Quality of Life Measurement for Vitiligo: Is It Important?

Tengku Noorsharifa Dayang Bestari Sinar^{1*}, Nelva Karmila Jusuf¹

Department of Dermatology & Venereology, Universitas Sumatera Utara Universitas Sumatera Utara Hospital, Medan

Keywords: Vitiligo, Quality of Life, SkinDex-29

Abstract: Introduction: Vitiligo is a chronic skin disease characterized by skin depigmentation caused by melanocytes destruction. Vitiligo could be considered as a psychosomatic disorder, which means physical and psychological factors concomitantly are involved in appearance, progression, relapse and remission of vitiligo. Vitiligo has a remarkable impact on patient's Quality of Life (QoL). Case: A 20-years-old girl, initially presented with milky white patches in the back of her neck and right shoulder since 5 years ago. There was no itch, pain or anesthesia. There was no family history of this disease or other autoimmune diseases. She suffers a psychological stress caused by her vitiligo and she has a low self-esteem, embarrassment and anxiety. From dermatological examination, on the colli posterior and acromial dextra there was depigmentation macules, numular-plaque sized, circrumscribed and leucotrichia in colli posterior. SkinDex-29 score showed a severe impact in patient's QoL. The patient treated with tacrolimus 0.1% ointment and had an improvement both in lesions and QoL. Discussion: Measuring the QoL is important in the management of vitiligo patient. QoL can be measured with QoL indexes, such as SkinDex-29 that evaluate three domains: symptoms, psychosocial and emotional status. Establishing a good doctor-patient relationship to multidisciplinary approach for the patient's compliance and a better outcome of the treatment. Conclusion: Vitiligo has devastating psychosocial effects that have great impacts on the patient's quality of life. Holistic approach is important to manage vitiligo patient, not only for treated the clinical aspect but also evaluate the QoL of the patient from time to time.

SCIENCE AND TECHNOLOGY PUBLICATIONS

1 INTRODUCTION

Vitiligo is a chronic skin disease characterized by skin depigmentation caused by melanocytes destruction (Bishoi et al, 2018). Prevalence of vitiligo around 0.1-2% in world population (Iannella et al, 2016). In 2012-2015, Department of Dermatology & Venereology, H. Adam Malik Medan General Hospital prevalence of vitiligo is 8.5%-16.1% (Jusuf, 2017). There is four hypothesis of vitiligo pathogenesis; (1) autoimunne hypothesis, (2) neurohumoral hypothesis, (3) autotoxic hypothesis, (4) chemicals exposure. In neurohumoral hypothesis, there is role of catecholamines, neuropeptide Y, and proopiomelanocortin (POMC) peptides that make melanocytes destructions (Birlea et al, 2012; Speeckaert et al, 2016).

Treatments for vitiligo are topical, physical, systemic and surgery. Whereas, the first line topical treatment is topical corticosteroids or calcineurin inhibitors. Quality of Life (QoL) has become an important aspect of patient's health care and the impact of disorders on the QoL is important in the holistic understanding of diseases. Therefore, vitiligo could be considered as a psychosomatic disorder, which means physical and psychological factors concomitantly are involved in appearance, progression, relapse and remission of vitiligo. Vitiligo became a large burden on patients's lives and many patients suffer from shame and embarrassment, low self-confidence, and social isolation (Hedayat et al, 2016).

The World Health Organization (WHO) defined QoL as individuals' perceptions of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns (Mitrevska et al, 2012). Health-related quality of life (HRQL) reflects patient's evaluation of the impact of disease and treatment on their physical, psychological, and social functioning and wellbeing (Prinsen et al, 1945). Measuring QoL can be done into three domains that agree with the health definition of

420

Sinar, T. and Jusuf, N. Quality of Life Measurement for Vitiligo: Is It Important?. DOI: 10.5220/0009990704200424 In Proceedings of the 2nd International Conference on Tropical Medicine and Infectious Disease (ICTROMI 2019), pages 420-424 ISBN: 978-989-758-469-5 Copyright © 2020 by SCITEPRESS – Science and Technology Publications, Lda. All rights reserved WHO: physical functioning (symptoms, functional difficulties), psychological state (emotional and cognitive functions), and social interaction (work, daily activities, public relations) (Mitrevska et al, 2012).

The well-established Skindex-29 is a threedimensional, dermatology-specific HRQL questionnaire. Twenty-nine items are combined to form three domains: symptoms, emotions, and functioning. The domain scores and an overall score are expressed on a 100-point scale, with higher scores indicating lower levels of quality of life (Prinsen et al, 1945). Study of Jusuf et al, at Department of Dermatology & Venereology of H. Adam Malik General Hospital Medan, among 30 vitiligo patients were evaluated for QoL using SkinDex-29. Most of patients's OoL were in moderately affected (70%) (Jusuf et al, 2018). Measuring QoL is important for evaluation of nonclinical aspects of the disease, discovery of functional and psychological limitations and in choosing treatment for initial phase of the disease.

2 CASE

A 20-years-old girl, initially presented with milky white patches in the back of her neck and right shoulder since 1 years ago. Five years ago, there was a white patch in the back of her neck in the size of coin. The patch became wider and the hair around it became white too. Around 1 year ago, the patch appears in her right shoulder. There was no itch, pain or anesthesia. There was no family history of disease like this or other autoimmune diseases.

She suffers from a psychological stress due to often glared by others or avoided for fear of infection or for disgust by others and even said it's a jinx. This make her has a low self-esteem, embarrassment and anxiety. She got discrimination from her big family when they gathered and she always got a negative stigma about her skin condition.

On general examination, the respiratory rate, blood pressure and heart rate is normal. On dermatologic examination on the colli posterior and acromial dextra there was depigmentation macules, 5 cm x 4 cm x 3cm in size, circrumscribed (Fig.1). There was leucotrichia in colli posterior. There is no disability of sensibility and no nerves enlargement. For her low self-esteem problem, we use SkinDex-29 questionnaires for measure her QoL and got total score is 110 with linear score is 75.86 which is have severe impact in patient's QoL.

Patient different diagnosed with vitiligo, hypopigmentation post inflammation, leprosy. Patient was treated with clobetasol propionate 0.05% cream twice daily. We educated patient about the disease and give encouragement to her psychological stress. We also suggested her to avoid physical trauma to prevent new lesion.



Figure 1. Macula depigmentation; (**A and B**) colli posterior, (**C and D**) right acromial. From the first follow-up (after 2 months treatment), there is no changes in size or color (Fig.2). No new patches. The treatment was changed with tacrolimus 0.1% ointment twice daily.



Figure 2. 1st follow-up after 2 months treatment. No changes in depigmentation macules (A, B and C)

From the second follow-up (after 2 months treatment), there are changes in colors but not in size (Fig.3). The lesion became pinkish. No new lesion.

The treatment continued with tacrolimus 0.1% ointment twice daily.



Figure 3. 2nd follow-up after 2 months treatment. Depigmentation macules became eritematous (A and B).

treatment) macule in right shoulder became smaller (Fig.4). No new lesion. We check the QoL and got the SkinDex-29 total score is 55 with linear score is

From the third follow-up (after 2 months 37.9 which is moderate impact in QoL. The treatment continued with tacrolimus 0.1% ointment twice daily.



Figure 4. 3rd follow-up after 2 months treatment. Depigmentation macules became smaller (A and B).

3 DISCUSSION

The diagnose of vitiligo in this case based on clinical history, physical and dermatological examination. Vitiligo is an acquired, chronic, pigmentary disorder characterized by the progressive loss of cutaneus melanocytes ad abnormality in their normal function, resulting in hypopigmentated skin areas which progressively become amelanotic. (Gianfaldoni et al, 2018) On the basis of the polymorphic distribution, extension, and number of white patches, vitiligo is classified into generalized (vulgaris, acrofacial, mixed), universalis, and localized (focal, segmental, and mucosal) types.(Birlea et al,2012) The clinical manifestation of vitiligo is the appearance of acquired milk-white macules with fairly homogeneous depigmentation and well-defined. (Birlea et al,2012) From our case that, the milk-white macule first appear in colli posterior.

The white macule is became larger and appear in different region and she got a low self-esteem from her skin condition. Depigmentation macules can be triggered by psychologic stress and stimulate hypothalamic-pituitary-adrenal (HPA) axis that secret catecholamine. Catecholamine will bound to α -receptor in arterial wall of the skin and mucose leading to epidermal– dermal hypoxia, and possibly oxidized by different oxidative systems with formation of quinones, semiquinone radicals, and oxyradicals that destroyed melanocytes.(Mohammed et al,2015)

Neural factors have a important role in vitiligo onset and exacerbation. Keratinocytes can synthesis and degraded catecholamine. Tyrosine was converted into melanin and catecholamine type neurotransmitters (neural signaling molecules that control both central and peripheral nervous systems by a tyrosine hydroxylase enzyme). Stress products such as reactive oxygen species (ROS) can be produced by exogenous and endogenous stimuli such as catecholamine. In addition, abnormally increased catecholamine can produce vasoconstriction leading to epidermal- dermal hypoxia, and possibly oxidized by different oxidative systems with formation of guinones, semiguinone radicals, and oxyradicals. However, local and systemic high levels of H₂O₂ produced by catecholamine are able to alter calcium homeostasis, so perturbing the uptake of l-phenylalanine, the amino acid precursor of tyrosine in melanocytes. It is reasonable to suggest that the increased levels of these oxidative radicals from oxidation of monoamine and their metabolites might contribute to melanocyte damage in the early phase of vitiligo.(El-Sayed et al,2018)

Vitiligo has a remarkable impact on QoL and brings social stigma and some people belive it is God's punishment for the sins. We use quality of life indexes for measure the QoL of the patient with SkinDex-29. This index has twenty-nine items that evaluate three domains: degree of symptoms, psychosocial functioning and emotional status. The possible answers are: never, rarely, sometimes, often, and always, given in a scale from 1 to 5 points respectively and the final score is established either by total score or mean for items of each domain (domain score). We use total score from Prinsen et al that facilitate the application this index in clinical practice, to round off the cutoffs for mild, moderate, and severe impairment to ≥ 20 , ≥ 30 , and ≥ 40 points, respectively, for the domain and overall scores. Prinsen et al,2011;De Paula et al,2014) The result from this index is 75.86 which has severe impact in patient's QoL. This have 7 items for symptoms, 12 items for psychosocial functioning and 10 items emotional status. From this index we can see that the disease has a great impact in her emotional and psychosocial function.

Psychosocial aspect is the most influent factor that affects the QoL of vitiligo patients. It derives from various subjective symptoms such as depression, anxiety, anger, embarrassment, self consciousness. Patients with vitiligo not only have visible skin symptoms, but are often glared at or even avoided for fear of infection or for disgust or even describe as God's punishment for the sins. They experience discrimination from others and believe that they do not receive adequate support from their doctors. (Mitrevska et al, 2012;Al-Mubarak et al,2011) This result a little different from our patient, whereas our patient experienced all of this especially from her big family.

Currently, no specific psychological therapeutic intervention prevails based on published evidence. Holistic approach is essential in dealing with vitiligo because of the profound and the far-reaching effects not only of the diseases, but also of treatments. It is necessary to talk to patients and educate about the disease also discuss the impact of their disease, how they cope with it, and how they feel about it. (Hedayat et al, 2016) The first step of improvement of QoL is establishing a good doctor-patient relationship for the motivation of the therapy, especially in phases of insufficient success. Multidisciplinary team approach can be helpful. Symptoms of anxiety and depression should be treated by a psychologist or even a psychiatrist. Coping responses are related to the level of selfesteem. (Hedayat et al, 2016;Mitrevska et al, 2012;Silververg et al,2014) Patients appreciate the opportunity to express difficulties related to their disease and to be listened to and understood. Those with a positive self image are better able to cope with the effect of physical disabilities. From our patient she has a severe QoL before, and after a 4 month treatment she can accept the disease and has an improvement of her QoL. She also attend a

higher education and not so low-self esteem and proud of herself.

4 CONCLUSION

Vitiligo is considered as a psychosomatic disorder and has a devastating psychosocial effect that have a great impact on patient's quality of life. Holistic approach is essential to manage vitiligo patient, not only to treated the clincal aspect but also it is important to evaluate the QoL of the patient from time to time.

REFERENCES

- Al-Mubarak L, Al-Mohanna H, Al-Issa A, Jabak M, Mulekar SV. 2011. *Quality of life in saudi vitiligo patients*. Journal of Cutaneous Aeshecic Surgery. 4(1):33-7.
- Bishnoi A, Parsad D. 2018. Clinical and molecular aspects of vitiligo treatments. Int. J. Mol. Sci. 19:1-15. doi:10.3390/ijms19051509
- Birlea SA, Spritz RA, Norris DA. 2012. Vitiligo. In: Goldsmith LA, Katz SI, Gilchrest BA, Paller SA, Leffell DJ, Wolff K, editors. *Fitzpatrick's Dermatology in General Medicine*. 8th edition. New York: McGraw-Hill. p. 792-803
- De Paula HR, Hada A, Weiss MA, Dini GA, Perreira LM. 2014. Translation, cultural adaptation, and validation of the American Skindex-29 quality of life index. An Bras Dermatol. 89(4):600-7. Doi:10.1590/abd1806-4841.20142453.
- El-Sayed MK, El-Ghany AAA, Mohammed RR. 2018. *Naural and endocrinal phatobiochemistry of vitiligo:* comparative study for a hypothesized mechanism neural and endocrin. Frontiers in Endocrinology. 9:1-12.
- Gianfaldoni S, Tchernev G, Wollina U, Lotti J, Satolli F, Franca K. 2018. *Vitiligo in children*: A better understanding of the disease. Open Access Maced J Med Sci. 6(1).181-4.
- Hedayat K, Arbakhsh M, Ghiasi M, Goodarzi A, Fakour Y, Akbari Z, et al. 2016. *Quality of life in patients with vitiligo*: a cross-sectional study based on vitiligo quality of life index (VitiQol). Health and Quality of Life Outcomes. 14(6):1-9.
- Iannella G, Greco A, Didona D, Didona B, Granata G, Manno A, et al. 2016. *Vitiligo*: pathogenesis, clinical variants and treatment approaches. Autoimmun Rev.15 (4):335-43.
- Jusuf NK, Putra IB, Utami DR. 2018. Quality of life in vitiligo patients at H.Adam Malik General Hospital Medan, Indonesia. SUMEJ. 1(1).41-47
- Jusuf NK. 2017. Pattern of pigmentation disorder in cosmetic dermatology clinic H. adam malik general

hospital, medan, 2012-2015. J Gen Proced Dermatol Venereol Indones. 2(1):1-6

- Mitrevska NT, Eleftheriadou V, Guarneri F. 2012. *Quality* of life in vitiligo patients. Dermatologic Therapy. 25:S28-S31.
- Mohammed GF, Gomaa AH, Al-Dhubaibi MS. 2015. *Highlights in pathogenesis of vitiligo*. World J Clin Cases. 3(3): 221-30.
- Prinsen CAC, Lindeboom R, De Korte J. 2011. Interpretation of Skindex-29 Scores: Cutoffs for Mild, Moderate, and Severe Impairment of Health-Related Quality of Life. Journal of Investigative Dermatology. 131: 1945-7. doi:10.1038/jid.2011.138.
- Silververg JI, Silverberg NM. 2014. *Quality of life impairment in children and adolescents with vitiligo*. Pediatric Dermatology. 31(3):309-18.
- Speeckaert R, van Geel N. 2016. Acquired pigmentary disorders. In: Griffiths C, Barker J, Bleiker T, Chalmers R, Creamer D, editors. *Rook's Textbook of Dermatology*. 9th edition. United Kingdom: John Wiley&Sons. p. 2209-63