# Cumulative life course impairment in patients with moderate to severe atopic dermatitis

**Learning Objective:** To highlight the role of CLCI as a novel patient-reported outcome bridging clinical severity and psychosocial impact in chronic dermatologic conditions.

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**Conflict of Interest**: None
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# Background

Atopic Dermatitis is the most common inflammatory skin disease that typically presents in infancy and early childhood with variable clinical courses

Prevalence rate of 20% in children and 11% in adult in Singapore

Moderate to severe cases could be referred to tertiary dermatology centers for further management

Impact on Quality of life is multi-faceted, can affect:
- Sleep
- Social interaction
- Self esteem

Birdi G, Larkin M, Chua S, Knibb RC. Quality of life and mental well-being of adults with atopic dermatitis living in the UK. *Clin Exp Allergy*. 2023;53(1):113-117. doi:10.1111/cea.14237

Atopic Dermatitis - Skin Research Institute of Singapore. 38. Skin Research Institute of Singapore (SRIS). Accessed August 13, 2024. https://www.a-star.edu.sg/sris/research/atopic-dermatitis

Atopic dermatitis. SingHealth. https://www.singhealth.com.sg/symptoms-treatments/atopic-dermatitis

# Gap: Current scoring systems (SGH)

## DLQI

**Dermatological Life Quality Index**

DLQI measures patients' perception of the impact of skin diseases on different aspects of their health-related quality of life **over the last week.**

## POEM

**Patient-Oriented Eczema Measure**

The Patient-Oriented Eczema Measure (POEM) is a questionnaire that allows patients to record the frequency of these seven symptoms **over the past week.**

## ItchyQuant

**Itch scale**

A cartoon-annotated self-reported pruritus severity numeric rating scale (NRS),

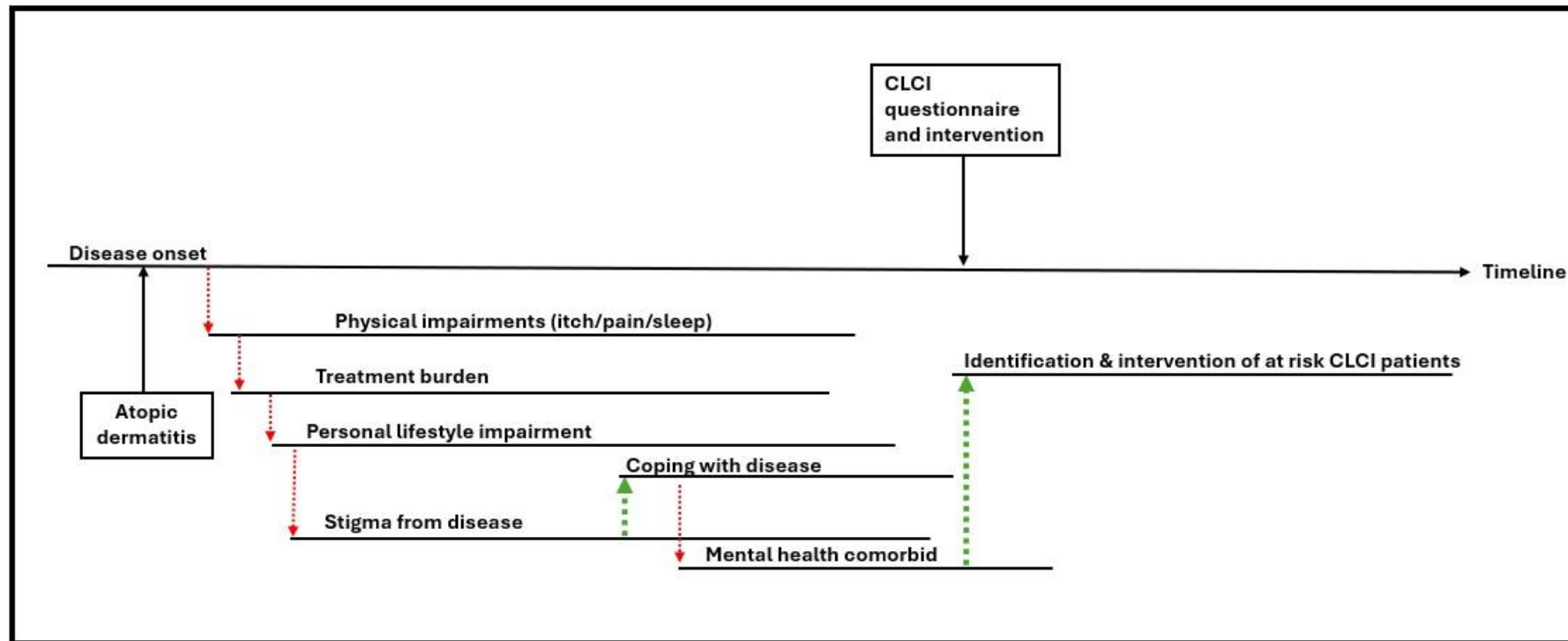# Cumulative Life Course Impairment



Fig.1 Schematic representation of the possible effect of a chronic disease on life course

**Cumulative Life Course Impairment (CLCI)** is a theoretical construct referring to **the non-reversible burden** of a chronic skin disease **over time**. In some patients and situations, this burden may lead to **chronic impairment and missed opportunities and, finally, persisting psychosocial and personal damage.**

# Methods

Design & Setting: Cross-sectional study (Jul 2024 – Mar 2025) Severe Atopic Dermatitis Clinic, Singapore General Hospital

Participants:82 adults (≥ 21 years) with moderate-to-severe AD
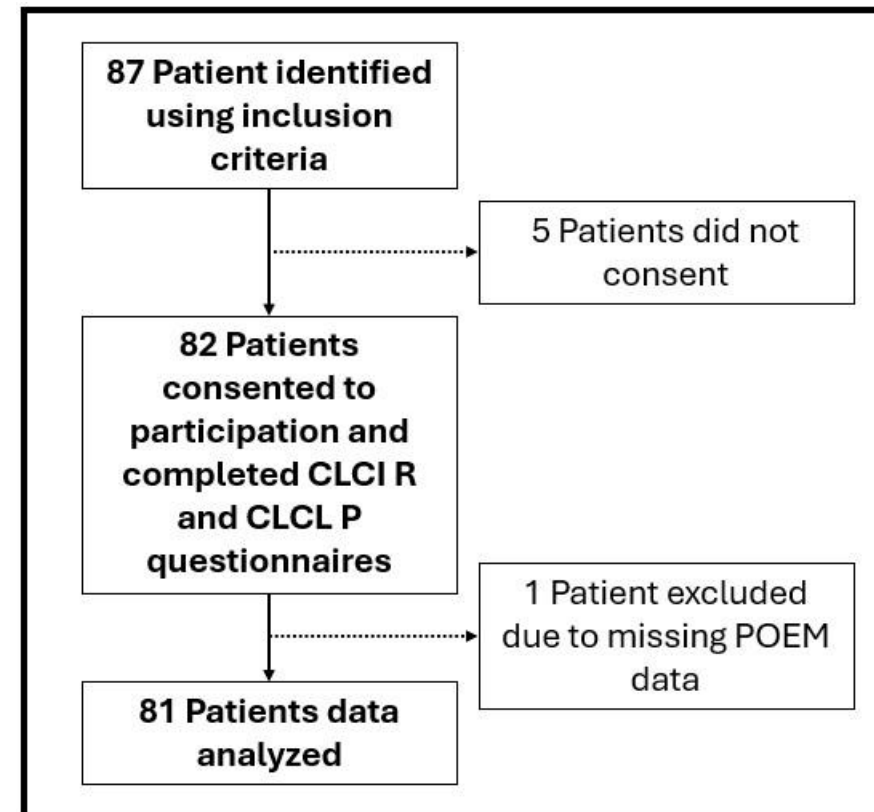
Excluded: other dermatologic diseases (e.g. urticaria)

Data Collection:
- Demographics, EASI, DLQI, POEM, ITCH, SLEEP
- Pre-visit questionnaires
- Private, non-digital interviews

**CLCI Assessment**:
DermCLCI-R: 30-items, lifetime impact (0–78 range)
DermCLCI-P: 30-items, future impact (2-week window)

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TABLE 2    Questionnaire on Cumulative Live Course Impairment in skin diseases—DermCLCI-p (UK version).

**Questionnaire on Cumulative Live Course Impairment in skin diseases – DermCLCI-p**

*The following questions will help us to understand how much you have experienced the following impairments due to your skin disease in the last two weeks.*

| | In the last two weeks, I experienced the following disease-related problems as burdensome: | not at all | somewhat | quite | very |
|---|---|---|---|---|---|
| 1 | ... limitations of physical performance | O | O | O | O |
| 2 | ... effort with the treatment of the disease | O | O | O | O |
| 3 | ... the idea of continuing the current treatment for the rest of my life | O | O | O | O |
| 4 | ... insufficient care by the attending physicians | O | O | O | O |
| 5 | ...other diseases | O | O | O | O |
| 6 | ... impairments of professional life/education | O | O | O | O |
| 7 | ... negative financial impacts | O | O | O | O |
| 8 | ... nervousness, anxiety or tenseness | O | O | O | O |
| 9 | ... not being able to stop or control worries | O | O | O | O |
| 10 | ... anxiety about the progression of the disease | O | O | O | O |
| 11 | ... feeling stressed by the disease | O | O | O | O |
| 12 | ... little interest or pleasure in my activities | O | O | O | O |
| 13 | ... depression, melancholy or hopelessness | O | O | O | O |
| 14 | ... thoughts of no longer wanting to live | O | O | O | O |
| 15 | ...problems in my family | O | O | O | O |
| 16 | ... problems in (previous) intimate partner relationships | O | O | O | O |
| 17 | ...problems in other social relations (friends, colleagues) | O | O | O | O |
| 18 | ...impairments in sex life | O | O | O | O |
| 19 | ... in terms of fulfilling my desire to have children | O | O | O | O |
| 20 | ... restrictions in leisure activities | O | O | O | O |
| 21 | ...impairments regarding choice of clothing | O | O | O | O |
| 22 | ... feelings of shame | O | O | O | O |
| 23 | ... prejudices of others | O | O | O | O |
| 24 | ... nutritional disadvantages | O | O | O | O |
| 25 | ... increased use of tobacco, alcohol, drugs, or the internet | O | O | O | O |
| 26 | ... sleep disorders | O | O | O | O |
| 27 | ... impairments in the quality of life | O | O | O | O |
| 28 | ...other: _____ | O | O | O | O |

| | | not at all | some-what | mode-rately | quite | very |
|---|---|---|---|---|---|---|
| 29 | I have come to terms with my disease and its associated impairments. | O | O | O | O | O |
| 30 | Through coping strategies or avoidance behaviours, I have learned to cope better with the disease. | O | O | O | O | O |

Braren-von Stülpnagel CC, Augustin M, Westphal L, Sommer R. Development of Measurement Tools to Assess Cumulative Life Course Impairment in Patients with Chronic Skin Diseases. Journal of the European Academy of Dermatology and Venereology. 2023;37(8):1626–33.

# Results - Demographics

| Characteristics | Total N= 82 | Severity (POEM) | | p-value |
| --- | --- | --- | --- | --- |
| | | Moderate N=70 | Severe N=11 | |
| **Treatment type, n(%)** | | | | |
| Topicals | 11 (13.4) | 11 (15.7) | - | 0.344 |
| Traditional immunomodulators | 19 (23.2) | 16 (22.9) | 2 (18.2) | |
| Jak-inhibitors | 22 (26.8) | 17 (24.3) | 5 (45.5) | |
| Biologics | 28 (34.1) | 24 (34.3) | 4 (36.4) | |
| **CLCI-R,** Median (IQR) | 25.0 (14-44) | 25.0 (14-44) | 19.0 (15-49) | 0.907 |
| **CLCI-P,** Median (IQR) | 12.5 (5-22) | 11.0 (4-22) | 19.0 (14-37) | **0.007** |
| **DLQI,** Median (IQR) **(N=81)** | 4 (2-6) | 3 (1-6) | 13.0 (8-17) | **<0.001** |
| **ITCH,** Median (IQR) **(N=66)** | 3 (2-6) | 3 (2-5) | 7 (7-8) | **<0.001** |
| **SLEEP,** Median (IQR) (N=66) | 3 (2-6) | 3 (2-5) | 6 (4-7) | **0.006** |
| **Disease duration (years),** Median (IQR) **(N=80)** | 21 (11-27.5) | 21.0 (11-25) | 32.0 (17-40) | 0.105 |

Abbreviations: IQR = interquartile range, HDB = Housing Development Board (Public housing in Singapore), POEM = Patient Oriented Eczema Measure, CLCI-R = Cumulative life course impairment (retrospective), CLCI-P = Cumulative life course impairment (prospective), DLQI = Dermatology Life Quality Index, ITCH = Itch visual analogue score, SLEEP = Sleep numeric rating scale.
Traditional immunomodulators: Cyclosporine, Methotrexate, Azathioprine, Mycophenolate Mofetil; Jak-inhibitors: Baricitinib, Abrocitinib, Upadacitinib; Biologics: Dupilumab.
P values are based on Mann-Whitney U test and Chi-squared test for continuous and categorical variables respectively.

**Table 1 Patient's demographic and clinical characteristics.**

| Spearman corelations | | Total N= 82 |
| --- | --- | --- |
| CLCI (R) - DLQI | Correlation Coefficient (r) | 0.247* |
| CLCI (P) - DLQI | Correlation Coefficient (r) | 0.611** |
| CLCI (P) – CLCI (R) | Correlation Coefficient (r) | 0.547** |
| CLCI (R) - ITCH | Correlation Coefficient (r) | 0.063 |
| CLCI (P) - ITCH | Correlation Coefficient (r) | 0.339** |
| CLCI (R) - SLEEP | Correlation Coefficient (r) | 0.232 |
| CLCI (P) - SLEEP | Correlation Coefficient (r) | 0.357** |
| CLCI (R) – Severity score | Correlation Coefficient (r) | 0.082 |
| CLCI (P) – Severity score | Correlation Coefficient (r) | 0.489** |
| CLCI (R) – Age of onset of disease | Correlation Coefficient (r) | -0.276* |
| CLCI (P) – Age of onset | Correlation Coefficient (r) | -0.362** |
| CLCI (R) – Disease duration | Correlation Coefficient (r) | 0.247* |
| CLCI (P) – disease duration | Correlation Coefficient (r) | 0.282* |

- Median CLCI P score was higher (19) in severe patients than moderate patients (11)
- CLCI P score correlated positively with disease severity score

# Results – CLCI (P)

| Items of Cumulative life course impairment (CLCI-P) | Not at all | Somewhat | Quite | Very |
|---|---|---|---|---|
| 1) Limitation in physical performance | 43 (52.4) | 19 (23.2) | 10 (12.2) | 10 (12.2) |
| **2) Effort with the treatment of disease** | 37 (32.9) | 27 (32.9) | 20 (24.4) | 8 (9.80) |
| **3) The idea of continuing current treatment for rest of life** | 18 (22.0) | 22 (26.8) | 21 (25.6) | 21 (25.6) |
| 4) Insufficient care by attending physicians | 73 (89.0) | 6 (7.30) | 2 (2.40) | 1 (1.20) |
| 5) Other diseases | 73 (89.0) | 6 (7.30) | 2 (2.40) | 1 (1.20) |
| 6) Impairment of professional life or education | 47 (57.3) | 24 (29.3) | 9 (11.0) | 2 (2.40) |
| **7) Negative financial impacts** | 28 (34.1) | 20 (24.4) | 17 (20.7) | 17 (20.7) |
| 8) Nervousness anxiety of tenseness | 41 (50.0) | 23 (28.0) | 14 (17.1) | 4 (4.90) |
| **9) Not being able to stop or control worries** | 40 (48.8) | 23 (28.0) | 16 (19.5) | 3 (3.70) |
| **10) Anxiety about the progression of disease** | 30 (36.6) | 24 (29.3) | 21 (25.6) | 7 (8.50) |
| **11) Feeling stressed by the disease** | 28 (34.1) | 28 (34.1) | 20 (24.4) | 6 (7.30) |
| 12) Litte interest or pleasure in my activities | 49 (59.8) | 22 (26.8) | 9 (11.0) | 2 (2.40) |
| 13) Depression melancholy or hopelessness | 60 (73.2) | 14 (17.1) | 4 (4.90) | 4 (4.90) |
| 14) Thoughts of no longer wanting to live | 73 (89.0) | 6 (7.30) | 2 (2.40) | 1 (1.20) |
| 15) Problems in my family | 63 (76.8) | 10 (12.2) | 4 (4.90) | 5 (6.10) |
| 16) Problems in (previous) intimate partner relationships | 72 (87.8) | 3 (3.70) | 3 (3.70) | 4 (4.90) |
| 17) Problems in other social relations (friends and colleagues) | 61 (74.4) | 13 (15.9) | 2 (2.40) | 6 (7.30) |
| 18) Impairments in sex life | 72 (87.8) | 5 (6.10) | 1 (1.20) | 4 (4.90) |
| 19) In terms of fulfilling my desire to have children | 65 (79.3) | 7 (8.50) | 6 (7.30) | 4 (4.90) |
| 20) Restriction in leisure activities | 42 (51.2) | 25 (30.5) | 6 (7.30) | 9 (11.0) |
| **21) Impairments regarding choice of clothing** | 33 (40.2) | 29 (35.4) | 10 (12.2) | 10 (12.2) |
| 22) Feelings of shame | 47 (57.3) | 24 (29.3) | 6 (7.30) | 5 (6.10) |
| 23) Prejudices of others | 59 (72.0) | 9 (11.0) | 7 (8.50) | 7 (8.50) |
| 24) Nutritional disadvantages | 59 (72.0) | 16 (19.5) | 2 (2.40) | 5 (6.10) |
| 25) Increased use of tobacco, alcohol, drugs or the internet | 69 (84.1) | 6 (7.30) | 5 (6.10) | 2 (2.40) |
| **26) Sleep disorders** | 35 (42.7) | 29 (35.4) | 11 (13.4) | 7 (8.50) |
| 27) Impairments in quality of life | 39 (47.6) | 25 (30.5) | 14 (17.1) | 4 (4.90) |

Note: All results are expressed as frequency and percentages. Bolded items are questions with >50% responding at least "Somewhat".

**Table 2 Summary of all items in Cumulative life course impairment – prospective (CLCI-P) questionnaire.**

- Questions that (>50% rated at least "somewhat") included domains related to
  1. Treatment burden (Q2-3, Q7)
  2. Mental health (Q9-11)
  3. Personal lifestyle (Q21,Q26)

# Results – Model

| Variables | Unadjusted estimate (95% CI) | P value | Adjusted estimate (95% CI) | P value |
|---|---|---|---|---|
| Age (years) | -0.01 (-0.02, 0.01) | 0.261 | | |
| Gender (Reference = Female) | 0.25 (-0.16, 0.65) | 0.231 | | |
| Ethnicity (Reference = Chinese) | | | | |
|    Non-Chinese | 0.03 (-0.38, 0.45) | 0.875 | | |
| Housing (Reference = HDB 1-4 RMS) | 0.02 (-0.49, 0.53) | 0.949 | | |
|    HDB 5 Rooms/Executive Flat/Condo/Others | | | | |
| Treatment group (Reference = Jak-inhibitors) | | 0.6114+ | | |
|    Biologics | -0.22 (-0.72, 0.27) | 0.380 | | |
|    Traditional immunomodulators | -0.21 (-0.75, 0.33) | 0.447 | | |
|    Topical | -0.42 (-1.06, 0.22) | 0.196 | | |
| Topical Vs Systemic treatments (Reference = Topical) | | | | |
|    Systematic treatment | 0.27 (-0.28, 0.83) | 0.336 | | |
| EASI severity (Reference = Moderate) | | | | |
|    Severe | 0.85 (0.06, 1.63) | 0.035 | | |
| POEM Severity (Reference = Moderate) | | | | |
|    Severe | 0.74 (0.21, 1.28) | 0.006 | | |
| DLQI | 0.09 (0.06, 0.12) | <.0001 | 0.07 (0.04, 0.10) | <.0001 |
| CLCI-R | 0.03 (0.02, 0.04) | <.0001 | 0.02 (0.01, 0.03) | <.0001 |
| Age of Onset of disease | -0.02 (-0.03, -0.01) | 0.002 | | |
| Disease Duration (Reference = < 21years) | | | | |
|    ≥ 21 years | 0.57 (0.22, 0.93) | 0.002 | 0.33 (0.05, 0.60) | 0.0194 |
| Sleep | 0.13 (0.05, 0.22) | 0.002 | | |
| Age (Reference = < 34years) | | | | |
|    ≥ 34years | -0.25 (-0.65, 0.14) | 0.202 | -0.38 (-0.66, -0.10) | 0.0077 |
| Itch | 0.13 (0.04, 0.21) | 0.003 | | |
| POEM | 0.06 (0.03, 0.08) | <.0001 | | |
| EASI | 0.03 (0.01, 0.06) | 0.009 | | |

Abbreviations, HDB = Housing Development Board (Public housing in Singapore), POEM = Patient Oriented Eczema Measure, CLCI-R = Cumulative life course impairment (retrospective), EASI = Eczema Area and Severity Index, DLQI = Dermatology Life Quality Index, ITCH = Itch visual analogue score, SLEEP = Sleep numeric rating scale. Traditional immunomodulators: Cyclosporine, Methotrexate, Azathioprine, Mycophenolate Mofetil; Jak-inhibitors: Baricitinib, Abrocitinib, Upadacitinib; Biologics: Dupilumab. Note: + refers to type 3 p value or overall p value. CI: Confidence interval

- Multi-variable modelling yielded **significant predictors**: **DLQI, CLCI-R** and **disease duration ≥21 years** , predicting a higher CLCI P score.
- In our model, **Age ≥34 years** ($\beta$= -0.383, p=0.007) predicts **a lower CLCI P score**
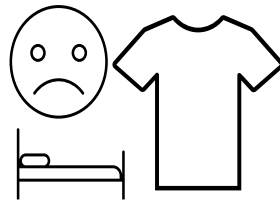
# Discussion



## KEY BURDEN DOMAINS

**Mental health impairment**
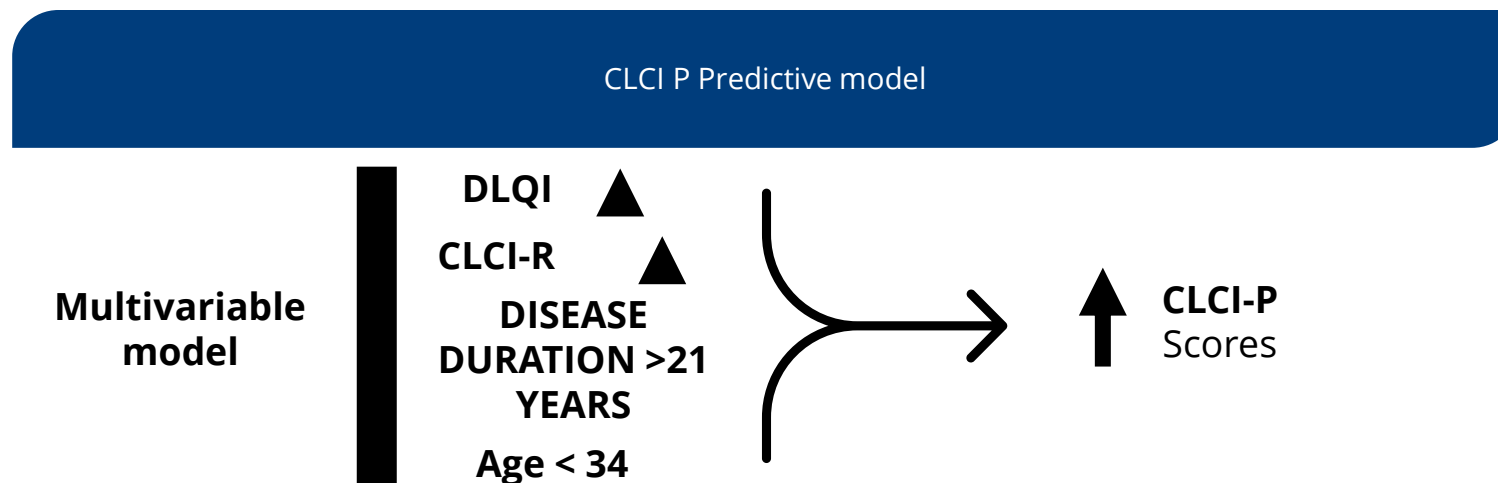Anxiety, worry, distress

**Treatment burden**
Frequent visits, financial costs &
side effects

**Personal life impairments**
Choice of clothing, sleep disturbance, feelings of shame

# Discussion



**CLCI P Predictive model**

**Multivariable model**

DLQI ▲

CLCI-R ▲

DISEASE DURATION >21 YEARS

Age < 34

→ ↑ **CLCI-P** Scores

• **Significant predictors for <u>higher</u> CLCI-P Score: DLQI, CLCI-R** and **disease duration ≥21 years.**

• Interestingly, **Age ≥34 years** predicts **a lower CLCI P score** which can be further explore in future studies. Possible theories could be better coping mechanism, increased ability to access healthcare.

# Conclusion

🕰️ **CLCI - Long-Term Impact**
Tracks cumulative burden across life course

⚖️ **Complex Burden Beyond Skin**
CLCI reflects intertwined mental, treatment, and social disruptions.

🌱 **Early Intervention Matters**
Early AD control may reshape life trajectory

# Summary

## Methods & demographics

**82 Patients recruited**
Median age: 29.5
65.9% Male
32.9% Female

**Severity (POEM)**
85% Moderate
15% Severe

**Mean CLCI P**
Significantly higher in severe disease (28.4 vs 15.9 , p=0.007)

## KEY BURDEN DOMAINS

**Mental health impairment**
Anxiety, worry, distress

**Treatment burden**
Frequent visits, financial costs &
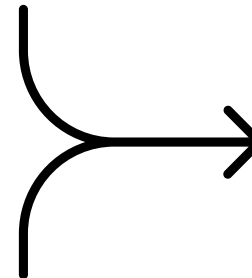side effects

**Personal life impairments**
Choice of clothing, sleep disturbance, feelings of shame

## CLCI P Predictive model

**Multivariable model**

DLQI ▲

CLCI-R ▲

**DISEASE DURATION >21 YEARS**

**Age < 34**

↑ **CLCI-P** Scores

# Thank you

**Authors**: Meng Jie Ho, Rehena Sultana, Karen Choo, Haur Yueh Lee
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**Learning Objective:** To highlight the role of CLCI as a novel patient-reported outcome bridging clinical severity and psychosocial impact in chronic dermatologic conditions.
**Takeaway Message**: Incorporating CLCI assessments into clinical practice may enhance patient-centered care by uncovering the hidden long-term burden of atopic dermatitis.

**Conflict of Interest**: None
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