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Hidden decay of impact after education for self-management of chronic illnesses: hypotheses

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Abstract

People with chronic illnesses can benefit from self-management education. However, those benefits are said to decay over time (there is some evidence that this 'decay of impact' does occur), and the reinforcements used to prevent that decay appear to be ineffective. We hypothesize that the reinforcements appear to be ineffective because decay of impact occurs only in a subgroup of these programs' participants, so any benefits of reinforcements in that subgroup are concealed by whole-group summary statistics. We also hypothesize that reinforcements can benefit those who need them – those who would otherwise have decay. One approach to testing these hypotheses requires analysis of individual-level data, which is uncommon in this field. Some useful data could come from studies that have already been completed, but the strongest evidence will require prospectively designed tests in future trials. If the hypotheses are false, then time and resources spent on reinforcements can be saved or redirected. If the hypotheses are true, then reinforcements can be implemented with less waste and they can be made more effective. These programs can also be improved to better fit their users' needs, and there can be a new basis for evaluating the programs' effectiveness.

Keywords

Chronic illness, self-management, backsliding, decay of impact, reinforcement

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Background

The global burden of chronic illnesses is increasing.[1] One response has been to help patients with chronic illnesses self-manage their conditions.[2] Educational programs can provide that help,[3–5] and those programs do have some benefits. They can, for example,

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increase self-efficacy, self-rated health status, and the frequency of aerobic exercise. However, their impact can decay over time and efforts to prevent the decay have failed. Here we present two hypotheses: one to explain that failure, and the other regarding how the decay might be prevented. We discuss how the hypotheses can be tested, and we indicate some implications for research and for practice if they are true.

In the context of health education in general, improvement followed by deterioration (i.e. 'decay of impact') was described 35 years ago,[6] and with regard to self-management education it is still considered to be important.[7] Decay after self-management education is not universal.[8] Still, even though it has not been a primary object of study, decay does seem to be common.[9–15] To prevent or mitigate that decay, reinforcements ('booster sessions') are recommended (p. 72).[2]

Nonetheless, in the context of education for self-management of chronic illnesses, reinforcements have been studied only occasionally, and their use has received almost no evidence-based support. In two studies of arthritis self-management education, reinforcement had no effect.[16,17] After a diabetes self-management intervention,[18] telephone follow-up did result in improvement on a biological measure (lipid ratio) but it 'did not generally produce meaningful incremental effects'. In that study, reinforcement was *counterproductive* on psychosocial measures (particularly on the Chronic Illness Resources survey), that is, it 'appeared to produce less improvement... than conditions not receiving the telephone follow-up'. In a different diabetes self-management program, 'automated telephone reinforcement did not improve the effectiveness' of the intervention,[19] and neither did reinforcement via a discussion group for peer support.[20] In the latter study, two results were the *opposite* of what one would expect: patients who were randomized to not receive reinforcement reported greater relief from health-related distress, and the reduction in their depression was also greater. In a pilot study of Internet-based support for self-management of dyspnea, patients with chronic lung disease did not benefit from a booster.[21] This is not intended to be an exhaustive and systematic review. The six studies cited above were found during a search for evaluations of reinforcements after chronic-illness self-management programs. The format, timing, and content of the self-management programs and of the reinforcements tested have certainly been diverse, as have the populations studied and the outcomes measured (see Appendix), and the number of studies is small. Even with those caveats in mind, evidence published to date, overall, does not lead to the conclusion that reinforcements are more useful than non-reinforcement: in the context of self-management education for people with chronic illnesses, claims that reinforcements are necessary and beneficial have little or no empirical basis.

Are reinforcements to prevent or mitigate the decay of impact really needed? If they are needed, why have they not consistently resulted in better outcomes than non-reinforcement? In this context, we cite the statement by Lorig et al.[22] indicating that these programs' effects may appear to be small because of important differences among the participants: 'It should be noted that the population is very heterogeneous for disease, age, education and symptom distribution. Thus group changes and mean effect sizes tend to be modest.'[22] That explanation implies that the effect sizes will not be small if they are not based on whole-group means. For example, there may be subgroups with very small effects or perhaps zero effects, which would dilute (partly hide, efface, or obscure) large effects in other subgroups. If that is true, then larger effects will be measured when homogeneous subgroups are analyzed separately. Consistent with that idea, some

analyses of subgroups of patients have already led to findings of potentially important differences between subgroups (such as Reeves et al.,[23] Swerissen et al.,[24] Smeulders et al.[25] and Nolte et al.[26]). In one of those studies, three subgroups were defined by their pattern of change after the intervention: substantial improvement, no change, and substantial decline.[26] A possible fourth subgroup, one with decay of impact, has not been studied, but it could explain why some reinforcements appear to be ineffective.

The hypotheses

If a subgroup of patients has decay of impact, that pattern of change could be hidden by other patterns of change in other subgroups. Furthermore, if effective reinforcements are given both to patients who need them and to those who do not, then the benefit to those who do need them will be diluted by the lack of benefit to those who do not. Therefore, we hypothesize that decay of impact occurs in only a subgroup of patients. We also hypothesize that reinforcements can benefit the patients who are most likely to have decay of impact.

These hypotheses may be relevant to a variety of interventions. While the prevalence of decay and the need for reinforcement could well differ between programs, what studies of those programs have in common is that whole-group summary statistics can conceal large effects in subgroups. Imagine a health-education program that increases the frequency of aerobic exercise. Its effect might last for 1 year in some patients and for only 3 months in others. In that case, even a successful reinforcement given 3 months after the original intervention would appear to have little or no effect unless data from the subgroup at risk for decay of impact are analyzed separately.

Testing the hypotheses

These hypotheses can be tested using individual-level data. The first step is to categorize individual patients according to their pattern of change: decay of impact, improvement-only, deterioration-only, and possibly others. Each patient's classification will depend on that patient's data rather than on group data, and therefore the most useful measures will be those with high reliability, preferably at least 0.9 (p. 265).[27] Using data that are as reliable as possible, the researcher can classify each patient into a pattern-defined subgroup.

The next step is to describe the prevalence and magnitude of the decay of impact. Evidence against the first hypothesis would be a finding that none or almost none of the patients had decay of impact. In contrast, evidence consistent with that hypothesis would be, for example, a finding that some patients had decay of impact and others did not, and a finding that differences in long-term outcomes between the decay-of-impact subgroup and other subgroups are large. If more than a few patients do have decay of impact, and if that decay is large, then the next step will be to look for demographic, clinical, and other predictors of having that pattern of change, so that patients who are at a high risk of having decay of impact can be identified before the decay begins.

Many studies of these interventions have included only 2 waves of measurement, and few have lasted longer than 6 months, but studies of the decay of impact must include at least 3 waves of measurement and they may also require longer follow-up.

Studies of health-education programs can take years of work and large budgets, but it might be possible to test these hypotheses now. If the outcome measures are sufficiently reliable, and if the pitfalls of post hoc analysis of subgroups are avoided,[23,28–30] then the hypotheses might be tested with existing data from long-term studies that

have already been completed. The statistical power of those tests could be increased by collaborative re-analysis of raw data.[31,32]

Retrospective and exploratory approaches to testing the hypotheses could be supplemented by approaches based on analogies with theory and evidence from other contexts. One example is Rothman's clear distinction between a change in behavior and maintenance of a new behavior.[33] In that theory, maintenance depends on satisfaction with outcomes, so patients who are dissatisfied with short-term outcomes of a self-management program would be predicted to have decay of impact, at least with regard to health-related behaviors.

As another example, if the decay of impact after these interventions is analogous in important ways to relapse after treatment for addiction, then the large body of work on predicting and preventing relapse (as reviewed by Hendershot et al.[34]) could be applied to predict who will have decay of impact and also to design effective reinforcements. Imagine again a health-education program that increases the frequency of aerobic exercise. Some of the patients who experienced that benefit might 'backslide' in particular situations: e.g. they might not maintain their new exercise regimen after a tiring day at work, or when a family member needs extra attention, or during an acute exacerbation of their chronic condition. Each such instance of decay of impact could be analogous to relapse in a 'high-risk situation,' which has been a main focus of relapse-prevention research. In addition to high-risk situations, there are 'background factors that determine an individual's 'set point' or initial threshold for relapse,' and one is self-efficacy,[34] which is also emphasized in many self-management interventions for people with chronic illnesses, so it would be reasonable to test whether self-efficacy and changes in self-efficacy can be used to predict decay of impact. Another of those background factors is social support: it is known to be important in relapse (as reviewed in Witkiewitz and Marlatt[35]) and its role in decay of impact is worth studying.

Prospectively designed tests of both hypotheses can be included in future studies. If the first hypothesis is supported, and if patients who are likely to have decay can be identified early enough, then the second hypothesis can be tested. That is, the effects of reinforcements can be measured after they are given only to those patients who are predicted to have decay, or, better still, to a randomly selected group of them. The second hypothesis may be more difficult to test than the first, at least in part because, as noted above, self-management programs and reinforcements are diverse. There are many possible combinations of frequency, format, and content of reinforcements, but only a few of them are likely to be rigorously tested, so it will be important to design candidate reinforcements carefully. Here again, previous findings and a reasonable theoretical framework could be useful. Regarding timing, the work of Hennessy et al.[14] on education for HIV/AIDS prevention shows how analysis of the decay of impact can inform decisions about when reinforcements should be given. Regarding content, relapse-prevention theory gives a logical basis for testing reinforcements designed to maintain and enhance self-efficacy. Also, if Rothman's theory[33] is correct (and recent research on weight loss does support it, e.g. Sciamanna et al.[36]) then reinforcements that merely repeat the content of the original health-education program might be less effective than reinforcements that focus on 'perceived satisfaction with received outcomes.'[33]

After the hypotheses are tested

Even if almost no patients are found to have substantial decay of impact, those who take part in these programs would still benefit,

as the idea that reinforcement is unnecessary would be supported, and resources that are now used for reinforcements could be saved or redirected.

If, on the other hand, reinforcements are both needed and effective for a subgroup of patients, there will be implications for research, and also for how those reinforcements are designed and implemented. Overall, one goal would be to minimize the costs of planning and implementing reinforcements by offering them preferentially to the patients who are likely to need them most. Another goal would be to optimize the target subgroup, format, timing, and content of reinforcements.

While the reinforcements can be optimized, the original intervention might also be improved to better fit the needs of patients who are likely to have decay of impact. This would alter the criteria by which these programs are evaluated: more successful programs would be those after which very few of the patients at risk for decay of impact actually have it, and programs in which the decay is small.

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Conflict of interest

The authors have no competing interests to disclose.

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Appendix

Brief summaries of references 16 – 21

Riemsma et al.[16] studied the effects of an educational program for arthritis self-management that included group-discussion sessions as boosters at 3, 6, and 9 months. At the 12-month follow-up, some patients still had benefits with regard to fatigue and self-efficacy. However, with regard to pain, affect, physical health, social interactions, and self-management behaviors, there were no statistically significant effects at that time. They concluded that the booster sessions did not enhance the effects of the self-management education.

Lorig and Holman[17] studied 589 patients who participated in an arthritis self-management educational program. They compared the effects of no reinforcement, reinforcement in group sessions, and reinforcement via a bi-monthly newsletter. After the program, the reductions in pain, disability, depression, and the frequency of physician visits were maintained for 20 months even in the patients who had no reinforcement, and neither of the two forms of reinforcement enhanced the original program's benefits.

Glasgow et al.[18] studied 320 patients who participated in a diabetes self-management program. Half of those patients received reinforcement via seven telephone calls over 12 months from a health counselor and the other half received no telephone follow-up. Half of them also received reinforcement regarding community resources while the other half did not. That reinforcement had three parts: (1) information about local availability of foods for proper nutrition, (2) eight newsletters over 12 months that focused on practical support from the community to maintain proper eating patterns, and (3) goal setting for related activities during follow-up meetings 3 months and 6 months after the program. The outcomes measured were behavioral, biological, and psychosocial. The results were that patients who had received telephone follow-up had greater improvement on only one outcome: the ratio of total cholesterol to HDL cholesterol ($p < 0.02$). One of the psychosocial outcomes was the use of community resources, which was measured using the Chronic Illness Resources survey. On that outcome, perhaps unexpectedly, the patients who had not received the telephone follow-up had greater improvement ($p < 0.02$). The authors speculated that the effects of one reinforcement program could have interfered with the effects of the other. That is, the support received via telephone follow-up with health counselors might have diminished the perceived need for support from the community.

Lorig et al.[19] studied 567 people in the San Francisco Bay Area who had type-2 diabetes. Each was randomly assigned to one of three groups: wait-list control (usual care), a 6-week disease-specific self-management program with no reinforcement, or the same program with reinforcement via monthly automated telephone calls. The main program and the reinforcements were given in Spanish. The outcomes measured were self-efficacy, three indices of health-system utilization, seven health indicators (symptoms, HbA1c, activity limitation, etc.), and four health-related behaviors. At the time of the 18-month follow-up, there was a statistically significant difference between the reinforcement group and the non-reinforcement group on only one of the 15 outcomes. Specifically, those in the reinforcement group were more likely to have monitored their blood-glucose level in the previous week. The authors concluded that the 'automated telephone reinforcement did not improve the effectiveness' of the program.

In a study of an Internet-based diabetes self-management program, Lorig et al.[20] compared data from 186 people who had received reinforcement with data from 209 who had not. The reinforcement comprised membership in an online discussion group that was intended to provide peer support. The measured outcomes were HbA1c, health distress, activity limitation, psychological depression, patient activation, self-efficacy, time doing aerobic exercise, and the number of physician visits. The results showed no benefit of the reinforcement. Unexpectedly, at the 6-month follow-up the only statistically significant difference between the reinforcement group and the non-reinforcement group was that the non-reinforcement group had a greater decrease in health distress (effect size for reinforcement = -0.234, $p = 0.007$). Similarly, at the 18-month follow-up the only statistically significant difference was that the non-reinforcement group had a greater decrease in depression (effect size for reinforcement = -0.222, $p = 0.018$). The authors concluded that this reinforcement in this context 'appeared to have no value.' They called for further study of how such a reinforcement is utilized and of whether such follow-up interventions are in fact needed.

Also studying an Internet-based program, Nguyen et al.[21] conducted a pilot

study in 16 people with chronic obstructive pulmonary disease. Some had previously participated in a dyspnea self-management program, so for them the Internet-based intervention was considered to be a booster. For the others the Internet-based program was the primary intervention and there was no reinforcement. There were 12 outcome measures: the physical functioning, role-physical, and general health perception scales of the Medical Outcomes Study SF-36; time doing exercise (endurance and strengthening, measured separately); perceived availability of social support (online and offline, measured separately); self-efficacy for managing dyspnea; the 'mastery' subscale of the Chronic Respiratory Questionnaire (CRQ); dyspnea as measured by the CRQ; severity of dyspnea-induced distress; and impact of dyspnea on 'normal work' (housework and work outside home, measured together). At the 3-month follow-up, on *none* of the 12 outcomes was there a statistically significant difference between the change in the reinforcement group and the change in the non-reinforcement group.