

CLINICAL REPORT

Hidden Victims of Childhood Vitiligo: Impact on Parents' Mental Health and Quality of Life

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This study aims to assess the impact of childhood vitiligo on the psychological status and quality of life of their parents, and to determine how this varies according to their children's disease condition. The study included 50 families of children with vitiligo (a total of 75 participants) and 50 families of normal children (a total of 79 participants). The psychosocial impact of the disease on parents was measured using the Self-rated Health Measurement Scale (SRHMS) and the Dermatitis Family Impact Questionnaire (DFI). SRHMS scores for parents of children with vitiligo were significantly lower than for parents with normal children. In addition, women had lower scores on SRHMS scale than men in the study group. The mean DFI score in affected families was higher than in unaffected families. Parents of children with vitiligo have significant psychological problems, and their quality of life is poorer than for parents of normal children. In conclusion, parents of children with vitiligo need as much care and attention as their affected children. Key words: vitiligo; childhood; parents; DFI; SRHMS; quality of life.

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Vitiligo is a common acquired skin depigmentation disorder with a worldwide prevalence of 0.5–2% (1). Approximately 50% of patients experience vitiligo before the age of 20 years, while 25% of children experience vitiligo onset before the age of 10 years (2). Vitiligo rarely causes physical discomfort; however, it often affects the patient's mental state, due to cosmetic problems, social pressure, and a wide range of severe psychological problems, such as fear, anxiety, depression and suicidal thoughts. Patients may develop inferiority complexes, social communication difficulties, embarrassment, irritability and fear of being talked about (3, 4). These problems are not confined to the patients, but may also affect those close to the patient, e.g. family members and other contacts.

There have been very few studies of the psychological impact of the disease and quality of life among young patients with vitiligo. A pre-study literature review of this disease and how it affects the patient and their family as a unit revealed little published evidence (5, 6). No research studies were found on the indirect psychological impact of childhood vitiligo on parents. The aims of this study were therefore to examine the complications of this disease and to evaluate the severity with which it affects family members and society in general. Clinical data on childhood vitiligo was collected, the interaction of aggravating factors between diseased children and their healthy parents was evaluated, and levels of psychosocial disturbances caused by childhood vitiligo on patients' parents were determined using psychology and quality of life questionnaires.

SUBJECTS AND METHODS

The patients group comprised children aged 3–18 years attending the dermatology clinic at the First Hospital of China Medical University. Fifty children with a confirmed diagnosis of vitiligo, as well as their healthy parents, were enrolled in this study between August 2012 and July 2013. Fifty healthy children and their parents, from the local community were enrolled as controls. Participants were matched for age, gender and parental education level. Patients and their controls were subjected to the same inclusion and exclusion criteria. Informed consent was obtained from the parents.

All children with vitiligo were included sequentially in this study. The clinical diagnosis of vitiligo was made by experienced dermatologists. All patients were examined in order to exclude other associated autoimmune diseases.

Inclusion criteria were: (i) children living with healthy biological fathers or mothers; (ii) a diagnosis of vitiligo confirmed by a certified dermatologist; (iii) disease duration of more than 1 month; and (iv) age between 3 and 18 years.

Exclusion criteria were: (i) one or both parents have neurotic diseases; and (ii) associated autoimmune or severe diseases.

Questionnaires

Two different questionnaires were administered to the parents. In addition, a general information datasheet was used to record demographic data such as age and sex. Clinical data for patients with vitiligo, such as age of onset, disease duration and progression and clinical types, were also obtained.

Self-rated Health measurement Scale (SRHMS). A Chinese language version of this 48-item questionnaire was used to

gather general information about participating parents, e.g. age, sex, region of residence, nationality, educational level, occupation, and personal monthly income, and to evaluate the psychological impact on parents in both case and control groups by self-rating 3 health aspects (physiological, psychological and social health). These items were divided into 9 dimensions (B1: physical symptoms and organic functioning; B2: physical activities of daily living; B3: physical mobility; M1: psychosocial symptoms and negative emotions; M2: positive emotions; M3: cognitive functioning; S1: role activity; S2: social resources and social contact; S3: social support) and categorized into 3 subscales (BZT: total score of physical health subscale; MZT: total score of psychosocial health subscale; SZT: total score of social health subscale). ZCZT represented the total score of the SRHMS. All items have a maximum possible score of 10 and a minimum possible score of 0, higher score indicating better self-rated health. The maximum possible scores for each subscale score and the total score of the SRHMS are 170, 150, 120 and 440, respectively (7, 8).

Dermatitis Family Impact Questionnaire (DFI). There has been no vitiligo family impact questionnaire developed thus far. We therefore adopted the DFI to evaluate parent's quality of life as influenced by their child's skin disease. A Chinese language version downloaded from Cardiff University's Department of Dermatology website was used (<http://www.dermatology.org.uk/quality/dfi/quality-dfi.html>). The questionnaire comprises 10 short, family-related questions, each scored 0–3 (0 = not at all, 1 = a little, 2 = a lot and 3 = very much). The score on each of the 10 questions is summed. A total score of 0–5 is regarded as a normal quality of life, 6–10 as low alteration, 11–20 as moderate alteration, and >20 as high alteration in quality of life. The content of the questionnaire included housework, food preparation, sleep of others in the family, family leisure activities, time spent shopping, expenses such as costs related to treatment, clothes, tiredness or exhaustion, emotional distress, relationships in the family, and the impact on the life of the main caregiver of helping with treatment (9, 10).

RESULTS

Demographic characteristics of participating parents and children

Fifty families (75 parents) in the study group and 50 families (79 parents) in the control group completed the study. The questionnaires were completed by both parents (50 parents, 66.6%) in 25 families in the study group, whereas both parents in 29 families (58 parents, 76.3%) did so in the control group. The questionnaires were completed by a single parent in 25 families (25 participants, 33.3%) in the study group and 21 families (18 parents, 23.7%) in the control group. The demographic characteristics of parents are shown in Table SI¹.

A total of 50 children with vitiligo, aged between 3 and 18 years (mean \pm SD age 10.14 \pm 3.72 years) were enrolled in this study. There were 22 boys and 28 girls. The most involved areas in the subject group were: head/face/neck in 27 subjects (54%), followed by trunk in 9 (18%), legs in 5 (10%), genitalia in 4 (8%), and hands and feet in 2

(4%). Clinical types included 40 cases of (80%) localized vitiligo, 7 (14%) of vitiligo vulgaris, 2 (4%) of segmental vitiligo, and 1 (2%) of generalized vitiligo. Thirty-four (68%) patients were in the stable stage and 16 (32%) were in the progressive stage of the disease. Fourteen (28%) patients had a family history of vitiligo. The control group comprised 23 boys and 27 girls, mean \pm SD age 8 \pm 3 years, similar to vitiligo children.

Self-rated Health measurement Scale score

Score comparison between study and control groups. As shown in Table I, all sub-scores and total SRHMS scores were significantly reduced in parents with children of vitiligo compared with parents of healthy controls, except for the physical health subscale score. There was no significant difference in physical health scores and their subscores between fathers and mothers who had children with vitiligo. The total score for social health in mothers was significantly lower than for fathers, although there were no significant differences in subscores for social health between fathers and mothers (all $p > 0.05$). However, for all dimensions of mental health and the total SRHMS score, mothers had significantly lower scores than fathers.

Impact of children's clinical condition on the parents. As shown in Table SII¹, there was no statistically significant difference in parent's SRHMS in relation to children's gender and duration of disease. Parents with children with progressive vitiligo had lower cognitive functioning (item M3) compared with parents with children with stable vitiligo. Children with vitiligo on non-exposed sites had lower scores for physical activities of daily living, as reported by their parents, compared with children with vitiligo on exposed sites. The clinical type of vitiligo had a different impact on role activity (S1), total scores of social health (SZT) and total SRHMS score (ZCZT).

Dermatitis Family Impact questionnaire (DFI)

Score comparison between study and control groups. A total of 50 DFI questionnaires were completed by families of children with vitiligo. Quality of life of the studied families was moderately altered (mean DFI score 11.0) compared with the control group, which appeared normal (mean score 1.7). Specifically, 6 (12%) families had a normal quality of life, 18 (36%) had a low alteration, 25 (50%) moderate alteration, and 1 (2%) high alteration in quality of life. The total DFI score and all subscores were significantly higher in parents of children in the study group than for those in the control group. On further analysis, we found a significant difference in DFI scores between parents, except for factors such as sleep, time shopping, expenditure, tiredness and treatment (Table II).

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Table I. Self-rated Health Measurement Scale (SRHMS) score

| Items | Study group (n=75) Mean (SD) | Control group (n=79) Mean (SD) | p | Patient's parents gender comparison | | |
|-------|------------------------------------|--------------------------------------|-------|-------------------------------------|--------------|----------------|
| | | | | Fathers (n=32) | | Mothers (n=43) |
| | | | | Mean (SD) | Mean (SD) | |
| B1 | 51.9 (8.3) | 54.2 (9.4) | 0.115 | 52.4 (8.5) | 51.6 (8.2) | 0.661 |
| B2 | 42.0 (6.4) | 43.6 (4.2) | 0.081 | 42.7 (6.0) | 41.6 (6.6) | 0.468 |
| B3 | 44.0 (4.1) | 45.3 (4.6) | 0.075 | 43.7 (4.5) | 44.3 (3.9) | 0.537 |
| BZT | 138.0 (12.5) | 143.0 (15.0) | 0.025 | 138.7 (12.2) | 137.4 (12.8) | 0.648 |
| M1 | 34.8 (9.1) | 38.9 (5.0) | 0.001 | 39.3 (8.0) | 31.4 (8.3) | 0.000 |
| M2 | 44.7 (15.4) | 54.5 (8.5) | 0.000 | 51.4 (16.8) | 39.8 (12.8) | 0.001 |
| M3 | 21.2 (4.2) | 22.8 (3.7) | 0.013 | 22.8 (3.8) | 19.9 (4.1) | 0.003 |
| MZT | 100.7 (22.0) | 116.2 (15.2) | 0.000 | 113.6 (20.6) | 91.1 (17.8) | 0.000 |
| S1 | 30.7 (4.9) | 32.6 (4.1) | 0.010 | 31.8 (4.8) | 29.9 (4.9) | 0.103 |
| S2 | 37.6 (7.3) | 40.6 (5.2) | 0.004 | 39.3 (5.7) | 36.3 (8.1) | 0.084 |
| S3 | 22.3 (4.6) | 23.8 (3.7) | 0.028 | 23.4 (4.2) | 21.5 (4.7) | 0.069 |
| SZT | 90.7 (14.0) | 97.0 (10.6) | 0.002 | 94.5 (12.3) | 87.8 (14.6) | 0.038 |
| ZCZT | 329.3 (35.21) | 356.2 (35.17) | 0.000 | 346.9 (33.0) | 316.3 (31.2) | 0.000 |

B1: physical symptoms and organic functioning; B2: physical activities of daily living; B3: physical mobility; BZT: total score of physical health subscale; M1: psychosocial symptoms and negative emotion; M2: positive emotion; M3: cognitive functioning; MZT: total score of psychosocial health subscale; S1: role activity; S2: social resource and social contact; S3: social support; SZT: total score of social health subscale; ZCZT: total score of the SRHMS. Independent samples *t*-test. SD: standard deviation.

Impact of specific conditions of childhood vitiligo on their parents. Children's gender, site of involvement and disease duration had no statistically significant impact on DFI score. Parents with children with stable vitiligo tended to be more affected than those with children with progressive vitiligo with regard to helping with treatment. Parents whose children were diagnosed with generalized and vulgaris types of vitiligo tended to be more affected by housework, food preparation, time shopping, and treatment, than those with children diagnosed with localized and segmental types of vitiligo (Table SIII¹).

DISCUSSION

Many previous studies have demonstrated that vitiligo has a dramatic effect on patients' self-confidence,

quality of life, emotions, work, and social and sexual lives. Studies have also shown that change in appearance, due to deformation, causes important aesthetic and emotional problems among patients, resulting in physical and psychological damage, which radically affects their lives and may drive them into social isolation and introversion (11, 12). Recent studies have shown that these problems also occur in children and adolescents with vitiligo, especially if the disease affects exposed areas of the body (13). However, whether the indirect effects of vitiligo spread from children to affect their parents' lives has not been studied. The current study determined that parents, being the closest and the most caring relationships to their affected children, are the new victims of vitiligo, and that vitiligo affects their

mental state and quality of life to various degrees.

SRHMS test results reflected the existence of differences in health status between those parents with children with vitiligo and those with unaffected children. Parents with children with vitiligo tended to be affected a great deal in terms of psychosocial and social health, and this was more pronounced for the mothers than the fathers. It seems reasonable that parents of children with vitiligo should be similar to the general population with regard to physical health subscale scores. However, because of the severe stress caused by their children's disease, they show a certain degree of psychological symptoms and negative emotions. Their long-term feelings of embarrassment cause them to isolate themselves gradually from friends and community, thereby reducing their chances of receiving care and support from society and friends. This results in a further reduction in their mental and social health scores compared with the general population.

The above assumption may also be applicable to the fact that parents of children with generalized vitiligo had lower social and general health status than those with segmental and localized types, and that parents with children with progressive vitiligo had lower cognitive functioning of mental health compared with parents with children in the stable stage of the disease.

Table II. Impact of childhood vitiligo on Dermatitis Family Impact Questionnaire (DFI) score

| Items | Study group (n=50) Mean (SD) | Control group (n=50) Mean (SD) | p | Patient's parents gender comparison | | |
|-----------------------|------------------------------------|--------------------------------------|-------|-------------------------------------|------------|----------------|
| | | | | Fathers (n=18) | | Mothers (n=32) |
| | | | | Mean (SD) | Mean (SD) | |
| Q1 Housework | 0.8 (0.7) | 0.2 (0.4) | 0.000 | 0.4 (0.5) | 1.0 (0.7) | 0.003 |
| Q2 Food | 0.8 (0.7) | 0.1 (0.2) | 0.000 | 0.4 (0.5) | 1.0 (0.7) | 0.003 |
| Q3 Sleep | 0.2 (0.4) | 0.0 (0.1) | 0.004 | 0.1 (0.2) | 0.3 (0.5) | 0.057 |
| Q4 Leisure | 1.4 (0.7) | 0.3 (0.5) | 0.000 | 1.1 (0.6) | 1.5 (0.7) | 0.045 |
| Q5 Time shopping | 0.7 (0.7) | 0.1 (0.2) | 0.000 | 0.4 (0.5) | 0.8 (0.8) | 0.126 |
| Q6 Expenditure | 1.0 (0.7) | 0.2 (0.4) | 0.000 | 0.8 (0.8) | 1.1 (0.7) | 0.150 |
| Q7 Tiredness | 1.4 (0.6) | 0.3 (0.5) | 0.000 | 1.4 (0.6) | 1.4 (0.6) | 0.790 |
| Q8 Emotional distress | 2.0 (0.7) | 0.0 (0.1) | 0.000 | 1.5 (0.5) | 2.2 (0.7) | 0.000 |
| Q9 Relationships | 1.1 (0.9) | 0.0 (0.0) | 0.000 | 0.7 (0.8) | 1.3 (1.0) | 0.049 |
| Q10 Treatment | 1.9 (0.7) | 0.5 (0.5) | 0.000 | 1.7 (0.8) | 2.0 (0.7) | 0.162 |
| Total | 11.0 () | 1.7 (1.7) | 0.000 | 8.4 (3.3) | 12.5 (4.4) | 0.001 |

p: independent samples *t*-test *p*-value; SD: standard deviation.

The highest score on the DFI scale was for emotional distress, followed by questions regarding treatment effect, leisure activities and tiredness, respectively. Sleep was the lowest factor affecting parents, probably because the disease causes no significant expression of itching or physical discomfort to the affected children. Parents of children with vitiligo are often physically and mentally fatigued, they tend to experience blame emotions and be very focused on their children's treatment and care. However, owing to long disease duration and the recalcitrant nature of the disease, their confidence about successful treatment tends to be reduced. We found that mothers tend to be more affected and more distressed, recording lower scores for quality of life compared with fathers. Comparing our results with those for studies of atopic dermatitis, we found that our subjects tended to be more sensitive and to have more varied parental disturbances in dealing with vitiligo (14).

For the majority of families in this study, due to the one-child policy in China during the past 30 years, the child with vitiligo was an only child. Whether parents with a child with vitiligo in a larger family would be similarly affected in terms of quality of life and mental health is an interesting topic for further study.

Conclusion

Parents are the most sensitive and the closest caregivers for their children. The results of this study of parents with children with vitiligo indicate that they experience psychological problems or social pressure due to their children's disease. Psychiatric intervention is recommended for parents with children with vitiligo. Moreover, educational programmes, aimed at increasing dermatologists' awareness of mental health issues and promoting the use of psychiatric screening questionnaires that might help increase recognition of psychiatric morbidity in parents who have children with vitiligo, are also recommended.

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