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Coping with symptoms after education for self-management of chronic diseases

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Abstract

One benefit of education for self-management of chronic diseases is to increase the use of cognitive techniques for coping with symptoms. Unfortunately, that benefit can deteriorate over time, and that phenomenon, which is sometimes called "decay of impact", has been studied only rarely. This study was done to understand the decay of impact with regard to the use of cognitive techniques for coping with symptoms, and especially to understand how that decay might be predicted. Data were analyzed from 381 adults suffering from chronic medical conditions, all of whom were involved in education to improve their self-management of their chronic condition(s). During the first year after the educational program, coping was measured four times. Variables associated with the decay of impact were found using statistical modeling (logistic regression). Decay of impact was found in almost half of the participants. The analysis provided moderately good predictions regarding the decay of impact. Given this new information, interventions to further improve coping with symptoms can be appropriately targeted to the people for whom they will be most beneficial.

Keywords: *Coping with symptoms, chronic diseases, health education, decay of impact*

1. Introduction

Many people who suffer from chronic diseases can learn skills that help them to self-manage their conditions, but in most cases the benefits of the programs that teach those skills are not large [1-3]. In addition, in almost none of the studies of these programs has the follow-up lasted longer than 6 months. Therefore, many important questions about the longer-term effectiveness of these programs have not been answered. Nonetheless, it is generally believed that at least some of the programs' positive effects are not long-lived [4,5]. The transience of those benefits is not ubiquitous [6], but it does appear to be common [4,7-11]. It is sometimes referred to as deterioration [9], attenuation [3,7,8], backsliding [12], relapse [10], and decay of impact [12].

One measure toward ensuring long-term benefits is to minimize or prevent the decay of impact, and that might be accomplished by reinforcement [12,13]. In some studies, reinforcement has been found to be useful, but in others it had no effect, and in at least one study reinforcement appeared to have a negative effect [14]. The reason for that lack of effectiveness is not understood, but the results of the present study may give one potential explanation.

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The Chronic Disease Self-Management Program (CDSMP, https://www.selfmanagementresource.com/) is based on self-efficacy theory [15], and one of its areas of emphasis is on learning the use of cognitive techniques for coping with symptoms. The focus of the present work was to find ways of identifying, as early as possible, those CDSMP participants who would later have decay of impact as regards coping with symptoms. This could serve as evidence on which to base appropriate measures against that decay.

2. Methods

2.1 The CDSMP

The program lasted six weeks, and it had one group-discussion session each week. Each group had two trained facilitators and from five to 13 participants. The data came from 76 such programs, which took place in all areas of Japan. As described elsewhere (CDSMP, https://www.selfmanagementresource.com/), one aim of the program was to help the participants learn how to use cognitive techniques for coping with the symptoms of chronic diseases.

2.2 The participants

The participants, all of whom had at least one chronic medical conditions, found out about the CDSMP and about the study either through the Japan Chronic Disease Self-Management Association (www.j-cdsm.org/) or from written information that was available at public service centers. Children were not included. Ethical approval was given by the University of Tokyo (Graduate School of Medicine, Research Ethics Committee, IRB# 1472). Written, informed consent for voluntary participation, both in the CDSMP and in the study, was obtained before the research started.

2.3 The data collection, the study's design, and how the variables were measured

Before the start of the first group-discussion session, the participants provided baseline data using a self-administered questionnaire. That included data on diagnoses, schooling, age, civil status, etc. Postal mail was used for the follow-up self-administered questionnaires, which were sent three months later, six months later, and one year later. For each one of six different cognitive techniques that were taught as methods for coping with symptoms, the frequency of the use of that technique was measured on a 6-point scale, with 0 indicating "never" and 5 indicating "always" [16]. Thus, the possible scores on that scale ranged from 0 to 30, with higher scores indicating that the coping techniques learned in the CDSMP were used more frequently and that more those techniques were used.

Two criteria were used to identify the presence of decay of impact: (A) the highest score on the coping scale was higher than the baseline score, which indicates improvement after the program began, and (B) the final measured score on the coping scale was lower that the highest score, which indicates decay after the improvement that was evidenced by (A). Those two criteria were applied at the level of each individual participant. If both criteria were met, that participant was categorized as among those with decay of impact. If both of those criteria (together) were not met, then one of the following three non-decay patterns was recognized: "improvement-only" if the final score was higher than the score before the program began, "no change" if all four scores were the same, and "deterioration" for any other combination of scores.

2.4 The analysis of variables associated with decay of impact

By definition, decay of impact is preceded by improvement, but that improvement is transient. Therefore, the goal of the analysis was to understand how transient improvement differs from improvement that is maintained (continuous). To achieve that goal, the characteristics of the participants who had decay were

compared with those of the participants who had improvement only. The method of analysis was logistic-regression modeling (multivariable). The predictor variables used were chosen via simple logistic-regression modeling, from among 28 variables that have been described in a previous report [17], with $P < 0.25$ as the criterion for deciding which of the variables to include as predictors in the initial model. Then the likelihood ratio was used for backward stepwise elimination. Each predictor had more than 10 events. Tests of multicollinearity were the variance inflation factor and tolerance statistics. The test for evaluating model fit was the χ^2 test of Hosmer and Lemeshow. Two indices of the overall utility of each multivariable model were computed: The first was the area under the receiver operating characteristic curve [18,19]. The second was Cohen's *d*, which was computed on the basis of that area [20]. IBM SPSS version 19 and Excel 12.3.3 were used to analyze the data.

3. Results

A total of 502 people provided data at baseline. However, the only data analyzed for the present work were those provided by people who completed the questionnaires both before the first CDSMP session (baseline) and also either two times or three times during the follow-up period, the reason being that it is possible to detect the decay of impact only if at least three serial measurements are available. Thus, the total number of people who provided usable data on coping was 381 (75.9% of 502). Coefficient alpha for the scale used to measure coping indicated an acceptable level of reliability (0.72).

The participants' mean age was 49 years (SD 14 years; range 18-83 years). Most of the participants were women (79%), and most had completed college (67%). About half were married and at the time of the study were living together with a spouse (53%). The mean number of years since their chronic disease had been diagnosed was 14, but the values for the individuals varied over a wide range (> 60 years to < 1 year). Having at least two diagnoses was common (> 40%), and having at least three diagnoses was not rare (> 15%).

A total of 183 participants (48%) had the decay-of-impact pattern on coping (Figure 1). For the multivariable model, the tests of multicollinearity showed no problem. Not including the intercept, there were 8 predictors in the initial model, of which 5 remained after stepwise backward elimination (Table 1). The chi-squared index of goodness-of-fit (final model) was 9.75 (df = 8, $P = 0.28$). This was the Hosmer-Lemeshow goodness-of-fit test, and therefore higher *P* values indicate better model-to-data fit. The area under the receiver operating characteristic curve was 0.635, which corresponds to a Cohen's *d* of 0.49.

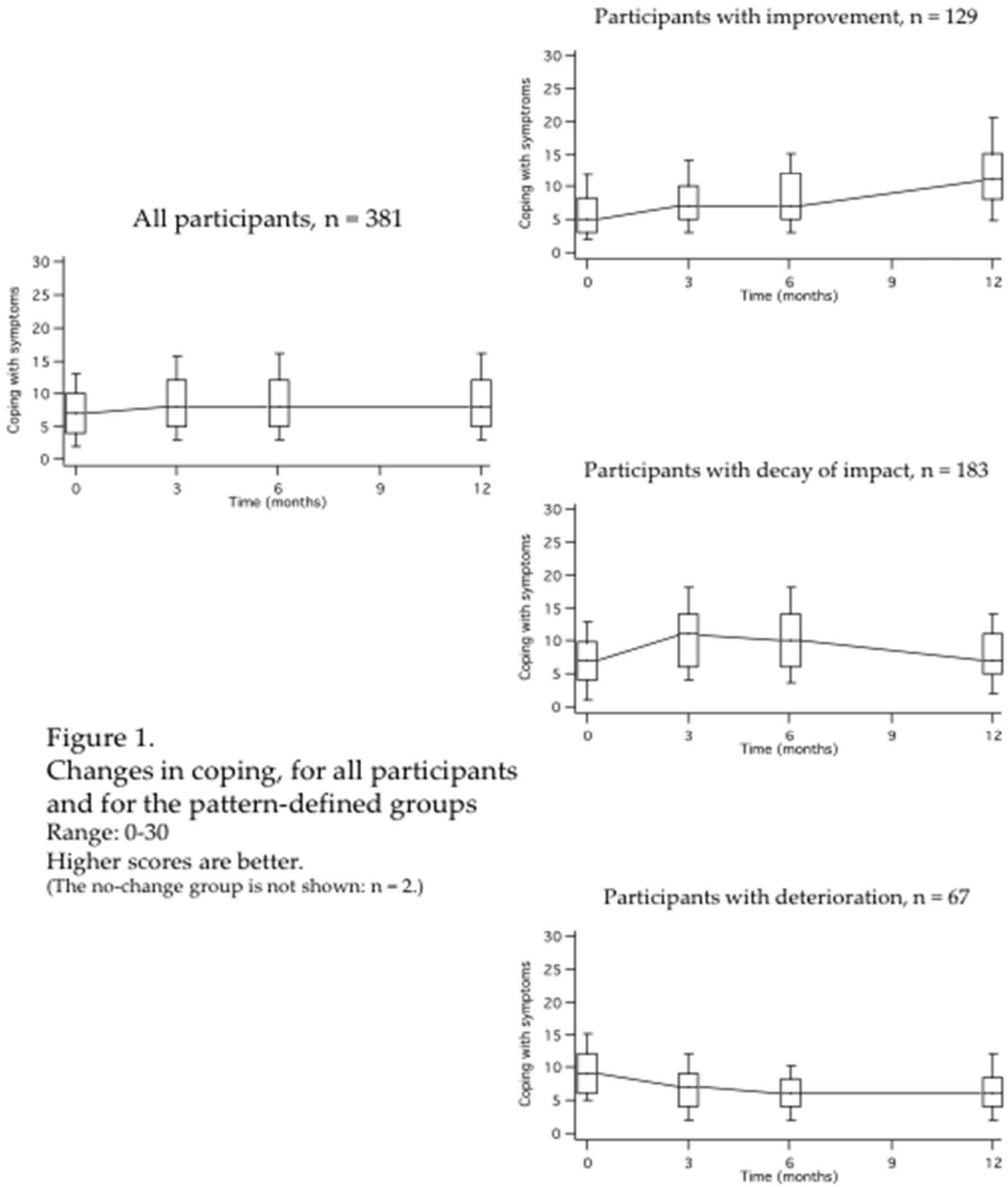

Figure 1.
Changes in coping, for all participants and for the pattern-defined groups
Range: 0-30
Higher scores are better.
(The no-change group is not shown: n = 2.)

Figure 1. Changes in coping, for all participants and for the pattern-defined groups

Table 1. Coping: predictors of having decay of impact (multivariable logistic regression)

Independent variables	Coefficient (i.e. β)	SE	Wald χ^2	*P*	AOR (95% CI)	AUC *d*
Initial model (before backward elimination)						0.625
Intercept	-2.94	1.00	–	–	–	0.45
Sex	-0.53	0.31	2.91	0.088	0.59 (0.32-1.08)	
Pulmonary disease	1.43	0.73	3.87	0.049	4.19 (1.00-17.5)	
Rheumatic disease	0.37	0.41	0.82	0.366	1.44 (0.65-3.20)	
Communication with MDs (BL)	0.04	0.03	1.00	0.317	1.04 (0.97-1.11)	
Coping with symptoms (BL)	0.01	0.03	0.23	0.628	1.01 (0.96-1.08)	
Anxiety (BL)	0.09	0.04	6.00	0.014	1.09 (1.02-1.17)	
Satisfaction with daily life (BL)	0.09	0.06	2.62	0.105	1.10 (0.98-1.23)	
Self-efficacy at 3 months	0.02	0.01	1.91	0.167	1.02 (0.99-1.04)	
Final model (after backward stepwise elimination; likelihood ratios, *P* for removal = 0.1)						0.635
Intercept	-1.21	0.59	–	–	–	0.49
Sex	-0.60	0.30	3.95	0.047	0.55 (0.30-0.99)	
Pulmonary disease	-1.44	0.73	3.93	0.047	0.24 (0.06-0.98)	
Anxiety (BL)	0.09	0.04	6.27	0.012	1.09 (1.02-1.17)	
Satisfaction with daily life (BL)	0.10	0.06	3.12	0.075	1.10 (0.99-1.23)	
Self-efficacy at 3 months	0.02	0.01	2.39	0.122	1.02 (0.99-1.04)	

SE: standard error, AOR: adjusted odds ratio, CI: confidence interval, AUC: area under the receiver operating characteristic curve, *d*: Cohen's *d*, which was computed from the AUC [20], MD: medical doctor, BL: Baseline.

4. Discussion

The prevalence of the decay-of-impact pattern with regard to coping with symptoms was rather high: almost half of the participants (48%) had that pattern. This indicates, as other work has before, that reinforcement is needed by many people who participate in this kind of health education [21]. For the final statistical model, the effect sizes (both d and the receiver-operating-characteristic-curve area) show that it is possible to predict which participants will have decay of impact.

Membership in a pre-defined group has been shown to be associated with the effect of this kind of health-education program [3,8,22,23]. In contrast to pre-defining the groups of interest, defining groups according to their pattern of measured changes after the program is still rare. More than four decades ago [12], the decay of impact was seen to be important in evaluating the effects of health education, and yet the details of that phenomenon remain largely unstudied. One implication of the results reported here is that there may be one answer to two specific questions, both of which are of great practical importance: First, why are the positive effects of the CDSMP small in magnitude [1]? And second, why have trials of reinforcement not been generally successful [4,14]? The answer implied by results such as those shown here is, again [21], that when statistical summaries do not take into account groups defined by their patterns of change, then important effects are obscured. To be specific, a possible answer to the first of the two questions above is that in many published studies the positive effects appeared to be smaller than they really were because they showed only a *mixture* of different-sized effects among various groups that could have been distinguished. As for studies of reinforcement, the results reported here indicate that any actual benefits of reinforcement could have been obscured when data from people who in fact had no need for reinforcement were *mixed* with data from those who actually both needed reinforcement and benefitted from it. Therefore, the present study shows again the

potential advantage of focusing attention on participants and also on groups that can be recognized and distinguished from each other according to the pattern of their change following the educational program.

3. Conclusions

Further research on this phenomenon might do well to adopt a robust theoretical framework such as that used in studies of relapse prevention [24,25], or perhaps an ecological approach [26]. The importance of self-efficacy in this study is consistent with the fact that the CDSMP was constructed on the basis of Bandura's theory of self-efficacy [15]. These results also show how the processes of changing behavior and of maintaining new behavior can be seen as having different mediators [27]. These results should influence how new interventions and new reinforcements are designed and implemented.

Application and implementation of the CDSMP remains an important area of research [28,29]. The present results indicate that future work should focus on reinforcement to maintain the program's benefits. Thus, among the goals of future research would be improved identification of the risk of decay of impact, as well as methods for minimizing that risk.

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