

Assessment of cumulative life course impairment in dermatology

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BACKGROUND

People with chronic skin diseases experience a range of physical and psychosocial impairments, which can accumulate over time. This **cumulative life course impairment (CLCI)**¹ may have a significant negative and long-lasting, sometimes non-reversible impact on patients' lives. A precise definition, clearer understanding of this process and an early identification of risk factors could open up pathways for prevention approaches.

The aims of this project were two-fold:

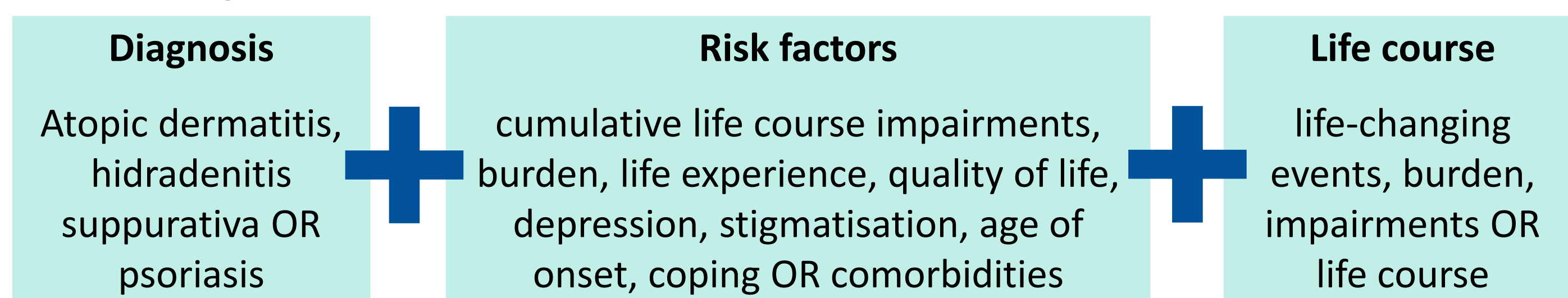
- To identify risk factors of CLCI and associated burden over time in patients with psoriasis, atopic dermatitis, and hidradenitis suppurativa;
- To develop measurement instruments to assess (a) persisting CLCI and (b) future risk for developing CLCI.

METHODS

Phase 1: Systematic Review

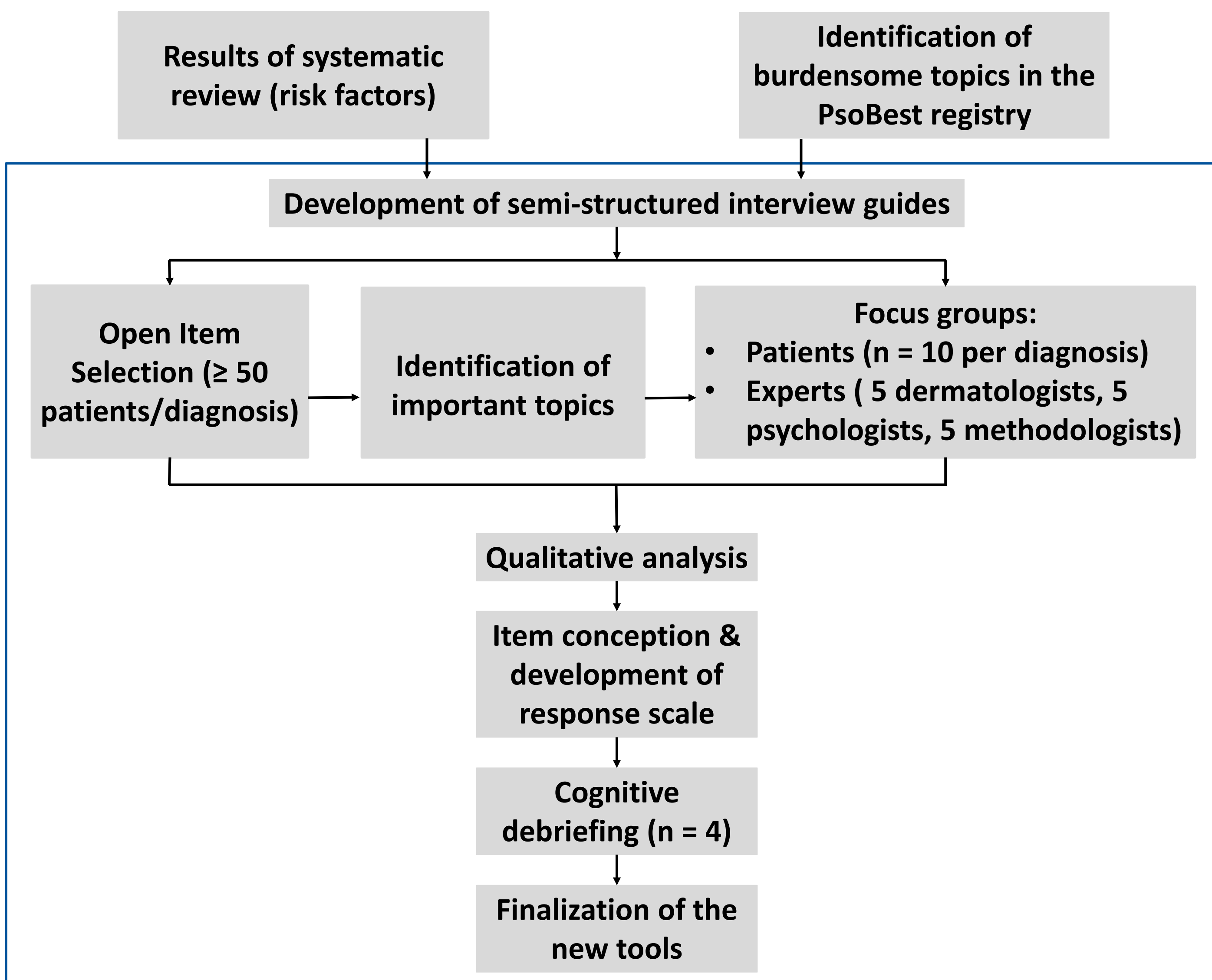
A systematic literature search (PROSPERO registration number: CRD42020179141) of PsycInfo, PubMed and Web of Science was performed to identify risk factors that have a negative cumulative effect on patients with chronic skin diseases.

Search String:



The last search was performed in March 2021. Abstracts and full-texts were screened by two independent reviewers. Studies were eligible if they were original articles published in English or German and had a longitudinal design (retrospective, prospective). Risk of Bias of individual studies was evaluated using the Critical Appraisal Skills Programme (CASP) checklists.

Phase 2: Questionnaire development



RESULTS

Phase 1: Systematic Review²

Included studies	Interrater agreement	Sample sizes	Study periods
k = 25	κ = 0.56	69 – 24,7755	6 months – 26 years

- Kimball Ab et al. (2010). J Eur Acad Dermatol Venereol, 24(9):989–1004.
- von Stülpnagel et al. (2021). J Eur Acad Dermatol Venereol, 35(11):2166–84.
- Braren-von Stülpnagel et al. (2023). J Eur Acad Dermatol Venereol, 00:1–8.

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Identified Risk Factors

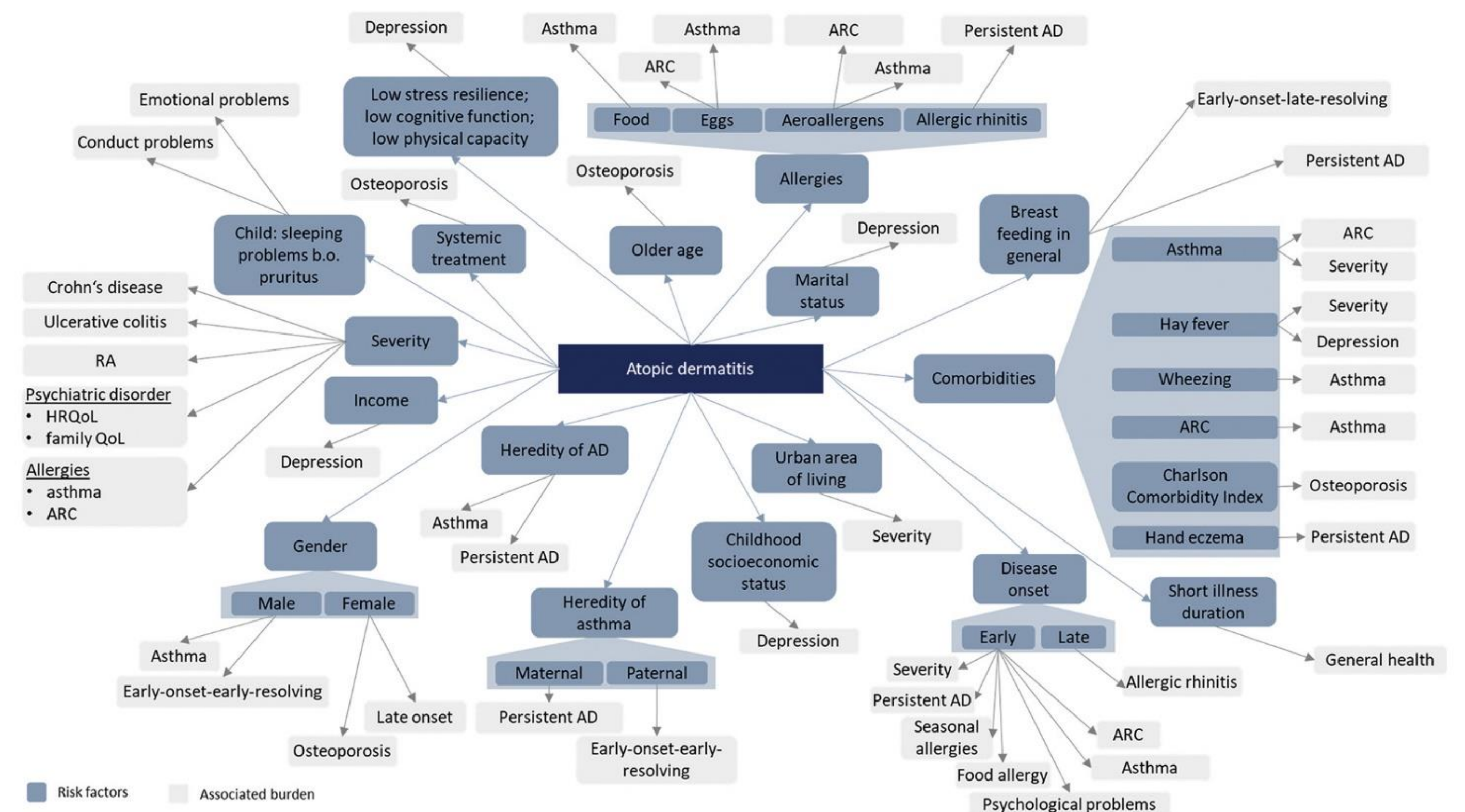


Fig. 1 Risk factors for CLCI in patients with atopic dermatitis, extracted from 13 studies.

Phase 2: Questionnaire development³

In addition to the sociodemographic (e.g., gender, age) and clinical (e.g., disease severity and comorbidities) risk factors identified in Phase 1, the 162 patients participating in open item selection reported **sexuality, risky health behaviors, as well as psychosocial and occupational impairments** as important factors. These were confirmed by the focus groups. Two questionnaires with 30 items each, rated on a 4-point-Likert scale (0 = not at all; 3 = very) were developed:

- the **DermCLCI-r** measures impairments due to skin disease retrospectively over the life course, how burdensome each impairment is to this day, and how life changing it was
- The **DermCLCI-p** assesses current CLCI status and predicts future risk.

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

The following questions will help us to understand
a) what negative impact the skin disease has had on you in the course of your life,
b) whether these impacts still persist and
c) whether they had a life-changing effect on you.

Note: Life-changing in this context means that your life would have been different in these areas without the skin disease.

Please mark with an "X" (3 X's per line) for each of the following statements:

	Since the onset of the first symptoms of the disease, I have found the following to be burdensome in the course of my disease:				If burdensome:			
	not at all	some-what	quite	very	ongoing		life-changing	
					yes	no	yes	no
1 ... limitations of physical performance	0	0	0	0	0	0	0	0
2 ... effort with the treatment of the disease	0	0	0	0	0	0	0	0
3 ... insufficient care by the attending physicians	0	0	0	0	0	0	0	0
4 ... other diseases	0	0	0	0	0	0	0	0
5 ... impairments of professional life/education	0	0	0	0	0	0	0	0
6 ... negative financial impacts	0	0	0	0	0	0	0	0
7 ... nervousness, anxiety or tenseness	0	0	0	0	0	0	0	0
8 ... not being able to stop or control worries	0	0	0	0	0	0	0	0
9 ... feeling stressed by the disease	0	0	0	0	0	0	0	0
10 ... little interest or pleasure in my activities	0	0	0	0	0	0	0	0
11 ... depression, melancholy or hopelessness	0	0	0	0	0	0	0	0
12 ... thoughts of no longer wanting to live	0	0	0	0	0	0	0	0
13 ... problems in my family	0	0	0	0	0	0	0	0
14 ... problems in (previous) intimate partner relationships	0	0	0	0	0	0	0	0
15 ... problems in other social relations (friends, colleagues)	0	0	0	0	0	0	0	0
16 ... impairments in sex life	0	0	0	0	0	0	0	0
17 ... in terms of fulfilling my desire to have children	0	0	0	0	0	0	0	0
18 ... restrictions in leisure activities	0	0	0	0	0	0	0	0
19 ... impairments regarding choice of clothing	0	0	0	0	0	0	0	0
20 ... feelings of shame	0	0	0	0	0	0	0	0
21 ... prejudices of others	0	0	0	0	0	0	0	0
27 I have come to terms with my disease and its associated impairments.	0	0	0	0	0	0	0	0
28 Through coping strategies or avoidance behaviours, I have learned to cope better with the disease.	0	0	0	0	0	0	0	0
29. How old are you? _____								
30. How old were you when your first disease symptoms appeared? _____								

Please mark with an "X" how strongly you have felt burdened by your disease in the respective years of your life (from the onset of your disease to your current age)

Fig. 2 Excerpt of the CLCI-r.

CONCLUSION

These two measurement tools assessing CLCI facilitate early, appropriate dermatological and psychosocial treatment in routine care. Their use may contribute to the reduction or prevention of CLCI and thus advance holistic care for people with chronic skin disease. The validation study is currently underway.

