

Appendix S1. Overview of systematic searches

PubMed. Search date: 10 January 2014

("rosacea"[MeSH Terms] OR Rosacea[tw] OR "rhinophyma"[MeSH Terms] OR Rhinophyma[tw] OR Phyma[tw] OR phymata[tw] OR phymatous[tw] OR gnathophyma[tw] OR metophyma[tw] OR blepharophyma[tw]) AND ("psychometrics"[MeSH Terms] OR psychometric*[tw] OR "quality of life"[MeSH Terms] OR "quality of life"[tw] OR "life quality"[tw] OR "life qualities"[tw] OR questionnaire[tw] OR qol[tw] OR HRQOL[tw] OR HRQL[tw] OR SF-36[tw] OR Short-form 36[tw] OR SF-12[tw] OR Short form[tw] OR Sickness impact profile[tw] OR DLQI[tw] OR Dermatology Life Questionnaire Index[tw] OR skindex[tw] OR scale[tw] OR inventor*[tw] OR qol[tw])

Embase, 1980 – Present, OVIDSP. Search date: 10 January 2014

- 1 (Rosacea or Rhinophyma or phyma or phymata or phymatous or gnathophyma or metophyma or mentophyma or otophyma or orophyma or blepharophyma or buccaphyma).mp.
- 2 qol.ab,ti,kw.
- 3 quality of life.mp.
- 4 life qualit\$.mp.
- 5 questionnaire?.mp.
- 6 (sf-8 or sf8 or short form 8 or shortform 8).mp.
- 7 (sf-12 or sf12 or short form 12 or shortform 12).mp.
- 8 (sf-20 or sf20 or short form 20 or shortform 20).mp.
- 9 (sf-36 or sf36 or short form 36 or shortform 36).mp.
- 10 hrqol.mp.
- 11 hrql.mp.
- 12 dlqi.ab,ti,kw.
- 13 skindex.mp.
- 14 scale?.mp.
- 15 or/2-14
- 16 1 and 15

PsycINFO, 1806 to Present, OVIDSP. Search date: 10 January 2014

- 1 (Rosacea or Rhinophyma or phyma or phymata or phymatous or gnathophyma or metophyma or mentophyma or otophyma or orophyma or blepharophyma or buccaphyma).mp.
 - 2 qol.ab,ti,tm,id.
 - 3 quality of life.mp.
 - 4 life qualit\$.mp.
 - 5 questionnaire?.mp.
 - 6 (sf-8 or sf8 or short form 8 or shortform 8).mp.
 - 7 (sf-12 or sf12 or short form 12 or shortform 12).mp.
 - 8 (sf-20 or sf20 or short form 20 or shortform 20).mp.
 - 9 (sf-36 or sf36 or short form 36 or shortform 36).mp.
 - 10 hrqol.mp.
 - 11 hrql.mp.
 - 12 dlqi.ab,ti,tm,id.
 - 13 skindex.mp.
 - 14 scale?.mp.
 - 15 inventor\$.mp.
 - 16 or/2-15
 - 17 skin disorders/
 - 18 16 and 17
 - 19 1 or 18
-

Appendix S1 *contd.*

CINAHL (Cumulative Index to Nursing and Allied Health Literature), Ebscohost. Search date: 10 January 2014

- S1 (MH "Acne Rosacea") or TX rosacea
- S2 TX rhinophyma
- S3 TX phyma
- S4 TX phymatous
- S5 TX otophyma
- S6 TX rosaceous
- S7 TX otophyma
- S8 S1 or S2 or S3 or S4 or S5 or S6 or S7
- S9 (MH "Quality of Life+") or IN quality or IN qol or TX "quality of life" or TX life N2 quality
- S10 TX questionnaire*
- S11 TX "sf 8" OR "shortform 8" OR "short form 8" OR "sf 12" OR "shortform 12" OR "short form 12" OR "sf 20" OR "shortform 20" OR "short form 20" OR "sf 36" OR "shortform 36" OR "short form 36"
- S12 (MH "Questionnaires+")
- S13 (MH "Scales")
- S14 TX scale*
- S15 TX skindex
- S16 (MH "Inventories") or TX inventor*
- S17 (MH "Psychometrics") or TX psychometric*
- S18 TX dlqi
- S19 TX psychosocial factor*
- S20 S9 or S10 or S11 or S12 or S13 or S14 or S15 or S16 or S17 or S18 or S19
- S21 S8 and S20

LILACS (Literatura Latino Americana e do Caribe em Ciências da Saúde). Search date: 10 January 2014

Rosacea OR Rhinophyma OR Phyma OR phymata OR phymatous OR gnathophyma OR mentophyma OR metophyma OR orophyma OR blepharophyma OR buccaphyma.

Table S1. Characteristics of included studies

Author Year of publication	Design; Intervention	Objective	HRQoL instru- ment	Patients, <i>n</i> (M/F) ^a	Sample	Age, years mean (SD)	Sub-type ^b	Severity, mean (SD) ^a	HRQoL baseline score Mean (SD) (M/F) ^a
Aksoy et al., 2010 (2)	Observational prospective cohort; Various therapies	To determine HRQoL of rosacea patients, its relationship to clinical and demographic variables, change in HRQoL following various treatments	DLQI	308 (87/221)	Rosacea patients from dermatology clinics at their first visit, being unresponsive to previously given therapy	42.7 (14.0)	1–3	Mean: 4.0 (1.9) Mild to moderate PODSI Range 0–12 sg 0–3 (135) sg 3.1–6 (134) sg 6.1–9 (36) Moderate: 41% Severe: 8% Mean: NP Self-assessment symptoms Range 0–4 Extent of rosacea/ phyma	6.9 (5.2) 3 (4.3)/7.7 (5.2)
Böhm et al., 2013 (5)	Observational study; Intervention: NA	To explore relationships between self-reported symptom severity and psychological sequelae, including HRQoL.	DLQI	168 (80/88)	Members of a German rosacea organization	56	NP	Mean: NP Self-assessment symptoms Range 0–4 Extent of rosacea/ phyma	sg 6.0 (5.2) sg 7.1 (4.9) sg 9.6 (5.4) 4.1 (4.7) 4.8 (5.3)/3.3 (3.9)
Hiltscher et al., 2001 (7)	Observational study; Intervention: NA	To investigate the impact of rosacea and rhinophyma on HRQoL	DLQI	40	Rosacea and rhinophyma patients from a University Hospital and from a private practice	54.4	1–3	16.5 (15.2)% Size of the rosacea foci 2.5 (nose), 2.4 (cheeks) Intensity of rosacea Range 0–4 NP	6.1 4.3 (4.6)
Langenbruch et al., 2011 (9)	Cross-sectional study on the quality of health care of rosacea; Intervention: NA	To collect data on quality of care of rosacea and to compare care indicators, including HRQoL, with those found in atopic dermatitis and psoriasis	DLQI	475 (93/370)	Members of a rosacea patient association	56.3 (12.5)	NP	Range 0–4 NP	5.6
Menezes et al., 2009 (10)	Prospective study; Pulsed dye laser	To evaluate the impact of the pulsed dye laser on patients' HRQoL	DLQI	22 (7/15)	Patients with rosacea subtype 1, who received pulsed dye laser therapy	55.6	1	NP	5.6
Shim et al., 2013 (12)	Prospective study; Pulsed dye laser	To investigate the impact of pulsed dye laser on patients' HRQoL	DLQI	20 (11/9)	Patients with rosacea subtype 1, who received pulsed dye laser therapy	42 (range 27–58)	1	NP	17.3
Weissenbacher et al., 2007 (13)	Randomized controlled trial; Pimecrolimus cream or vehicle	To investigate the effect of pimecrolimus cream 1% in the treatment of papulopustular rosacea	DLQI	40 (25/15)	Patients with rosacea from a single centre	58 (range 36–76)	2	≥6.0 as well as erythema ≥ 2 and scaling ≥ 1 PODSI Range 0–9	6.1
Baldwin et al., 2010 (3)	Open-label multicentre trial; Doxycycline 40 mg monotherapy or as add on therapy (12 weeks)	To explore the effect of mild to severe rosacea and its treatment on HRQoL	RosaQoL	966 (282/684)	Rosacea patients who would have otherwise been treated with 100 mg doxycycline	50.6 (range 18–87)	2	Mild to severe IGA Range 0–4 and Moderate to severe CEA Range 0–4	3.3

Table S1 contd.

Bamford et al., 2012 (4)	Randomized, double-blind trial; 220 mg of zinc sulphate or placebo	To determine whether oral zinc sulphate would be associated with significant improvement in rosacea	RosaQoL 44	Patients from outpatient family practice clinics and a dermatology department of a healthcare system	NP	NP	NP
			22 (7/20) sg: Zinc	52.8 (IQR 48.7, 57.0) sg: Zinc	6.3 (IQR 5.8, 6.9) RSS Range 0–12 sg: Zinc	3.1 (IQR 2.9, 3.3) SX: 3.2 (IQR 2.8, 3.5) EX: 3.3 (IQR 3.0, 3.5) FX: 2.4 (IQR 2.0, 2.8) sg: Zinc	
			22 (7/19) sg: Placebo	47.3 (IQR 41.9, 52.7) sg: Placebo	6.9 (IQR 6.3, 7.6) RSS Range 0–12 sg: Placebo	3.3 (IQR 3.1, 3.5) SX: 3.2 (IQR 2.9, 3.6) EX: 3.5 (IQR 3.3, 3.7) FX: 2.6 (IQR 2.2, 3.2) sg: Placebo	
Fleischer & Suephy, 2005 (6)	Observational study; Azelaic acid gel (monotherapy) or azelaic acid gel and combination treatment (combination therapy)	To examine the clinical efficacy and HRQoL changes resulting from treatment of rosacea with azelaic acid gel	RosaQoL 583 (135/448)	Rosacea patients for whom their physician believed azelaic acid was appropriate	NP	NP	NP
			583 (135/448)	50.9 (14.6)	3.5 (1.3) (3.9/3.4) Mild to moderate IGA Range 0–7	3.2 (0.7) SX: 3.1 EX: 3.4 (0.8) FX: 2.7 (1.0)	
Kini et al., 2010 (8)	Cross-sectional study; Intervention: NA	To determine the impact of rosacea on HRQoL among the 3 cutaneous types of rosacea	RosaQoL 135 (36/99) 34 (8/26) sg: subtype1	Rosacea patients from a dermatology clinic	NP	NP	Overall NP 2.6 (0.6) SX: 2.4 (0.7) EX: 2.7 (0.8) FX: 2.5 (0.8) sg: subtype 1 2.6 (0.8) SX: 2.7 (0.8) EX: 2.6 (0.9) FX: 2.3 (1.0) sg: subtype 2 3.0 (0.6) SX: 3.0 (0.7) EX: 3.1 (0.7) FX: 2.5 (0.9) sg: subtype 3
			47 (10/37) sg: subtype2	56.2 (14.9) sg: subtype2			
			54 (18/36) sg: subtype3	55.7 (14.6) sg: subtype3			
Salamon et al., 2008 (11)	Cohort; Intervention: NA	To evaluate the HRQoL in people with rosacea and to compare with HRQoL of people without skin lesions	SF-36 40 (9/31) 24 sg: rosacea, no concomitant diseases	Patients with rosacea from a dermatology clinic	NP	NP	PCS: 44.7 (11.1) MCS: 43.1 (14.4) PCS: 48.3 (8.9) MCS: 43.1 (14.4) sg: rosacea, no concomitant diseases

Studies 1–7 used the DLQI, studies 8–11 used the RosaQoL, study 12 used the SF-36. ^aDetails for subgroups (sg) when available. ^bSubtype 1 = erythematotelangiectatic rosacea. Subtype 2 = papulopustular rosacea. Subtype 3 = phymatous rosacea. PODSI: Perioral Dermatitis Severity Index (Wollenberg 2006). IGA: Investigator Global Assessment. CEAA: Clinician Erythema Assessment. RSS: Rosacea Severity Score, adapted from Standard Grading System for Rosacea (Wilkin 2004); DLQI: Dermatology Life Questionnaire Index; RosaQoL: Rosacea Quality of Life Index; HRQoL: health-related quality of life; NA: not applicable; NP: not provided; F: female; M: male; SX: Symptom; FX: Function; EX: Emotion.

Table SII. Critical appraisal of health-related quality of life (HRQoL) studies in rosacea patients

Author	Size of study sample	Grading of severity	Subtypes mentioned	Comparison ^a	HRQoL Instrument ^b	Study design	Level of evidence ^c
Aksoy et al., 2010 (2)	>200	Present	Present	–	DLQI ++	Cohort	II
Baldwin et al., 2010 (3)	>200	Present	Present	–	RosaQoL +++	Non-RCT	II
Bamford et al., 2012 (4)	20–50	Present	Absent	–	RosaQoL +++	RCT	III
Böhm et al., 2013 (5)	51–200	Present	Absent	–	DLQI ++	Survey	II
Fleischer & Suephy, 2005 (6)	>200	Present	Absent	–	RosaQoL +++	Non-RCT	II
Hiltscher et al., 2001 (7)	20–50	Absent	Present	–	DLQI ++	Case series	III
Kini et al., 2010 (8)	51–200	Absent	Present	–	RosaQoL +++	Cross-sectional	II
Langenbruch et al., 2011 (9)	>200	Present	Absent	+	DLQI ++	Cross-sectional	II
Menezes et al., 2009 (10)	20–50	Absent	Present	–	DLQI ++	Non-RCT	III
Salamon et al., 2008 (11)	20–50	Absent	Present	+	SF-36 +	Cross-sectional	III
Shim & Abdullah, 2013 (12)	20–50	Absent	Present	–	DLQI ++	Non-RCT	III
Weissenbacher et al., 2007 (13)	20–50	Present	Present	–	DLQI ++	RCT	III

^a–: absent; +: to controls with other skin diseases or healthy persons. ^b+: generic instrument; ++: dermatology specific instrument; +++: rosacea-specific instrument. ^cStudy design and Level of evidence adapted from the National Institute for Clinical Excellence (NICE): Guideline Development Methods, 2005: Levels of evidence for studies of the accuracy of diagnostic tests.

DLQI: Dermatology Life Questionnaire Index; RosaQoL: Rosacea Quality of Life Index.