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Diabetes rehabilitation: development and first results of a Multidisciplinary Intensive Education Program for patients with prolonged self-management difficulties

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Abstract

For a number of diabetes patients regular care may be insufficient. A Multidisciplinary Intensive Education Program (MIEP), based on the empowerment approach, has been developed to help patients obtain their treatment goals (adequate self-management, glycemic control and quality of life). The aim of this pilot study is to determine the effects of MIEP and it's mechanisms of influence. MIEP consisted of 12 days group-sessions and individual counseling. At baseline and 3-months follow-up, blood-glucose (HbA_{1c}), quality of life, health locus of control, distress, and knowledge were obtained ($N = 51$). Paired *T*-tests and regression analyses were conducted. HbA_{1c} and knowledge improved significantly, patients rated themselves healthier and were more *internal* and less *powerful others* oriented. Baseline scores explained effects in HbA_{1c} and quality of life. Locus of control significantly contributed in effects on quality of life. MIEP benefited patients with prolonged self-management difficulties, and this form of care seems to complement regular care.
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1. Introduction

Diabetes mellitus is a growing public health issue [1], which can cause serious disabling complications. Risks of developing these complications can be significantly reduced by optimal glycemic control [2], which is the maintenance of low blood-glucose near levels found in persons without diabetes [3,4]. Optimal glycemic control can be achieved by correct and conscientious self-management [5], which consists of home blood glucose monitoring, injecting insulin and adjusting the insulin dose to actual needs, varying nutrition to daily needs and regular exercise [6,7]. However, diabetes self-management is demanding and requires much effort, discipline, skill and knowledge. Not surprisingly, a considerable number of patients never reaches optimal glycemic control [8]; less then 15% has normal or near normal glycemic control and about 25% has poor control [2,9]. Besides sub-optimal glycemic control, several studies found that a considerable number of patients experience diabetes-related psychosocial problems [10,11].

Diabetes education is considered to be essential in reaching good self-management and glycemic control [12–14]. Usually, the aim is to increase knowledge of self-management principles and self-management skills in order to achieve sufficient glycemic control. A meta-analysis [15] showed that education programs increase knowledge about diabetes mellitus, but have moderate effects on glycemic control and even smaller effect on psychological outcomes. Most diabetes education programs primarily focus on knowledge and glycemic control, while psychological aspects and determinants of self-management behavior, such as coping with diabetes and health locus of control receive less attention [16]. Usually, a lack of knowledge is not the main issue [17], but rather a variety of problems that contribute to prolonged self-management difficulties [18]. Besides a focus on knowledge and self-management skills to achieve satisfying glycemic control, health-related quality of life should be a matter of concern in treatment of diabetes education [16,19,20].

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Based on the patient empowerment approach [21], a Multidisciplinary Intensive Education Program (MIEP) was developed (see Section 1.2). MIEP focuses on patients with continued poor regulation and/or psychosocial problems related to diabetes, despite intensive regular care. This paper describes the development and effects of MIEP examined in a pilot study in 51 participants. The aim of this study is to determine the effects of this newly developed form of diabetes education on glycemic control and quality of life and to gain insight into the mechanisms of effect.

1.1. Empowerment

The empowerment approach to diabetes-education [21] involves a great amount of patient collaboration. The patient empowerment approach seeks to maximize self-awareness and a sense of personal autonomy, which enable patients to take charge of their own diabetes self-management [22].

Anderson et al. [22] mentioned three aspects of diabetes treatment that argue in favor of the empowerment approach in diabetes education. First, the most important choices affecting the patient's health and well-being are made by the person suffering from diabetes him/herself, not by educators or physicians. The choices the patient makes each day about his or her self-management, cumulatively, have a far greater impact on blood glucose levels, overall health and well-being than the decisions made and advise given by health care providers. Second, patients are in control of their diabetes self-management; no matter what health providers recommend patients can veto any recommendation. Third, the consequences of a patient's choices about diabetes care accrue first and foremost to patients themselves.

Education based on patient empowerment should focus on achievement of self-selected goals, psychosocial adaptation, enhanced control [22], and problem solving strategies [23]. Empowerment can be more effective in attaining patient-oriented and medical outcomes [24,25].

1.2. Program

Fig. 1 gives an overview of the program. MIEP consists of a core module of 5 weeks consisting of 2 days a week filled with group sessions and individual counseling. Subsequently, MIEP includes revisits after 6 and 12 weeks. Groups comprise six to nine patients. The diabetes education team consists of an internist, a diabetes nurse specialist, a nutritionist, a social worker, a psychologist, a physiotherapist, an occupational therapist, an activity therapist and a podiatrist. The diabetes nurse specialist co-ordinates the program.

The program highlights a wide variety of subjects related to diabetes self-management (see Fig. 1). These issues are subjects during several sessions throughout the program. The program applies a four-phase learning sequence that integrates learning and practice. In the first phase, patients receive information from a team member about one of the issues mentioned, in the second phase followed by group

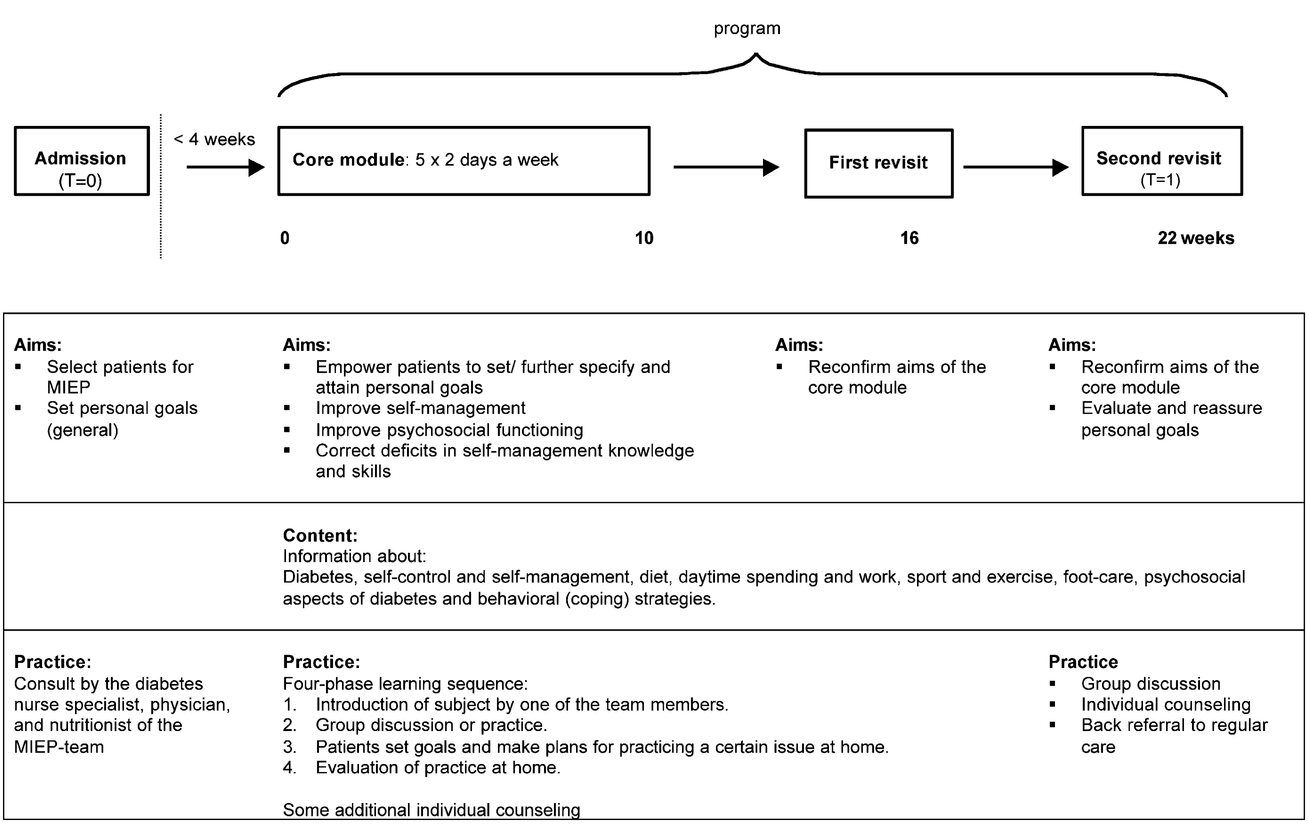

Fig. 1. Multidisciplinary Intensive Education Program (MIEP).

discussions or practice. In the third phase of the sequence, patients set goals and plan how to practice a certain issue at home. In the fourth phase practice at home is evaluated. This four-phase learning sequence is repeated for different aspects of diabetes self-management, tailored to the issue at hand. Not only do team members provide activities separately, as disciplines work together combinations of issues are made in co-operative sessions.

Before patients enter the program, they set personal goals, which could become more specified during the 10-week program. Frequently mentioned personal goals were lowering HbA_{1c} or improving glycemic control. Further personal goals were the avoidance of hypoglycemia, obtaining a higher level of self-direction in self-management, the acceptance of diabetes and establishing a greater ability to combine diabetes and other activities. Patients receive individual counseling tailored to their personal goals to help them reach their goals.

2. Method

2.1. Patients

Patients, monitored at the diabetes clinic of the University Hospital Groningen, were included on basis of the following criteria: sub-optimal glycemic control ($HbA_{1c} > 7.5\%$) for at least 1 year and/or frequent or severe hypoglycemia and/or psychosocial limitations resulting from diabetes. In contrast to inclusion based on the level of HbA_{1c}, inclusion based on hypoglycemia and psychosocial problems was not strictly defined. Rather, these criteria were verified by the referring physician and during an interview on admission to MIEP. Exclusion criteria were age <18 or >70 years, severe co-morbidity or a severe major life-event during the 6 months preceding MIEP. All patients had received conventional care for at least 1 year without improvement in HbA_{1c}, hypoglycemia and psychosocial problems. Selection of patients was based on medical reports and on the admission interview. After having finished the program, which took place in the rehabilitation center, patients were referred back to their own physician in the university hospital.

2.2. Design

A longitudinal pre-test–post-test design was used. A pre-measurement ($T = 0$, hereafter T0) was done at admission, before patients entered MIEP. At the second revisit, which is also the last day of the program, a post-measurement ($T = 1$, hereafter T1) was obtained.

2.3. Measurements

The primary outcome variables of the study were glycemic control (HbA_{1c}) and quality of life. The secondary outcome variables were diabetes-related symptoms (except the sub-scale of cognitive distress) and the number of (severe) hypoglycemia occurrences. Several process variables (cognitive distress, health locus of control and knowledge) were measured as well.

Glycemic control was measured by glycosylated hemoglobin (HbA_{1c}) indicating the mean blood-glucose levels over the previous 6–8 weeks. Patients with diabetes should strive for HbA_{1c} values near normal (as in healthy individuals; <7.0%) [7], since an elevated HbA_{1c} level is strongly related to the development of complications [2]. The self-reported number of hypoglycemia in the previous 4 weeks as well as severe hypoglycemia for which assistance was required was obtained.

Quality of life was measured with the RAND-36 [26,27]. The RAND-36 consists of 9 sub-scales of which 6 were used in this study: physical functioning, social functioning, mental functioning, vitality, general health perception and health change. Each scale is transformed to a 100-point scale with 0 representing the lowest possible quality of life and 100 representing the highest possible quality of life.

Diabetes related symptoms were measured with the diabetes symptom checklist (DSC) developed by Grootenhuis et al. [28]. The DSC measures symptoms of diabetes complications. It consists of 8 sub-scales: hyperglycemia (five items; range 0–15), hypoglycemia (three items; range 0–9), cardiovascular (four items; range 0–12), neuropathy-pain (six items; range 0–18), neuropathy-sensory symptoms (four items; range 0–12), fatigue (four items; range 0–12), ophthalmic symptoms (five items; range 0–15) and cognitive distress (four items; range 0–12). A low score represents few symptoms and a high score represents a lot of symptoms. In contrast to the 7 other sub-scales of the DSC, the cognitive distress represents a psychological state and was used as a process variable.

The Dutch version of the health locus of control scale of Wallston, Wallston and DeVellis [29], for diabetes patients, was used [30]. The MHLC includes three sub-scales: *Internal* (i.e. control depends on own effort), *Powerful Others* (i.e. control depends on others such as the physician) and *Chance* (i.e. control depends on luck or chance). Each scale consists of six items. The range of each scale varies from 6 to 36, where a high score represents a stronger orientation on the specific locus of control.

A revised version of the diabetes knowledge scale (DKS) [31,32] was used to measure knowledge. This scale consists of 30 items, which were summed (range: 0–30) with higher scores indicating better diabetes knowledge.

2.4. Statistics

The statistical package SPSS/PC+ for Windows was used. To determine differences between pre- and post-measure paired *T*-tests were used ($P < 0.05$). To investigate the mechanisms of effect stepwise regression analysis were applied. The behavioral determinants (MHLC, knowledge, cognitive distress) were used as independent variables.

Health related quality of life and HbA_{1c} were dependent variables in these analyses. Age, sex and the baseline value of the outcome variable were controlled for. The criteria used were a probability of F to enter ≤ 0.05 and probability of F to remove ≥ 0.10.

3. Results

3.1. Patients

Out of the 58 patients that were eligible for the education program, 51 were evaluated. Seven patients (three male, four female) did not complete the program and were excluded from the study. Two of these patients quit because of hearing problems that made participation in group-sessions impossible, and five discontinued the program because of motivational reasons. Table 1 shows the characteristics at baseline of the included patients.

Table 1
Patient characteristics

Sex[a]	
Male	25 (49%)
Female	26 (51%)
Education[a]	
Primary school	19 (37%)
Lower secondary vocational school	13 (26%)
Higher secondary vocational school	16 (31%)
Pre-university school	3 (6%)
Age[b]	49.10 (15.15)
HbA_{1c} (%)[b]	8.14 (1.31)
BMI[b]	29.14 (6.62)

[a] Number (percentage) of patients of sex and education.
[b] Mean (S.D.) of age, HbA_{1c} and BMI.

3.2. Outcomes of the program

Table 2 shows that patients significantly improved their glycemic control: mean HbA_{1c} declined from 8.14 (1.31) at T0 to 7.75 (1.11) at T1. Change in HbA_{1c} correlated -0.58 ($P < 0.001$) with HbA_{1c} at T0, indicating that patients with worst glycemic control improved most. Fifty percent of the patients showed a clinical relevant improvement of at least 0.5% HbA_{1c}, while, on the other hand, 18% of the patients worsened ≥ 0.5 on HbA_{1c}. The other 32% of the patients remained relatively stable (14%, <0.5 improvement; 12%, <0.5 deterioration and 6%, no change at all). Overall, no change in the number of hypoglycemia in a 4-week period was found. However, change in HbA_{1c} (T1–T0) correlated significantly ($r = -0.46$; $P < 0.01$) with change in number of hypoglycemia, indicating that patients that improved most in HbA_{1c} experienced more hypoglycemia, whereas

Table 2
Program outcomes

	T0	T1	*t*
Metabolic control			
HbA_{1c}	8.14 (1.31)	7.75 (1.11)	2.40*
N of hypoglycemia (4 weeks)	4.06 (6.40)	4.21 (4.71)	−0.16
Self-testing for blood glucose (%)	94	100	–
Quality of life and health status			
Physical functioning	77.75 (24.91)	74.79 (25.11)	−1.02
Social functioning	74.02 (21.19)	79.17 (18.65)	1.73
Mental functioning	71.06 (17.28)	70.58 (15.82)	−0.47
General health perception	52.65 (17.53)	52.60 (17.59)	−0.29
Health change	46.87 (22.92)	59.89 (26.16)	3.71**
Self-reported symptoms			
Headache	3.14 (3.16)	3.19 (2.83)	0.00
Hyperglycemia	1.68 (1.71)	1.28 (1.50)	−1.78
Hypoglycemia	2.80 (2.56)	2.31 (2.18)	−1.55
Cardiovascular complaints	1.58 (1.92)	1.42 (1.90)	−0.85
Pain	1.37 (2.14)	1.20 (2.03)	−0.72
Neurological complaints	2.14 (2.44)	1.96 (2.35)	−0.67
Fatigue	4.05 (3.12)	3.52 (2.71)	−1.61
Visual complaints	1.82 (2.14)	1.53 (2.26)	−1.16
Process and mediating variables			
Health locus of control			
Internal	22.79 (3.63)	23.87 (3.96)	2.15*
Powerful others	19.40 (4.45)	18.23 (4.05)	−2.06*
Chance	18.57 (3.63)	17.87 (3.19)	−1.26
Cognitive distress	3.04 (2.30)	2.66 (2.02)	−1.53
Knowledge	20.22 (4.85)	22.93 (3.38)	4.94**

* $P < 0.05$.
** $P < 0.01$.

patients that improved less in HbA_{1c} showed less hypoglycemia. Most patients (84%) reported both at T0 and at T1 that they had not experienced any severe hypoglycemia for which help was required. Four (8%) patients who had one to three severe hypoglycemia reported none at T1. Two patients (4%) required five and six times assistance, improved to three and two times help respectively. One patient (2%) had one severe hypoglycemic period at both times, and one patient (2%) who had none at T0, needed help three times at T1.

Health change was the only quality of life sub-scale on which patients improved significantly. At baseline patients scored 46.87 (22.92) (patients indicated their health slightly worse than a year ago), 3 months after treatment patients scored 59.89 ($t = 3.71$; $P < 0.01$). At T1, 44% of the patients indicated their health to be better than 1 year earlier, and 46% of the patients indicated that their health was about the same as before, while 10% reported their health had deteriorated during the past year.

No significant changes on self-reported symptoms on the diabetes symptom checklist were found, although on most sub-scales, small improvements were found and relatively little patients worsened.

3.3. Mechanisms of effect

To gain insight into mechanisms of effect of MIEP, several determinants of self-management were measured. At follow-up patients had a more *internal* locus of control and less *powerful others* locus of control (see Table 2). Patients also improved on the diabetes knowledge test ($t = 4.94$; $P < 0.01$). No significant decrease in cognitive distress was found ($t = -1.53$, ns).

To investigate the role of the process variables in outcome variables stepwise regression analyses were conducted. Table 3 shows that HbA_{1c} after treatment is partly explained by HbA_{1c} before treatment. People with relative high HbA_{1c} at T0 improved most. None of the process variables significantly adds variance to this analysis.

Most changes in quality of life aspects were predicted by their baseline values: lower baseline scores are related to greater improvement, meaning that patients with the highest need for improvement show the greatest effect. Changes in physical functioning and health change were predicted by other variables as well (see Table 3). Change in physical functioning was predicted by age, physical functioning at baseline and change in *chance* health locus of control respectively. Elderly patients and patients with high initial physical functioning improved relatively little, while patients with the largest reduction in health locus of control increased relatively more in physical functioning. Change in health change is predicted by respectively health change at baseline, and by change in *internal* health locus of control. Patients who increased most in *internal* health locus of control reported a relative greater improvement in health change. Although knowledge improved significantly, this did not contribute in mechanisms of effect.

Table 3
Outcomes of regression analyses[a] on changes in HbA_{1c} and quality of life

		R^2	F	Beta
Change in HbA_{1c} (T1–T0)		0.32	21.34***	
Predictor	HbA_{1c} T0			−0.57***
Change in quality of life (T1–T0)				
Physical functioning		0.29	5.82**	
Predictors	Age			−0.30*
	Physical functioning T0			−0.41**
	Chance health locus of control (T1–T0)			−0.33*
Social functioning		0.48	40.90***	
Predictor	Social functioning T0			−0.69***
Mental functioning		0.21	11.58**	
Predictor	Mental functioning T0			−0.45**
General health perception				
Predictor	No predictors			
Health change		0.27	8.27**	
Predictors	Health change T0			−0.48**
	Internal health locus of control (T2–T0)			0.31*

Criteria: probability of F to enter ≤0.050, probability of F to remove ≥0.100; independent variables inserted in analyses: baseline (T0) measure of the dependent variable, age, sex, change in health locus of control, knowledge and cognitive distress.

[a] Method: stepwise.

* $P < 0.05$.

** $P < 0.01$.

*** $P < 0.001$.

4. Discussion and conclusion

This study indicates that the Multidisciplinary Intensive Education Program has shown beneficial effects on glycemic control. In the group as a whole, HbA_{1c} improved significantly. Patients with worst control at baseline improved most, and half of the patients showed a clinically relevant decline in HbA_{1c}. The number of hypoglycemia did not diminish, most likely due to the fact that tighter glycemic regulation is related to an increase in hypoglycemia [5,33–36]. However, the number of severe hypoglycemia did not increase and the few patients that experienced severe hypoglycemia at baseline improved considerably in this respect.

4.1. Discussion

Limited changes in health related quality of life were found, which may be both explained by applying a general quality of life measure and the selection of patients. MIEP is aimed at a specific group of diabetes patients with poor glycemic control and psychosocial limitations resulting from diabetes, but without major co-morbidity (exclusion criterion). Several studies indicate that diabetes does not have a great impact on general quality of life, but that complications do [5,33–36]. At baseline of MIEP, participants already reported a rather good quality of life with scores over 70 on most RAND-36 sub-scales. However, patients referred to MIEP are at risk of developing diabetes-related co-morbidity, which will affect overall quality of life [37]. To detect the diabetes related psychosocial problems in the participants of MIEP a more disease-specific quality of life measure will probably shed some more light on the effects on health-related quality of life. The question remains whether patients with the highest need for diabetes rehabilitation, that is with complex problems, were referred and selected adequately. To better reach this potential group of patients, referring physicians, who likely mainly focus on glycemic control, should be better informed about this new form of diabetes education and its target population.

In many cases traditional diabetes education is foremost oriented at knowledge [9,17,32], although other variables might be more important to focus on. The results show that patients had a higher level of knowledge after treatment and were more *internal* and less *powerful others* oriented. Health locus of control can be regarded as an indicator of the concept of empowerment. Empowered patients should be mainly *internal* oriented and have a low *powerful others* and *chance* orientation. According to the changes in HLOC patients became more empowered after MIEP. Health locus of control was a determinant of program-effects; patients who became less *chance* oriented reported an increase in physical functioning and patients who became more *internal* oriented considered their health better to be than a year before.

Interestingly, analyses did not indicate knowledge as a determinant of outcomes of the treatment, supporting research that showed the limited effects of improving knowledge in advanced education [32]. To analyze mechanisms of effect more accurately, a greater group of patients is needed and a wider variety of behavioral determinants should be measured.

The group of patients that participated in MIEP was rather heterogeneous with respect to age, glycemic control and quality of life. It is reasonable to assume that personal goals of patients will diverge on these aspects, too. In regression analyses on program-effects baseline scores were controlled for, and had an effect in all regression analyses except for general health perception. That is, patients with worst glycemic control, health change, physical, social or mental functioning at baseline improved relatively more on the outcome concerned. Subgroup analysis might therefore be preferable, but the present study included too small a number of patients to elaborate on this idea.

Practical limitations of the study made it impossible to conduct a randomized trial, which leaves room for alternative explanations for effects. Patients who were referred to MIEP had poor glycemic control or limitations for at least 1 year despite intensive regular care. That is, patients already received extra attention for their diabetes, which makes it implausible that effects of MIEP are only due to simply giving attention. Furthermore, data were collected 12 weeks after the core module of treatment, when possible effects of just giving attention would have disappeared.

This study indicates that tailored intensive diabetes self-management education for patients who profit unsatisfactorily from intensive regular care, contributes significantly to improvement in HbA_{1c}, prevention of severe hypoglycemia and to a lesser extent to general health-related quality of life. More research is needed to specify the group of patients who primarily benefit from such a program, and to better clarify the mechanisms of effect involved in diabetes education. The mere knowledge that the program is effective is not enough, to find out how it works (mechanisms of effect) may be even more important. For example, what is the role of behavioral determinants we studied? To determine stability of effects over time patients have to be monitored for a longer period after treatment.

4.2. Practice implications

For patients who failed to achieve their treatment goals under prolonged intensive regular care, intensive education programs might be beneficial, although the selection procedure of patients and the measurement of effects need more attention. Diabetes treatment largely involves patients' own efforts and it forces patients to make informed decisions each day, which makes patient centered education, as in the empowerment approach, the preferable form of education. Especially patients with poor glycemic control (HbA_{1c}) should be referred to programs like MIEP, since several studies showed a strong relation between improved glycemic control and reduced risks of developing complications [2,38].

It is important to measure psychological distress and process variables accurately, with disease-specific measures, to determine effects of diabetes education in this respect and be able to optimize treatment.

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