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Illness Representations in Families with a Chronically Ill Adolescent: Differences between Family Members and Impact on Patients' Outcome Variables

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Abstract

The impact of parents' illness representations on well-being and illness-related strain of adolescents suffering from a chronic skin disease was examined. Because family characteristics have proved to be important for coping, adolescents' perceived family cohesion was also assessed. Five categories of illness representations (causes, control, timeline, curability, and effective treatments) were assessed from 30 adolescents and their parents. Comparisons revealed differences between family members' illness representations. Perceived family cohesion was a good predictor of adolescents' well-being and strain, whereas parents' illness representations had only little impact. In families with high similarity between the parents' illness representations, the adolescents reported more well-being. Results are discussed with regard to developmental characteristics of adolescence, nature of outcome variables and methodological problems.

Keywords

adolescents, family, illness-related strain, illness representations, well-being

THE CONCEPT of illness representations was developed to describe how people conceptualize disease information and salient medical experience. Similarly, representations of health comprise of health-related knowledge, attitudes and experiences (Farr & Markova, 1995; Flick, 2000). There are different research traditions on the topic of how people conceptualize illness and health. Murray (1990) describes two main theoretical approaches: the cognitive approach (Leventhal, Benyamini, Brownlee, Diefenbach, Leventhal, Patrick-Miller, & Robitaille, 1997; Leventhal, Leventhal, & Cameron, 2001; Leventhal, Safer, & Panagis, 1983) and the social approach (Herzlich, 1973; Moscovici, 1988; Sontag, 1997). The cognitive approach aims at describing how individuals process illness- and health-related information in order to build personal, idiosyncratic theories about illness and health, while the social approach highlights the sociological and social psychological processes that result in shared beliefs about health and illness and a common understanding of certain illnesses within a society or a subgroup of a society. Both approaches complement each other, but most studies in this field focus either on individual or social representations of illness and health. In the present study, the cognitive approach to representations of illness is taken.

According to this approach, illness representations consist of stable categories like beliefs about causes, control, identity, time-line, curability and possible cures (Lau, Bernard, & Hartman, 1989; Leventhal, Meyer, & Nerenz, 1980; Turk, Rudy, & Salovey, 1986). The content of the categories varies between individuals according to personal experience with an illness or observed experiences made by significant others (Horne & Weinman, 1998). Illness representations are central to understanding coping with acute and chronic illness, because the content of illness representations influences illness-related behaviour, compliance and varied outcome variables like well-being and illness-related strain (Heijmans, 1999; Heijmans, de Ridder, & Bensing, 1999; Maes, Leventhal, & de Ridder, 1996; Moss-Morris, Petrie, & Weinman, 1996; Petrie, Weinman, Sharpe, & Buckley, 1996; Scharloo, Kaptein, Weinman, Hazes, Willems, Bergam, &

Roijmans, 1998; Schiaffino, Shawaryn, & Blum, 1998; Weinman & Petrie, 1997).

In the case of chronic illness, not only the illness representations of the patient, but also the representations of relatives and other persons close to the patient are important in order to understand and predict the coping effort of the patient (Weinman, Petrie, Sharpe, & Walker, 2000). The role of the family in the context of illness representations and coping with a chronic illness is manifold: family members are sources of information that may influence the patient's illness representations (Leventhal et al., 1980), supportive families may help the patient to build more adaptive representations (Lau, Quadrel, & Hartman, 1990), close family members and the support they give are important factors in coping with a chronic illness (Aymanns, Fillip, & Klauer, 1995; Coyne & DeLongis, 1986; Schröder & Schwarzer, 2001). Most patients with a chronic illness live within a family or a similarly close relationship, and consequently the illness representations of close relatives like spouses, parents or children should be assessed for a broader understanding of coping behaviour and coping outcomes (Heijmans et al., 1999).

In the context of illness representations and coping with chronic illness in a family, the role of family characteristics like emotional closeness (cohesion) has not been studied in great detail. Family stress theory shows that in many cases higher cohesion is linked to a more effective family coping with severe stressors like chronic illness (Drotar, 1997; Olson, 2000; Patterson & Garwick, 1998; Skinner, John, & Hampson, 2000). Including the concept of illness representations in this line of argumentation, some hypotheses about associations between family cohesion, illness representations within a family and individual coping can be put up: cohesive families should be better prepared to build a family illness representation that is shared more or less by all family members. A shared meaning or 'paradigm' of the illness is necessary to take joint actions against the stressor in order to cope successfully with it (Cohen, 1999; Patterson & Garwick, 1998; Reiss & Oliveri, 1980). In conclusion, in families with family members sharing similar beliefs about the illness of one family member as an indicator

of a generally high family cohesion, coping with the chronic illness of the family member should be more effective and coping outcomes should be more positive.

In families with a chronically ill child the parents have a central role concerning treatment, adherence, adjustment to the illness and disease outcomes in the child (Williams, Holmbeck, & Greenley, 2002). The relation of parent and family functioning to the psychological adjustment of young children with chronic conditions has been examined in many studies and reviews (e.g. Casey, Sykes, Craig, Power, & Mulholland, 1996; Cohen, 1999; Drotar, 1997). More recently, adolescents' coping with a chronic illness and the role of parents and other family members in the course of coping and adjustment has become a topic of interest (Seiffge-Krenke, 1998; Skinner et al., 2000; Williams et al., 2002), one reason being that approximately 10 per cent of all adolescents suffer from a chronic condition (Suris & Blum, 2001). During adolescence a chronic medical condition can challenge the management of developmental tasks like autonomy, establishing close relationships to non-relatives and consolidation of a positive image of oneself (Fritz & McQuaid, 2000). Despite the growing independence of the adolescent patients from their parents, parents are still strongly involved in the management of the illness, and the adolescent's illness demands much co-operation between parents and adolescent and between parents (Seiffge-Krenke, 1998). Therefore, the impact of parents' illness representations on coping and outcome variables of chronically ill adolescents deserves attention. Not only the content of mothers' and fathers' representations of their adolescent child's illness, but also the similarity between parents' illness representations may be an important factor for coping outcomes in the adolescents, because shared illness meaning between the parents may indicate a stable and predictable family structure that contributes to a healthy development of the children (Block, Block, & Morrison, 1981; Deal, Halverson, & Wampler, 1989). To sum up: individual illness representations have proved to be important in coping with a chronic illness. In the case of adolescents suffering from a chronic illness, also the illness representations of the

parents may be influential in the adolescents' coping process. In particular the existence of a shared parental illness representation, i.e. a high similarity in mother's and father's understanding of the adolescent's illness, could affect the adolescent's well-being and perceived strain. Parental illness representation and adolescent's outcome variables should be linked by emotional closeness (cohesion) between the family members.

The first aim of the present study was to determine the similarities or dissimilarities between illness representations of family members (patients, mothers and fathers) in families with a chronically ill adolescent: on a group level, what categories of illness representations are different between family members? The second research question concerns variables that influence patients' outcome variables, i.e. well-being and illness-related strain: to what extent are these variables explained by parents' illness representations and perceived cohesion of the family? For the third research question the level of analysis is changed to the family as a unit: in families with a high similarity between illness representations of the parents, are patients better adjusted in terms of their well-being and strain?

Method

Sample and procedure

The sample included 30 families with one adolescent child suffering from atopic eczema, a chronic skin disease. Symptoms are severe itching and a red, flaking and inflamed skin. There is no uniform manifestation of the illness, and causes for a change in symptoms vary individually. The itchy skin leads to excessive scratching which in turn leads to more itching and inflammation.

The mean age of the adolescents was 17.2 years (SD = 1.6), 13 participants were female. The patients were contacted in a rehabilitation clinic. Severity of atopic eczema was rated by the clinic staff using a scoring system ranging from 3 to 9 (Rajka & Langeland, 1989). The mean severity score was 5, indicating a mild to moderate mean symptom severity. In all patients, atopic eczema was diagnosed immediately after birth or during the first year.

Questionnaires were sent to the parents if the patients agreed. From the original sample of 38 adolescents who lived at home with both parents, four refused to permit a contact with their parents. In four cases, only the mothers but not the fathers returned the questionnaire, resulting in $n = 30$ complete data sets. The mean age of the 30 mothers and 30 fathers was 46.1 years ($SD = 4.9$) and 51.0 years ($SD = 10.3$), respectively. Siblings of the chronically ill adolescents were not included in the study.

Assessment of illness representations

Five categories of illness representations were assessed from the adolescents and their parents: beliefs about the time-line of atopic eczema, about curability, effective cures, attribution of causes and beliefs about control.

Beliefs about the *time-line*, *curability* and effective *cures* were assessed in an interview with the adolescent patients. Questions were: What do you think is the course your illness will take? Do you think your illness is curable? What kind of treatments do you regard as helpful? The parents were asked the same questions in a written format: What do you think is the course your child's illness will take? Do you think the illness of your child is curable? What treatments do and your child regard as helpful? Parents were asked to write down their answers.

Answers concerning the time-line and curability were then categorized by three independent raters. Time-line was categorized as either 'chronic' or 'non-chronic'. Answers concerning the curability of the illness were categorized as either 'curable' or 'non-curable'. The mean inter-rater reliability for the two categories was .81. The number of helpful treatments mentioned in each interview and questionnaire was counted.

Attribution of *causes* of the illness was assessed using a questionnaire. The questionnaire consists of 25 possible causes of atopic eczema, which represent external or internal causes. Causes were derived by analysing self-help literature for patients with atopic eczema. Causes were then further differentiated in external-naturalistic (e.g. 'Do you think your atopic eczema is caused by pollution?') and external-psychosocial (e.g. lack of social support) causes and internal-naturalistic (e.g. malfunctioning of

immune system) and internal-psychosocial (e.g. suppression of emotion) causes. Cronbach's α of the scales in a group of $n = 55$ adolescents suffering from atopic eczema was .62 (internal-naturalistic), .79 (external-psychosocial), .84 (internal-naturalistic) and .86 (internal-psychosocial). The same questionnaire was used in the sample of parents, only the wording of the items was changed from 'Do you think your atopic eczema is caused by . . .?' to 'Do you think your child's atopic eczema is caused by . . .?'. Cronbach's α of the scales in a group of $n = 41$ mothers of adolescents with atopic eczema and $n = 32$ fathers of adolescents with atopic eczema was .64/.59 (external-naturalistic), .74/.72 (external-psychosocial), .81/.84 (internal-naturalistic) and .84/.85 (internal-psychosocial). Items were answered on a four-point rating scale.

Control beliefs were assessed by three items taken from a German Health Locus of Control Questionnaire (Lohaus & Schmitt, 1989). The items represent internal, powerful others and chance locus of control beliefs (Levenson, 1981). Answers to the items were given on a six-point rating scale. Again the same items were presented to the adolescents and their parents, only that the wording was slightly changed (instead of 'my illness', 'my child's illness').

Assessment of patients' well-being, illness-related strain and perceived cohesion of the family

To assess the *patients' well-being* a questionnaire for adolescents (BFW, Grob, 1995) was used. It consists of six subscales and two second order scales. The six subscales are: (1) Positive attitude towards life (six-point rating scale, Cronbach's α for a group of $n = 55$ adolescents with atopic eczema = .84); (2) Problems (six-point rating scale, $\alpha = .58$); (3) Somatic complaints and reactions (four-point rating scale, $\alpha = .77$); (4) Self-esteem (six-point rating scale, $\alpha = .84$); (5) Depressive mood (six-point rating scale, $\alpha = .84$); and (6) Joy in life (four-point rating scale, $\alpha = .61$). The two second order scales are called 'contentedness' and 'negative state'.

For assessment of *patients' strain* the Marburg Atopic Dermatitis Questionnaire (MNF, Stangier, Ehlers, & Gieler, 1996) was used. It assesses five aspects of disease-specific functioning of the

patients: (1) Social stigmatization (*Crohnbach's a* for a group of $n = 55$ adolescents with atopic eczema = .87); (2) Restrained emotional coping with atopic eczema ($a = .88$); (3) General emotional distress ($a = .82$); (4) Impact on quality of life ($a = .58$); and (5) Awareness of restriction in active problem-related coping ($a = .55$). Items were answered on a five-point rating scale.

Family cohesion as perceived by the adolescents was measured using a German adaptation of the FACES II (Olson, Russell, & Sprenkle, 1983; Schmidt, Rosenthal, & Brown, 1988; von Schlippe, 1985). The scale consists of 16 items (e.g. 'Family members consult other family members on their decisions') with a five-point rating scale; a -reliability of the scale was .92.

Results

Differences of illness representations between family members

Table 1 shows the results for the categories causes, control and treatments for the patients, the mothers and the fathers. There were significant differences concerning the causes of the illness: both mothers and fathers believed more strongly in internal-naturalistic causes of atopic eczema (e.g. bodily malfunctioning) than the patients. Beliefs about control differed in two respects between the family members: patients believed significantly stronger than both parents in an internal locus of control, and mothers scored significantly higher on beliefs in external-powerful locus of control (i.e. health care providers) than fathers and patients. Fathers reported significantly fewer effective treatments than both patients and mothers. Table 2 shows the intercorrelations of the categorical variables time-line and curability. There were no significant correlations between patients, mothers and fathers concerning their belief in the curability of atopic eczema (number of patients, mothers and fathers who believed in the curability/non-curability of atopic eczema did not differ significantly: $\chi^2 (4, N = 90) .70, NS$), while beliefs about the time-line were significantly correlated between mothers and fathers, both believing significantly stronger in a chronic course of the illness than in a chronic time-line.

Table 1. Means and standard deviations for patients', mothers' and fathers' beliefs about causes, control and helpful treatments

Category	Patient (n = 30)		Mother (n = 30)		Father (n = 30)		p	Scheffé-test
	M	(SD)	M	(SD)	M	(SD)		
Cause								
external-naturalistic	3.50	(.77)	3.54	(.67)	3.30	(.75)	NS	
external-psychosocial	2.48	(.74)	2.31	(.73)	2.22	(.67)	NS	
internal-naturalistic	2.45	(.70)	2.90	(.63)	2.83	(.57)	< .5	patient < father, mother
internal-psychosocial	2.88	(.78)	2.82	(.76)	2.79	(.78)	NS	
Control								
internal	4.63	(1.13)	4.03	(1.35)	3.85	(1.51)	= .5	patient > father, mother
external-powerful others	3.40	(1.50)	4.41	(1.15)	4.22	(1.50)	< .5	patient, father < mother
external-chance	2.77	(1.52)	2.76	(1.48)	2.52	(1.40)	NS	
Treatments (number)	5.03	(2.36)	4.10	(2.30)	1.86	(1.87)	< .01	father < mother, patient

Table 2. Correlations between patients', mothers' and fathers' beliefs about time-line (chronic vs. non-chronic) and curability (curable vs. non-curable)

	Patient	Mother
<i>Timeline</i>		
Mother	-.27	
Father	.03	.59**
<i>Curability</i>		
Mother	.35	
Father	.24	.33

** $p < .01$

Prediction of patients' well-being and illness-related strain

To answer the question whether the patients' well-being and illness-related strain can be explained by perceived cohesion of the family and the parents' illness representations, linear regression analyses were computed (Table 3). The control variable 'illness severity' was not included because it showed no significant correlation to any of the outcome variables. Fathers' and mothers' beliefs about causes, control and effective treatment were entered as predictors in the analyses; time-line and curability were omitted because of their categorical nature. In general, well-being and illness-related strain could be explained to some extent by the variables entered in the analyses (with the exception of 'social stigmatization'). Perceived cohesion was a significant predictor in explaining both aspects of general well-being, contentedness and negative state. Cohesion was also an important variable in explaining two aspects of illness-related strain, i.e. emotional distress and restriction in active problem-related coping: in both cases, high perceived cohesion predicted less strain. Only some aspects of fathers' and mothers' beliefs about causes and control of atopic eczema proved to be significant predictors of well-being and strain. Fathers' beliefs about high powerful others locus of control predicted high negative state, and beliefs about high chance locus of control predicted less restrained emotional coping and less impact on quality of life. Fathers' external-psychosocial causes predicted negative state, while high beliefs in internal-psychosocial causes on the mothers' side predicted high emotional distress.

Table 3. Regression analyses to predict patients' well-being and illness-related strain

	Contentedness		Negative state		Social stigmatization		Restrained emotional coping		Emotional distress		Impact on quality of life		Restriction in active problem-related coping	
	β	R^2_{Corr}	β	R^2_{Corr}	β	R^2_{Corr}	β	R^2_{Corr}	β	R^2_{Corr}	β	R^2_{Corr}	β	R^2_{Corr}
Cohesion	.58**	.31**	-.44**	.59***	-.29	.14*	-.44*	.42***	-.49*	.21*	-.46*	.18*		
Fathers' illness representations:														
Powerful others locus of control			-.48**											
Chance locus of control														
External-psychosocial causes			.40**											
Mothers' illness representations:														
Internal-psychosocial causes														.55**

*** $p < .001$, ** $p < .01$, * $p < .5$

Patients' adjustment and similarities between parents' illness representations

In order to analyse the illness representations within the family, first the parental representations had to be classified as either similar or dissimilar. For this reason, a score that indicates the similarity or dissimilarity of the parents' illness representations had to be built. Olson, Portner and Lavee (1985) suggest both mean and discrepancy scores to indicate similarity between family members, but studies comparing different types of dissimilarity scores showed that all types of scores have methodological problems (Calsyn, Winter, Rodes, Trusty, Pruett, & Lira, 1998; Mathijssen, Koot, Verhulst, de Bruyn, & Oud, 1997). For the present study a procedure similar to that described by Heijmans et al. (1999) was used. First, the two categories 'causes' and 'control' were chosen for computing a dissimilarity score because they are core categories of illness representations. 'Number of effective treatments' was omitted because the significant differences in this category between mothers and fathers (see Table 1) may more likely reflect different knowledge about the daily treatment of atopic eczema than different opinions about the usefulness of certain treatments. The fathers in the study were hardly involved in the daily care for the patients, and therefore their beliefs about effective treatments probably are not as well grounded as mothers' beliefs. Beliefs about the time-line and curability were omitted because they are categorical variables. Then dissimilarity scores were computed for each family by subtracting the father's scores on each category from the mother's scores. The two resulting scores for causes and curability were summed up and divided by two, creating a score of the mean dissimilarity between father and mother on the two categories. The resulting dissimilarity score ranged from -5.45 to 3.48 ($M = -0.49$, $SD = 1.99$). A higher score, either negative or positive, reflects more dissimilarity between the parents. Families with parents having a dissimilarity score beyond one standard deviation from the mean were labelled as 'dissimilar' (12 families), while families with parents within one standard deviation from the mean were labelled as 'similar' in their beliefs about causes and control (18 families). As could be expected, the patients

perceived the two types of families as differently cohesive, with similar families being perceived as significantly more cohesive than dissimilar families ($F(1,28) = 4.19$, $p < .5$). Table 4 shows the results of ANOVAs comparing patients' well-being and illness-related strain of the two types of families. Adolescents who live in families with parents sharing similar beliefs about causes and control of atopic eczema reported significantly more general well-being ($F(1,28) = 6.93$, $p < .5$ for contentedness and $F(1,28) = 4.36$, $p < .5$ for negative state). There were no significant differences between the two types of families on the five scales measuring illness-related strain.

Discussion

Differences between family members' illness representations

On a group level, family members reported quite similar beliefs about curability and chance locus of control. Concerning the causes, there also seems to be considerable agreement between the three groups, with the exception of internal-naturalistic causes. Here both mothers and fathers reported significantly stronger beliefs about bodily malfunctions being important causes of atopic eczema. Focusing on internal-naturalistic causes might be helpful for the parents to focus on a biomedical model of the illness that places responsibilities beyond their influence. But on the side of the adolescent, believing that one's body is defective is not in accordance with the developmental task of 'accepting one's body' (Havighurst, 1982), and consequently attributing the illness to causes not connected with one's body might be helpful to maintain a positive self-concept.

There were two significant differences between adolescents and parents concerning beliefs about internal locus of control and the time-line of atopic eczema that may reflect typical aspects of adolescents' view of the world and the self. The adolescents believed much stronger than their parents that they themselves are in control of the illness, probably indicating a domain-specific development of internality (Edelstein, Grundmann, & Mies, 2000; Helgeson & Franzen, 1998): because of the high importance of the illness for the adolescents'

Table 4. Patients' well-being and illness-related strain in families with similar and dissimilar parents' beliefs about causes and control

	<i>Similar illness representations (n = 18)</i>		<i>Dissimilar illness representations (n = 12)</i>	
	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>
<i>Well-being:</i>				
Contentedness*	4.78	.43	4.13	.87
Negative state*	2.29	.65	2.85	.73
<i>Illness-related strain:</i>				
Social stigmatization	2.57	.89	2.76	.70
Restrained emotional coping	2.95	.81	2.78	.90
Emotional distress	2.54	.66	2.98	.75
Impact on quality of life	2.85	.79	2.52	.41
Restriction in active problem-oriented coping	2.90	.58	3.10	1.09

* $p < .5$

lives they ascribe themselves high internal control, even in spite of the uncontrollable nature of atopic eczema. Second, the adolescents did not agree with the mothers and fathers on a chronic time-line of their illness. There is some agreement in the literature that atopic eczema is a chronic condition (Fennessy, Coupland, Popay, & Naysmith, 2000), and therefore believing that the illness is not chronic is on one hand illusionary, but on the other hand this belief may protect the adolescents against feeling hopelessly handicapped in their plans for their future life. In sum, adolescents and parents showed some agreement and some differences in their illness representations, but to decide whether these similarities and differences are typical for families with a chronically ill child or just a characteristic of the sample is not within the scope of the present study. To determine the developmental meaningfulness of these differences, the results should be compared to families with no chronically ill adolescents or to families with chronically ill grown-up children living in the same household.

Regarding mothers and fathers, there seems to be considerable agreement concerning their illness representations, except for the number of effective treatments, beliefs about powerful others external locus of control and curability. Given the fact that mothers of chronically ill children and adolescents are much more involved in the daily routines concerning the illness (Silver, Westbrook, & Stein, 1998), the observed differences may reflect the different

level of knowledge about treatment and the role of professional health care providers in the treatment of atopic eczema. More fathers believed in non-curability than in curability of atopic eczema. This could reflect either resignation or a realistic view of the illness, but there are no data in the present study that could support any of these assumptions.

Parents' illness representations, cohesion and patients' well-being and strain

Adolescents' perceived family cohesion was the most important factor in explaining well-being and illness-related strain, again pointing to the predominant role of family functioning in coping with a stressor like chronic illness (Drotar, 1997). Surprisingly little variance of well-being and illness-related strain was explained by the parents' illness representations. Fathers' external locus of control beliefs and beliefs about external-psychosocial causes had some predictive value, but neither other causal attributions nor any of the mothers' illness representations were predictive. An exception is the mothers' belief about internal-psychosocial causes. The results raise two questions: why does it seem that fathers' illness representations are more important in explaining well-being and strain than mothers' illness representations, and why is, on the whole, the explanative power of the parents' illness representations so limited? The first question is not easy to answer. There are some hints

concerning the special and still underestimated role of the father in families with chronically ill children (Cook, 1984). Maybe during adolescence fathers' opinions become more important and adolescent girls and boys pay more attention to their fathers' opinions than to their mothers', but there is still no convincing proof for that. A plausible answer to the second question lies in the fact that the adolescents' world becomes increasingly larger and includes friends, teachers and maybe also other adults apart from the parents who communicate their beliefs about the illness to the adolescents (Gottlieb & Sylvestre, 1994; DiGirolamo, Quittner, Ackerman, & Stevens et al., 1997; Meijer, Sinnema, Bijstra, Mellenbergh, & Wolters, 2000; Stawski, Auerbach, Barasch, Lerner, Zimin, & Miller, 1995). Including the opinions of these important others could result in a more comprehensive pattern of adolescents' well-being and illness-related strain. Also, the cross-sectional nature of the study and the outcome variables that were assessed may have limited the possibility to detect links between parents' illness representations and adolescents' coping. Weinman et al. (2000) found in their study some associations between the illness representations of myocardial infarction patients' spouses and health-related lifestyle changes of the patients. If spouses attributed the patients' myocardial infarction to poor health habits, then improvements in patients' exercise level six months later were observed. These data indicate that there might be some impact of close relatives' illness representations on the coping efforts of patients. Including illness-related actions as outcome variables and expanding the time frame of the present study could lead to similar results.

Similarity between parents' illness representations and patients' well-being and strain

Turning the attention to the families as a unit of analyses and whether parents share similar views about their child's illness revealed that in families with a higher similarity between the parents the adolescents reported more general well-being, but not less illness-related strain. Similarity between parents' view about the illness can be viewed as one aspect of family cohesion as perceived by the adolescents, again pointing to the family as an important factor for

adolescents well-being, even in spite of the growing autonomy from the parents during adolescence (Fritz & McQuaid, 2000; Seiffge-Krenke, 1998). Consequently, the parents of chronically ill adolescents should be included in the planning of treatment programmes, and their beliefs about atopic eczema should be a topic of discussion between health care providers, adolescents and parents.

Illness-related strain of the adolescents did not differ between the two groups of families. Here again other factors besides the parental similarity may be more important for strain caused by atopic eczema. Though severity of the illness showed no relation to strain, other illness-related experiences like interruptions of activities because of itching, difficulty in finding comfortable clothes or offending comments by other people probably add more to the experience of strain.

Regarding the dissimilarity score to classify dissimilar and similar families, the method used here served as a helpful tool, but is far from solving the problem typically associated with difference scores (Cronbach & Furby, 1970; Mathijssen et al., 1997). There is still no sound measure of shared illness representations within a family or other social systems, and more research and methodological work is needed to clarify the structure of illness representations and to find ways to assess illness representations of social systems in order to understand the impact of the social system's representations on individual patients' coping behaviour and coping outcomes.

Concluding remarks

Though some associations between shared parental illness representations and adolescents' well-being have been found, the exact nature of the underlying process that guides the connection is still to be explained. Most probably the illness representations of all family members guide the family communication about the adolescent's illness and are at the same time changed during the family discourse. Coping with the adolescents' atopic eczema can be regarded as part of a family health-promotion project (Valach, Young, & Lynam, 1996) which is progressed by communication between parents and adolescents (Young, Lynam,

Valach, Novak, Brierton, & Christopher, 2001). Illness-related communication about atopic eczema and how to cope with it are one part of such health-promotion projects. Exchange about health-related topics, for instance what health-enhancing actions can be taken by the adolescents and the parents in order to deal more efficiently with atopic eczema, are probably another important part. The concepts of health and health-related representations within a family of chronically ill adolescents were not assessed in the present study, but could add to a broader understanding of coping and well-being.

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