

Supplementary Material

The Humanistic Burden of Vitiligo: A Systematic Literature Review of Quality-of-Life Outcomes

M. Picardo,¹ R.H. Huggins,² H. Jones,³ R. Marino,³ M. Ogunsola,³ J. Seneschal⁴

¹San Gallicano Dermatological Institute IRCCS, Rome, Italy; ²Henry Ford Health System, Detroit, MI, USA; ³Incyte Corporation, Wilmington, DE, USA; ⁴Department of Dermatology and Pediatric Dermatology, National Reference Center for Rare Skin Disorders, Hôpital Saint-André, CNRS, UMR-5164, ImmunoConCept, F-33000, Bordeaux, France

Contents

Appendix S1. Search Strategy.....	2
Figure S1. Number of Studies by Year of Publication*	4
Figure S2. Number of Studies by Country and Geographic Region*	5
Table S1. Generic Quality-of-Life Assessment Tools and Outcomes Among Studies That Reported Total Scores in the Overall Population.....	7
Table S2. Generic Quality-of-Life Assessment Tools and Outcomes in Interventional Studies.....	9
References	11

Appendix S1. Search Strategy

Search String 1: PubMed

(vitiligo[TITLE/ABSTRACT] OR leukoderma[TITLE/ABSTRACT] OR
leucoderma[TITLE/ABSTRACT])

AND

("quality of life"[TITLE/ABSTRACT] OR QoL[TITLE/ABSTRACT] OR "patient reported
outcomes"[TITLE/ABSTRACT] OR PROs[TITLE/ABSTRACT])

AND

English[LANGUAGE]

PubMed prescreen hits, 278

Search String 2: EMBASE

('vitiligo':ti,ab,kw OR 'leukoderma':ti,ab,kw OR 'leucoderma':ti,ab,kw)

AND

('quality of life':ti,ab,kw OR 'QoL':ti,ab,kw OR 'patient reported outcomes':ti,ab,kw OR
PROs:ti,ab,kw)

AND

'english':la

NOT

('conference abstract':it OR 'conference paper':it OR 'conference review':it)

EMBASE prescreen hits, 297

Search String 3: Scopus

TITLE-ABS-KEY(vitiligo OR leukoderma OR leucoderma)

AND

TITLE-ABS-KEY("quality of life" OR QoL OR "patient reported outcomes" OR PROs)

AND

(LIMIT-TO(LANGUAGE, "English"))

Scopus prescreen hits, 43

Search String 4: Cochrane Database

Title/abstract/keyword (vitiligo OR leukoderma OR leucoderma)

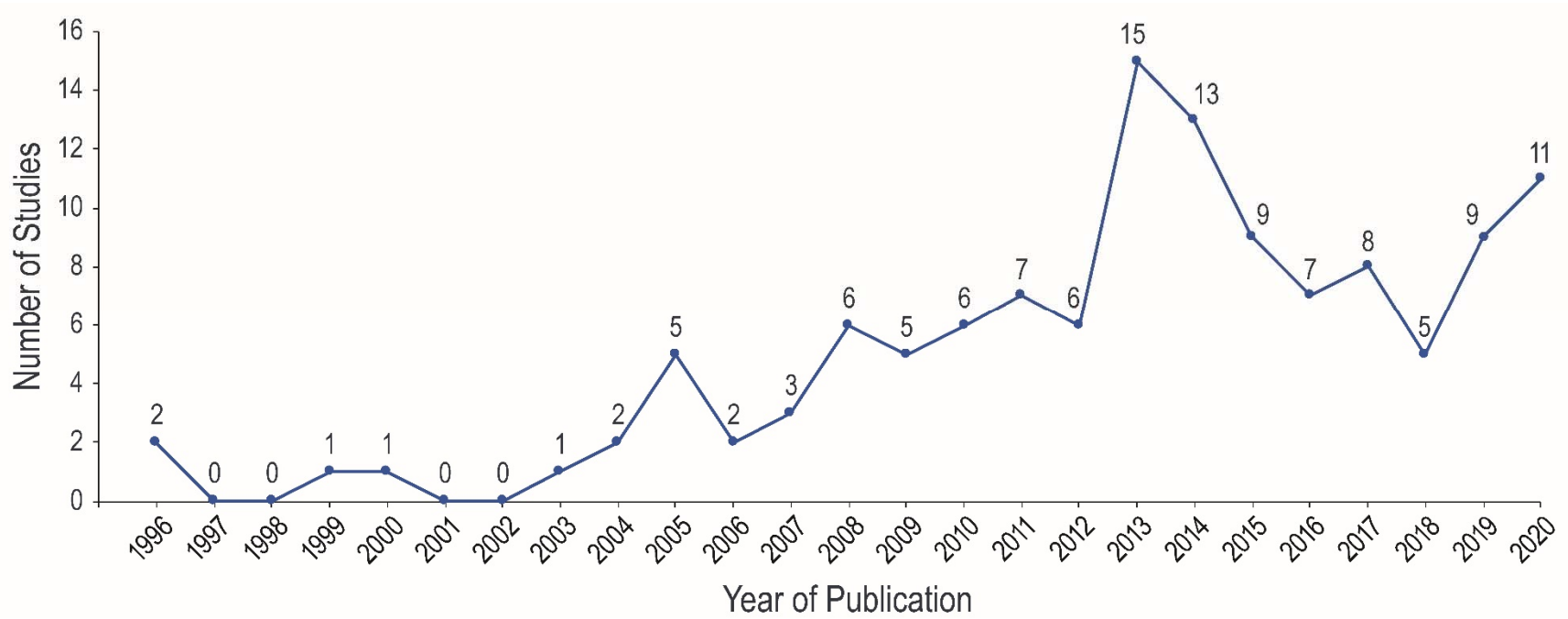
AND

Title/abstract/keyword ("quality of life" OR QoL OR "patient reported outcomes" OR PROs)

Cochrane database prescreen hits, 2

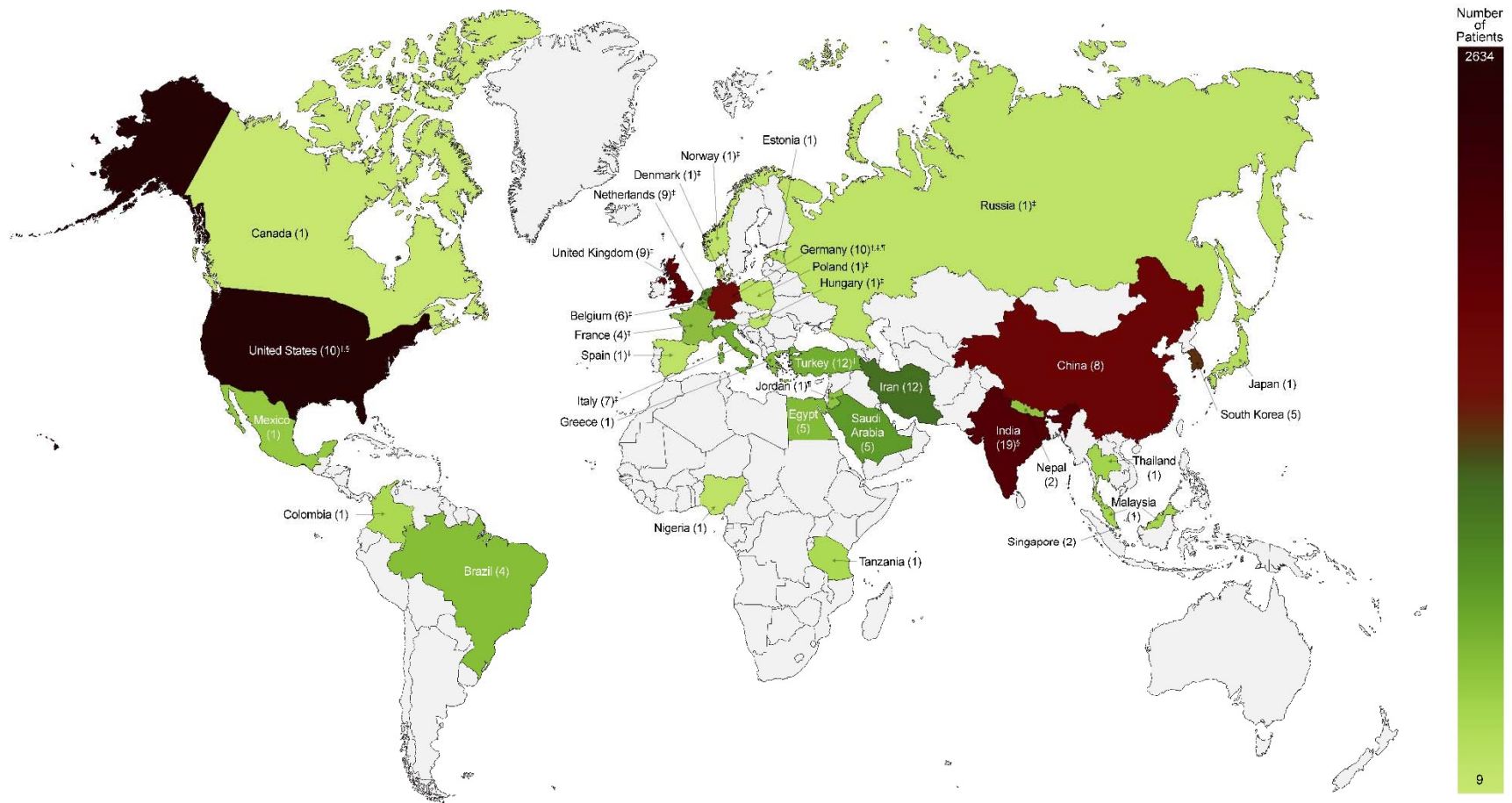
Total number of prescreen hits with duplicates removed: 335

Figure S1. Number of Studies by Year of Publication*



* 6 included studies published in 2021 were not included in the graph because the 2021 publication period is incomplete.

Figure S2. Number of Studies by Country and Geographic Region*



Number of patients is the sum of patients across studies from each country with multiples from the same patient population excluded. Among multinational studies, where the number of patients from each country was not available in the published studies, the full population was included for each country. The number of unique studies is shown in parentheses after the name of each country.

* Countries were assigned to geographic regions as follows: Africa (Nigeria, Tanzania), Europe (Belgium, Denmark, Estonia, France, Germany, Greece, Italy, Netherlands, Norway, Poland, Russia, Spain, United Kingdom), Eastern Asia (China, Japan, Malaysia, Singapore, South Korea, Thailand), Southern Asia (India, Nepal), Middle East (Egypt, Iran, Jordan, Saudi Arabia, Turkey), North

America (Canada, Mexico, United States), and South America (Brazil, Colombia).

† Includes 2 studies conducted in Europe (Germany) and North America (United States).

‡ Includes 1 study conducted in Europe (Belgium, Denmark, France, Germany, Hungary, Italy, Netherlands, Norway, Poland, Russia, Spain, United Kingdom) and the Middle East (Turkey).

§ Includes 1 study conducted in North America (United States) and Southern Asia (India).

¶ Includes 1 study conducted in Europe (Germany) and the Middle East (Jordan).

Table S1. Generic Quality-of-Life Assessment Tools and Outcomes Among Studies That Reported Total Scores in the Overall Population

Study	Country	Sample Size at Baseline	Total Score, Mean (SD)	Total Score, Median (Range)
<i>SF-36</i>				
Ghaderi 2014 ¹	Iran	70	478 (142)	--
Ghajarzadeh 2012 ²	Iran	100	63.8 (19.4)	--
Linthorst Homan 2008 ³	Netherlands	232	PCS, 54.9 (7.0) MCS, 48.1 (10.7)	--
Linthorst Homan 2009 ⁴	Netherlands	245	PCS, 54.0 (8.6) MCS, 46.3 (11.2)	--
Xu 2017 ⁵	South Korea	37	70.4 (15.3)	--
<i>SF-36 v2</i>				
Yang 2017 ⁶	United States	100	PCS, 53.6 (8.32) MCS, 48.0 (10.8)	--
<i>SF-12</i>				
Ezzedine 2015 ⁷	France	280	PCS, 55.4 (7.1) MCS, 38.8 (11.3)	PCS, 57.5 (31.4–68.7) MCS, 38.6 (12.7–62.4)
<i>PedsQL</i>				
Bilgic 2011 ⁸	Turkey	16	Children (8–12 y): PedsQL-C, 78.6 (15.1) PedsQL-P, 73.3 (16.4)	--
		25	Adolescents (13–18 y): PedsQL-C, 76.5 (8.50) PedsQL-P, 73.5 (10.1)	--
Önen 2018 ⁹	Turkey	41	PedsQL-C, 77.0 (13.2) PedsQL-P, 72.3 (13.3)	--
Ucuz 2020 ¹⁰	Turkey	30	PedsQL-C, 90.2 (–)	-- (77.3–91.7)
<i>GHQ</i>				
Temel 2019 ¹¹	Turkey	50	23.2 (5.38)	--
<i>GHQ-28</i>				
Hamidizadeh 2020 ¹²	Iran	99	26.5 (15.2)	--
<i>EQ-5D</i>				
Radtke 2009 ¹³	Germany	1023	83.6 (–)	--
<i>SRHMS</i>				
Amer 2015 ¹⁴	China	75	329 (35.2)	--

Study	Country	Sample Size at Baseline	Total Score, Mean (SD)	Total Score, Median (Range)
<i>PHS</i>				
Temel 2019 ¹¹	Turkey	50	3.92 (3.03)	--
<i>VAS</i>				
Al-Shobaili 2015 ¹⁵	Saudi Arabia	134	Life disturbance, 8.1 (1.14) Life satisfaction, 2.0 (0.33)	--
Gupta 2014 ¹⁶	India	161	5.81 (3.15)	--
<i>VAS-based questionnaire</i>				
Al-Shobaili 2014 ¹⁷	Saudi Arabia	48	5.74 (3.26)	--
<i>EQ-VAS</i>				
Balieva 2017 ¹⁸	Europe, Turkey	25	83.1 (10.3)	--
<i>PBI</i>				
Radtke 2010 ¹⁹	Germany	680	1.03 (1.12)	-- (0–4)
<i>PBI 2.0</i>				
Topp 2019 ²⁰	Germany	46	1.5 (1.3)	--
<i>DFI</i>				
Amer 2015 ¹⁴	China	50	11.0 (–)	--
<i>QLCCDQ</i>				
Andrade 2020 ²¹	United States	117	5.9 (1.1)	--
<i>DeFIS</i>				
Savas Erdogan 2020 ²²	Turkey	29	14.5 (9.33)	-- (0–45)

DeFIS, Dermatological Family Impact Scale; DFI, Dermatitis Family Impact; EQ-5D, EuroQol 5-Dimension; EQ-VAS, EuroQol Visual Analog Scale; GHQ, General Health Questionnaire; MCS, mental component score; PBI, Patient Benefit Index; PCS, physical component score; PedsQL, Pediatric Quality of Life; PedsQL-C, PedsQL Child; PedsQL-P, PedsQL Parent; PHS, Perceived Health Status; QLCCDQ, Quality of Life in a Child's Chronic Disease Questionnaire; SF-12, Short-Form 12; SF-36, Short-Form 36; SRHMS, Self-Rated Health Measurement Scale; VAS, Visual Analog Scale.

Table S2. Generic Quality-of-Life Assessment Tools and Outcomes in Interventional Studies

Study	Country	Sample Size at Baseline	Treatment Group	Baseline	Follow-Up		P Value vs Baseline	P Value vs Comparator
				Total Score	Last Follow-Up	Total Score		
<i>EQ-5D-5L</i>								
Batchelor 2020 ²³	United Kingdom	--	Topical corticosteroids	Mean (SD), 0.9 (0.1)	9 months	Mean (SD), 0.9 (0.2)	NA	Ref
		--	NB-UVB	Mean (SD), 0.9 (0.2)	9 months	Mean (SD), 0.9 (0.1)	NA	NS
		--	Topical corticosteroids + NB-UVB	Mean (SD), 0.9 (0.2)	9 months	Mean (SD), 0.9 (0.1)	NA	NS
<i>CHU-9D</i>								
Batchelor 2020 ²³	United Kingdom	40	Topical corticosteroids	Mean (SD), 1.0 (0.1)	9 months	Mean (SD), 1.0 (0.1)	NA	Ref
		39	NB-UVB	Mean (SD), 0.9 (0.1)	9 months	Mean (SD), 1.0 (0.0)	NA	NS
		40	Topical corticosteroids + NB-UVB	Mean (SD), 0.9 (0.1)	9 months	Mean (SD), 0.9 (0.1)	NA	NS
<i>VAS</i>								
Akdeniz 2014 ²⁴	Turkey	15	NB-UVB + topical calcipotriol + betamethasone	Mean (SD), 9.53 (0.19)	6 months	Mean (SD), 3.27 (0.78)	<0.01	NA
		15	NB-UVB + topical calcipotriol	Mean (SD), 9.73 (0.12)	6 months	Mean (SD), 3.20 (0.56)	<0.01	NA
		15	NB-UVB	Mean (SD), 9.53 (0.17)	6 months	Mean (SD), 4.07 (0.78)	<0.01	NA
Al-Shobaili 2015 ¹⁵	Saudi Arabia	134	308-nm monochrome excimer light	Life disturbance: Mean (SD), 8.1 (1.14) Life satisfaction: Mean (SD), 2.0 (0.33)	16 weeks	Life disturbance: Mean (SD), 2.7 (0.14) Life satisfaction: Mean (SD), 6.8 (1.05)	<0.001	NA

Study	Country	Sample Size at Baseline	Treatment Group	Baseline	Follow-Up		P Value vs Baseline	P Value vs Comparator
				Total Score	Last Follow-Up	Total Score		
Ibrahim 2020 ²⁵	Egypt	19	MBEH 20%	Mean (SD), 8.3 (2.43)	12 months	Mean (SD), 1.47 (1.98)	<0.001	NA
		20	MBEH 40%	Mean (SD), 9.1 (0.97)	12 months	Mean (SD), 2.45 (2.78)	<0.001	NA
<i>VAS-based Questionnaire</i>								
Al-Shobaili 2014 ¹⁷	Saudi Arabia	48	308-nm excimer laser	Mean (SD), 5.74 (3.26)	16.8–20.2 sessions	NA	<0.05 for shorter treatment duration	NA
<i>Questionnaire</i>								
Singh 2013 ²⁶	India	12	PUVA	NA	36 weeks	Mean (SD), 10.5 (7.6)*	NA	0.04
		7	PUVA sol	NA	36 weeks	Mean (SD), 3.6 (2.8)*	NA	Ref
Zhang 2017 ²⁷	China	75	Yiqiqubai granule	NA	6 months	NA	<0.05 for 3/4 domains	NS
		78	308-nm excimer laser	NA	6 months	NA	<0.05 for 3/4 domains	NS
		80	Yiqiqubai granule + 308-nm excimer laser	NA	6 months	NA	<0.05 for 3/4 domains	NS

CHU-9D, Child Health Utility 9-Dimension; EQ-5D-5L, EuroQol 5-Dimension five level; MBEH, monobenzyl ether of hydroquinone; NA, not available/applicable; NB-UVB, narrow-band ultraviolet B; NS, not significant; PUVA, psoralen plus ultraviolet A; VAS, Visual Analog Scale.

* Higher scores indicated better quality of life in the study-specific questionnaire.

References

- 1 Ghaderi R, Saadatjoo A. Evaluating of life quality in Iranian patients with vitiligo using generic and special questionnaires. *Shiraz E-Med J* 2014; **15**.
- 2 Ghajarzadeh M, Ghiasi M, Kheirkhah S. Associations between skin diseases and quality of life: a comparison of psoriasis, vitiligo, and alopecia areata. *Acta Med Iran* 2012; **50**: 511-5.
- 3 Linthorst Homan MW, de Korte J, Grootenhuis MA et al. Impact of childhood vitiligo on adult life. *Br J Dermatol* 2008; **159**: 915-20.
- 4 Linthorst Homan MW, Spuls PI, de Korte J et al. The burden of vitiligo: patient characteristics associated with quality of life. *J Am Acad Dermatol* 2009; **61**: 411-20.
- 5 Xu ST, Oh EH, Kim JE et al. Comparative study of quality of life between psoriasis, vitiligo and autoimmune bullous disease. *Hong Kong J Dermatol Venereol* 2017; **25**: 57-64.
- 6 Yang Y, Zapata L, Rodgers C et al. Quality of life in patients with vitiligo using the short form-36. *Br J Dermatol* 2017; **177**: 1764-6.
- 7 Ezzedine K, Grimes PE, Meurant JM et al. Living with vitiligo: results from a national survey indicate differences between skin phototypes. *Br J Dermatol* 2015; **173**: 607-9.
- 8 Bilgic O, Bilgic A, Akis HK et al. Depression, anxiety and health-related quality of life in children and adolescents with vitiligo. *Clin Exp Dermatol* 2011; **36**: 360-5.
- 9 Önen Ö, Kundak S, Özek Erkurun H et al. Quality of life, depression, and anxiety in Turkish children with vitiligo and their parents. *Psychiatr Clin Psychopharmacol* 2018; **29**: 492-501.

- 10 Ucuş I, Altunışık N, Sener S et al. Quality of life, emotion dysregulation, attention deficit and psychiatric comorbidity in children and adolescents with vitiligo. *Clin Exp Dermatol* 2021; **46**: 510-5.
- 11 Temel A, Bozkurt S, Senol Y et al. Internalized stigma in patients with acne vulgaris, vitiligo, and alopecia areata. *Turk J Dermatol* 2019; **13**: 109-16.
- 12 Hamidzadeh N, Ranjbar S, Ghanizadeh A et al. Evaluating prevalence of depression, anxiety and hopelessness in patients with vitiligo on an Iranian population. *Health Qual Life Outcomes* 2020; **18**: 20.
- 13 Radtke MA, Schafer I, Gajur A et al. Willingness-to-pay and quality of life in patients with vitiligo. *Br J Dermatol* 2009; **161**: 134-9.
- 14 Amer AA, McHepange UO, Gao XH et al. Hidden victims of childhood vitiligo: impact on parents' mental health and quality of life. *Acta Derm Venereol* 2015; **95**: 322-5.
- 15 Al-Shobaili HA. Treatment of vitiligo patients by excimer laser improves patients' quality of life. *J Cutan Med Surg* 2015; **19**: 50-6.
- 16 Gupta V, Sreenivas V, Mehta M et al. Measurement properties of the vitiligo impact scale-22 (VIS-22), a vitiligo-specific quality-of-life instrument. *Br J Dermatol* 2014; **171**: 1084-90.
- 17 Al-Shobaili HA. Correlation of clinical efficacy and psychosocial impact on vitiligo patients by excimer laser treatment. *Ann Saudi Med* 2014; **34**: 115-21.
- 18 Balieva F, Kupfer J, Lien L et al. The burden of common skin diseases assessed with the EQ5D: a European multicentre study in 13 countries. *Br J Dermatol* 2017; **176**: 1170-8.

- 19 Radtke MA, Schafer I, Gajur AI et al. Clinical features and treatment outcomes of vitiligo from the patients' perspective: results of a national survey in Germany. *Dermatology* 2010; **220**: 194-200.
- 20 Topp J, Augustin M, von Usslar K et al. Measuring patient needs and benefits in dermatology using the patient benefit index 2.0: a validation study. *Acta Derm Venereol* 2019; **99**: 211-7.
- 21 Andrade G, Rangu S, Provini L et al. Childhood vitiligo impacts emotional health of parents: a prospective, cross-sectional study of quality of life for primary caregivers. *J Patient Rep Outcomes* 2020; **4**: 20.
- 22 Savas Erdogan S, Falay Gur T, Dogan B. Anxiety and depression in pediatric patients with vitiligo and alopecia areata and their parents: a cross-sectional controlled study. *J Cosmet Dermatol* 2021; **20**: 2232-9.
- 23 Batchelor JM, Thomas KS, Akram P et al. Home-based narrowband UVB, topical corticosteroid or combination for children and adults with vitiligo: HI-Light vitiligo three-arm RCT. *Health Technol Assess* 2020; **24**: 1-128.
- 24 Akdeniz N, Yavuz IH, Gunes Bilgili S et al. Comparison of efficacy of narrow band UVB therapies with UVB alone, in combination with calcipotriol, and with betamethasone and calcipotriol in vitiligo. *J Dermatolog Treat* 2014; **25**: 196-9.
- 25 Ibrahim S, El Mofty M, Mostafa W et al. Monobenzyl ether of hydroquinone 20 and 40% cream in depigmentation of patients with vitiligo: a randomized controlled trial. *J Egypt Womens Dermatol Soc* 2020; **17**: 130-7.
- 26 Singh S, Khandpur S, Sharma VK et al. Comparison of efficacy and side-effect profile of oral PUVA vs. oral PUVA sol in the treatment of vitiligo: a 36-week prospective study. *J Eur Acad Dermatol Venereol* 2013; **27**: 1344-51.

- 27 Zhang C, Zhou L, Huang J et al. A combination of Yiqiqubai granule and 308-nm excimer laser in treatment of segmental vitiligo: a prospective study of 233 patients. *J Dermatolog Treat* 2017; **28**: 668-71.