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COMMENTARY

Origins of the ACE Study

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"The truth about childhood is stored up in our bodies and lives in the depths of our souls."

—Alice Miller, PhD

It has now been 20 years since the original article of the Adverse Childhood Experiences (ACE) Study was first published by the *American Journal of Preventive Medicine*.[1] During that time, the ACE Study has attracted worldwide interest and follow-up. The progression of this attention, in spite of significant initial resistance, has provided useful research insights that I have been asked by the editors of *AJPM* to document and share.

The ACE Study was a direct outgrowth of significant counterintuitive findings derived from the introduction of a new technology in the early 1980s for the treatment of obesity in Kaiser Permanente's Department of Preventive Medicine in San Diego, California.[2] Unexpectedly, we discovered that such major weight loss was actually threatening to many patients. Pursuing this, we came to realize that obesity, a major public health problem from a societal standpoint, was from the involved patient's standpoint often an unconsciously chosen solution to unrecognized traumatic life experiences that were lost in time and further protected by shame, secrecy, and social taboos against exploring certain realms of human experience.

Early in the obesity program, a young woman weighing more than 400 pounds presented seeking help with her weight. Our first mistake was in accepting her diagnosis of what the problem was. She was enrolled into the program and we treated her manifest symptom by entering her into a weekly 2-hour group meeting, providing weekly biomedical evaluation, and absolute fasting supplemented by a commercial meal replacement product in order to prevent complications from fasting. Her weight loss was dramatic, and she dropped to 132 pounds within a year. After holding that weight for several weeks while slowly resuming her consumption of increasing amounts of regular food, she suddenly gained almost 40 pounds within 3 weeks, a rate we had not previously considered physiologically possible. In a shorter period of time than she had taken to lose the weight, she was back to her original weight and then she disappeared for 12 years.

Before she vanished, in explaining her extraordinary re-gain, she said she thought she was sleep eating, and told us that she had been a sleepwalker as a child but had not done that for years. Pursuing why that was recurring now, and after her initial denials of understanding why, she told us that she had been sexually propositioned at work "by a much older married man," which was when the sleep eating began. Given her unusual response to this sexual proposition triggered by her weight loss, we next pursued the basis for her extreme response. Within several minutes, she told of her grandfather sexually abusing her starting at age 10 years, the age her weight gain began, with the abuse continuing for the next decade. I recall thinking naively that this was the second incest case I had seen in 23 years of practice. Little did I know!

Several weeks later, another unexpected sexual abuse case led to us questioning all incoming obesity patients about childhood sexual abuse. The results were overwhelming: It seemed every other person among 186 consecutive patients acknowledged such a history. I recall thinking that this could not be—surely people would know if this were going on—but after confirming the histories of these patients with relatives, friends, and even the sheriff in a small Mississippi town, I slowly came to realize that the stories were true, but no one wanted to know. Nevertheless, to be certain, I asked five colleagues to interview the next 100 incoming patients. They confirmed my findings, and an analysis of the 286 cases provided a 55% patient-acknowledged prevalence of childhood sexual abuse in our Obesity Program.

As we gathered these histories, we learned of other types of abusive childhood experiences, and of growing up in seriously dysfunctional households. A number of patients agreed to be videotaped so that what they had to say could be shared with physicians for teaching purposes. As a result of learning the context and histories of their abusive childhood experiences leading to subsequent obesity, smoking, drug and alcohol use disorders,

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and other coping devices, we realized there was a Public Health Paradox in that they were describing how many of our most intractable public health problems were indeed that from a societal standpoint, but from the standpoint of the person involved were often unconsciously attempted *solutions* to problems long hidden since childhood. An early insight was provided by one patient telling us she was raped at age 22 years and gained 105 pounds in the following year. She then muttered to herself, "Overweight is overlooked, and that's the way I need to be." In other words, our treatment was an unwitting attempt to remove their solution, and perhaps that accounted for treatment failures, flight from treatment, or re-gaining of weight.

Given the unexpected nature and significance of our repeated findings, they were presented at a national obesity conference in 1990 in Atlanta, Georgia. There, the findings were attacked. One member of the audience, under the guise of asking a question, made the pronouncement, "You really must understand, Dr. Felitti, that those more familiar with these matters recognize that these statements by patients are fabrications to provide a cover explanation for failed lives."

There was a dinner for speakers that evening and seated next to me was Dr. David Williamson, a senior scientist at the Centers for Disease Control and Prevention (CDC). I well remember his memorable start to our conversation: "If what you're saying is true, it has major importance for the nation and the practice of medicine, but no one is going to believe your 286 cases no matter how well you have studied them. We need an epidemiologically sound study with thousands of cases, and from a general population, not some group that you've somehow managed to accumulate." Unused to such discussions with an epidemiologist, I explained the unusual department we had back home that could fulfill such a need. We then discussed the optimal number of cases for such a study and settled on 26,000 as a reasonable number, this being about a 6 months' throughput for the Health Appraisal Division of our Department of Preventive Medicine, where more than 50,000 adult Kaiser members chose to receive each year an uncommonly comprehensive medical evaluation. He then arranged for me to present my findings at the CDC and for senior CDC people to make a site visit in San Diego to confirm our ability to carry out the proposed work.

The CDC presentation was well received, and I was introduced there to Dr. Robert Anda, a physician epidemiologist long interested in the underlying causality of public health problems. The subsequent CDC visit to San Diego went very well, and Dr. Anda and I then began the lengthy and complicated planning for what we called the Adverse Childhood Experiences (ACE) Study, of which we were the two co–principal investigators. The purpose of the ACE Study was to determine the prevalence of ACE in a general population and how they played out in adults decades later. We selected for study the ten most common categories that we had found in our clearly middle-class obesity population. Dr. Anda assembled a team of CDC analysts and familiarized himself with existing systems of Kaiser Permanente data archives that we would use in the prospective arm of the study. We planned what would become the transfer of 440,000 pages of anonymized, bar-coded patient data. After 3 years of detailed planning, we presented our proposed ACE Study protocol to the Kaiser Permanente IRB in 1994. Incredibly, it was turned down flat. Otherwise sensible people told us we could not use our patient questionnaire "because it will cause patients to decompensate, perhaps even become suicidal." It took 9 months of battling to win acceptance of the ACE Questionnaire, and then only if a responsible person carried a cellphone 24 hours a day for the next 3 years to accept calls from patients whom our questions about childhood experiences might make decompensate or suicidal. No such calls were ever received; instead several dozen notes and letters of thanks were received from patients. One, from an elderly woman, summarized the others: "Thank you for asking. I feared I would die and no one would ever know what had happened."

Clinical operations of the ACE Study began in 1995. The first thing that happened was that three of my 30 nurse practitioner/physician assistant examiners quit to work in other departments rather than deal with material like childhood sexual abuse. Nevertheless, the remaining 27 became remarkably adept at comfortably dealing with the ten categories of ACE that we had chosen to study in adults.

In two waves, separated by a midpoint pause to allow potential corrections, we asked 26,000 consecutive adults undergoing comprehensive medical evaluation if they would help us understand the relation of childhood experiences to adult health and well-being decades later. Of these, 17,337 agreed to participate, and we transferred their prospective data over the next 20 years to the CDC for analysis. Meanwhile, Dr. Anda and his analytic team imaginatively worked out a selection of possible disease outcomes to match against the number of categories (not events) that our patients acknowledged having experienced as children. The number of categories experienced was known as the ACE Score. Our first publication was submitted to several major medical journals, each of which flatly rejected it. Thankfully, the *American Journal of Preventive Medicine* accepted the article, even granting it three editorials. This would turn out to have profound results, including that the keystone article

published in May 1998 became the most cited article they had ever published. Shortly, Dr. Anda and I presented our findings at the National Press Club in Washington, accompanied by an elderly patient who described firsthand her childhood experiences and their adult consequences. Subsequently, we have been invited to countries all over the northern hemisphere in order to present our findings.

Initially, numerous attempts occurred to challenge the validity of our discomforting findings, but these efforts disappeared after a year or so as our follow-up publications started to appear, including in those major journals that had rejected our initial publication. To date we have published more than 75 articles, and others around the world have significantly added to this list. Our initial publications focused on the unrecognized prevalence of ACE, then on their strong dose–response relationships decades later to adult emotional states, coping mechanisms, biomedical disease, and premature death. As a result, Dr. Anda and I have had innumerable speaking engagements including presentations to Congress, state legislatures, and a wide range of organizations and institutions. This spread of ACE information has been strongly assisted by two highly successful blogs created by the journalist-publisher Jane Stevens: ACEsConnection.com and ACEsTooHigh.com.

Surprisingly, strong interest and engagement first appeared in school systems, not in medical settings. Although there was common physician interest, there was also obvious resistance to using this information clinically. In response, I decided to integrate the ACE Questionnaire into the lengthy adult medical history questionnaire filled out at home as Step 1 of our Health Appraisal process. This went quite smoothly in spite of collegial predictions that the questions would enrage patients, who in any case would lie in their answers. Neither occurred. After 2 years, a University of California mathematician with a start-up data mining company offered at no charge to carry out a 135,000-patient study to determine whether these added questions had any discernable effect. Being involved in getting his company on the New York Stock Exchange, he requested that the results not be published. Given the generosity of his offer, that limitation was accepted. Unexpectedly, he found that the addition of the ACE questions triggered a 35% reduction in outpatient visits and an 11% reduction in emergency room visits in the subsequent year compared with the prior year for those patients.

Hearing of this by word of mouth, many assumed that this decreased utilization was the result of referral for psychotherapy, but almost no such referrals were made. Our basic approach was to say in the exam room, "I see on the questionnaire that . . . . Can you tell me how that has affected you later in your life?" And we listened, period. Later, we learned from patients that our apparent acceptance of them after hearing their dark secret was of profound importance. After lengthy consideration, we came to see that "Asking" (initially by an inert mechanism), followed up by face-to-face "Listening" and "Accepting" was a powerful form of "Doing." In other words, we had come upon a mechanism for reducing traumatic shame, which shame had the secondary effect of causing stress-related symptoms and hence doctor visits.

Given our sample size, the economic implications of a reduction of this magnitude in medical utilization are in the multibillion-dollar range for any large organization. Numerous legislatures, state and federal, have become involved because of the multibillion-dollar implications of the ACE Study findings for population health as well as medical care budgets. The WHO has been collecting data annually with an International Version of the ACE Questionnaire in more than two dozen European and Asian nations, and the CDC has added since 2009 an ACE module to its annual Behavioral Risk Factor Surveillance Study, with almost all states currently participating.[3] Thus, in spite of the slow progress over the past 20 years, the international breadth and strength of interest in understanding the implications and extent of the ACE findings strongly suggest that our keynote AJPM article will ultimately have a major role in advancing well-being and medical care.

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