

COMPREHENSIVE EVALUATION OF QUALITY
OF LIFE AND SOCIO-ECONOMIC FACTORS AFFECTING
VITILIGO PATIENTS IN PRIVATE CLINICS
OF ALMATY, KAZAKHSTAN

EVALUARE CUPRINZĂTOARE A CALITĂȚII VIEȚII
ȘI A FACTORILOR SOCIO-ECONOMICI CARE AFECTEAZĂ
PACIENȚII CU VITILIGO ÎN CLINICI PRIVATE
DIN ALMATY, KAZAHSTAN

A. MARKABAYEVA*, Y. VALLE**, D. OSPANOVA***, S. OSPANOVA****, A. NURBAYEV*****,
A. IGLIKOVA*****, T. LOTTI*****

Summary

Vitiligo is a non-communicable, immune-mediated skin disease of which both triggers and disease pathogenesis are poorly understood. It affects 0.5%-1.5% of the world population. In the absence of vitiligo-specific treatments, UVB phototherapy remains a standard treatment option with 65%-70% efficacy [1,2]. Treatment outcomes and patient's quality of life are dependent on true costs of and willingness to pay for vitiligo therapy.

Authors conducted DLQI interviews with vitiligo patients and collected data on: number of visits; number of

Rezumat

Vitiligo este o afecțiune cutanată neinfecțioasă, mediată imun, în cazul căreia atât factorii declanșatori, cât și patogeniza bolii sunt insuficient cunoscute. Această boală afectează 0,5%-1,5% din populația globului. În absența tratamentelor specifice pentru vitiligo, fototerapia UVB rămâne o opțiune standard de tratament cu o eficacitate de 65%-70% [1,2]. Rezultatele tratamentului și calitatea vieții pacienților depind de costurile reale ale terapiei vitiligo și de disponibilitatea pacienților de a plăti pentru tratament.

Autorii au efectuat interviuri DLQI (Indexul Dermatologic de Calitate a Vieții) la pacienții cu vitiligo și

- * Dermatologist, Laser Medical Center, Aesthetic cosmetology and plastic surgery „Darus plus.” Almaty, Kazakhstan Lecturer Department of the «Health Management with the course of nursing», Kazakh Medical University Continuing Education, Almaty, Kazakhstan.
Dermatolog, Centrul Medical Laser, cosmetologie estetică și chirurgie plastică „Darus plus.” Almaty, Kazahstan. Conferențiar. Departamentul pentru «Managementul Sănătății, cursul de asistenți medicali», Educație Continuă la Universitatea de Medicină Kazakh, Almaty, Kazakhstan.
- ** CEO VR Foundation, New York, New York 10119, USA.
CEO Fundația VR, New York, New York 10119, S.U.A.
- *** Chair of Master's and Doctoral education, Kazakh Medical University Continuing Education, Almaty, Kazakhstan.
Președintele Departamentului de Educație de Masterat și Doctorat, Educație Continuă la Universitatea de Medicină Kazakh, Almaty, Kazakhstan.
Catedra de masterat și de educație de doctorat, Universitatea de Medicină din Kazahstan de Educație Continuă, Almaty, Kazakhstan.
- **** Assistant professor Department of Dermatology and Venereology Kazakh Medical University Continuing Education, Almaty, Kazakhstan.
Asistent universitar Departamentul de Dermatologie și Venerologie, Educație Continuă la Universitatea de Medicină Kazakh, Almaty, Kazakhstan.
- ***** Scientific Secretary, Kazakh Medical University Continuing Education, Almaty, Kazakhstan.
Secretar Științific, Educație Continuă la Universitatea de Medicină Kazakh, Almaty, Kazakhstan.
- ***** Senior Lecturer, Population Health and Social Science Department Kazakhstan School of Public Health, Almaty, Kazakhstan.
Lector, Departamentul pentru Sănătatea Populației și Științe Sociale, Facultatea de Sănătate Publică Kazahstan, Almaty, Kazakhstan.
- ***** Chair of Dermatology, University of Rome „G.Marconi”, Rome, Italy.
Președinte al Departamentului de Dermatologie, Universitatea din Roma „G.Marconi”, Roma, Italia.

phototherapy treatments received; and their outcomes from private clinics in Almaty, Kazakhstan. This research revealed a high level of deterioration in quality of life among vitiligo patients, and was prominent when lesions were located on the exposed parts of the body regardless of the area affected and duration of the disease. The average monthly expense for vitiligo phototherapy treatments cost between \$1,254 and \$2,756, where in the country's capital city the average monthly income is \$832. Given the data on vitiligo relapse after a successful treatment outcome, a vitiligo patient would typically spend \$3,560 every 4-5 years on phototherapy alone.

The results of the study will help dermatologists focus on individual characteristics of vitiligo patients in order to improve treatment outcomes and their quality of life. This data will also help design patient activation measures [3], and allow for better planning and implementation of dermatological services to the general population and for vitiligo patients, in particular, throughout the healthcare system in Kazakhstan.

Key-words: vitiligo, DLQI, phototherapy.

Intrat în redacție: 16.02.2017

Acceptat: 3.03.2017

au acumulat informații cu privire la: numărul de examinări, numărul de tratamente prin fototerapie de care au beneficiat pacienții, și rezultatele obținute în clinici private din Almaty, Kazakhstan. Această cercetare a relevat o deteriorare semnificativă a calității vieții pacienților cu vitiligo, care a fost mai accentuată în situațiile în care leziunile erau situate în regiuni expuse ale corpului, indiferent de zona afectată de boală și de durata bolii. Costurile medii pe lună ale fototerapiei în vitiligo sunt situate între 1.254 \$ și 2.756 \$, în condițiile în care salariul mediu lunar în capitala țării este de 832 \$. Conform datelor privind recurența vitiligo după un rezultat bun al tratamentului, un pacient cu vitiligo va cheltui de regulă 3.560 \$ la fiecare 4-5 ani numai pentru fototerapie.

Rezultatele studiului îi vor ajuta pe medicii dermatologi să se concentreze asupra caracteristicilor individuale ale pacienților cu vitiligo în scopul de a îmbunătăți rezultatele tratamentului și calitatea vieții. Aceste date vor fi utile de asemenea pentru dezvoltarea de măsuri de activare a pacienților [3], permițând o planificare și implementare mai bună a serviciilor dermatologice în rândurile populației generale și ale pacienților cu vitiligo în special, în cadrul sistemului de sănătate din Kazakhstan.

Cuvinte cheie: vitiligo, DLQI, fototerapie.

Received: 16.02.2017

Accepted: 3.03.2017

Introduction

Vitiligo is a non-communicable, immune-mediated skin disease. The triggers and pathogenesis of this disease are poorly understood. It continues to be a loathed, mysterious, and stigmatized pigmentation disorder among the general population. Knowledge of the disease is characterized by controversial data and hypothesis that are confusing both for clinicians and for patients that are seeking effective treatments, or at least satisfactory cosmetic results.

Patients are often demoralized due to the chronic nature of the disease, its length of treatment, a lack of single effective therapy, and unpredictable course of the disease [4,5]. Vitiligo sickness rate is around 0.5-1.5% worldwide. [5]

Vitiligo may affect a patient's mental and overall health condition, as well as his/her functional and social adaptation. It also diminishes the patient's self-confidence level, and as a result damages psychological condition and life quality. [6-10].

According to UN data [11], health-related quality of life may be considered as an integral characteristic of physical, mental, and social

functioning of both healthy and sick individuals, based on their subjective perception.

A Physician's better understanding and evaluation of dermatological patients would help in increasing the effectiveness of future treatments. This would also strengthen healthcare and social arguments for development of dermatological services in Kazakhstan. [12, 13] Modern healthcare practices should consider not only traditional evaluation criteria for skin diseases, but also the psychological impact of the disease on patients [14], which will ultimately improve quality of healthcare. [15]

Objectives: (a) to determine a connection between biomedical and socio-hygienic quality of life parameters of individuals with vitiligo; (b) to identify economic segment of vitiligo patients.

Material and methods

The study included 81 patients 16 years old and above who were diagnosed with vitiligo by a dermatologist. Inclusion criteria were patients at least 16 years old with vitiligo. Exclusion criteria were patients with other dermatological diseases and chronic diseases, such as: diabetes, hypertension, heart disease, obstructive pulmonary disease, musculoskeletal diseases, cancer, and

any other condition that might negatively impact quality of life. The study coverage: dermatological clinics in the city of Almaty, Republic of Kazakhstan. Study period: from September 2014 to February 2015. Authors explained aims and objectives of the study, and inclusion/exclusion criteria to participating doctors. All participants in the study did so voluntarily and were informed about its objectives.

Patients were interviewed about vitiligo using the Dermatology Life Quality Index (DLQI) questionnaire and additional generic questions. We calculated the following costs incurred by patients in dermatological clinics of Almaty: topical treatment (\$28–\$55), systemic treatment (\$82–\$108), light and laser treatment (\$270–\$545) and surgical treatment (\$1,000 or more). All data, such as DLQI points and correlation between different variables, were processed by a SPSS 20 program.

DLQI authors Finlay and Khan designed the questionnaire to determine the quality of life of patients with dermatoses [15] back in 1994. The questionnaire was divided into six sections: symptoms and feelings - SF (questions 1 and 2), daily activities - DA (questions 3 and 4), recreation - R (questions 5 and 6), personal relationships - PR (questions 8 and 9), work and school - WS (question 7), and treatment - T (question 10). Additional generic questions regarding vitiligo included personal data questions (gender, age, marital status, level of education, employment); disease related questions (first spots, triggers, localization, current treatment and its effectiveness); cost assessment (medical centers where treatment was received, monies spent, willingness to pay for medical procedures).

Results

Base: 81 patients 16 to 74 years old, including 25 males (30.9%) and 56 females (69.1%). The largest age groups are: 25-39 years (39.9%) and 16-24 years (35.8%). Respondents' education level: high school - 12.3%, college - 6.2%, higher education - 81.5%. Respondents' employment status: 63.0% - employed; 13.6% - unemployed; 11.1% - university/college students; 12.3% - schoolchildren.

Disease duration was distributed as follows: 10 years and above – 79%; 5-10 years – 18,5%; from birth to 4 years – 2,5%.

Affected areas distribution: less than 10% of the total body skin surface - 40.7%; from 10 to 25% - 40.7%; from 25 to 50% - 13.6%; from 50 to 75% - 2.5%; and from 75 to 100% - 2.5% of all participants.

Complete leukotrichia of the affected areas was found in 2.5%, partial leukotrichia - 51.9%; while this symptom was absent in 45.7% of all participants.

Looking at disease onset, the study identified the following most common triggers: psycho-emotional stress - 46.9%; extended sun exposure - 30.9%; other factors - 19.8%. Other factors include: allergies, diathesis, gastritis, heredity, alternative medicine, as well as list of some drugs (cefazolin, dietary supplements, djufaston, cardiomagnil, methotrexate, proteins, travokort), and some cosmetic devices.

An average DLQI score for vitiligo patients was 10.01 ± 8.03 (males: 9.84 ± 1.3 ; females: 10.09 ± 1.16). Where the age group of 25-39 years old had the highest score: 27. The study determined blow impact of disease localization on embarrassment (Table 1). Pearson's correlation coefficient reflects a significant inverse correlation between the localization of vitiligo spots and monthly expenses on re-pigmentation (Table 2).

43.2% of employed patients spend \$270-\$545 monthly, where majority are women (41.1%). 7.4% of employed respondents pay \$1,000. 23.5% of respondents spend \$0 on their treatment. The lower spending groups are university/college students (19.8%) and schoolchildren (6.2%).

Coefficient of Student's T criterion among biomedical indicators compared to six DLQI sections provided here below (Table 3).

While assessing monthly expenses results and willingness-to-pay threshold with six DLQI sections, the following was discovered (Table 4).

It should be noted that 43.2% of patients spend \$270-\$545 on a monthly basis; a majority of them are women. 23.5% of patients do not spend money on their treatment. 19.8% of patients spend \$28–\$55; 7.4% of respondents spend \$1,000 or more; and 6.2% spend \$82–\$108 monthly.

Table 1. Impact of disease localization on feeling of embarrassment (Pearson's Chi - squared test)

		DLQI Embarrassment				
Localization		None at all (abs/%)	Insignificant (abs /%)	Much (abs /%)	Very bad (abs /%)	P - level
Mouth area	Yes	0/0.0	0/0.0	8/47.1	9/52.9	0.001***
	No	13/20.3	22/34.4	10/15.6	19/29.7	
Wrist	Yes	6/14.6	8/19.5	9/22.0	18/43.9	0.2
	No	7/17.5	14/35.0	9/22.5	10/25.0	
Eyelids	Yes	2/5.7	7/20.0	8/22.9	18/51.4	0.01*
	No	11/23.9	15/32.6	10/21.7	10/21.7	
Face	Yes	4/8.9	15/33.3	5/11.1	21/46.7	0.002
	No	9/25.0	7/19.4	13/36.1	7/19.4	
Forearm	Yes	5/31.2	5/31.2	0/0.0	6/37.5	<0.05*
	No	8/12.3	17/26.2	18/27.7	22/33.8	
Hair	All	2/100	0	0	-	<0.05*
	Some	7/16.6	10/23.8	11/26.2	14/33.3	
	No	4/10.8	12/32.4	7/18.9	14/37.8	

Note: * = P < 0.05; ** = P < 0.01; *** = P < 0.001.

Table 2. Assessment of relationship between monthly expenses and disease localization. (Pearson's Chi - squared test)

Localization		None %	\$28-55 %	\$ 82-108 %	\$270-545 %	\$1000 %	P value
Wrist	Yes	36.6	4.9	7.3	43.9	7.3	0.004**
	No	10.0	35.0	5.0	42.5	7.5	
Face	Yes	26.7	4.4	8.9	46.7	13.3	0.01*
	No	19.4	38.9	2.8	38.9	0.0	
Mouth area	Yes	58.8	0.0	0.0	17.6	23.5	0.001***
	No	14.1	25.0	7.8	50.0	3.1	
Eyelids	Yes	31.4	0.0	11.4	45.7	11.4	0.001***
	No	17.4	34.8	2.2	41.3	4.3	
Forearm	Yes	18.8	31.2	6.2	12.5	31.2	0.001***
	No	24.6	16.9	6.2	50.8	1.5	
Crotch	Yes	41.7	11.1	11.1	30.6	5.6	0.002**
	No	8.9	26.7	2.2	53.3	8.9	

Note: * = P < 0,05; ** = P < 0,01; *** = P < 0,001; ¹ - Mouth area. ² - Forearm.

The major group of 40.7% responded that they are willing to pay for vitiligo treatments "\$28-\$55"; „nothing at all" - 18.5%; „\$82-\$108" - 6.2%, „\$270-\$545" - 2.5% and „\$1,000" - 2.5%. Whereas, high willingness to pay \$270-\$545 and above \$1,000 was observed in the group of 25-39 years old.

An average price of one excimer laser procedure in Almaty, Kazakhstan is \$54, while UVB phototherapy cost is \$21. A typical vitiligo treatment protocol [1, 2] requires 90 to 200 UVB sessions, three times per week, which could take between 8-18 months in total.

Based on the above estimates, the authors would argue that vitiligo patients spend \$3,135

on UVB phototherapy procedures and \$7,837 on excimer laser treatments, on average, before achieving an acceptable re-pigmentation of vitiligo spots.

We have calculated the average number of procedures required within a three year treatment period: UVB phototherapy requires on average 178 sessions (min 3, max 353); Excimer laser therapy - on average 26.5 sessions (min 2, max 51).

Considering cost per session of UVB (\$21) and excimer laser (\$54), a vitiligo patient in a private healthcare Almaty system supposedly spends between \$1,460 and \$3,560 on re-pigmentation over a 3 year timeframe. The

Table 3. Analysis of biomedical results of DLQI survey (Student's T criterion)

Indicator		SF		DA		R		WS		PR		T	
		M	Sd	M	Sd	M	Sd	M	Sd	M	Sd	M	Sd
Gender	Male	2.7*±1.30		2.2±1.66		2.2±1.96		1.5±1.53		0.8±1.62		0.3*±0.55	
	Female	1.8±1.36		2.2±2.18		2.4±2.13		1.6±1.52		1.6±1.89		0.8±1.06	
	P-value	0.04		0.9		0.5		0.8		0.4		0.02	
Age	25-39	2.5*±1.38		2.4±2.04		2.3±2.24		1.3**±1.47		0.7±1.83		0.6±1.05	
	40 >	1.6±1.59		1.7±1.80		1.9±1.63		2.6±1.34		1.6±1.78		0.5±0.68	
	P-value	0.03		0.2		0.4		0.003		0.1		0.6	
Marital status	Married	2.3*±1.63		2.5±1.96		2.7*±1.76		2.5**±1.26		1.4±1.98		0.5±0.88	
	Divorced N(2) ²	0.0±0.0		0.0±0.0		0.0±0.0		0.0±0.0		0.0±0.0		0.0±0.0	
	P-value	0.05		0.08		0.03		0.007		0.3		0.4	
Education/qualification	Secondary	1.2±1.31		0.6±0.69		1.3±0.48		0.8±1.03		0.0±0.0		0.7±0.82	
	Higher	2.3*±1.35		2.6**±2.01		2.6*±2.13		1.7±1.54		1.1*±1.91		0.7±1.02	
	P-value	0.01		0.002		0.04		0.07		0.05		0.9	
Affected area	<10	2.4*±1.39		1.7±1.60		1.7*±1.64		1.4±1.66		1.1±1.72		0.6±0.70	
	10-25	1.6±1.40		2.4±2.16		2.9±1.99		1.8±1.38		1.0±1.92		0.6±0.99	
	P-value	0.02		0.1		0.01		0.2		0.9		1.0	
Duration	0-4	3.0±0.0		6.0*±0.0		6.0*±0.0		3.0±0.0		0.0±0.0		3.0*±0.1	
	5-10	1.7±0.88		2.4±2.32		2.4±2.35		1.2±1.37		1.6±1.99		1.0±1.16	
	P-value	0.06		0.05		0.05		0.09		0.2		0.03	

Note: * = P < 0.05; ** = P < 0.01; *** = P < 0.001.

¹ - Result not determined. ² - Number of observations.

Table 4. Social-hygienic analysis of vitiligo patients with DLQI sections, (Student's T criterion)

Indicator		SF		DA		R		WS		PR		T	
		M	Sd	M	Sd	M	Sd	M	Sd	M	Sd	M	Sd
Monthly costs	\$ 82 - 108	2.6±1.14		3.8*±3.03		4.2*±2.49		1.8±1.64		1.0±1.41		2.2**±0.83	
	\$270 - 545	2.1±1.43		1.8±1.52		1.9±1.73		1.3±1.60		1.6±0.8		0.5±0.65	
	P-value	0.4		0.02		0.01		0.5		0.8		0.001	
Willingness to pay	\$28 - 55	1.9±2.51		1.9±2.51		2.5±2.09		2.1±1.16		1.6±2.41		0.9±1.28	
	\$82 -108	3.8±3.03		3.8±3.03		4.2±2.49		1.8±1.64		1.0±1.41		2.2*±0.8	
	P-value	0.1		0.1		0.1		0.5		0.5		0.05	

Note: * = P < 0,05; ** = P < 0,01; *** = P < 0,001.

following treatment costs are not included in the estimate: topical treatment (ex: cream), systemic procedures (micronutrients, immune-modulators), symptomatic interventions (treatment and rehabilitation of chronic infection foci, psychological correction), as well as cosmetic procedures.

We should also consider additional expenses occurring in case of vitiligo relapse. Our colleague A.A. Kassymkhanova (Shymkent, Kazakhstan) identified in her study remission period of vitiligo patients: > 1 year - 97% of patients; > 2 years - 68%; > 3 years - 45%; > 4 years - 33%. The maximum period was 56 months, and minimum: 4 months. Based on the above data, we

may assume that a vitiligo patient will spend between \$1,460 - \$3,560 every four-five years.

Discussion

Average DLQI score in vitiligo patients in this research was 10.01± 8.0, which is significantly higher than in many other studies conducted in Italy (4.3), the UK (4.8), Belgium (4.9), Estonia (4.7), Indonesia (4.4), Japan (5.9), Germany (7.0) and France (7.2). However, it was lower than in India (10.67) or Saudi Arabia (14.7) [18,19,20-26]. The difference in scores might be due to the skin phototype, as well as social and ethnic differences.

In this study DLQI for females (10.09) was higher than for males (9.84). However, our study revealed that men are more prone to anxiety due to itching, embarrassment, awkwardness associated with skin disease. The WHO Madrid Statement on healthcare aspects of fairness and gender equality - sets gender as the main determinant of health [27]. However, gender evaluation is done differently, setting requirements too high for men, which leads to unfairness and inequality associated with health risks, healthcare usage and treatment results. Similar results were obtained in the study of vitiligo's impact on family members [28].

The age group of 25-39 year olds is more inclined to emotional stresses, as well as the embarrassment affecting attendance at work or school. This is a period of emotional maturity, start of independent life, financial stability, and self-realization (including professional one), family creation, delivering and bringing up children, a period of high activity, spiritual and professional growth. This group has the highest willingness-to-pay (\$1,000). Similar age related data were received in previous studies [24, 29].

According to assessment of disease localization on feeling of embarrassment, spots localized at visible areas have very strong influence of life quality [30]. Although vitiligo localization at the wrist does not affect the DLQI score, we have identified connection between spot localization on wrist and monthly treatment expenses of \$270-\$545 (43.9% of respondents, $P = 0.004$).

Married people feel embarrassed and uncomfortable when in society, while engaged in recreational activities, or at work. This may be connected with a desire to correspond to the partner status, or fear of divorce. A study in China registered similar data on marital relation instability [31].

Patients with higher education note that vitiligo diminishes quality of daily life, leisure, and personal relationships. With higher mental formation, there is inflated self-criticism, which affects quality of life [28].

Patients with an affected area of less than 25% of the body feel uncomfortable and embarrassed on holidays, where they need to wear open clothes or beachwear [32]. Meanwhile, monthly

expenses of \$270-\$545 in the main group related to disease localization on eyelids, wrists and face.

Regardless of how long patients had the disease, they experience an ongoing deterioration of life quality, both in everyday life and on holidays. At the same time, dissatisfaction with received treatment and sensitivity to disease increase among patients with long history of vitiligo [33] is prevalent. This may be due to proliferation of the disease.

In this study, the monthly costs are set with vitiligo impact on daily activities, leisure activities and during treatment. 43.2% of patients pay \$270-545 per month for their treatment, most of whom are women. At the same time, patients are willing to pay in the event of difficulties connected with leisure, personal relationships, or treatment difficulties. Whereas, a major group (40.7%) belonged the category of patients willing to pay "\$28 -\$55". We attribute such discrepancy to inability to plan a budget, lack of clear understanding of spending effectiveness, and the impact of unplanned and spontaneous purchases. A study conducted in Germany obtained different figures, which is probably due to the social, cultural and economic differences between our countries [24]. We have identified the amount of expenses per vitiligo patient in the paid healthcare sector of average from \$1,460 to \$3,560. Considering vitiligo relapse data, we may assume that vitiligo patient will pay \$1,460-\$3,560 each 4-5 years.

Conclusions

The vitiligo problem is hugely important, as cosmetic changes may significantly affect patients' future life quality. They may define employment opportunities, social activities, and family creation. The disorder most often develops with patients younger than 25 years old, meaning that mostly people of socially active age have the disorder (which is confirmed by our research).

The research in the Almaty private healthcare sector indicated deterioration of Life Quality for vitiligo patients aged 25-39 years (10.01 ± 8.0), which is more pronounced for male patients vs female. Male patients have stronger feelings of embarrassment, which significantly reduces self-esteem and lead to their social seclusion.

Based on the research, vitiligo patient spends \$1,472 to \$3,560 every 4-5 years, depending on remission period, on medical procedures and consultations in private medical centers.

The vitiligo problem should be on the radar of the practicing doctors and healthcare system, in order to improve vitiligo patients' life quality and to increase their right and opportunities.

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Conflict de interese
NEDECLARATE

Conflict of interest
NONE DECLARED

Correspondance address: T. Lotti
Dermatology, University of Rome „G. Marconi“, Rome, Italy.