and family members. Family members are hidden patients which are often missed in clinics, they suffer psychologically and never seek consultation for their suffering.

**Objective:** To analyze effect of vitiligo on family member's quality of life and to identify the different aspects of a family member's FDLQI that may be affected by having a family member with Vitiligo.

**Materials and Methods:** Consenting adults family members of 50 patients with Vitiligo, attending the OPD of a tertiary care, teaching hospital completed the standard FDLQI questionnaire.

**Results:** Based upon the FDLQI scoring, quality of life of 62% of patient's family member were found to be affected in varying degrees (mean total score:  $11.94 \pm 7.721$ ). 10 aspects of FDLQI of family members were identified which were adversely affected the patients skin disease. These were categorized into 10 main topic areas: Emotional distress (70%), Physical well-being (56%), personal relationship (58%), People's attitude (66%), Social life (56%), Leisure activities (52%), Burden of care (74%), Effect on housework (52%), Financial aspect (78%).

**Conclusion:** Vitiligo can have a profound impact on not just patient's but his/her family member's quality of life.

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## 1. Introduction

Vitiligo is an acquired, usually progressive depigmentary disorder characterized by achromic macules and histologically manifested as degeneration of melanocytes in the skin.

Skin being the largest organ of the body has the most impact on an individual, any blemish on skin can affect quality of life of patients and family members. Social stigma associated with vitiligo affects patients profoundly as onlookers tend to stare at individuals with vitiligo which impacts social life of patients and family members.<sup>1-4</sup> In few parts of the world it is often confused with leprosy and is considered as communicable which oppresses the patient further.<sup>5</sup>

More than 50% patients develop vitiligo under 20 years of age and a positive family history is seen in 13% of

patients which adds on to the concern of family members for the disease.<sup>6,7</sup> Due to ill-defined treatment protocols and unpredictable results it is often frustrating for the patient and family members of patients to regularly visit a hospital and take leaves from the work. Family members are hidden patients who are often missed in clinics, they suffer psychologically and never seek consultation for their suffering.<sup>8,9</sup> There is a need to identify and measure severity of psychological impact of vitiligo on family members of vitiligo.

## 2. Materials and Methods

Convenient sampling of the patients was done. A 10 question questionnaire of family quality life index (FDLQI)<sup>9</sup> by Cardiff university was translated in local language(Hindi) by two forward and backward translations and after approval by Cardiff university, Institutional ethics

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committee and Research advisory committee a prospective observational study was carried out in which 50 patients of both genders and all age groups presenting with vitiligo for minimum 6 months duration and accompanied by an adult family member were enrolled. Questionnaire was filled either in Hindi or English depending upon the preferred language by the family members.(Figure 1)

Questionnaire evaluated 10 quality of life areas under the following headings:<sup>9,10</sup>

1. Emotional distress
2. Physical well being
3. Personal relationships
4. People's attitude
5. Social life
6. Leisure activities
7. Burden of care
8. Effect on housework
9. Effect on job
10. Financial aspect

Each question was scored from 0 to 3 where Not at all/Not relevant/unanswered was scored zero, A little -one, quite a lot -two and very much was scored as three.<sup>9,10</sup>

### 2.1. FDLQI score range was from zero to thirty.

Other variables of study were age, gender, family history, type of vitiligo, relationship with patient and site of involvement which was classified as on exposed areas or unexposed areas.

### 2.2. Statistical analysis

Data was compiled using Microsoft excel version 2013 and analysis was done using SPSS software version 20. Numerical data was expressed as mean and SD. Independent test was applied to assess the difference between 2 groups whereas difference between more than 2 groups was analyzed using ANOVA. P value less than 0.05 was considered statistically significant.

## 3. Results

In our study 58% were parents, 20% were spouse and rest 22% were either grandparents, siblings or adult son/daughter. Mean age of the patients were  $24.56 \pm 16.61$  years. Table 1 gives the demographic details about our study.

### 3.1. Quality of life areas affected

The data from the 50 interviews were presented under the 10 quality of life areas. The percentage of family members affected in various quality of life areas along with the intensity of affliction were compared(Figure 2).

Mean of all quality of life areas is compared in Figure 3. The most impacted factor was financial aspect,

impacting 78% of the families. Out of which 32% were severely affected, 22% moderately affected and 24% were mildly affected. Burden of care was the second most impacted factor affecting 74% families. Parents were the most impacted group as they are involved in direct care giving to the child. Emotional distress was the third most expressed concern in our interviews, with 70% of the family members impacted in one way or the other. As much as 66% families felt that people's attitude had made them uncomfortable, caused distress or embarrassment due to the patient's disease. Personal relationships were impacted in 58% family members. Many family members (58%) felt that their job was affected directly or indirectly. 56% families were affected in terms of physical well being. Social life, Effect on housework and Leisure activities were the lesser impacted aspects in our interview. Social life was affected in 56% families. Both Effect on housework and Leisure activities were impacted in 52% of the families.

### 3.2. Study variables and mean total scores

In our study family members of patients with lesions on exposed areas had higher FDLQI as compared to those when the lesions were present in non exposed area (P value : 0.01). Figure 4 depicts the correlation between study variables and mean FDLQI scores.

Surprisingly, the mean FDLQI was higher in family members of male patients as compared to female patients (P value : 0.002). This suggests that the family distress increases with age of male patient and could be attributed to challenges faced by male patients in finding good jobs.

Family members of a patient who had a positive family history of vitiligo were slightly more affected as compared to the group in which family history was absent. These group of patients were especially concerned and fearful of developing the disease themselves, or passing it on to their children.

Parents were the most affected group, followed by spouse and other family members. Wives were more affected when their husband suffered with vitiligo in contrast to husbands of female patients. Adult off springs were the least impacted group by their parent's illness and the most important concern was fear of contracting the disease themselves.

### 3.3. Study Limitations

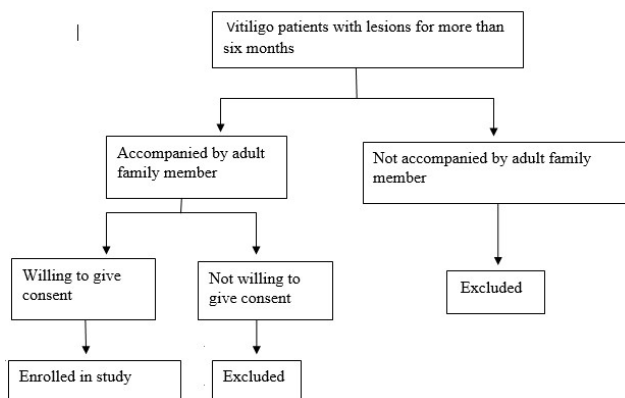
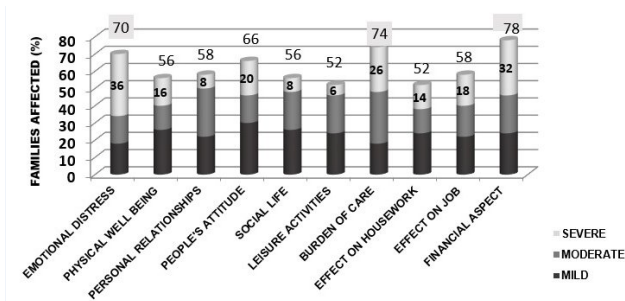
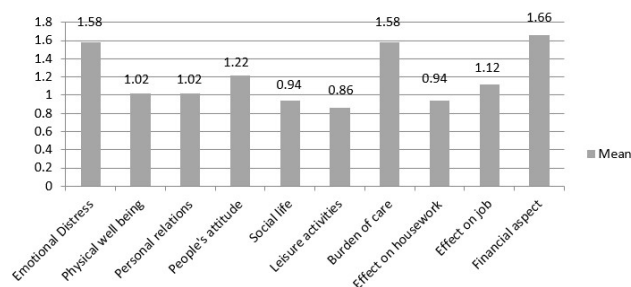
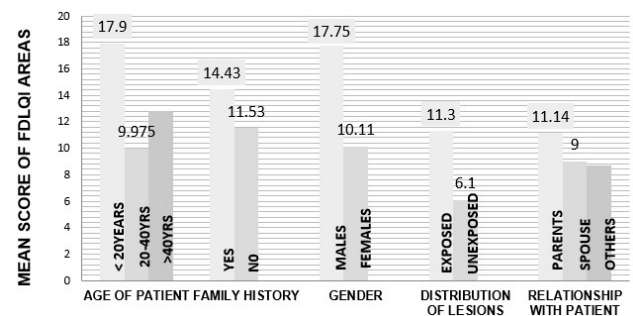
The limitation of our study was low sample size but similar studies had nearly same sample size so we believe that results won't differ greatly in higher sample size.

## 4. Discussion

Family members of patients ailing with a dermatological problem are usually as miserable as the patient themselves and share the patient's agony and pain. They are the hidden victims and at times are more severely impacted than the

**Table 1:** Demographic Profile of enrolled patients

Mean Age of Patients (Years)	24.56 ± 16.61	
Range (5-64 years)		
Gender of the Patient	Females: 76% (38)	Males: 24% (12)
Family Member's relation to Patient	Parents: 58% (29)	
	Mother: 28%	Father: 30%
	Spouse 20% (10)	
	Husband: 16%	Wife: 4%
	Other: 22% (11)	
Type of Vitiligo	Siblings: 6%	Grandparents: 6%
	Son/Daughter: 10%	
Site of Involvement	Vitiligo Vulgaris: 80%	Other: 20%
	Exposed: 80%	Non-Exposed :20%
Family History	Present: 14%	Absent: 86%

**Fig. 1:** Illustration of methodology followed in present study**Fig. 2:** Family Life Quality Areas Affected**Fig. 3:** Mean FDLQI scores for individual items**Fig. 4:** Correlation between study variables and mean FDLQI scores

patient.<sup>11</sup> Often this arena is overlooked and most of our studies focus on quality of life of the patients. It is pivotal to consider the family members mental health while planning the treatment as this can impact our treatment outcome significantly. In previous studies it was reported that many patients of vitiligo experience suicidal thoughts, anxiety, depression, social discrimination and difficulty in social communication.<sup>12–14</sup>

In the past, a couple of studies have been done using FDLQI in childhood vitiligo. One such study was recently published by Gahlaut et al who determined QOL in parents with children suffering from vitiligo and the other one was conducted by Basra et al which included both inflammatory and non inflammatory skin diseases.<sup>9,14,15</sup>

Other studies conducted by Bin Saif et al from Saudi Arabia and Hindjani from Iran have determined family QoL in adults patients of vitiligo.<sup>16,17</sup>

In our study family members of male patients were more significantly impacted than females. This could be due to the fact that men are still considered the most significant member in the family and contributes primarily in financial support to the family. Having vitiligo significantly decreases their prospects for job and thus this could be a major factor impacting the families financially and emotionally. This result is similar to a study conducted by Binsai et al in

Saudi Arabia and the author stated that the finding could be due to Saudi Arabian culture where men play a more significant role in family setting.<sup>16</sup> Another study found that the parents of female patients were affected more than the male patients, however this study did not include adult patients in the study.<sup>13</sup> Study conducted by Amer et al did not show any statistically significant gender difference.<sup>14</sup>

Family members of patients with lesions over the exposed areas were more significantly impacted than those who had lesions on non exposed area. This is attributed to greater cosmetic distress and social acceptability seen in family members when the lesions are present on exposed areas of the body. Similar results where QOL scores were found to be higher in patients with lesions on exposed areas in contrast to lesions on non exposed areas had been observed by previous studies.<sup>14–16</sup>

Out of the 10 quality of life areas the most impacted factor was financial aspect, this is contrary to other FDLQI studies where emotional distress is the most impacted factor.<sup>15</sup>

This could be attributed to the inclusion of adult patients in our study, inability to find suitable employment and the lack of proper healthcare infrastructure which increases the financial burden on the families. Burden of care was the second most impacted factor.

Most families felt that they needed great deal of time to look after their patients, apply creams and give medicines. Parents were the most impacted group as they are involved in direct caregiving to the child.

In our study 70 % families experienced emotional distress, out of which 36% families were severely affected. Mean value of emotional distress was similar to burden of care domain and only less than financial burden domain. In a study conducted by Amer et al and Gao et al, impact of childhood vitiligo on Parents Mental Health and Quality of Life was evaluated and they found emotional domain to be most affected.<sup>13</sup> Similar results were observed by Gahalaut et al.<sup>15</sup>

As many as 66% families felt that people's attitude had made them uncomfortable, caused distress or embarrassment due to the patients disease. Parents complained of their child being bullied at school by other children due to his/her disease.<sup>14</sup>

Personal Relationships were impacted for 58% family members. The affected family members felt that their relationship with the patient and with the other family members was affected due to the disease. 58% family members felt that their job was affected directly or indirectly because of the patient's condition. They complained of inability to concentrate on their work, and need for taking out time from their schedule to care for the patient.

56% families were affected in terms of physical well being. They felt that caring for the patient is physically exhausting, hectic and has taken a toll of their health.

Certain miscellaneous issues which were not part of the structured interview were also identified, such as many family members were concerned about the marriage of the patient and inability to find suitable matches for marriage and getting multiple rejections due to vitiligo. Many family members were extremely concerned of contracting the disease themselves or to other family members.

The significant impact vitiligo has on family members of the patients forces us to rethink and restructure our current strategies to cope with vitiligo stigma. We need to find solutions which are easy and simple to implement. We need to devise strategies and guidelines at the level of individual practitioner, institutional level such as tertiary care hospitals and medical colleges and at the level of community/society. A private practitioner should take a comprehensive approach while counseling the patient, and should always include a family member along with the patient while doing the counseling. Most often we as practitioners successfully alleviate patients concerns but the patient struggles explaining the same to the family members. In this scenario, family can cope better when the family hears about the nature and prognosis of disease straight from the practitioners and experts. In our study financial aspect was clearly the most impacted factor, therefore a private practitioner should always consider the socioeconomic status of the patient and should refer the non affording patients with low socioeconomic status to a non profit hospital or tertiary care center where the patient can avail treatment at low cost, doing so will prevent these patients from being lost to follow up. At the level of institute we need to formulate strategies whereby we can counsel both the patient and the family members. All patients should be adequately counseled along with the family members and signs of anxiety and depression should be identified. An effective collaboration with Psychiatry department is pivotal especially for those patients and family members who require psychiatric help. Support groups should be structured for the patients and family members, where they can interact with each other and healthcare provider. Institutes and tertiary care hospitals should aim to provide subsidized medications, phototherapy sessions and surgical treatment modalities. Displaying posters about vitiligo awareness at hospitals, clinics and public places will not just make the family members but also the common population/ community more educated about the disease. Rallies, skits and talks regarding vitiligo awareness should be delivered at the level of community/society.

## 5. Conclusion

This study is an honest step towards studying the underlying impact of vitiligo on family members which poses a huge challenge for current campaign on vitiligo awareness.

Our study shows that vitiligo can have a profound impact on not just patient's but his/her family members quality of life too. Financial aspect, Emotional distress and Burden of care are the quality of areas which were most impacted in our study. Most of the policies in our healthcare infrastructure does not incorporate skin diseases, which further increases financial burden on the patients and families. Our current campaigns and strategies for vitiligo awareness will certainly go into vain unless we incorporate the family members in our plans and develop a more comprehensive approach. Thus there's a need for our policymakers to recognize the magnitude of discomfort vitiligo poses to the patients and their families. Families of patients suffering from vitiligo suffer silently and most often are more severely impacted than the patients themselves. Therefore, not just the patient but the family members too should be adequately counseled and comforted, and recommended psychiatric help if necessary. This would alleviate the patients anxiety further, making families more compliant and thus would increase the treatment outcome.

### 5.1. Statement of Ethics

Approval from Institutional ethics committee (IEC), Research Advisory committee (Code no.IEC-2017-01), licence for use of FDLQI form was taken from Cardiff University (Licence ID- CUQoL2499) and informed consent was taken from all the participants in study.

### 6. Disclosure statement

None.

### 7. Financial disclosure

The author declared that the study received no financial support.

### 8. Conflict of interest

None.

### 9. Peer- review

External and internal peer reviewed.

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