

Advancing the Science of Behavioral Self-Management of Chronic Disease: The Arc of a Research Trajectory

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Abstract

This article describes advances in the behavioral self-management of chronic disease from the perspective of a 25-year trajectory of National Institute of Health–funded research in arthritis and cardiopulmonary diseases that has sought to develop a transdisciplinary understanding of how applied behavioral science can be used to improve health behaviors, functional status, and health outcomes. The article traces the arc of a novel research program—conducted in collaboration with physician-scientists at Columbia, Weill Cornell Medical College, and New York University School of Medicine—that runs through social cognitive theory, behavioral economics, and the emerging science of positive psychology in an effort to develop promising new approaches to fostering the adoption and maintenance of health-related behavioral change. The article concludes with what has been learned and what the implications of the work are for advancing behavioral self-management and patient education to improve patient outcomes and achieve the compression of morbidity.

Keywords

arthritis, behavioral economics, cardiopulmonary diseases, chronic disease, compression of morbidity, health outcomes, positive psychology, social cognitive theory, transdisciplinary research

I am honored to accept this award and I am proud to be part of the legacy that Jim and Sarah Fries have created to celebrate Elizabeth's life and work. As the 25th recipient of this award, I stand on the shoulders of Kate Lorig, Noreen Clark, Lawrence Green, Albert Bandura, James Prochaska, Donald Morisky, Russell Glasgow, Victor Strecher, David Sleet, and Andrea Gielen, among others—all giants in the field of health education. Their contributions have provided the foundation on which my work sits. Thus, I feel privileged to be counted among those whom I have admired and respected for their work to advance the cause of human health through health education research.

I will do three things here. First, I will be autobiographical and briefly recount the personal narrative that has animated my work. Second, I will trace the arc of a 25-year trajectory of NIH (National Institutes of Health)–funded research that I have conducted in collaboration with physician-scientists at Columbia, Weill-Cornell Medical College, and New York University School of Medicine. I will briefly describe and discuss three projects, all of which have sought to develop a transdisciplinary understanding of how behavioral self-management of chronic disease can improve health outcomes and compress morbidity. Finally, I will conclude with a few thoughts about what my colleagues and I have learned and what I believe are the implications of this work for future efforts.

Personal Experience and Inspirational Insight

Like many who point to a formative moment that shapes destiny, both personal experience and inspirational insight have shaped the arc of my research. The first moment for me—a galvanizing personal experience—came in 1977. I was a 25-year-old doctoral student at the University of Illinois when my father became acutely ill. He had to be hospitalized, and because he was self-employed and could not afford health insurance, his illness proved financially ruinous. The crisis led me to write an essay about the high costs of medical care that *The New York Times* published on its op-ed page that year (Allegrante, 1977). President Jimmy Carter read my op-ed page article and invited me to the White House to speak with his special assistant for health affairs, Dr. Peter Bourne. It was my first attempt at advocacy and it was the kind of heady personal experience that had an indelible

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impact on me. But more important, because my father had been a smoker, possessed low health literacy, and could neither afford nor fully understand the importance of the medicine he was prescribed, the clinical problem of nonadherence to his prescribed treatment came into sharp focus.

The second moment—inspirational insight—would not come into focus until some years later, when I had completed my doctorate and was a junior professor at Columbia. I read this article in the *New England Journal of Medicine* that described how increasing life expectancy was reshaping how medicine should be thinking about chronic disease, lifestyle change, and the contours of morbidity at the end of life. It had been written by James Fries (1980), a Stanford rheumatologist and physician-scientist while a fellow at the Center for Advanced Studies in the Behavioral Sciences, and it was brilliant scholarship. The emerging model for our national health that Jim outlined was based on the assumption that the curves for survival and morbidity at the end of life would produce a “compression of morbidity.” Social interactions, health promotion, and personal autonomy would prove to be instrumental in this transformation.

It was not until 1987, however, that my personal experience and the inspirational insight from trenchant scholarship would converge to provide context for my own research trajectory. That year, I had begun a year-long sabbatical leave as a Pew Health Policy Fellow at the RAND Corporation, where I had met the health economist Joe Newhouse and his merry band of colleagues at the RAND/UCLA Center for Health Policy Study. Newhouse had designed the RAND health insurance experiment and was riding a wave of publications that were reshaping concepts of health insurance and its effects on health behavior and health outcomes (see, e.g., Lohr et al., 1986). By the time I had arrived in Santa Monica, he was working with Bob Brook, Sheldon Greenfield, and John Ware on a RAND project called the Medical Outcomes Study, which produced the Short Form (or SF-36) Health Survey (McHorney, Ware, Lu, & Sherbourne, 1994; McHorney, Ware, & Raczek, 1993; Ware & Sherbourne, 1992) and many other innovations in the measurement of health status. (See RAND, 2017a, 2017b, for a bibliography and descriptions of the RAND Health Insurance Experiment and the RAND Medical Outcomes Study.) Together, they had also become instrumental in stimulating the Robert Wood Johnson Foundation to fund the Clinical Scholars Program (Robert Wood Johnson Foundation, 2017). That program has seeded many of the faculty development efforts at medical schools over the past four decades that have advanced the cause of prevention and behavioral intervention research.

Three Theoretical Perspectives, Three Studies

With new insights into health outcomes research, I returned to New York and embarked on what would become a 10-year

collaboration in arthritis research with colleagues at the Hospital for Special Surgery. As the lead behavioral scientist and director of education for the new NIH-funded Arthritis Center—a multi-institutional collaboration between Weill Cornell, the City University of New York, Rockefeller, and Columbia—I was very much at the center of what proved to be a remarkable multidisciplinary team with which I feel privileged to have collaborated for those years. My role was to bring health education theory, concepts, and methods to the center’s program of research.

This is where I met Mary Charlson, a physician-scientist and Yale-educated clinical epidemiologist, with whom I forged a productive collaboration that endured for over two decades. In 1987, Mary had published what would turn out to be an important paper on the measurement of comorbidity. She had developed a prognostic instrument—now known as the Charlson Comorbidity Index—which is one of the most highly cited instruments used in medicine and clinical epidemiology (Charlson, Pompei, Ales, & MacKenzie, 1987). On the recommendation of self-care education proponent Lowell Levin at Yale (a former editor of *Health Education Monographs*), Mary had recruited me to join the Arthritis Center whose application for funding I had participated in writing before leaving for RAND. It was in the Arthritis Center where we developed an organizational model for multidisciplinary clinical research (Charlson et al., 1993) and conducted the first of the three question-driven studies to advance the behavioral science of chronic disease self-management.

Social Cognitive Theory and Arthritis

Central to our thinking was the evolving role of the physician in the emerging context of the new outcomes-oriented medicine. In particular, we were interested in what physicians—and their patients—had to do, and be good at, to improve chronic disease management and its health outcomes. This was an area of research that Larry Green and his doctoral and postdoctoral students—Lawren Daltroy, Don Morisky, Pat Mullen, and Debra Rotter in particular—had begun pioneering at Johns Hopkins in the 1970s. It also became a career-long focus of Noreen Clark’s work in asthma and the role of self-regulation theory in chronic disease management.

We knew from their work and that of others that traditional physician-centered practice focused on clinical proficiency in conducting (a) a physical examination, asking questions, and taking a history; (b) developing a diagnosis; and (c) implementing a treatment plan. We also knew that traditional practice presented several problems and pitfalls: patients often resisted medical advice, that education about disease was not correlated with changes in patient behavior, and that patient motivation was variable. The kind of physician control and cultural authority inherent in this model of practice was more effective for acute care than it was in other ways for long-term behavioral management of chronic

diseases like arthritis, which required skills in coping, communication, and control (Daltroy & Liang, 1993).

The challenge in treating chronic conditions required physicians to move patients along a set of stages of change across several dimensions. The 2005 Fries Health Education Award recipient Jim Prochaska had described these stages in a seminal paper, "In Search of How People Change," which was published in the *American Psychologist* in 1992 (Prochaska, DiClemente, & Norcross, 1992). Thus, doctors and other members of the health care team had to find ways to help their patients move, for example, from why they should change to how to change, and from contemplation to action.

This meant that doctors had to become proficient not only at the customary clinical skills and tasks; they had to become, in effect, skilled applied behavioral scientists. Listening to what patients had to say about their utilities and preferences, calibrating their outcome expectations of treatment, and discussing with them anticipated problems of compliance and barriers to treatment adherence were critical to improving outcomes. Doctors needed to do this by engaging their patients in a partnership that would foster trust and rapport and build patient confidence—confidence in the doctor, confidence in the treatment, and confidence in themselves.

At the same time, Kate Lorig, my counterpart at Stanford's Arthritis Center and recipient of the first Fries Health Education Award in 1992, was teaching patients how to engage physicians in such a partnership. Kate had been working with Hal Holman, a Stanford physician-colleague, as well as with Jim Fries, on developing the Arthritis Self-Management Program (2017). They were demonstrating good results with a program that utilized concepts from social cognitive theory, whose development was being pioneered by another Stanford colleague, the psychologist, Albert Bandura. In one study, she and her colleagues demonstrated that the reductions in pain and physician visits that arthritis patients participating in her program had achieved through behavioral self-management endured for up to 4 years after baseline. In addition, the biological progression of the disease was much less than would have been expected (Lorig, 1990).

Bandura's social cognitive theory—the basis for Kate Lorig's program—positioned self-efficacy as a core belief that was central to behavioral change. It influenced behavioral self-management both directly and through its impact on outcome expectations of behavior, goals, and perceptions of the sociostructural factors. Thus, the emphasis was on cognition and its relation to behavior. Bandura would later give and publish his own 2002 Fries Health Education Award Lecture. Since then, that paper—"Health Promotion by Social-Cognitive Means" (Bandura, 2004)—has continued consistently to be among *Health Education & Behavior's* most downloaded and most cited papers.

My growing interest in Kate's work and that of Bandura was rewarded when I visited Stanford in 1990. I had gone to

participate in the annual meeting of the NIH-funded Arthritis Centers' education, epidemiology and health services researchers, and I had taken along Pamela Kovar, a physical therapist whose doctoral research I was sponsoring. Following a presentation by Bandura himself, and a consultation with Kate, we left the meeting with an idea that would lead us to our first study.

That study was of supervised fitness walking in people with osteoarthritis of the knee, a painful and usually disabling disease that limits functioning and frequently leads to joint replacement. Until we conducted our counterintuitive, randomized controlled trial that assessed the safety and efficacy of walking in people with the disease, doctors had been prescribing rest and counseling patients to avoid weight-bearing activity. The challenge was to demonstrate that walking could improve functional status without exacerbating symptoms. Our colleagues were skeptical. *I was skeptical*. But then we published the results of our trial in the *Annals of Internal Medicine* in 1992 (Kovar et al., 1992), demonstrating that supervised fitness walking, along with group meetings for patients that were designed to foster patient self-efficacy and provide social support, produced clinically meaningful changes in functional outcomes. These changes included significant improvement in distance walked, as well as favorable changes in general physical activity and perceptions of the impact of arthritis (Allegrante, Kovar, MacKenzie, Peterson, Gutin, 1993).

The study proved to be a seminal contribution and changed clinical practice in the management of osteoarthritis. It also spawned nationwide interest in walking programs for people with arthritis (Burton & Yanker, 1990). More important, it provided additional evidence supporting social cognitive theory and the role of self-efficacy as a means by which we could help people adopt new behavior (Allegrante, & Marks, 2003; Marks, Allegrante, & Lorig, 2005a, 2005b), as well as the function-enhancing effects of regular walking in people deconditioned or disabled by arthritis.

Behavioral Economics and Cardiovascular Disease

Building on the work of this study, we turned our attention to the problem of multiple-behavior change in cardiovascular disease management. Despite assiduous efforts from the 1970s onward to find strategies that could help patients with heart disease to adopt and maintain risk-reduction behaviors, many studies had shown disappointing results. There was, however, one notable exception: A 1983 report in the *American Journal of Public Health*, by Don Morisky and Larry Green, demonstrating that health education improved all-cause mortality in poor urban hypertension patients at 5 years (Morisky et al., 1983). It was the first study to provide evidence of how health education not only facilitated adherence to treatment but also could achieve changes in more distal health outcomes.

By 1998, we had become interested in the emerging field of behavioral economics for new ideas, which set the stage for the second study. We were particularly interested in the implications of what Michael Roizen, a physician at the University of Chicago, was doing. During a grand-rounds presentation in New York, Roizen described how he was encouraging his patients to change their health habits by framing the benefits of lifestyle changes in net-present value terms, an economic concept from microeconomic theory. The idea was simple and intuitive: If you could convince patients they could get biologically younger by stopping smoking, changing diet, or engaging in physical activity, they would be more likely to adopt the recommendations to do so. But it had not been tested. So, Michael and I wrote an editorial for *Health Education Research* (Allegrante & Roizen, 1998) that posed the question of whether such an approach could prove effective in fostering the adoption of new behavior.

That editorial became the argument and basis for a randomized controlled trial that Mary Charlson and I proposed for NIH funding as part of the NIH Behavior Change Consortium (Ory, Jordan, & Bazzarre, 2002). A new initiative directed by then NIH program officer Marcia Ory—the 2016 American Academy for Health Behavior (2017) Research Laureate—the consortium was a collective of 15 NIH-funded multiple-behavior-change projects. Each of the projects was conceived with the goal of evaluating and comparing the efficacy and effectiveness of novel, theory-based intervention approaches to change health behaviors in diverse populations (Nigg, Allegrante, & Ory, 2002). The 2012 Fries Health Education Award recipient Russ Glasgow (see Glasgow, 2013) and I were among the behavioral-scientist coinvestigators in the consortium.

In the study Mary and I proposed, we hypothesized that net-present value messages would be more effective in fostering behavioral changes that would reduce cardiovascular morbidity and mortality than the standard future-value approach that characterized most risk-factor communications. To test this approach, we conducted the first trial of the concept in a study of 660 post-coronary angioplasty patients (Charlson et al., 2002). In the experimental condition, patients selected multiple risk-factors behaviors for change. Each risk factor selected was assigned a numeric biologic age (or the net-present value) that approximated the relative potential to improve current health status by modifying that risk factor. Risk reduction in a control condition was framed as the value of preventing future health problems. In the end, the trial results proved disappointing; communicating risk based on net-present value did not result in significant differences in health outcomes (Charlson, et al., 2008). Despite the findings, we published work that illuminated how patients made decisions about selecting among multiple behaviors, regardless of the net-present value of the behavior in terms of biologic age (Allegrante, Peterson, Boutin-Foster, Ogedegbe, & Charlson, 2008).

Michael Roizen and Columbia heart surgeon Mehmet Oz have gone on to further develop and commercialize the

concept of biologic age in a web-based application called *RealAge*®. This program essentially enables you to calculate and score your biologic age based on your health habits, medical history, and genetic characteristics. One recently published evaluation of *RealAge*® has shown that the score generated is a valid measure of mortality risk in its user population (Hobbs & Fowler, 2014). Such health risk appraisals, including those developed by the Centers for Disease Control and Prevention, have been used as a means to recruit and motivate people in workplace health promotion programs to narrow the gap between their chronological age and their health-risk age (see, e.g., Hughes et al., 2011).

Positive Affect and Self-Affirmation and Cardiopulmonary Diseases

The third effort in this arc of research came when we were funded through the NIH Translational Behavioral Science Research Consortium. This was a large contract developed in cooperation with the National Heart, Lung, and Blood Institute, the major goal of which was to support innovative research designed to facilitate adoption and maintenance of behavior change in the secondary prevention of adverse outcomes among patients with chronic cardiopulmonary diseases. The idea was that basic behavioral science discoveries might present potentially promising opportunities for translation to clinical populations where prior behavioral change approaches, based on existing models of health behavior, had been disappointing.

We found inspiration for this new work in two sources. The first was the growing cultural fascination with positive psychology and the new science of happiness, as illustrated, for example, by Martin Seligman's book, *Authentic Happiness* (2002), and *Time Magazine's* coverage devoted to the "Science of Happiness" (*Time*, 2005). The second source was from neuroscience and what scientists were learning about the biology of the relationship of stress to health outcomes and the pathways by which stress exerted influence on aging and disease at the cellular level. Pressman and Cohen (2005) at Carnegie Mellon University, for example, theorized it is the trait (or at least an enduring-state) of positive affect that influences health outcomes. In such a main-effect model, the behavioral and biological pathways that link positive affect to the onset or progression of physical disease run through the production of endogenous opioids, activity of the autonomic nervous system and the hypothalamic-pituitary-adrenal axis, social ties, and health practices—including behavior such as adherence to medical regimens. An alternative to the main-effect model theorized that positive affect may influence health primarily through its ability to ameliorate the potentially oxidative influence of stressful life events. We had become increasingly convinced it was stressful life events and daily hassles that got in the way of people making and sustaining healthful behavior changes. Pressman and Cohen's stress-buffering model showed the behavioral

and biological pathways linking stress to disease onset or progression. It also showed the places in the process where a state of positive affect may buffer the effects of stress. We sought to influence the link between stress and positive affect and health practices.

Remarkably, there was little or no prior well-designed empirical intervention research on affect or mood in health behavior change. When affect or mood had been studied, the focus had been largely on epidemiologic observational studies of the role of negative emotions such as anger, depression, and hostility. Few studies had focused on optimism, positive emotions, or positive affect as a basis for behavioral intervention. Thus, the stage was set and the aim of our study was to translate the findings from basic behavioral research on positive affect into a feasible approach that could facilitate health behavior change among patients with chronic cardiopulmonary disease, specifically, coronary artery disease, asthma, and hypertension (Peterson et al., 2013).

There were two psychological constructs of interest to us: *positive affect* and *self-affirmation*.

Positive affect—a mild, happy feeling state—was a construct with which a Cornell psychologist, Alice Isen (Isen, Daubman, & Nowicki, 1987), had worked and produced extensive experimental data. Her research, which focused on how positive affect could shape consumer buying behavior, proved pivotal. She and her colleagues had shown in their studies that the mild, happy feeling state could be induced by seemingly modest positive events. These events included receiving a small, unexpected gift, experiencing an unexpected compliment, or—our research team’s favorite and that of those on whom we tested this idea—seeing the faces of smiling babies. In addition, positive affect had been shown to influence thought processes and behavior, including effort and success, as well as task motivation, problem-solving and coping, and decision making. Efforts to induce positive affect had demonstrated robust effect sizes in small cross-sectional studies of various behaviors. Yet no large randomized trials had investigated whether positive affect could help to facilitate health behavior change in clinical populations with chronic disease.

The second construct, self-affirmation, addresses a person’s self-concept and involves the active use of positive statements (or self-talk) to build confidence. Claude Steele (1988), another Stanford psychologist and former Columbia provost, who has pioneered in studying this construct, had demonstrated that self-affirmation also helps people in overcoming negative expectations regarding their own ability to stay resolved when undertaking new behavior. It does this by helping them remember and draw on previous experiences of success. Moreover, by enhancing self-affirmative thoughts, the effects of “stereotype threat” can be reduced. This is especially important to members of minority groups. Thus, self-affirmations may increase the acceptance of threatening health messages.

By combining positive affect and self-affirmation, we believed we could achieve synergistic effects that would

increase the openness of patients to information, bolster their ability to cope with the barriers to behavioral change or stress, and induce feelings of positive affect.

So, our third program of research—which comprised three separate clinical trials that utilized common methods—built upon our previous studies and previous experience (Charlson et al., 2007). It was the first time that the same behavioral intervention was evaluated synchronously in parallel randomized trials using identical methods, and common clinical and psychosocial measures, including measures of affect, stress, social support, and self-efficacy. Moreover, by design, each of the trials had a common theoretical perspective and cross-linking themes woven through their objectives and methodology. Perhaps most important, because most behavioral interventions up to this point had focused on changing how people *thought* about things, this new line of research focused on how people *felt*.

We did this by designing identical patient workbooks for our intervention and control arms. The workbooks contained several common elements that were pilot-tested (Peterson et al., 2010). Each of the elements contained or provided

- Disease-specific knowledge and information about the consequences of not engaging in the recommended behavioral change
- A behavioral contract and commitment and specific activities to support goal-setting, tailoring, and self-monitoring
- Informative, instructive, and inspirational “vignettes” that patients could read and that had been informed by the stories of real patients with whom we had worked to design the workbooks

However, the patients in the intervention arm of each trial received a workbook that was titled *Staying Positive*. The *Staying Positive* workbooks included a specific chapter containing information and activities designed to help patients induce their own positive affect on a daily basis, and help them use self-affirmation statements to build and maintain their confidence to stick with their treatment regimen (Mancuso, Sayles, Robbins, & Allegrante, 2010; Peterson et al., 2014).

The trial of physical activity following coronary angioplasty demonstrated that significantly more patients who received the patient education intervention enhanced with positive affect compared with the control condition were able to achieve a sustained and clinically significant increase in physical activity (the equivalent of walking 4.2 miles/week) at 12 months after angioplasty (Peterson et al., 2012). In the study of medication adherence, the positive affect intervention also led to significantly higher medication adherence compared with the control condition in hypertensive African Americans (Ogedegbe et al., 2012). However, the enhanced intervention did not prove effective in the trial of physical activity in asthma patients (Mancuso

et al., 2012). In a subsequent cross-study analysis of pooled data (Charlson et al., 2014), we showed that the positive affect interventions enabled patients across all three trials to maintain success in behavior change in the face of increased perceived stress, new depressive symptoms, or decreased social support. Increases in positive affect were also significantly associated with decreased stress and increased success in behavior change.

Conclusion

What have we learned and what are the implications of this arc of research? First, I think our work confirms the importance of starting with a cohesive theoretical perspective and the value of experimentation. Bandura's social cognitive theory, Prochaska's transdisciplinary theory, and behavioral economics all provide important frameworks with which to understand complex behavior and guide intervention. As Green (2004) has quoted Bandura, "A theory that denies that *thoughts* can regulate actions does not lend itself readily to the explanation of complex human behavior." However, the intervention studies that my colleagues and I have most recently conducted suggest that perhaps we need to revise Bandura and say this: "A theory that denies that thoughts *and emotion* can regulate actions does not lend itself readily to the explanation *or change* of complex human behavior."

Second, research on affect and emotions in health behavior is still novel and still in its infancy. Some of the promise of what we have discovered can be found in the ongoing work of Martin Seligman and colleagues whose research has conceptualized seven habits of healthy people, one of which is a *Positive Mind Set* that includes optimism, mindfulness, and gratitude (Seligman et al., n.d.). It can also be found in the work of Vic Strecher, who spoke movingly as the Fries Health Education Award Lecturer in 2014 of the health benefits of having purpose in life (see Strecher, 2017).

Finally, while my colleagues and I have sought to harness positive affect in a novel research program to provide empirical evidence of its potential in health behavior change, it remains to be demonstrated whether our findings can be replicated, scaled, and codified in cost-effective clinical practice. Moreover, there is also the question of whether the interventions we have tested will be effective in varied circumstances or whether and how they will need to be adapted for broader dissemination in other populations and settings. An ambitious program of future research devoted to the further study of these constructs should seek to answer such questions in the rapidly shifting context for health care delivery.

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