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Instruments to assess stigmatization in dermatology

Narzędzia do oceny stygmatyzacji w dermatologii

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Summary

Stigmatization is the assignment of negative perceptions to an individual because of a perceived difference from the population at large. Skin conditions are frequently the reason of social rejection with a consequent negative influence on the personal and social life of patients.

The aim of the current study was to review the available instruments that can be successfully utilized to measure the stigmatization level among dermatological patients.

We performed our search on PubMed up to November 2016 and utilized combinations of key phrases containing such words as stigmatization, skin, dermatology, names of various skin conditions (psoriasis, vitiligo, acne, etc.), measurement. The search found a considerable number of articles – 548. After filtering them through a precise selection process, 58 articles remained. We concentrated only on the methodological aspects to assess stigmatization in various dermatoses.

The review ascertained that there exist numerous instruments in the form of questionnaires. They were utilized in various researches in order to assess the stigmatization level in patients with skin problems. We divided them into two main groups: dermatology specific instruments (6 questionnaires) and dermatosis/disease specific ones (8 questionnaires). It is recommended to use dermatology-specific instruments to compare the stigmatization level in various skin conditions. They can be utilized as well as a first line tools to study the feeling of stigmatization in specific skin diseases; however, where it is possible, they should be supplemented with the disease-specific instrument for deeper analysis of both qualities of life and stigmatization.

Keywords: stigmatization • measurement • dermatology

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Abbreviations: **ICF** – International Classification of Functioning, Disability and Health, **P-scale** – Participation scale, **PSQ** – Perceived Stigmatization Questionnaire, **QES** – Questionnaire on Experience with Skin Complaints, **SEQ** – Stigmatization and Eczema Questionnaire.

INTRODUCTION

According to the medical dictionary, stigmatization is the assignment of negative perceptions to an individual because of perceived difference from the population at large; it may occur on the basis of physical appearance (including race or sex), of mental or physical illness, or of various other qualities [4]. The medical field recognizes a number of diseases, the sufferers of which are stigmatized, such as the majority of mental disorders, AIDS, venereal diseases, leprosy, and certain skin diseases. Individuals with mental illness are stereotyped as dangerous, unpredictable, and as weak-willed. Along with the stigma faced by the individual, associative stigma can impact the family and friends of that person. Skin conditions, especially in regards to their aesthetic aspect, are frequently the reason of social rejection. This has a negative influence on the personal and social life of patients. Skin plays an important role in establishing interpersonal relationships, and thus cutaneous disorders, which have a significant impact on physical appearance, influence other people's attitudes [9,10]. Visible skin changes may arouse fear, disgust, aversion or even intolerance, and other people may be afraid of the possible contagious character of the disease. This underlines the importance of proper stigmatization assessment in patients suffering from various dermatoses.

AIM OF THE STUDY

The aim of the current study was to review the available instruments that can be successfully used to measure the stigmatization level in dermatological patients.

METHODOLOGY

In order to collect the necessary data, we performed our search namely on the scientific web site engine PubMed up to November 2016. The following key words, terms and phrases were used to obtain as more as possible complete information: stigmatization and dermatology, stigmatization and skin, stigmatization and psoriasis, stigmatization and atopic dermatitis, stigmatization and vitiligo, stigmatization and other skin problems including acne, hidradenitis suppurativa, rosacea, eczema, genetic skin disorder, ichthyosis, scars, hair loss, birth mark and stigmatization and measurement. The search found a considerable number of articles. In PubMed, using the key word "stigmatization and dermatology" we found 65 articles and selected 14 (not all found articles related to the searched topic/title; for that reason we are giving the number of selected articles, i.e. the articles with contents corresponding to our search); using the key word "stigmatization and skin" – 158 articles, selected 24; "stigmatization and psoriasis" – 53 articles, selected 8; "stigmatization and acne" – 9 articles, selected 1; "stigmatization and hidradenitis suppurativa" – 3 articles, selected 2; "stigmatization and rosacea" – 5 articles, selected 2; "stigmatization and eczema" – 6 artic-

les, selected 1; "stigmatization and ichthyosis" – 2 articles, selected 1 and "stigmatization and measurement" – 220 articles, selected 5.

We would like to specify that during the selection process we tried to avoid duplication: for instance, among the articles related with psoriasis, under "stigmatization and psoriasis" search, only 8 were taken into final analysis, as most of them were selected previously during the search with "stigmatization and dermatology" and "stigmatization and skin" key words. Some duplication was found and corrected later. The above-mentioned selected articles served as a basis for the current review where we concentrated only on the methodological aspects to assess stigmatization in various dermatoses.

STIGMATIZATION ASSESSMENT IN DERMATOLOGY

Having in mind the great impact of the stigmatization process on one's life, the measurement of its level is necessary to provide proper service to the patients. Numerous instruments in the form of questionnaires exist in order to assess the stigmatization level in patients with skin problem. They were grouped in Table 1. We divided them into two main groups: dermatology specific instruments (6 questionnaires) and dermatosis/disease specific ones (8 questionnaires).

DERMATOLOGY-SPECIFIC STIGMATIZATION INSTRUMENTS

6-Item Stigmatization Scale

In the 6-Item Stigmatization Scale [12], patients had to answer 6 questions using one of four possibilities scored from 0 to 3 points: "not at all", "sometimes", "very often", and "always". Higher scoring meant greater feeling of stigmatization (range 0–18). The stigmatization questionnaire identifies 6 dimensions of stigma experience, including anticipation of rejection, feelings of being flawed, sensitivity to the opinions of others, guilt and shame, negative attitudes and secretiveness.

Questionnaire on Experience with Skin Complaints

The Questionnaire on Experience with Skin Complaints (QES) [8] is a fully standardized self-rating instrument that focuses on the feelings of stigmatization of patients with different skin diseases and the coping with the stigma experience. It consists of six scales and 38 items in total. High scores on the 'interference of skin symptoms and self-esteem (self-esteem)' scale are related to frequent perceptions of worthlessness, loneliness, and uncleanliness and high scores on the 'outward appearance and situation-caused retreat (retreat)' scale to a lack of physical attractiveness or sexual desirability within the context of the skin disease. Additional items question special ways of clothing or avoidance of public situations. High scores on the 'rejection and devaluation (rejection)' scale correspond to intense anticipated or perceived reactions of others and high scores on

Table 1. Instruments to assess stigmatization in dermatology

Instruments to assess stigmatization in dermatology				
Type	N	Instrument	Disease	Reference
Dermatology specific	1	6-Item Stigmatization Scale	all dermatoses	[11]
	2	Questionnaire on Experience with Skin Complaints	all dermatoses	[18]
	3	Short version of the Questionnaire on Experience with Skin Complaints (QES)	all dermatoses	[19]
	4	Participation scale (P-scale)	all dermatoses	[16]
	5	Perceived Stigmatization Questionnaire (PSQ)	all dermatoses	[9,12,13]
	6	Stigma scale measuring the stigma of having skin defect	all dermatoses	[15]
Disease specific	1	Feelings of Stigmatization Questionnaire	psoriasis	[7]
	2	The Stigmatization and Eczema Questionnaire (SEQ)	atopic dermatitis	[21]
	3	Dehabilitation Scale	leprosy	[1,20]
	4	Semantic differential scales	leprosy	[8,20]
	5	Herpes-related Stigma Scale	herpes	[2]
	6	10-item stigma scale of The Pan-African Study Group on Onchocercal Skin Disease (1995)	onchocercal skin disease	[17]
	7	13-item, 39-point stigma scale	onchocercal skin disease	[6]
	8	Acne adapted Feelings of Stigmatization Questionnaire	acne	[10]

the 'composure' scale describe calmness and confidence in a satisfactory life in spite of the skin disease. High scores on the 'concealment' scale are related to frequent tendencies to hide the diagnosis and keep the disease a secret and high scores on the 'experienced refusal' scale to frequently feelings of stigmatization in very specific situations, such as shopping or using public transportation.

Short version of the Questionnaire on Experience with Skin Complaints (QES)

This questionnaire consists of four scales with 4–7 items each and a total of 23 items: 'reduction in self-esteem' and consequent retreat; 'composure' in the face of the negative social effects of the skin disease; 'rejection' in public and private situations because of disease symptoms and 'concealment' of outward evidence of the disease [19]. Higher values in the categories of reduction in self-esteem, rejection and concealment indicate higher stigmatization effects. In regards to the composure parameter, however, higher values indicate lower stigmatization effects. Each item ranges in value between 0 and 4.

Participation scale (P-scale)

The participation scale measures the extent to which people participate in common social events. The key issue of stigma is that it excludes people from participating in such events. The P-scale [16] is an 18-item instrument which covers eight out of the nine participation

domains of the International Classification of Functioning, Disability and Health (ICF) [22]. A five-point rating scale is used to measure the level of participation for each item. For each subject the scores obtained for the 18 items were added up. If the score was 12 or less, people were considered not to be restricted in their domestic and social life situation. Scores of 13 to 90 represent restriction at different intensities; 13 to 32 as moderate, 33 to 52 as severe and 53-90 as extreme restrictions.

Perceived Stigmatization Questionnaire (PSQ)

The Perceived Stigmatization Questionnaire (PSQ) [9] asks participants to rate how often a person experiences a variety of stigmatizing behaviors. A parent form of the Perceived Stigmatization Questionnaire (PSQ) asks parents to rate how often their child experienced a variety of stigmatizing behaviors commonly reported by people with appearance distinctions [12,13]. The questionnaire consists of 21 items classified into three scales: absence of friendly behavior, staring/confused behavior and hostile behavior. Items are rated on a 5 – point Likert scale, ranging from 'never' (1) to 'always' (5). Higher scores indicate higher perceived stigmatization.

Stigma scale measuring the stigma of having skin defect

Neil JA [15] developed and described an instrument that focused on the body image and the skin specifically and measures the emotional challenges of having

skin defect. The author stressed on the importance of the appearance of the skin, concealment of the defect, looking at the disfigurement of others. Thirty-five primary items were developed to measure the latent variable of stigma. After analyzing of each item, the final instrument was reduced to 24 items, all at a 6th grade reading level. The results from a preliminary analysis of the Stigma scale indicated that it is a reliable tool to measure body image and the skin related to stigmatization. The author suggests that the scale can be useful in identifying those who are experiencing major body images issues.

DERMATOSIS/DISEASE-SPECIFIC STIGMATIZATION INSTRUMENTS

Feelings of Stigmatization Questionnaire

In the Feelings of Stigmatization Questionnaire [7] patients had to give answers to 33 items using one of 6 possible answers scored from 0 to 5: “definitely yes”, “yes”, “rather yes”, “rather no”, “no”, “definitely no”. The overall scoring could range from 0 to 165 points. Similarly to the 6 – item Stigmatization Scale, the higher the score, the more severe the patient’s feeling of stigmatization. The questions were designed to explore 6 different dimensions of the stigma: anticipation of rejection (8 items), feeling of being flawed (6 items), sensitivity to the opinions of others (5 items), guilt and shame (5 items), secretiveness (5 items), and positive attitudes (4 items). The instrument was specially designed to assess the stigmatization in psoriatic individuals.

The Stigmatization and Eczema Questionnaire (SEQ)

Feelings of Stigmatization Questionnaire [7] were adapted for use with atopic dermatitis patients to assess perceptions of stigmatization (SEQ) [21]. Items include “I sometimes avoid social situations because of eczema”, “Having eczema makes me feel different from other people” and “I often think that others think that eczema patients are dirty”.

Dehabilitation Scale

This 52-item scale covers four areas related to stigma: family relationship, vocational conditions, social interaction and self-esteem. The items consist of positive and negative statements, with 5 point Likert-type response scales (strongly agree to strongly disagree). The results are summed, divided by the maximum possible score, and multiplied by 100 to get the “score-quotient”. This instrument was designed especially for leprosy patients and used only in this group of subjects [1,20].

Semantic differential scales

A very different approach to stigma measurement was proposed with the creation of semantic differential scales [8,20]. This technique requires respondents to rate subjects such as “a person with mental illness”, “a person

with tuberculosis” or “a person affected by leprosy” on multipoint response scales (7-point in the quoted studies). The rating 1 represents a very unfavorable view (“bad”, “sad”, “worthless”), whereas 7 indicates a positive concept (“good”, “happy”, “valuable”). A rating of 4 is considered neutral. The rating of individual items is summed and the mean is calculated. In this way one can compare community perception or attitudes to various conditions. In dermatology it was used only in leprosy patients.

Herpes-related Stigma Scale

In order to address herpes-related stigma, the authors adapted the original HIV stigma scale that measured perceived stigma among adults with HIV [3]. The original scale contains 40 items, with four sub-scales (personalized stigma, disclosure concerns, negative self-image, and concern with public attitudes about people with HIV). Participants responded using a four-point Likert-type scale (1 = strongly disagree, 4 = strongly agree) with the higher scores indicating more perceived stigma. An example of an item from each of the subscales are as follows: ‘I have been hurt by how people reacted to learning I have herpes’ (personalized stigma); ‘I work hard to keep my herpes a secret’ (disclosure concerns); ‘I feel I’m not as good as others because I have herpes’ (negative self-image); and ‘Most people think a person with herpes is disgusting’ (concern with public attitudes about people with herpes). Four questions were removed from the scale since the researchers believed the statements would not apply to herpes in the same way they apply to HIV/AIDS (e.g. ‘I worry about people discriminating against me because I have HIV/AIDS’).

10-item stigma scale of The Pan-African Study Group on Onchocercal Skin Disease (1995)

This scale was developed, validated and used by The Pan-African Study Group on Onchocercal Skin Disease (1995) [17]. A 10-item stigma scale was constructed around the following indicators: disclosure, esteem, leadership, heterosexual relationships, pity, avoidance, shame, marriage and sexual functioning.

13-item, 39-point stigma scale

The 13-item, 39-point stigma scale [4] was created by expanding the 10-item stigma scale of The Pan-African Study Group on Onchocercal Skin Disease (1995) [17]. An item was added pertaining to the embarrassment caused by itching in front of others, as were items on perceptions of what others think of the person and his/her family. Responses for stigma items were coded as follows: 0=no, 1=uncertain, 2=possibly or conditionally and 3=yes.

Acne adapted Feelings of Stigmatization Questionnaire

The authors adapted the original Ginsburg & Link Feelings of Stigmatization Questionnaire [7,10] to measure feelings

of stigmatization in individuals with acne. To have an adequate modification of the questionnaire in order to correspond to the study topic, they replaced word “psoriasis” in each statement with word “acne”.

Afterwards, they adapted culturally the questionnaire to the Greek language.

CONCLUSIONS

During the preparation of the current review various dermatology – and disease-specific instruments have been identified which could be used to measure the stigmatization experience among patients with skin problems. Some of them present a high scientific level with the proper description of the validation process. This group contains for example 6-Item Stigmatization Scale, Questionnaire on Experience with Patients Complaints,

Perceived Stigmatization Questionnaire and Feeling of Stigmatization Questionnaire.

To the best of our knowledge this review is the first available attempt to identify and group a questionnaire for the stigmatization assessment in patients suffering from different skin diseases. We would like to recommend the use of dermatology-specific instruments to compare the stigmatization level in various skin conditions. They could also be of use even as the first line to study the feeling of stigmatization in specific skin diseases; however, were it is possible based on available questionnaires, they could be supplemented with the disease-specific instrument. The disease-specific questionnaires allow deeper analysis both of quality of life and stigmatization. Some studies showed that there was a significantly positive correlation between the results obtained with dermatology – and disease-specific stigmatization instruments [9].

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