

Developing an online-intervention to reduce self-stigmatization in people with visible chronic skin diseases: a study protocol

Traxler J¹, Stuhlmann CFZ¹, da Silva N¹, Sommer R¹

¹ Institute for Health Services Research in Dermatology and Nursing (IVDP), University Medical Center Hamburg-Eppendorf, Hamburg, Germany

BACKGROUND

Many people with visible chronic skin diseases experience social stigmatisation and exclusion, preventing full social participation. A particular problem arises from the **self-stigmatisation** of those affected, i.e. an internalisation of these prejudices and devaluation of their own person. This has negative effects on psychosocial wellbeing and quality of life. Currently, no interventions against self-stigma are available for this target group in German language.

This project aims to

1. develop a novel online program to reduce self-stigma in people with skin disease and
2. test its feasibility and effectiveness.

PHASE 1: PROGRAM DEVELOPMENT

Methods

In Phase 1, two systematic reviews were conducted in order to

- a) identify predictors and mechanisms of self-stigma in people with visible chronic skin conditions (PROSPERO registration number: CRD42021286638), and
- b) summarize interventions available for this target group (PROSPERO registration number: CRD42021284948).

Electronic database searches of PubMed, EMBASE, Web of Science and PsycINFO (last search performed: May 2023) followed PRISMA guidelines. Studies were eligible if they were original empirical articles, written in English or German language, and aimed to investigate (a) predictors or mechanisms of self-stigmatization in skin disease or (b) interventions to reduce self-stigma in adults with visible skin disease. For each, two independent reviewers conducted the abstract and full text screening as well as data extraction.

Study quality and risk of bias was assessed with (a) the Johanna Briggs Institute (JBI) Checklist for Analytical Cross-Sectional Studies and (b) the Critical Appraisal Skills Programme (CASP) Checklist. Results were synthesized narratively.

The results were used to determine intervention targets and appropriate strategies in order to design the program structure and content.

Results review 1 – predictors & mechanisms of self-stigma

The initial search yielded 887 records, of which 29 were included. Study characteristics are shown in Table 1.

Table 1. Characteristics of Included Studies (k = 29)

Study Design	k	Valid %	Language	k	Valid %
Cross-sectional	28	96.6	English	28	96.6
Longitudinal	1	3.4	German	1	3.4

Region of Study	Number of Studies	Valid %	Skin Diseases ^a	Number of Studies
Europe	23	79.3	Psoriasis	17
Middle East	2	6.9	Vitiligo	6
Asia	2	6.9	Alopecia Areata	3
Africa	1	3.4	Dermatitis	3
North America	1	3.4	Hidradenitis Suppurativa	3

Sample Sizes
M = 152 (SD = 266)
Range = 35 – 1,485

^a Samples could include multiple skin diseases

Several psychosocial variables were found to be significant predictors of self-stigma, including social stigma, coping strategies, and social support (Table 2). Evidence for sociodemographic and clinical factors was mixed.

Table 2. Number of Studies with Significant Psychosocial Predictors and Correlates of Self-Stigma by Effect Size^b

	Large predictor	Medium predictor	Small predictor	High correlation	Moderate correlation	Low correlation
Potential Targets for Intervention						
Social Stigma	2	0	0	2	0	0
Coping Strategies	0	1	0	1	2	0
Social Support	0	1	0	1	0	0
Not Suitable as Intervention Targets						
Attachment Style	1	1	0	0	0	0
Quality of Life	1	0	0	7	9	5
Psychological Distress	1	1	0	7	5	8

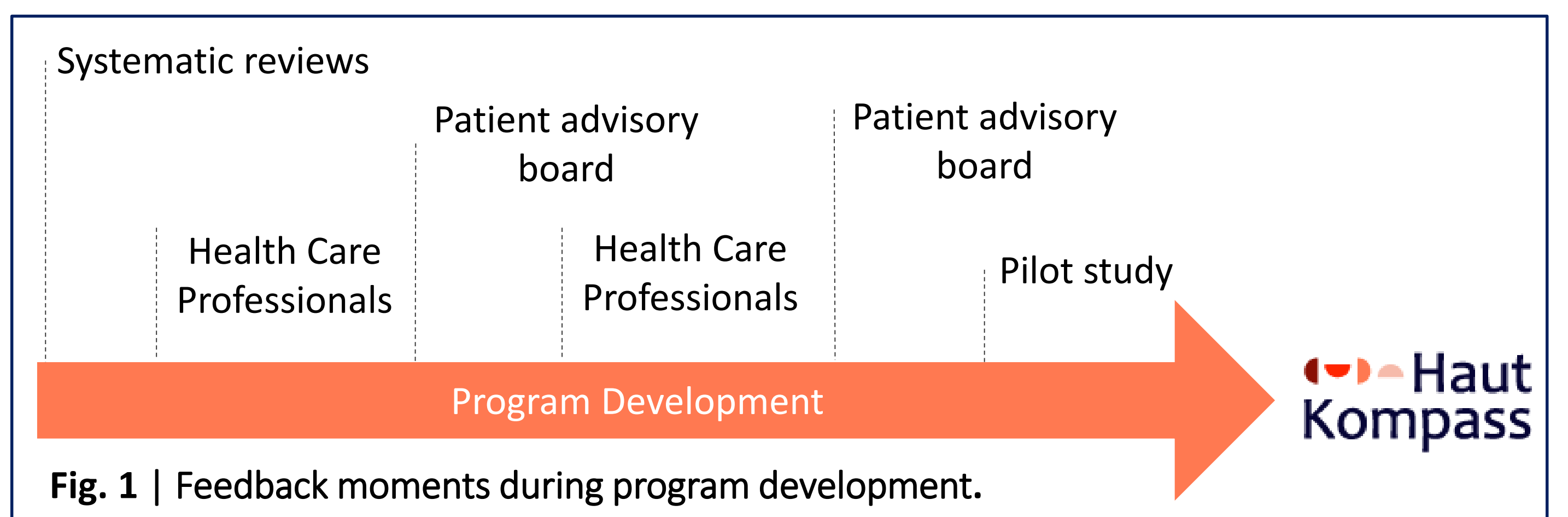
^b Effect size categories as follows: $f^2 = 0.02$ indicates a small effect; $f^2 = 0.15$ indicates a medium effect; $f^2 = 0.35$ indicates a large effect; Correlations: $r = 0.10$ indicates a small effect; $r = 0.30$ indicates a moderate effect; $r = 0.50$ indicates a large effect (Cohen, 1988)

Results review 2 – interventions against self-stigma

In total, 5,298 records were identified. The included studies ($k = 19$) examined various intervention approaches in different settings (group, individual, online, or combinations of these). All studies reported predominantly positive effects on self-stigma and related variables. Study designs and quality were heterogeneous. The results pointed to a lack of evidence-based interventions in dermatology, especially for people with non-communicable, chronic inflammatory skin diseases, thus highlighting the high need for a new intervention. Further, no such interventions are available in German language.

Results – HautKompass program

Based on these results, the **online program “HautKompass”** (eng.: “skin compass”) is being developed in a participatory approach. Eight self-learning modules target self-stigma through **psychoeducation and cultivation of self-compassion and coping strategies**. An advisory board consisting of patients with the different target diagnoses ($n = 6$) as well as health care professionals (psychologists & dermatologists, $n = 3$) were consulted for their opinions on various aspects of the program development (e.g., program content, communication, design and user-friendliness; see Fig. 1). A pilot study ($n = 25$) will be conducted prior to the RCT.

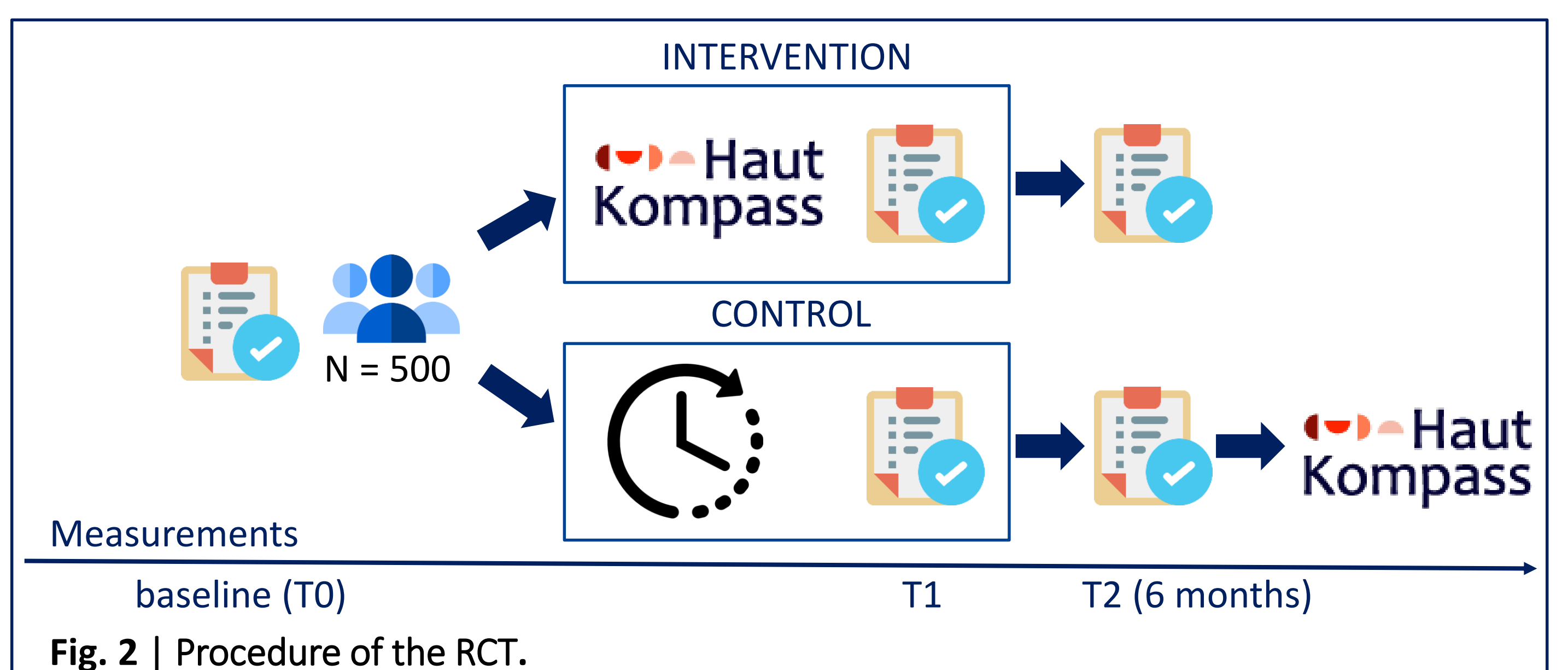


PHASE 2: RANDOMIZED CONTROLLED TRIAL

Methods

In Phase 2, a randomized controlled trial with a 6-months follow-up interval will be conducted to assess the feasibility and effectiveness of the new HautKompass program.

Patients with atopic dermatitis, alopecia areata, hidradenitis suppurativa, psoriasis, and vitiligo ($n = 100$ per diagnosis)



Measures

- Self-stigma: Weight Bias Internalization Scale —adapted for skin disease
- Illness Identity: Inclusion of Illness in the Self scale
- Quality of Life: EUROHIS-QOL-8 & Dermatology Life Quality Index
- Coping: Body Image Coping Strategies Inventory
- Body Image: Multidimensional Body-Self Relations Questionnaire & Cutaneous Body Image Scale
- Self-Compassion Scale: Self-Compassion Scale – Short Version
- Anxiety: Generalized Anxiety Disorder-7
- Depression: Patient Health Questionnaire-9
- Suicidality: Paykel Suicide Scale

Expected results & conclusion

HautKompass is a low-threshold, flexible online intervention and the first of its kind available in the German language. The programme is **expected to reduce self-stigma through improving self-compassion and acceptance** in people with different visible chronic skin diseases. This would be a substantial advancement of psychosocial care with the potential to greatly improve quality of life and wellbeing in dermatological patients.

Funding: Federal Ministry of Education and Research (BMBF; Funding number: 01GY2105)

Contact: Juliane Traxler
Institute for Health Services Research in Dermatology and Nursing Professions (IVDP),
University Medical Center Hamburg Eppendorf
j.traxler@uke.de

