The impact of skin disfigurement in patients with autoimmune connective tissue disorders on quality of life, willingness-to-pay, and time trade-off: A cross-sectional analysis

To the Editor: Cutaneous manifestations of autoimmune connective tissue diseases (ACTDs) can be disfiguring; however, the impact remains poorly understood.[1] The aim of this study was to evaluate disfigurement impact on the quality of life (QoL) and disease burden of a predominantly skin of color ACTD population.

The Boston University Institutional Review Board approved this study. Eligible participants included adults with diagnosed ACTD. Surveyed data included demographics and ACTD history. The Dermatology Life Quality Index (DLQI) approximated QoL,[2] whereas willingness-to-pay (WTP) and time trade-off estimated disease burden.[3] A modified, previously validated disfigurement scale was used.[4] As minimal changes were made to the existing scale, additional validation was not performed. Patient-rated disfigurement was obtained with a five-item Likert scale (Supplementary Fig 1, available via Mendeley at https://doi.org/10.17632/w89f52n7dx.1). For observer-rated disfigurement, a board-certified dermatologist independently rated disfigurement, using a scale of 1 (minimal) to 9 (severe). Correlation analyses were performed with Spearman's rank test.

Ninety-eight participants with ACTD completed the survey out of 105 approached (response rate = 93.3%), including 91.8% female and 70.1% non-white individuals (Table I). The mean age of participants was 49.9 ± 13.1 years. The mean DLQI score was 9.57 ± 7.56. A severely limited QoL was most common in participants diagnosed with multiple ACTD (Supplementary Fig 2, available via Mendeley at https://doi.org/10.17632/w89f52n7dx.1).[5] A quarter of participants (24.5%) reported non-surgical cosmetic procedure use (Table II). Of these, 58.3% utilized non-surgical cosmetic procedures for improved cosmesis of their ACTD. Most non-surgical cosmetic procedure users (83.3%) believed these procedures improved their self-esteem.

The majority of participants (81.6%) believed that their ACTD caused disfigurement and had higher

Table I. Demographic characteristics, disease burden measures, and quality of life of the study population

	n (%)	DLQI score, mean (SD)	P-value*
Sex (n = 98)			.68
Female	90 (91.8)	8.50 (5.43)	
Male	8 (8.2)	9.66 (7.74)	
Race/ethnicity (n = 97)			.64
Asian	6 (6.2)	11.17 (6.74)	
Black or African American	32 (33.0)	7.91 (7.32)	
Hispanic or Latino	21 (21.6)	9.75 (7.46)	
White	29 (29.9)	10.62 (8.75)	
Multiple	5 (5.2)	9.20 (3.35)	
Other	4 (4.1)	13.50 (6.46)	
Language (n = 98)			.16
English	85 (86.7)	9.98 (7.79)	
Spanish	13 (13.3)	6.67 (4.91)	
Education (n = 96)			**.007**
High school or less	30 (31.3)	7.30 (5.84)	
Any college	53 (55.2)	11.88 (8.24)	
Beyond college	13 (13.5)	6.54 (5.59)	
Income (n = 90)			.12
$0-59,999	33 (36.7)	7.70 (6.98)	
$60,000-79,999	24 (26.7)	10.09 (8.19)	
$≥80,000	33 (36.7)	11.55 (7.74)	
ACTD diagnosis† (n = 98)			**.02**
Lupus	55 (56.1)	9.42 (6.47)	
Scleroderma	16 (16.3)	12.56 (9.34)	
Multiple ACTD	11 (11.2)	12.80 (8.11)	
Other	16 (16.3)	5.06 (7.07)	
Non-surgical cosmetic procedure history‡ (n = 98)			.10
Yes	24 (24.5)	11.75 (7.26)	
No	74 (75.5)	8.85 (7.56)	
Disease, sad, what helped§ (n = 91)			<**.001**
Medicine	19 (20.9)	14.00 (9.15)	
Cosmetic procedures	2 (2.2)	10.00 (8.49)	
Visits to your physician	12 (13.2)	7.00 (5.88)	
Visits to your therapist (if applicable)	6 (6.6)	14.33 (9.69)	
Multiple	37 (40.7)	10.22 (6.01)	
N/A, have not felt sad about my disease	15 (16.5)	3.33 (4.12)	
WTP50‖ (n = 95)			**.006**
$10-50	39 (41.1)	6.97 (7.33)	
>$50	56 (58.9)	11.29 (7.27)	
WTP25¶ (n = 92)			**.001**
$10-50	49 (53.3)	7.24 (7.29)	
>$50	43 (46.7)	12.30 (7.11)	
Time spent covering up disease in last week (n = 98)			.35

Table I. Cont'd

	n (%)	DLQI score, mean (SD)	P-value*
None	41 (41.8)	8.20 (8.34)	
10-30 min	19 (19.4)	9.58 (7.62)	
30 min to 1 h	26 (26.5)	10.35 (6.65)	
1 h or more	12 (12.2)	12.42 (6.27)	
ACTD caused disfigurement# (n = 98)			.002
Yes	80 (81.6)	10.68 (7.58)	
No	18 (18.4)	4.67 (5.24)	

Bold *P*-values denote significance, designated as $P < .05$.
ACTD, Autoimmune connective tissue disease; *DLQI*, dermatology life quality index; *N/A*, not applicable; *SD*, standard deviation; *WTP*, willingness-to-pay.
*P-values for differences in DLQI scores between groups were calculated using 1-way analysis of variance or independent sample t-tests.
[†]Lupus includes individuals diagnosed with systemic and/or cutaneous lupus erythematosus. Scleroderma includes individuals diagnosed with limited and/or diffuse systemic sclerosis. Multiple ACTD includes individuals diagnosed with more than one autoimmune connective tissue disease. Other ACTD includes morphea (n = 7), mixed connective tissue disease (n = 3), eosinophilic fasciitis (n = 3), and dermatomyositis (n = 3).
[‡]Participants were asked about history of non-surgical cosmetic procedure(s).
[§]Participants were asked if their disease had made them feel sad, and if so, what helped. Multiple specify that multiple answer choices were selected, for example, medicine and visits to your physician.
[‖]Participants were asked willingness-to-pay for a month's worth of cream that could provide 50% improvement in their disease.
[¶]Participants were asked willingness-to-pay for a month's worth of cream that could provide 25% improvement in their disease.
[#]Participants were asked if they believe their autoimmune condition has caused disfigurement.

DLQI scores (10.68 ± 7.58) than those who did not (4.67 ± 5.24) ($P = .002$). Participants were willing to exchange 5.7 hours daily, or 40.1% of monthly income, for a therapeutic cure. The mean monthly WTP for 25% and 50% improvements were $97 and $130, respectively.

The mean patient-rated disfigurement was 8.10 ± 4.17. Patient-rated disfigurement positively correlated with DLQI ($r_s = 0.53$; $P < .001$), WTP50 ($r_s = 0.22$; $P = .04$), WTP25 ($r_s = 0.25$; $P = .02$), proportion of monthly income willing to spend on a cure ($r_s = 0.33$; $P = .002$), and time trade-off ($r_s = 0.29$; $P = .007$). The mean observer-rated disfigurement was 3.80 ± 2.29. Observer-rated disfigurement positively correlated with patient-rated disfigurement ($r_s = 0.39$; $P < .001$) and DLQI ($r_s = 0.39$; $P < .001$), but did not correlate with other disease burden measures. The mean patient-rated disfigurement and observer-rated disfigurement did not differ by

ACTD type ($P = .21$ and $P = .07$, respectively, Supplementary Table I, available via Mendeley at https://doi.org/10.17632/w89f52n7dx.1).

We found a substantial impact on QoL in ACTD patients. Participants who felt that their ACTD caused disfigurement had more severely impacted QoL than those who did not. Both disfigurement scales correlated with worsened QoL, whereas only patient-rated disfigurement correlated with disease burden. Thus, it is important for clinicians to inquire about QoL and disease burden, as these may be difficult to assess with physical examination alone. As the majority of non-surgical cosmetic procedure users reported use for their ACTD and had improved self-esteem, such procedures may improve patient disease perception. Further research is needed to determine whether non-surgical cosmetic procedures can improve disease burden and QoL in ACTD patients. Limitations include response bias and single institution design, possibly limiting generalizability. Clinicians should inquire and consider QoL impact when providing care.

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Table II. Non-surgical cosmetic procedure use by autoimmune connective tissue disease patients (*n* = 24)

	n (%)
ACTD diagnosis* (*n* = 24)	
Lupus	16 (66.7)
Scleroderma	5 (20.8)
Multiple ACTD	2 (8.3)
Other	1 (4.5)
Treatment† (*n* = 24)	
Neurotoxins	2 (8.3)
Filler	9 (37.5)
Laser	12 (50.0)
Other	2 (8.3)
Cosmetic procedure for general appearance‡ (*n* = 24)	
Yes	11 (45.8)
No	13 (54.2)
Cosmetic procedure for ACTD§ (*n* = 24)	
Yes	14 (58.3)
No	10 (41.7)
Cosmetic procedure improve self-esteem‖ (*n* = 24)	
Yes	20 (83.3)
No	4 (16.7)
Amount spent on cosmetic procedures in the past month (*n* = 24)	
$0-50	16 (66.7)
$51-100	4 (16.7)
$101-500	4 (16.7)
$>500	0 (0.0)
Amount spent on cosmetic procedures in the past year (*n* = 22)	
$0-50	9 (40.9)
$51-100	3 (13.6)
$101-500	2 (9.1)
$501-1000	7 (31.8)
>$1000	1 (4.5)
Amount spent on cosmetic procedure in lifetime (*n* = 24)	
$0-50	3 (12.5)
$51-100	0 (0.0)
$101-500	2 (8.3)
$501-1000	8 (33.3)

Continued

Table II. Cont'd

	n (%)
$1000-5000	9 (37.5)
>$5000	2 (8.3)

ACTD, Autoimmune connective tissue disease.
*Lupus includes individuals diagnosed with systemic and/or cutaneous lupus erythematosus. Scleroderma includes individuals diagnosed with limited and/or diffuse systemic sclerosis. Multiple ACTD includes individuals diagnosed with more than one autoimmune connective tissue disease. Other ACTD includes morphea (*n* = 7), mixed connective tissue disease (*n* = 3), eosinophilic fasciitis (*n* = 3), and dermatomyositis (*n* = 3).
†Percentages do not sum to 100% because participants may have reported history of more than one type of non-surgical cosmetic procedure.
‡Participants were asked whether they used non-surgical cosmetic procedures for their general appearance.
§Participants were asked whether they used non-surgical cosmetic procedures for their autoimmune connective tissue disease.
‖Participants were asked if the non-surgical cosmetic procedure(s) improved their self-esteem.

Conflicts of interest

None disclosed.

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