

Compliance in contact allergy with focus on cosmetic labelling: a qualitative research project

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Elimination of the allergen is an effective remedy in allergic contact dermatitis. When contact allergy to a preservative is diagnosed, the patient is instructed to read the labelling of contents and to avoid the use of products containing the allergens. The present study, using qualitative research methods, was performed to examine how socially different groups of patients handle everyday life with allergic contact dermatitis caused by preservatives in consumer products. 8 women were interviewed about reading the ingredient labelling on cosmetic products. Observational studies were carried out as well. The study illustrates that the patients experienced problems when trying to read the labelling of contents. The problems were related to social status and ranged from not being able to read the chemical names of the preservatives to doubting the accuracy of the ingredient labelling. The study indicates that non-compliance with instructions on reading the ingredient labelling is not only a question of patients' lack of knowledge, but also the result of patients not possessing the resources necessary to act in accordance with the medical instructions. The present study is, to our knowledge, the first to apply qualitative research methods to contact dermatitis. The study points out interesting observations about social status and resources in relation to compliance. Further research on this area is necessary to expose the extent of the problem.

Key words: allergic contact dermatitis; Bourdieu; compliance; cosmetics; information; ingredient labelling; preservatives; social class. © Blackwell Munksgaard, 2004.

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Patients with contact allergy are instructed to avoid the allergens to which they are sensitive, and, in the case of sensitization to ingredients in consumer products, the patients are instructed to read carefully the ingredient labelling on the product.

By the 6th Amendment to the EU Cosmetics Directive, which came into force on 1 January 1997, all cosmetics in the EU should be labelled with their ingredients (1). The purpose of the Directive is to make it possible for patients with contact allergy to identify and avoid allergens in cosmetics (2). Further, it improves the options for the dermatologist in diagnostic work and adds to the general openness with regard to exposure from environmental chemicals.

Compliance, defined as '... the extent to which the patient's behaviour ... coincides with medical or health advice.' (3) is of major importance for the prognosis of allergic contact dermatitis. However, discrepancies between medical instructions and patients' actions often occur and are frequently taken as an expression of patients' lack

of knowledge or understanding (4). In order to bring patients' actions into line with the medical instructions, health personnel have given additional instructions (5, 6), handed-out written patient information (7) and established 'eczema schools' (8).

These interventions are implicitly based on the assumption that patients' actions in relation to illness are mainly based upon cognitive knowledge. However, studies inspired by sociologic theories indicate that differences in social life circumstances non-consciously lead to socially different ways of coping with illness (9–11).

The aim of the present study was to analyse how patients from different social backgrounds manage everyday life with contact allergy caused by preservatives in consumer products and to investigate the kind of knowledge on which their actions are based. A qualitative research method, including interviews and observational studies, was applied. This method allows an in-depth investigation of patients' ways of thinking (12).

This information is important for understanding compliance and non-compliance and provides the background for future patient information and interventions.

Materials and Methods

Theoretical perspective

The study was based on the empirical and theoretical works of the French sociologist Pierre Bourdieu (13, 14). Bourdieu has studied the process of learning, primarily from the social conditions of the process. One of the fundamental concepts in Bourdieu's theory is habitus, which is defined as a system of several built-in dispositions that organizes the individual's capacity to act, perceive and prefer in a specific way in different social contexts. The dispositions are not innate but acquired and formed by the social circumstances during childhood, during education and through socialization in general (13). Habitus predisposes people to make choices, which are not necessarily conscious (14).

Another central concept, capital, is used to describe any form of resource, of either material or symbolic character, e.g. in the form of money, educational qualifications or titles, which enables people to act in a social context (15).

Practices – everyday activities – are, therefore, according to the theory of Bourdieu, shaped both by the habitus, which disposes people to act in particular ways, and by the availability of various types of capital. Analogous social circumstances in childhood and in adult life thus generate analogous habitus, which means that it is possible to show regularities in the actions of various social classes.

Materials

Participants were recruited from hand-eczema patients visiting the outpatient dermatological clinic, Gentofte Hospital, in the period 1 January 1998 to 31 December 2001. Inclusion criteria were age 30–50 years, treatment of the eczema with a potent topical corticosteroid for at least 4 weeks during the last 4 years, and a non-occupational contact allergy to one or more of the following preservatives: formaldehyde, quaternium-15, iodopropylbutylcarbamate, 2-bromo-2-nitropropane-1,3-diol, imidazolidinyl urea, diazolidinyl urea, methylidibromo glutaronitrile, phenoxy-ethanol and methylisothiazdinone/chloromethylisothiazolinone.

40 patients were available for the study. They were according to sociological criteria grouped into 3 subpopulations by stratified selection (Table 1).

Table 1. Stratified selection

Stratum			
Sex*	Postal code†	Educational level‡	Number
Men	High	Higher education	1
		Middle-range training	
		Short-range or no training	
	Medium	Higher education	
		Middle-range training	
		Short-range or no training	
Low	Higher education	5	
	Middle-range training		
	Short-range or no training		
Women	High	Higher education	2
		Middle-range training	3
		Short-range or no training	
	Medium	Higher education	4
		Middle-range training	
		Short-range or no training	
	Low	Higher education	1
		Middle-range training	
		Short-range or no training	
Total			26

Stratification was performed with respect to *sex, †postal code as an expression of social conditions and ‡education. The postal codes in the county of Copenhagen were classified into 3 subgroups based on the average price of 1-family houses in 2000: low postal codes including areas with average price of 1-family houses less than kr.1.5 million, medium postal codes including average prices between kr.1.5 million and kr.2 millions and high postal codes including areas with average prices above kr.2 million. Educational level was classified according to the Danish Ministry of Education (27); higher education, middle-range training and short-range or no training.

The purpose was to construct 3 social positions or classes that possessed similar resources and characteristics. The first stratum was sex, the second stratum was postal code as an expression of social conditions and the third stratum was educational level. The descriptions of patients' occupations in their medical records provided the background for an estimate of educational level.

For 1 man and 13 women with addresses outside the county of Copenhagen, classification according to postal code was not unambiguous and they were excluded. The remaining 26 patients were distributed over the subgroups seen in Table 1. Only patients characterized by similar values of postal code and educational level, both being high, medium or low, were included in the study.

6 women were mixed types, where the postal code and educational level did not have the same value, and they were excluded from the study.

The patients will, in the following, be referred to as higher, middle and lower social position.

It was the original intention to achieve participation from 2 men and 2 women from each stratum. Letters requesting the patients to take part in the interviews were in the first round sent to the only man and the 2 women in higher social position, 4 women in middle social position (no males in this position) and 2 men and 2 women in lower social position. 2 women in higher, 4 women in middle and 1 woman in lower social position agreed to participate. Then letters in second round were sent to 2 men and 1 woman in lower social position, all of whom, however, declined. In the third round, letters were sent to 4 women in lower social position, of whom 1 accepted to participate. Taken together, letters were sent to 18 patients (5 men and 13 women), and 2 women from higher, 4 from middle and 2 from lower social positions agreed to participate in the study.

Of the 10 (5 men and 5 women) patients declining to participate, 9 were by stratified selection characterized as lower social position and one as higher social position. Reasons given for declining to participate were lack of time or just not wanting to participate.

Method

Semi-structured interviews were carried out by an interview guide and observations of reading of labellings were performed. The interviews were inspired by Bourdieu's way of performing active and methodical listening (16).

The interview guide included questions regarding demographic variables, social trajectory, rituals in relation to illness in childhood, practices in relation to treatment of contact dermatitis in adult life, information retrieval and everyday life with contact eczema at home, at work and when purchasing cosmetics. Information obtained at the interviews also included frequency of hand-eczema eruptions [no eruptions, few eruptions (less than 4 per year), frequent eruptions (more than 4 per year) or constant eruptions].

The investigator conducted all interviews that were carried out either in the participants' home or at Gentofte Hospital. The interviews were carried out in October and November 2002 and were of about 1½–2 h duration. All conversations and the verbal part of the observational studies were tape recorded with the patients' permission and later transcribed verbatim. Permission to keep a register of the patients was obtained from The Danish Data Protection Agency.

Constructing 3 social groups

After the interviews, the women were reclassified according to their social backgrounds. Bourdieu

has shown a close connection not only between educational background and practices, but also related to differences in social background defined by fathers' education. By similar levels of education the significance of social background increases (13).

First data on patients' educational background, according to level of education (higher education, middle-range and short-range training), provided the background for a theoretical forming of 3 social groups. Then, patients' occupation as well as the parents and the partners' education and occupation were taken into consideration.

One woman had higher education, 4 had middle-range and 3 had short-range training. 1 of the partners had higher education, 6 had short-range or no educational training. 1 woman had no partner. The fathers all had short-range or no educational training. Although some of the patients, their fathers or their partners had similar educational backgrounds, they possessed different resources that enabled them to take different social positions in working life. This is shown in a short presentation of the 3 groups below.

The evaluation of patients' social backgrounds, trajectories and actual life circumstances resulted in 1 woman selected as higher social position being transferred to middle social position.

The woman in higher social position is in the singular because this group consists of just 1 person. She had an academic education and was employed in a high academic position and her father was a skilled and self-employed worker.

The women in middle social position refers to a group consisting of 5 women. They had short or middle-range training, e.g. office training or physiotherapist, and they were employed as salaried employees. Their fathers as well as their partners had short-range or no educational training and were employed either as salaried employees or public employees in leading positions.

The women in lower social position refers to a group consisting of 2 women. They had middle- or short-range educational training, and they were employed as salaried employees or skilled workers. Their partners as well as their fathers had short or no educational training. Their partners were employed as skilled workers, their fathers as unskilled workers.

Data coding

The transcribed interviews were coded using a qualitative analysis method that was inspired by Bourdieu's way of analysing data (13). Data concerning the informants' practices in relation to

purchasing cosmetics were systematized in a table, which enabled an overview and systematizing of the social differences in the informants' actions.

Results

The severity of the hand eczema with respect to frequency of eruptions was distributed between the 3 social groups as shown in Table 2.

Practices in higher social position

The woman in higher social position reads the ingredient labelling whenever she purchases cosmetic products, including products she has previously used without allergic reactions. She can read and pronounce the names of the preservatives, and due to an education and occupation in the chemistry-field she also knows the chemical structure of the preservatives.

Interviewer: '...some have told me that they find it difficult to read the labelling of contents...'. Woman: '...well yes...but I don't think so...that's because I can read the names and I can also pronounce them because I know their chemical structure...'.

She often doubts the correctness of the ingredient labelling, '...because you actually couldn't see that the products contained them [the preservatives]...and some times they did anyway...()...even though I am a chemist I find it hard to work out...'. Sometimes she writes a letter to the production manager of the company concerned. If necessary, she reminds them that she has not had a reply, '...then I send a reminder and entitle myself professor...and then they reply...'.

Practices in middle social position

The women in middle social position sometimes read the ingredient labelling when purchasing cosmetics they have no previous experience of using. When they buy a product they previously have used without allergic reactions, they often

do not look through the labelling of contents. This is not an expression of lack of knowledge, '...I am aware that they [the producers] all of a sudden put in something different...'.

The reason they give for not reading the labelling of contents is that it is difficult to read the names of the preservatives and other substances. The following example illustrates how these women read the names of the preservatives, '...Formaldehyde I can of course remember...but then there is...Qua...ter...mi...num 15 and then there is something...eh...eh...Mety...klo...rosol...or something like that...'.

Some of them have spotted a frequently occurring preservative they are allergic to, and first of all look for that in the labelling of contents, '...some of them just leapt out...and exactly that one...di...mi...so...li...dinyl...or whatever it is called...I can see it right away when it is there...that is the one I first look for...then you can leave out all the others you don't really know...like eight – cero – one...or what ever they are called...'. Others compare the first syllable of the substances to the first syllables of the preservatives.

The women in middle social position express that when they read the labelling, they often doubt, whether they have read or, as they put it, decoded it correctly. None of them have written letters to the producers. They ask the shop assistant's advice, or they ask the shop assistant to contact the producers' customer service.

Practices in lower social positions

The women in lower social position hardly ever read the ingredient labelling on cosmetic products. They first of all buy the products they have previously tolerated. They do, however, know that the content of cosmetics is frequently changed and that they would benefit from reading the labelling of contents, but they express great difficulties in reading the names of the ingredients in the product. As the following excerpt from an observation of a woman comparing her written information to the labelling on a moisturizer clearly illustrates, they spell their way through the list of ingredients, '...well...so...then it says...(looking at the tube)...pro...(looking at her list)...pro...(looking at the tube)...py...le...ne...(looking at her list)...are you there...phew...no...I don't think you are...(looking at the tube)...gly...(looking at her list)...no...(looking at the tube)...gly...c...o...l...gly...col...(looking at her list, sighing)'.

Table 2. Frequency of hand eczema eruptions

	Women in higher social position	Women in middle social position	Women in lower social position
Few eruptions		1	
Frequent eruptions		2	
Constant eruptions	1	2	2

Frequency of hand eczema eruptions for the women in the 3 different social groups.

When the women in lower social position buy a cosmetic product they have no previous experience of, they use different techniques in order to ensure that the product does not contain allergens. They count the letters in each preservative on their written information and compare the number of letters with the number of letters in the substance on the labelling, '...it is hell to put it mildly...I can't even read the words...so I have to count the letters in the labelling of contents...to find out whether it was more or less the same...as in my own list...and then they don't have the same endings...then what...am I allergic to the product or not...I think it is very difficult...'.

None of them have written letters to the producers and none of them have asked the shop assistant to contact the producers' customer service. They ask the shop assistant to help counting or to read and compare the 2 lists.

Discussion

The diagnosis of allergic contact dermatitis is often challenging and requires a high degree of expertise and experience from the clinician. Because elimination of the allergen is an effective remedy in allergic contact dermatitis, the next big challenge being to make sure that the patient is informed and is able to handle the situation. If these last steps are not taken care of, the problem will not be solved for the patient and the testing is rendered pointless.

Compliance with avoidance of contact allergens for patients with contact allergy is often not satisfactory. Only very little documentation is available within this area, but a few previous studies do indicate that high compliance and understanding will improve the prognosis (17, 18).

Understanding of the factors generating patients' actions and influencing compliance is important, and this understanding can be

obtained through qualitative research. The present study shows that non-compliance to reading the lists of ingredients is not entirely a question of lack of knowledge and indicates that knowledge is not enough to ensure behaviour in accordance with the medical instructions.

However, the woman in the higher social position was the only one acting in accordance with the medical instructions (Table 3). As opposed to this, women in middle social position found it difficult to read the terms of the substances, and they developed different techniques to exclude reading the non-relevant substances. The fact that they also bought cosmetics without reading the labelling of contents was not interpreted as lack of knowledge, but a consequence of not possessing the specific resources necessary.

Women in lower social positions were to a greater extent than the other 2 groups at risk of exposure to allergens, as they usually did not read the labelling of contents, even though they knew that they would benefit from it. However, a study prepared by The Danish Ministry of Education in 1990 points out that 12% of the Danish population between the ages of 18 and 67 years have considerable difficulties reading ordinary everyday text, such as tabloid articles and price lists. The study also shows that people with short-range training have the greatest difficulty (19).

It is well known that many patients cannot fulfil the reading tasks required to function in the health care environment. Health literacy is defined as the capacity of individuals to read and understand health information (20). Even though efforts have been made to improve the comprehensibility of written patient-education material, it is in many cases still written at a too high a level for low-literate patient to comprehend (21). There is no unambiguous connection between educational length and level and ability to read (22), but low-literacy patients often have short-range educational training or none at all (23, 24).

Table 3. Practices

	Women in higher social position	Women in middle social position	Women in lower social position
Explicit knowledge	Yes	Yes	Yes
Read labelling	Always	Sometimes	Rarely
Readability of labelling	Easy	Difficult	Very difficult
Techniques	—	Spot frequently occurring preservative	Count letters
		Compare first syllables	Spell
Doubts	Correctness of labelling	The decoding	The counting
In case of doubts	Writes letters to producers	Ask shop assistant to contact producer	Ask shop assistant to read or count

An overview of socially different practices in relation to reading labelling on cosmetics.

In the present study, 10 of 18 patients declined to participate in the study and 9 of these were classified as lower social position. One possible explanation of the high dropout rate from patients in this social position is that they were not able to read or did not understand the letter inviting them to participate. The intention to achieve participation from 4 patients from each stratum failed as only 2 women from lower social position agreed to participate.

In the present study only the woman in higher social position questioned the accuracy of the ingredient labelling, just as she was the only one writing letters to the producers. The women in middle and lower social position questioned whether they had read the labelling or counted the letters correctly, and they did not write letters to the producers. This does not necessarily mean that they are not capable of writing letters, even if one cannot exclude the possibility. It is more likely that the behaviour is simply not within the bounds of possibility set by their habitus and resources. Furthermore, they have no titles or other resources that could ensure responses to their letter.

From the medical perspective the women in middle and lower social positions might be classified as non-compliant, as they do not always read the labelling of contents when purchasing cosmetics. But in the sociological perspective the women are still acting reasonably appropriately within the limits imposed by their resources. It is, for example, reasonably appropriate when the women in lower social positions stick to the products they have previously tolerated, because they do not possess the resources necessary to read the ingredient labelling.

From this perspective the women all act reasonably in accordance with the medical instructions, but they do it in socially different ways. Health staff might not acknowledge these social translations or versions of the medical instructions as the medical instructions carried out in practice.

The strength of the present study is the detailed information obtained by the interviews in the tradition of qualitative research methods. This information is necessary to understand the factors that promote or impede compliance with reading the labelling of cosmetics. The weakness of the study is the dropout from a total of 10 patients, but we have no reason to believe that these patients differ from the patients that accepted to participate.

Allergic contact dermatitis is a common disease affecting around 10% of the population, and contact sensitization has been shown to increase with

decreasing degree of occupational training (25, 26). Results from the present study, however, indicate that compliance – defined as patients' actions in exact accordance with the medical instructions – is best in well-educated patients in higher social position, because the instructions given by health personnel to a greater extent fit the resources that these patients possess. In order to make it possible for patients with other resource compositions to avoid allergens in cosmetics, new and easier ways to identify allergens should be invented, as for example colour codes to identify allergens. Also, alternative educational methods and materials to bring our instructions into line with patients' resources should be used.

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