Follow-up of Patients with Chronic Environmental Illness and Multiple Chemical Sensitivity (MCS) following Multidimensional Therapeutic Intervention

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Abstract:

Objective: The aim of this study was to determine, whether a multidimensional therapeutic approach can produce lasting improvements in the health of severely and chronically ill environmental medicine patients. **Design and participants:** An observational follow-up study was done on 105 patients with environmental illness and/or chemical sensitivity (n=49) of a specialised clinic for environmental medicine, psychosomatic and psychiatric illnesses and addiction. **Evaluations:** Patients symptom scores and health-related quality of life were assessed at the time of the first visit (t0) and six (t6) and twelve months later (t12) in a follow-up study. Data on history of exposure to pollutants, diagnoses, comorbidity, patients belief system concerning their illness and therapeutical measures were obtained from the doctor in charge. **Results:** A low contribution of comorbidity, a coherent belief system concerning the illness, a diagnosis of chemical sensitivity and repeated visits to the clinic, were all positive predictors of improvement. The therapeutic measures with the best positive effect were minimising exposure to relevant pollutants, training for coping, complementary psychotherapy and implementation of a rotary diversified diet (where applicable). Single contacts were not effective. Deterioration prevailed in patients with a non-coherent belief system concerning their illness. **Conclusion and relevance to clinical practice:** Relevant improvement in symptom scores and quality of life can be seen to be obtainable with the help of multidimensional therapeutic interventions treating all aspects of the illness, even in those serious and often complicated cases with long-standing environmental illness/chemical sensitivity.

Introduction

In spite of the increasing number of studies dealing with the prevalence of pollution-related diseases and with Multiple Chemical Sensitivity (MCS), there is hardly any information available as to the therapeutic options available to such patients (Caress et al. 2002; Gibson et al. 2003; Kreutzer et al. 1999; Meggs et al. 1996). However some of these patients are severely impaired in their health and urgently need medical assistance, without appropriate therapeutic standards being available. The discussion about MCS and other chronic environmental medical disorders continues

to be dominated by controversies concerning the causes of the disorders (psychiatric versus toxicological). The resulting therapeutic recommendations differ considerably from one another. (Ashford and Miller 1998; Bornschein et al. 2000; Davidoff et al. 2000; Joffres et al. 2001; Siegel and Kreutzer 1997).

Furthermore, as in all cohorts with severe primary disorders, these patients are relatively often subject to reactive psychological problems which also need to be taken into account in their treatment (Bauer et al. 2003; Caress et al. 2002). Other authors have also shown that both physiological and psychological factors are involved in triggering the acute symptoms displayed by MCS patients (Fiedler et al. 2004).

Further difficulties in treatment are due to the strong chronicity of the illnesses and to the fact that MCS patients often display an accompanying intolerance towards foods and also medications. This can lead to malnutrition or subnutrition, which has to be treated as a first priority. On the other hand, the use of medication in treating concomitant diseases may be severely restricted.

The aim of this observational study was, first of all, to determine whether a multidimensional therapeutic approach, taking into account all the above-mentioned aspects, can actually produce measurable and lasting improvements in the health of relatively severely impaired, chronically ill environmental medicine related patients. On the other hand, we wanted to obtain some indication as to which therapeutic measures are particularly promising and which additional factors play a part as predictors of the further course of the disease. The study was carried out in a specialised clinic for environmental medicine, addiction and psychosomatic disorders in Northern Germany and was funded by the German Federal Department for Health and Social Security.

Additional results of the study – including MCS risk factors in the field of exposure, vulnerability and comorbidity; a comparative analysis of different symptom scores and intolerance scores with various comparison groups; and the results for sociomedical variables – can also be obtained from the online research report, or else they have already been published (Bauer et al. 2003, 2004).

Methods

Study design: The study takes the form of an open, prospective, observational study.

Study population: All new patients visiting the clinic's environmental medical outpatient department or ward between 1 January 2001 and 30 December 2001, in whom a relevant environmental medicine (=EM) component of their disorder and/or MCS were diagnosed, were asked to take part in the follow up study. The follow-up questionnaire was sent to patients together with a stamped return envelope six (t6) and twelve months (t12) after their first visit to the clinic (=t0), and they were asked to complete and return the questionnaire. Patients who did not respond, were contacted once again in writing six weeks later. All patients received a t6 follow up questionnaire and approx. 50% received a t12 questionnaire. All in all, 142 patients met the inclusion criteria, and of these 113 took part in the follow up survey (total response rate for t6 or t12 = 80%, t6 alone = 75%, t12 alone = 67%). 8 questionnaires were excluded due to over-reporting or lack of information (>5 missing items in > 2 instruments), so that 105 patients were included in the data analysis (t6: n=97, t12: n=55, t6 and t12: n=105, only t12 data: n=8).

All subjects were informed about the study in advance and gave their written consent. The approval of the ethics committee in charge was obtained.

Instruments :Physician's questionnaire: In a standardised questionnaire, the doctor in charge of treating the patient provided details of the patient's general data, history of exposure to pollutants, diagnoses, comorbidity, vulnerability and their belief system concerning their illness, as well as the therapeutic measures taken at the clinic (included here: training for coping, complementary psychotherapy) and the therapeutic recommendations to the patient after counselling (included here: counselling and recommendations for reducing individual exposure to pollutants, for adopting a rotary diversified diet, for carrying out external psychotherapy, for taking vitamin or mineral supplements). In order to validate the data supplied by the physicians, the data of 50 patients were coded a second time in a blind set-up. The interrater agreement is given in brackets: relevance of exposure (76%), degree/extent of exposure (86%), connection between exposure and illness and proportion of comorbidity (85%), vulnerability (82%) and belief system for the illness (76%) (for details cf. Bauer et al. 2003). At the clinic, diagnoses are routinely made in the context of team conferences.

Patient questionnaire: Every participating patient completed a patient questionnaire before being treated at the clinic (baseline=t0). Apart from general questions, this contains the following instruments:

1. Nottingham Health Profile (NHP): The NHP is a widely used instrument for measuring the subjective physical, social and emotional impairment caused by illness (Hunt et al. 1985). It consists of 38 items, which are to be answered with a *Yes* or *No* and are assigned to 6 subscales. Each subscale lies in the range of 0-100 (for details see: Mcdowell and Newell 1996).

2. Symptom list of the Neurotox questionnaire (SL): The SL is a shortened version of the ”Neurotoxicity Screening Survey (NSS)” by Singer (1990), consisting of 42 items. The SL comprises neuropsychological and neurological symptoms, which are often mentioned by cohorts subjected to pollutants (e.g.: dizziness, problems concentrating, headaches, anxiety, paraesthesia etc.). The SL enquires multidimensionally into the frequency of occurrence (0 to 3 points) and the severity (0 to 3 points) of 41 symptoms, as well as one symptom designed to measure over-reporting. The 41 symptoms (frequency x severity = 0 to 9 points) are used to create a sum score (SL-SUM). The following comparison groups are available (cf. table 1): 1. healthy control group (n=47), 2. patients subject to chronic alcohol abuse (n=46), 3. patients with psychosomatic disorders (n=17), 4. patients with neurological disorders without any history of exposure to pollutants (n=46), and 5. patients with illnesses following exposure to organic solvents or pesticides (n=50) (for details about comparison groups, construct and criterion validity, discriminant analysis and reliability coefficients see Bauer et al. 2001b, 2003; Martens 2002).

3. Quick Environmental Exposure and Sensitivity Inventory (QEESI)

The QEESI developed by Miller and Prihoda (1999) looks into chemical intolerance reactions (e.g. towards the smell of paint, perfumes), other intolerances (e.g. foods, caffeine, drugs), and the symptoms and consequences of intolerances for one’s quality of life (e.g. on diet, leisure activities). 10 questions are asked in each category, whereby the respective level is to be given on a scale of 0 to 10. This produces a value between 0 and 100, which is described as an index (e.g. Chemical Intolerance Index). Furthermore, a masking index is formed (0-10 points).

4. General Health Questionnaire (GHQ)

The GHQ is a screening instrument for determining current psychiatric disorders, in particular depression and anxiety disorders. The short form GHQ-12 is used here and the scores can range from 0 to 12 points. Values below 2-3 are considered unremarkable (for details see: Goldberg and Hillier 1979, Mcdowell and Newell 1996).

Follow-up Instruments: In previous surveys, the SL in particular, and to a slightly smaller degree also the NHP, had proved sensitive to change and were therefore used as progress parameters (Kohlmann et al. 1999). Furthermore, the change in the sum score SL-SUM over time correlates significantly with changes in the NHP scores and with the subjective self-assessment of the patients concerning changes in their health (Bauer et al. 2003; Kohlmann et al. 1999). Furthermore patients were asked if they had followed recommendations and the number of visits to the clinic was recorded (number of contacts).

Statistics: The changes over time were calculated by subtracting the follow-up score (t6, t12) from the baseline score (t0) to give “t0 - t6” and “t0 - t12” -Scores. Unfavourable developments are indicated by a negative sign. In view of the study design (observational study) no hypothesis tests were carried out. Effect strengths were calculated using the formula (t0 - t6 or t12)/SD t0-t6 or SD t0-t12, SD=standard deviation), as a measure of the size of the observed effects. Effect sizes (ES) of 0.2 to 0.3 are described as being slight, an ES of 0.3-0.6 is moderate and an ES >0.6 is strong (COHEN 1988). The Pearson correlation coefficient was used to determine the connection between scores and continuous variables (age, duration of illness). In a small number of cases, there was missing data for just one instrument (SL or NHP) or for just one time (t6 or t12); hence the values of n given in the tables and figures differ slightly from one another.

Definitions: MCS: The diagnosis of MCS (EM cases with MCS) was made using the criteria laid down by Cullen (1987). A considerable proportion of patients had MCS-related diagnoses but did not fulfil the MCS criteria (= EM cases with intolerances). For the purpose of comparison, a group of EM patients was formed whose diagnosis included neither MCS nor other intolerances (EM cases without MCS or intolerances).

Patients’ belief systems concerning their illness: The patient’s belief system concerning his or her illness was assessed by the doctor in charge as being

“coherent” (=EM cases B, all cases = EM cases A) if the patient was open-minded about a multidimensional model of his or her illness, and was willing to reflect realistically on his or her treatment and coping experiences so far, and on his or her expectations. If these conditions were not met by a patient, the patient’s belief system concerning his or her illness was rated as being “non-coherent” (=EM cases C) (in most cases a rigid, one-dimensional belief system rejecting the relevance of comorbidity).

Therapeutic concept :

The therapeutic concept pursued by the clinic is adjusted to fit the individual case and consists of training measures to improve coping; counselling and recommendations for the reduction of exposure, changes in diet and supplementation of nutrients; as well as complementary psychotherapeutic and behavioural measures.

Training for coping: This training involves reflecting upon and consolidating behavioural strategies for social and job situations, in particular coping strategies; conflict management; changing one’s lifestyle, particularly in terms of nutrition and consuming alcohol or cigarettes; and identifying situations in which exposure and contamination/hazards may occur. Furthermore it includes reflecting upon conflicting targets, structuring them and assigning a hierarchy to them. Where appropriate it also includes reflecting upon, reappraising and changing problematic belief systems concerning one’s illness and in this context putting into the right perspective unrealistic expectations concerning the possibility of medical intervention.

Complementary psychotherapy: This comprises measures for solving individual intrapersonal and interpersonal conflicts, as well as supportive cognitive and behavioural therapy.

Reduction of exposure: Strategies for reducing exposure are worked out individually with each patient and include such things as refurbishing one’s home, dental restoration, reducing exposure to pollutants at one’s place of work by means of suitable protective measures, and so on. In MCS patients, measures for reducing exposure are necessary as regards triggers of acute symptoms (e.g. perfumes, tobacco smoke, disinfectants, exhaust fumes etc.).

Rotary diversified diet: All EM patients are advised to revise their diet, focussing on fresh foods that have been subjected to little processing. In order to achieve an

improvement in non-specific tolerance given the corresponding symptoms, a rotary diversified diet is recommended: foods that are not tolerated are reintroduced after waiting for a period, only being eaten every 4 to 7 days and alternated with foods from other food families (rotation).

Supplementation of vitamins and minerals: Depending on the individual clinical picture and uptake status, the clinic's EM patients are advised to take food supplements.

Results

The baseline scores (t0) for the patient questionnaires of the 105 patients are summarised in table 1, together with reference scores to give an idea of the severity of the illness. The clearest impairment of the clinic's EM patients (EM cases A) is seen in the SL-SUM (neuropsychological and neurological symptoms) and in the symptom score of the QEESI (QEESI-SSUM), as well as the NHP-E (energy) and NHP-P (pain). Patients with MCS displayed less favourable scores on all scales of the QEESI (intolerances) than the EM patients without MCS or intolerances. For the other instruments included here (SL, NHP, GHQ), no significant differences were noted between patients with MCS and those without (data not shown, cf. Bauer et al. 2003).

The general data of the 105 EM cases A are shown in table 2. Their average age was 47.1 years, 69% of the patients were female and 31% male. At 9.4 years, the duration of the illness was very long and hence indicates a chronic clinical picture in most respondents. Neither age nor the duration of illness had any influence on the progress of the illness as measured by the correlation with the t0-t6 differences in the SL-SUM (Pearson correlation = -0.08 (age) and -0.01 (duration)).

While analysing the data, it was noticed that the patients' belief system concerning their illness (coherent vs. non-coherent) was an outstanding predictor for the progress of the disorder: with EM cases B (=coherent) and EM cases C (=non-coherent) displaying almost identical baseline scores for the SL-SUM, this symptom score dropped from 115.8 (t0) to 99.1 at t12 in the EM cases B. The SL-SUM of the EM cases C, on the other hand, increased from 116.0 to 139.7, indicating a deterioration in their condition. Figure 1 illustrates the contrasting progress of the illness.

The EM cases C included more male patients and more smokers than the EM cases B. Their level of education was somewhat lower, and fewer of these respondents were in paid employment than among the EM cases B (cf. table 2). The patient groups EM cases B and EM cases C behaved in such opposite ways in all strata that all further results will be stratified only for the EM cases B, since the number of EM cases C was insufficient for further stratification.

Among the EM cases B, the best successes were achieved in MCS patients, whose SL-SUM decreased by a total of 29% (t12) (figure 2). The effect size (ES) was 0.65 (t6) and 1.60 (t12), so that this can be described as a pronounced effect (cf. table 3). Patients whose illness was preceded by a known exposure event profited most clearly from the therapeutic offer when there was little comorbidity (ES t6=0.48, ES t12=0.72). Patients in whom – despite similar symptoms – neither known exposure events nor known comorbidity appeared to be sufficient to explain the severity of their illness profited somewhat less from the multidimensional approach (table 3).

The quality of the contact with the clinic also proved to be an important predictor of progress (table 3). Patients with multiple contacts had a distinctly higher baseline value of 136.2 for their SL-SUM than did patients with a single contact (SL-SUM=109.6). During the time t6 the SL-SUM of patients with multiple contacts dropped by 19% to 109.7 and subsequently (t12) to 97.7 (28%), even falling below the t12 scores of patients with a single contact (99.6). Patients with “multiple contacts” visited the clinic 3.4 times on average.

Patients who received training for coping (see Methodology) and/or psychotherapy had distinctly higher baseline values for their SL-SUM compared with the overall group. The SL-SUM of patients receiving training for coping was reduced from 130.5 to 107.9 (17%) during t6 and subsequently to 92.6 (29%) (table 3). The improvements were even clearer in patients who *in addition* (all of them also received training for coping) took part in psychotherapeutic measures at the clinic (t0=129.0 and t12= 55.0) (figure 4). However this was only the case with a few subjects. The improvement seen in patients carrying out *external* psychotherapy was only about one third that seen with internal complementary psychotherapeutic measures. Patients who did <u>not</u> follow the recommendation of undertaking external psychotherapeutic measures were only better off at time t6 (ES=0.79). However this effect did not persist (table 4).

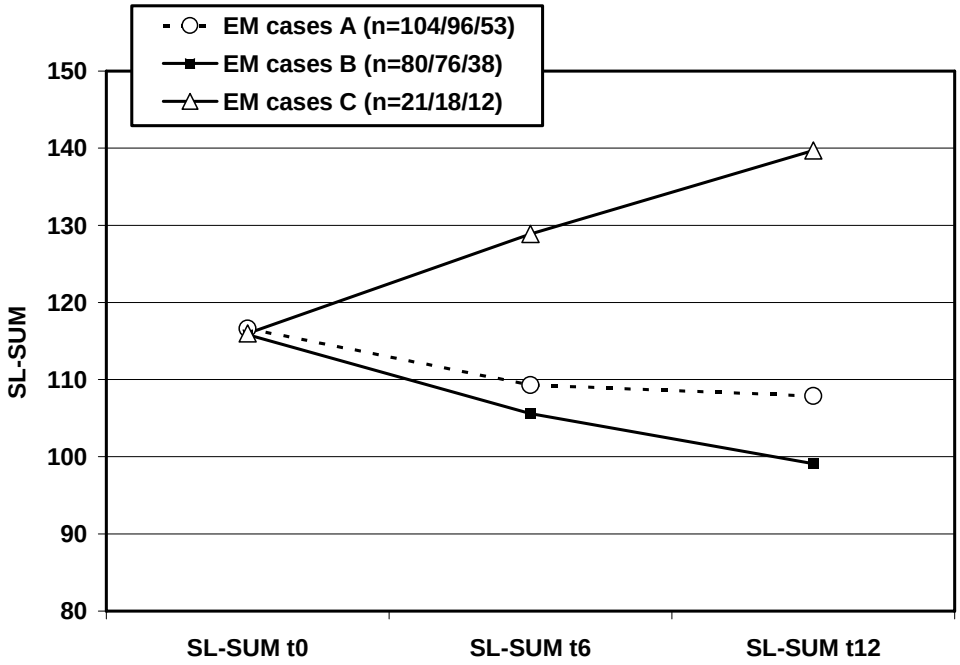

Figure 1: Sum score of the symptom list (SL-SUM) over time in all follow up patients (EM cases A) and stratified according to the patients' belief system concerning their illness (EM cases B and C (n= t0/t6/t12)

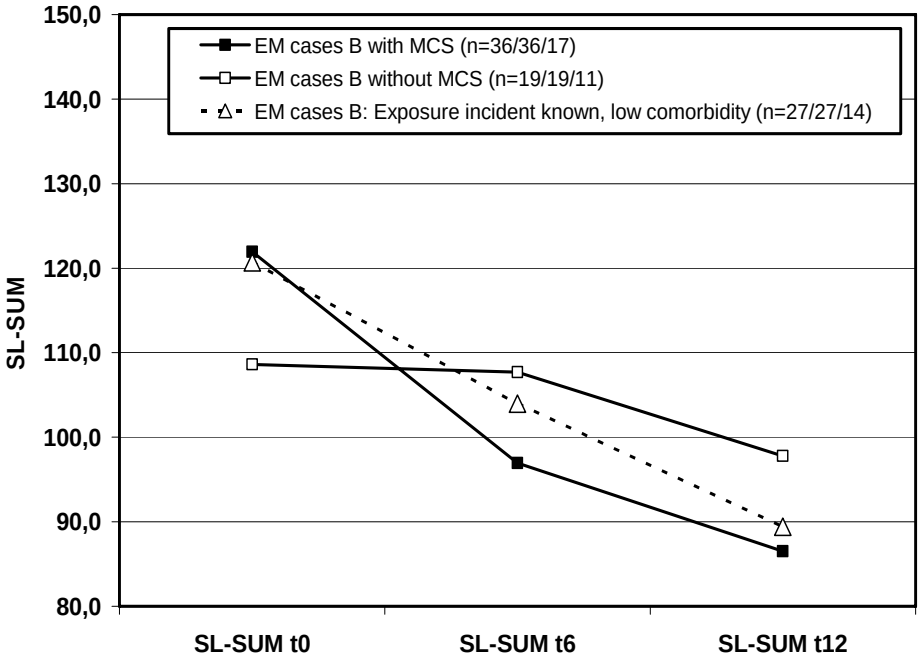

Figure 2: Sum score of the symptom list (SL-SUM) over time in patients with MCS, patients without MCS or other intolerances, and in patients with known and relevant exposure to pollutants and a low level of comorbidity (n= t0/t6/t12, EM cases B)

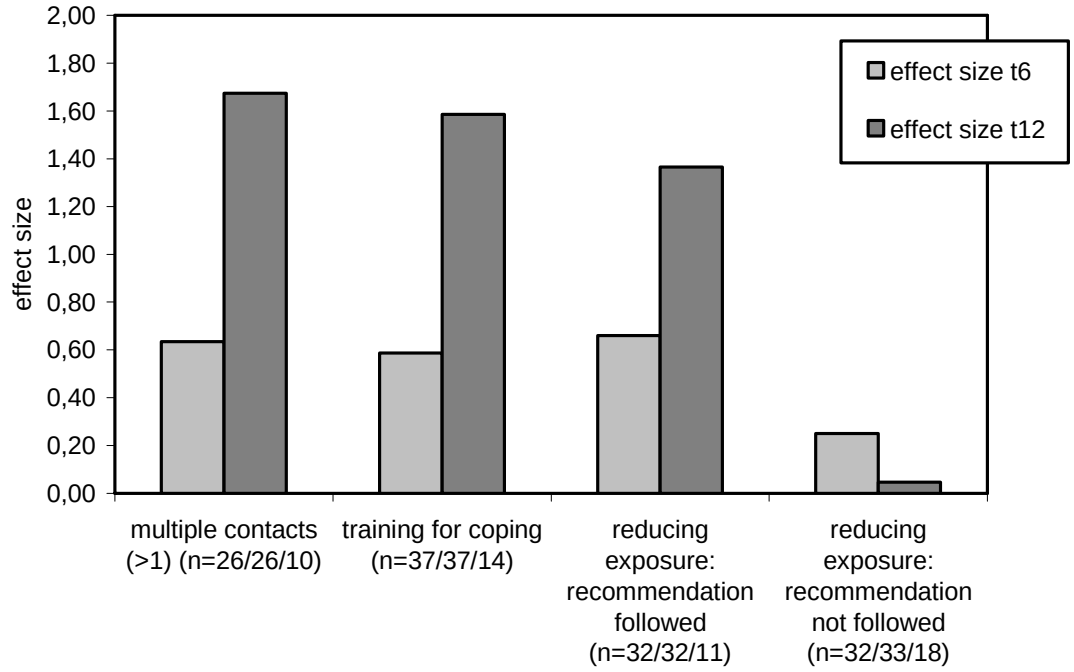

Figure 3: Effect sizes (ES) calculated from t0-t6 and t0-t12 differences in the SL-SUM of patients with multiple contacts; patients receiving training for coping; and patients who largely implemented or did not implement recommendations about measures to reduce exposure (n= t0/t6/t12, EM cases B)

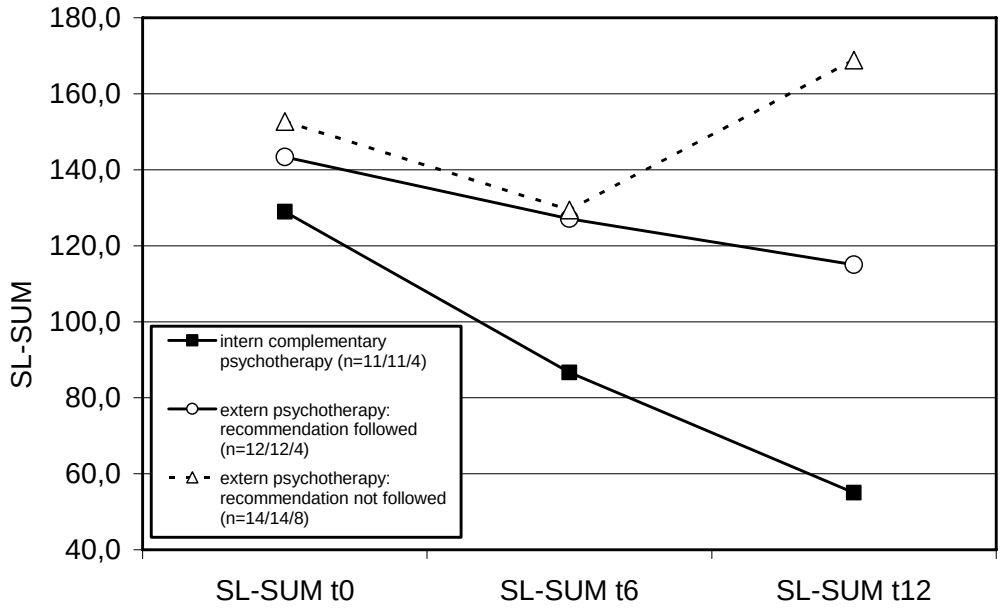

Figure 4: Sum score of the symptom list (SL-SUM) over time for patients receiving complementary psychotherapy at the clinic (=internal); patients who followed the clinic's recommendation to take external psychotherapeutic measures; and those who largely did not follow this recommendation (n= t0/t6/t12, EM cases B)

When measures were carried out to reduce exposure, the SL-SUM decreased by 20% at time t6 (ES=0.66) and then remained constant. On the other hand, patients who largely failed to take the recommended measures to reduce exposure saw hardly any improvement, especially when comparing t0 and t12. Patients who largely followed recommendations to adopt a rotary diversified diet (recommended in the case of non-specific food intolerances) also profited more than patients who did not follow this recommendations, especially in terms of their t12 scores (ES=0.97 vs. -0.27). On the other hand, the development of the SL-SUM in patients who followed the recommendations on taking vitamin or mineral supplements hardly differed from that of patients who did not follow this recommendations (table 4).

In summary, a visit to the environmental medical department of the clinic appears to have had a positive effect on neuropsychological and neurological symptoms during the first 6 months after their visit, independently of the patient's compliance. However this effect does not last if important therapeutic recommendations are not implemented.

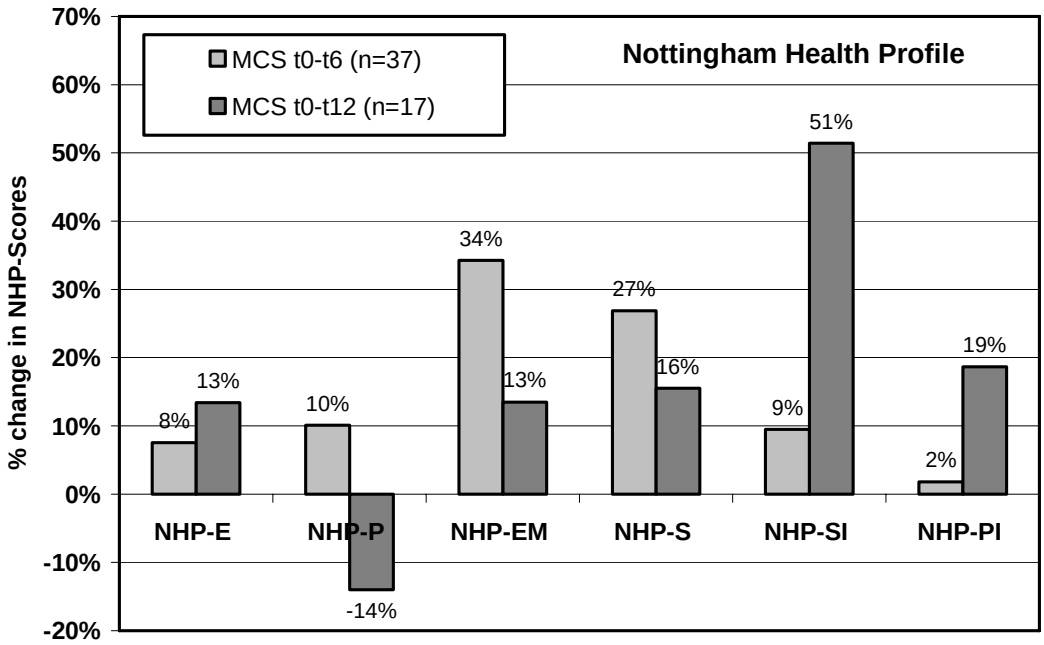

Figure 5: Percentage change in the field of health-related quality of life (NHP) over time for patients with MCS (EM cases B, deterioration is indicated with a negative sign) (E=Energy, P=Pain, EM=Emotional Reaction, S=Sleep, SI=Social Isolation, PI= Physical Immobility)

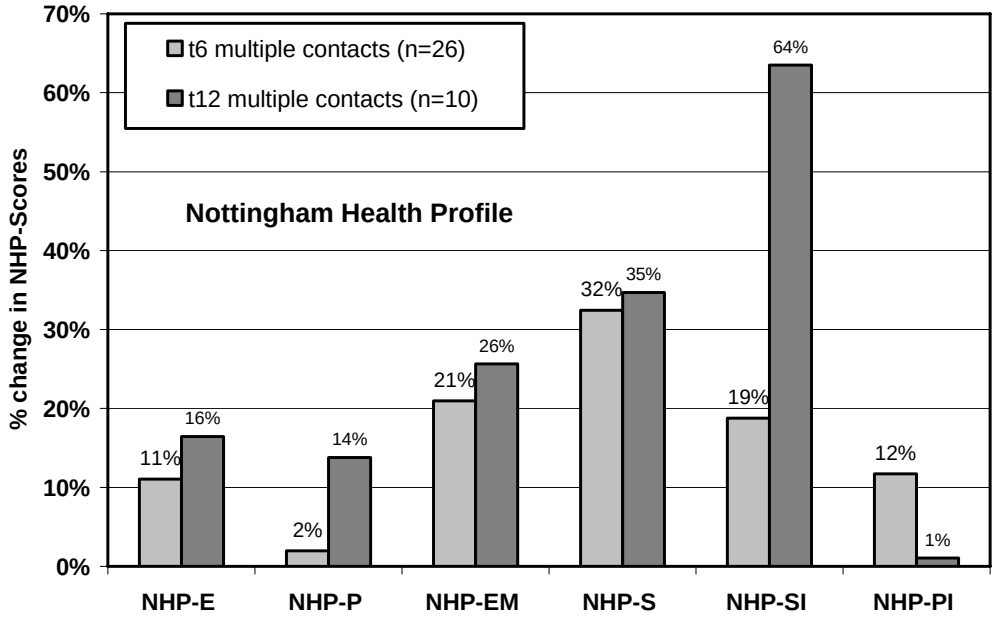

Figure 6: Percentage change in the field of health-related quality of life (NHP) over time for patients with multiple contacts to the clinic (EM cases B) (E=Energy, P=Pain, EM=Emotional Reaction, S=Sleep, SI=Social Isolation, PI= Physical Immobility)

In view of the large amount of data generated by the analysis of the NHP results for 6 sub-scales, only summary results are presented here as well as results stratified for patients with MCS and patients with multiple contacts (figure 5 and 6). Further results cannot be presented here in tabulated form; they are however available in the online research report (Bauer et al. 2003).

The effects seen in the NHP scores were less pronounced overall than those seen in the SL-SUM scores. Among the EM cases B, slight improvements (9-16%) in the NHP-E (t0=58,7; t6=58,1; t12=51,6), NHP-EM (t0=31,7; t6=28,3; t12=28,8), and NHP-S (t0=35,0; t6=29,3; t12=29,7) were noted, while no lasting changes were observed on the NHP-PI and NHP-P. An exception to this was the NHP scale “Social Isolation” (NHP-SI), which improved in EM cases B at t12 (t0=20,2; t6=20,0; t12=13,9), but also markedly in EM cases C (t0=25,7; t6=15,4; t12=9,2). Among EM cases C deterioration in the other scores NHP-P (t0=37,0; t6=53,3; t12=50,8), NHP-S (t0=28,6; t6=34,6; t12=41,4), and NHP-PI (t0=21,4; t6=28,6; t12=26,0) were noted while the NHP-E remained nearly uneffected very high (t0=84,4; t6=80,7; t12=77,5).

In MCS patients too (EM cases B with MCS), little influence was exerted on the NHP scales for “Energy” (NHP-E: t0=55,4) and “Pain” (NHP-P: t0=37,5). On the other hand, initial improvements at time t6 were noted for the scales NHP-EM (t0=28,5; t6=18,7; t12=24,6) and NHP-S (t0=30,2; t6=22,1; t12=25,5), which did not however last. Lasting improvements were only seen on the scale NHP-SI (t0=19,5; t6=17,6; t12=9,5) (figure 5).

Clear improvements in the NHP were only achieved in patients who visited the clinic repeatedly, and here they were also largely maintained at time t12 (figure 6).

Discussion

The follow-up study presented here is an open observational study and not a placebo-controlled double-blind intervention study. It cannot therefore be reliably determined whether the corresponding interventions did indeed cause the effects described. Thus patient groups receiving certain therapeutic measures differed from those patients who did not receive them. In particular, a higher proportion of patients with particularly poor baseline scores took part in expensive and time-consuming measures such as training for coping or complementary psychotherapy. Other patients would perhaps also have profited from these. However, no placebo-controlled double-blind intervention studies have been conducted in this area of research to date, and in view of the nature (and the cost) of the therapeutic measures, even one sided blinding or the administration of placebos is not possible, or else ethically unacceptable in severely ill patients. This observational study can therefore provide some indication of which therapeutic approaches are promising for the described patient populations.

Furthermore no statement can be made about why patients did not carry out recommended therapeutic measures. These reasons could, however, have an influence on the follow-up data: hence particularly those patients who noticed a distinct initial improvement after visiting the clinic may conceivably have refrained from carrying out further measures - despite recommendations to the contrary (cf. figure 4). However such an effect would not falsely suggest a non-existent efficacy of the recommended measures; on the contrary, it would conceal an existing efficacy. The consistency of our results is therefore supported by the fact that those patients who largely followed the recommendations, displayed distinctly better scores in the

long run (t12) than patients who largely failed to implement them, even though in the short term (t6) both groups displayed improvements.

The environmental medical patient cohort described here (EM cases A) is furthermore selected in the direction of severe, complicated and chronic courses of the illness, since in Germany milder and more straightforward cases can be treated by office-based doctors with additional training in environmental medicine. In the EM patients seen by office-based doctors, it is often enough to end exposure to relevant contaminants in order to achieve clear improvements in health in 60-70% of patients, as reported by Bauer et al. (2001a) who looked at a cohort of n=506 EM patients. In the patient cohort described here, such measures (e.g. refurbishing one's home, moving house, changes in one's place of work) were not adequate in order to achieve an improvement in health. For this reason, these patients are referred by office-based EM specialists to the specialised clinic.

Only 6% of the cohort of EM patients treated by office-based doctors described by BAUER et al. (2001a) were diagnosed as having MCS, as compared with 47% of the EM cases A in the specialised clinic. Hence the clinic's patient cohort is biased in the direction of EM patients suffering from MCS.

Compared with healthy control groups, the EM cases A had distinctly less favourable scores on all the instruments included in the patient questionnaire (table 1). With the exception of the NHP-SI (social isolation) and the GHQ (current anxiety and depression) this was also true in comparison with a group of in-patients with chronic alcohol abuse. Compared with psychosomatic in-patients, the EM cases A had higher baseline values in the field of the SL-SUM (neurological and neuropsychological symptoms) and on the NHP-P (pain) and NHP-PI (physical immobility), but better scores on the NHP-EM (emotional reaction), NHP-S (sleep) and NHP-SI (social isolation), as well as distinctly better scores on the GHQ (anxiety, depression) (Bauer et al. 2003; Martens 2001).

In terms of their scores on the QEESI (Quick Environmental Exposure and Sensitivity Inventory) by Miller and Prihoda (1999), the MCS patients included in this study were similar to the MCS cohorts described by Miller and Prihoda (1999). The EM cases A without MCS had distinctly lower scores than MCS patients in the field of the QEESI, however higher ones than the healthy control group described by Miller and Prihoda

(1999). In terms of the other scores used in this study (SL, NHP, GHQ), patients with MCS did not differ from EM patients without MCS (Bauer et al. 2003).

Only few studies exist concerning the course of the disease in MCS patients, and in these studies no mention is usually made as to whether and which therapeutic measures were adopted. According to Gupta and Horne (2001), details provided by MCS patients concerning preferred treatments were particularly good at explaining the course of the illness predicted by their doctors. Patients who from the start claimed to have fixed expectations about their treatment, involving the total avoidance of exposure and a preference for alternative methods over conventional treatment approaches, received a positive prognosis from their doctor significantly less often than those patients who were quite open-minded in their expectations. Unfortunately Gupta and Horne (2001) did not actually carry out a follow-up, so that it remains unclear whether the doctors' predictions concerning the further course of the illness were indeed correct. Nevertheless, this may correspond to what the clinic describes as "non-coherent belief system concerning the illness " (=EM cases C) and which was identified as an important negative predictor for the course of the illness.

Black et al. (2001) carried out a follow-up of 18 MCS patients after nine years. While the symptom scores on the psychometric tests (SCL-90-R, Illness Behaviour Scale) remained virtually unchanged, 11% of patients stated that they felt fine again, 45% felt much or very much better, 33% felt somewhat better and 11% were unchanged or worse off than before. All 18 patients continued to believe that they had MCS and took this into account in the way they led their lives. These results by Black et al. (2001) speak more for patients having found better ways of dealing with their illness than for a "healing process". Lax and Henneberger (1995) report similar observations in 35 MCS patients, 16 of whom reported during the follow-up (after 6-30 months) that they felt better, even though they mentioned more symptoms than at the outset of the study. Lax and Henneberger (1995) assumed that a learning process was taking place, in that patients were paying more attention to their symptoms than they had at the beginning of the study. In the cohort of patients described by us, a similar "symptom-learning effect" was possibly overcompensated by real improvements, because the symptom scores decreased markedly in many cases.

Our results concerning the favourable effects particularly of the therapeutic measures "training for coping", "measures for reducing exposure" (following the appropriate

counselling) and “complementary psychotherapy” also indicate that particularly learning better ways of dealing with EM illnesses and MCS are of considerable importance for the patients’ wellbeing. In this context, patients with multiple contacts profited much more from this treatment approach than patients with a single contact, despite higher baseline scores. This presumably reflects the fact that the many different aims of training and counselling can only be adequately communicated through multiple contacts. Gibson et al. (2003) also found that 65% of 362 MCS patients found psychotherapeutic measures helpful, though only if their aim was learning to “cope” with the disorder. According to Gibson et al. (2003), strategies for reducing exposure were in fact the therapeutic measure that was carried out most frequently by 917 MCS patients interviewed (n=875) and which was described by far the most often (94%!) as “very helpful” (56%) or “somewhat helpful” (38%), compared with other forms of treatment/other measures.

Conclusions

To summarise, the results of the follow up observation at the specialised clinic suggest that a multidimensional, inter-disciplinary form of treatment with training measures, accompanied by measures for reducing exposure, changes in lifestyle and – where necessary – with supporting psychotherapy incorporated in the overall treatment concept, is promising in these severely affected EM patients.

The results are already being used at the clinic to implement measures for improving the quality of treatment. The percentage of patients receiving training for coping is to be substantially increased, for example, as is the rate of multiple contacts. This is particularly the case in patients who, from their doctor’s point of view, display an “non-coherent belief system concerning their illness“ and who clearly require special help. The compliance with the recommendations given is also to be increased in this way.

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Table 1: Results of symptom and intolerance scores of the follow-up group (EM cases A) and comparison groups[a]

Instrument	Score*	EM cases A t0 (n=105)	1. healthy controls (n=47)	2. controls with chronic alcohol abuse (n=46)	3. controls with psychosomatic illness (n=17)
Symptom-List (SL)	SL-SUM	116,6	18,3	50,6	77,8
Nottingham Health Profile[b]	NHP-SUM	35,9	2,7	15,0	35,9
	NHP-E	64,4	2,2	13,4	54,8
	NHP-P	42,0	3,4	5,9	13,2
	NHP-EM	33,6	2,4	24,6	49,5
	NHP-S	33,9	6,6	19,8	45,8
	NHP-SI	21,3	0,4	23,8	42,8
	NHP-PI	22,2	2,9	5,7	9,0
General Health Questionnaire	GHQ	4,3	0,8	4,3	7,6

Instrument	Score	EM cases A with MCS (n=49)	EM cases A without MCS (n=27)	2. controls with chronic alcohol abuse (n=46)	3. controls with psychosomatic illness (n=17)
Chemical Intolerance	QEESI-CI	72,5	25,3	19,0	20,6
Other Intolerance	QEESI-OI	47,0	22,2	13,2	12,8
Sum of Symptoms	QEESI-SS	62,5	48,4	20,9	34,3
Masking	QEESI-M	2,6	4,1	5,5	4,1
Life Impact	QEESI-LI	60,9	26,2	19,4	19,4

[a]: comparison groups from: Martens 2002

[b]: NHP: E=Energy, P=Pain, EM=Emotional Reaction, S=Sleep, SI=Social Isolation, PI= Physical Immobility

Table 2: General data of EM patients in the follow-up group (EM cases A) as well as stratified according to the patients' belief system concerning their illness (B and C[a])

	EM cases A (n=105)	**EM cases B (n=81)**	**EM cases C (n=21)**
age (years)(mean +/- SD)	47,1± 10,2	47,3 ± 10,8	46,6 ± 8,1
years of illness (mean +/- SD)	9,4 ± 8,2	10,0 ± 8,8	7,3 ± 5,2
frequency of medical consultation (last 12 months) (mean +/- SD)	34,3 ±29,5	34,6 ±29,4	35,8 ±31,5
female patients	68,6%	69,1%	61,9%
male patients	31,4%	30,9%	38,1%
smoking today	18,1%	13,6%	33,3%
diagnosis of MCS	46,7%	48,1%	47,6%
exposure:			
a) relevant exposure incident known, low comorbidity	35%	37%	29%
b) relevant exposure incident known, relevant comorbidity	31%	32%	24%
c) relevant exposure incident known, high degree of comorbidity	12%	11%	19%
d) similar symptoms as a), but unknown causes (low exposure, low comorbidity)	21%	20%	29%
education at school:			
a) not finished any school	2,0%	2,4%	0%
b) finished junior high school	37,1%	34,6%	47,6%
c) finished high school with medium qualification	30,5%	32,1%	28,6%
d) finished high school with university qualification	30,5%	30,9%	23,8%
training for occupation:			
a) no training/not finished	18,3%	22,2%	9,5%
b) normal training/apprenticeship	62,5%	58,0%	81,0%
c) university education	19,2%	19,8%	9,5%
in payed employment today	38%	41%	24%
employment lost/given up because of illness	40%	36%	62%

SD = standard deviation; [a]: Belief system is "coherent" = EM cases B, belief system is "non-coherent" = EM cases C

Table 3: Symptom scores (SL-SUM) according to EM patients characteristics at times t0, t6 and t12 and values characterizing changes[ab] (negative values indicate deterioration)

	SL-SUM t0	**SL-SUM t6**	**SL-SUM t12**	**SD t0-t6**	**SD t0-t12**	**ES t0-t6**	**ES t0-t12**
EM cases A (n=104/96/53)	116,6	109,4	107,9	34,6	38,0	0,21	0,23
EM cases B (n=80/76/38)	115,8	105,6	99,1	35,6	36,4	0,29	**0,46**
EM cases C (n=21/18/12)	116,0	128,9	139,7	36,9	35,2	-0,35	-0,67
EM cases (B) with MCS (n=36/36/17)	121,9	96,9	86,5	38,6	22,2	**0,65**	**1,60**
EM cases (B) with intolerances (n=20/20/10)	123,0	115,2	121,8	28,7	38,8	0,27	0,03
EM cases (B) without MCS or intolerances (n=19/19/11)	108,6	107,7	97,8	31,0	52,2	0,03	0,21
EM cases (B): exposure incident known, low comorbidity (n=27/27/14)	120,7	104,0	89,4	34,6	43,4	**0,48**	**0,72**
EM cases (B): exposure incident known, relevant comorbidity (n=26/26/11)	111,9	101,7	86,7	41,3	39,0	0,25	**0,65**
EM cases (B): exposure incident known, high degree of comorbidity (n=8/8/4)	(126,8)	(104,0)	(162,0)	nc	nc	nc	nc
EM cases (B): similar symptoms, causes unknown (low exposure, low comorbidity) (n=14/14/9)	123,6	111,1	(101,2)	31,8	(14,1)	**0,39**	(1,59)
EM cases (B) with single contact							

(n=49/49/28)	109,6	101,8	99,6	30,3	39,9	0,26	0,25
EM cases (B) with multiple contacts (>1) (n=26/26/10)	136,2	109,7	97,7	41,7	23,0	**0,64**	**1,67**
EM cases (B) who received education for coping (n=37/37/14)	130,5	107,9	92,6	38,5	23,9	**0,59**	**1,59**
EM cases (B) who received intern complementary psychotherapy (n=11/11/4)	129,0	86,7	(55,0)	51,1	nc	**0,83**	nc

[a]: SD = standard deviation ; ES = Effect size (ES= (t0-tx)/SD t0-tx);

[b]: ES >= 0,3 are given in bold face, data based on n<10 were set in brackets or not calculated (=nc)

Table 4: Symptom scores (SL-SUM) at times t0, t6 and t12 according to EM patients B (n=81) compliance with recommendations and values characterizing changes[ab]

	SL-SUM t0	**SL-SUM t6**	**SL-SUM t12**	**SD t0-t6**	**SD t0-t6**	**ES t0-t6**	**ES t0-t6**
reducing exposure:							
recommendations followed (n=32/32/11)	128,6	102,6	102,4	39,4	19,2	**0,66**	**1,36**
recommendations not followed (n=32/33/18)	115,0	108,1	112,8	27,6	47,7	0,25	0,05
extern psychotherapy:							
recommendations followed (n=12/12/4)	143,4	127,1	115,0	30,3	nc	**0,54**	nc
recommendations not followed (n=14/14/8)	152,7	129,4	(168,9)	29,4	nc	**0,79**	nc
rotary diversified diet:							
recommendations followed (n=34/35/14)	125,8	108,0	100,4	32,5	26,1	**0,55**	**0,97**
recommendations not followed (n=25/25/11)	119,5	107,2	129,0	39,6	34,9	**0,31**	-0,27
supplementation of vitamins and minerals:							
recommendations followed (n=47/48/19)	121,8	107,4	110,7	34,0	48,9	**0,42**	0,23
recommendations not followed (n=11/11/4)	114,4	106,4	118,8	20,7	nc	**0,39**	nc

[a]: SD = Standard deviation ; ES = Effect size (ES= (t0-tx)/SD t0-tx); negative values indicate deterioration

[b]: ES >= 0,3 are given in bold face, data based on n<10 were set in brackets or not calculated (=nc)

Abbreviations:

EM: Environmental medicine

ES: Effect size

GHQ: General Health Questionnaire

MCS: Multiple Chemical Sensitivity

NHP: Nottingham Health Profile

QEESI: Quick Environmental Exposure and Sensitivity Inventory

SD= Standard deviation

SL: Symptom List of the Neurotox-Questionnaire

SL-SUM: Sum Score of the SL

t0: time of the first visit of the patient at the clinic (baseline)

t6: six months after t0

t12: twelve months after t0