A RANDOMIZED FIELD TRIAL OF ACINDES: A CHILD-CENTERED TRAINING MODEL FOR CHILDREN WITH CHRONIC ILLNESSES (ASTHMA AND EPILEPSY)

J. A. TIEFFENBERG, MD, MPH, MS, E. I. WOOD, MD, RN, A. ALONSO, STAT., M. S. TOSSETTI, TEACHER, AND M. F. VICENTE, TEACHER

ABSTRACT  A randomized field trial of a child-centered model of training for self-management of chronic illnesses was conducted of 355 Spanish-speaking school-aged children, between 6 and 15 years old, with moderate to severe asthma and epilepsy, in Buenos Aires, Argentina. The model, based on play techniques, consists of five weekly meetings of 8–10 families, with children’s and parents’ groups held simultaneously, coordinated by specially trained teachers and outside the hospital environment. Children are trained to assume a leading role in the management of their health; parents learn to be facilitators; and physicians provide guidance, acting as counselors. Group activities include games, drawings, stories, videos, and role-playing. Children and parents were interviewed at home before the program and 6 and 12 months after the program, and medical and school records were monitored for emergency and routine visits, hospitalizations, and school absenteeism. In asthma and epilepsy, children in the experiment showed significant improvements in knowledge, beliefs, attitudes, and behaviors compared to controls (probability of experimental gain over controls = .69 for epilepsy and .56 for asthma, with $\sigma^2 = .007$ and .016, respectively). Parent participants in the experiment had improved knowledge of asthma (39% before vs. 58% after) and epilepsy (22% before vs. 56% after), with a probability of gain = .62 ($\sigma^2 = .0026$) with respect to the control group. Similar positive outcomes were found in fears of child death (experimental 39% before vs. 4% after for asthma, 69% before vs. 30% after for epilepsy), as well as in disruption of family life and patient-physician relationship, while controls showed no change. Regarding clinical variables, for both asthma and epilepsy, children in the experimental group had significantly fewer crises than the controls after the groups ($P = .036$ and $P = .026$). Visits to

The authors are from the Research Division, Self-Help Training Project of ACINDES, Association for Health Research and Development, Buenos Aires, Argentina. Reprints: J. A. Tieffenberg, ACINDES. (E-mail: info@acindes.com.ar), Mariano Palliza 767, Olivos, Provincia de Buenos Aires, Argentina, CP 1636.
physicians showed a significant decrease for those with asthma \((P = .048)\), and emergency visits decreased for those with epilepsy \((P = .046)\).

An 18-item Children Health Locus of Control Scale (CHLCS) showed a significant increase in internality in experimental group children with asthma and epilepsy \((P < .01)\), while controls did not change or performed worse 12 months after the program. School absenteeism was reduced significantly for those with asthma and epilepsy (for the group with asthma, fall/winter \(P = .006\), and spring \(P = .029\); for the group with epilepsy, \(P = .011)\).

**Conclusion.** The program was successful in improving the health, activity, and quality of life of children with asthma and epilepsy. The data suggested that an autonomous (Piagetian) model of training is a key to this success, reinforcing children's autonomous decision making.

**KEY WORDS** Asthma, Children, Chronic illnesses, Diabetes, Self-help, Training.

Chronic physical conditions (such as asthma, epilepsy, and diabetes) have increasing importance in health care.\(^1\) In the US, for example, the three conditions together affect at least 3,747,000 children and adolescents under 18 years old (85% with asthma, 10.9% with epilepsy, and 4.1% with diabetes).\(^4\) Asthma is considered the principal cause of school absenteeism due to chronic physical conditions, and all three are the cause of a large number of emergency visits,\(^5\) with negative effects on family dynamics and children's well-being,\(^6\) which is of concern especially when the current medical treatment possibilities are so promising.\(^7,8\)

For asthma, the growing concern about the increase in morbidity and mortality,\(^9,10\) despite the availability of promising therapeutic tools, spawned the development of several educational and self-help programs.\(^11-16\) However, for other chronic problems such as epilepsy, the efforts aimed at improving outcome through self-management and child autonomy are only just beginning.\(^17\)

Most programs developed to date are "disease specific," Interest has been mounting in studies directed toward chronic illness as a whole.\(^17\) However, most programs are located in medical centers. We do not know of any training program with a common methodology for chronic conditions. In an attempt to fill this need, we developed a self-management training model for Spanish-speaking children 6 to 15 years old with asthma and epilepsy.

**THEORETICAL RATIONALE**

The program is based on the hypothesis that, by learning about the alternatives from which they can choose, children acquire tools to build an autonomous model of behavior that is in agreement with their health-expected values. This requires placing the children in the center and recognizing their leading role in the management of their own health.