Abstract

In the USA during the past 5 years, there has been a renaissance of scientific interest and research into health education and programs of self-management. It has not, however, always been possible to translate gains in healthy individuals into similar progress for persons with chronic illness. Among chronic disorders affecting children, asthma ranks as a prominent cause of morbidity and school absenteeism. To accomplish this, NIH and NIAID has supported a variety of asthma self-management programs aimed at enhancing knowledge of disease among patients and parents. A further goal has been to translate this knowledge to changes in behavior in order to reduce morbidity of disease. The most successful programs have been conducted by non-physician health care professionals (nurses, social workers, teachers). The least successful programs have included mass distribution of printed materials by pharmaceutical companies and lay organizations. It is believed that broader application of such programs will help not only the patient but the physician improve the care of asthmatic individuals.

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In the past decade there has been a renaissance of scientific interest and research into health education and programs of self-management, especially as they may apply to the control of chronic disabling diseases. Heightened public awareness of the precise role that individuals may play in promoting their own health has increased during this time through media exposure and improved patterns of lifestyle. It has not always been possible, however, to translate gains made by healthy people into similar progress for those with chronic illness.

In the 1970's, research support became available for studies which explored the means and methods of modifying behavior patterns in individuals in order that they might improve the quality of their lives and take advantage of progress in modern medicine. Changes observed to date include those related to our enhanced understanding of the harmful effects of cigarette smoking and improved compliance in taking medication to control hypertension.

On the basis of preliminary evidence that children with asthma could learn effective ways of managing their disease with reduced reliance upon the health care system, the National Heart, Lung and Blood Institute (NHLBI) and the National Institute of Allergy and Infectious Diseases (NIAID) as well as other federal and nonfederal funding agencies have helped to promote the development of programs whose goals are to encourage and facilitate the self-management of asthma. These programs have included educational reading materials and other learning aids and are aimed not only at children with asthma, but also at the parents, teachers and other health practitioners within the community.

A variety of programs were reviewed at a meeting entitled Self-Management Educational Programs for Childhood Asthma, held in Los Angeles in June, 1981 and sponsored by the NIAID in conjunction with the Asthma and Allergy Foundation of America and the Center for
Interdisciplinary Research on Immuno-logic Diseases at the University of California, Los
Angeles, Calif. [1]. It was apparent that a wide variety of programs were not only available, but
also desirable in order to accommodate the needs of many different localities and groups of
patients.
However, the mere availability of a program, even if proven effective, did not mean acceptance.
Another task remained, namely, to provide sufficient informa-
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tion in a critical fashion that would permit the recipient of potential programs to not only
understand their content, but also their implications in potentially changing patient and physician
behavior. Thus in 1983, NIAID in cooperation with the NHLBI jointly sponsored a follow-up
workshop on Self-Management of Childhood Asthma [2] which was aimed at exploring in
greater depth the implications of such programs. This workshop, therefore, focused upon issues
other than the straightforward presentation of available programs. For example, how would such
programs impact on traditional physician-patient relationships, who would bear the cost, who
should receive such services, and what would be appropriate settings. It was apparent that the
presence of self-management programs represented the beginning of new thought processes on
the part of health providers in accomplishing time-honored goals.
The concept of individuals self-managing their illness in a modern medical context is in some
ways new. Thoresen and Kirmil-Gray [3] have provided a model of how cognitive social
learning occurs and show just how complicated the process may be. They demonstrate that it is
not sufficient to simply prescribe a medication in a measured quantity, but rather it is important
to consider the individual, the environment of the individual and a variety of external and
internal influences. It is also important to explore reasons why individuals manifest compliant or
noncom-pliant behavior, and a framework for understanding patterns of behavior has been
developed. Bruhn [4] provides methods for measuring outcome when a particular intervention is
attempted and serves to provide a basis for an active scientific exploration of those features of
self-management of asthma programs which work and which do not work.
A brief description of two programs serve as the introduction to other programs. The Asthma
Care Training (ACT) program developed at UCLA was designed as a supplement to help
asthmatic children take charge of their disease, based on the theme ‘You’re in the driver’s seat’
[5]. The overall goal is to reduce the number and severity of asthmatic attacks as well as any
unnecessary restrictions on the asthmatic child’s daily activities. The program is designed for
teaching small groups of asthmatic children between ages 6–12 and their parents in clinics,
hospitals, doctors’ offices, nurses’ offices, and classrooms. The program consists of a series of
five 1-hour sessions for both children and parents. They are designed to be
taught by elementary school teachers, health educators and nurses with teaching experience. This
program has been successful both in demonstrating changes in outcome measures as well as
having been adopted for distribution in the USA by the Asthma and Allergy Foundation of
America. Moreover, a Spanish language version is now being evaluated.
Another program of asthma self-management has been developed at Columbia University in
Illustrated lectures and teaching session along with pamphlets are provided by health educators,
graduate students and others during six 50-min sessions. The teaching content explores limits on
activity, self-management of asthmatic attacks at home and establishing channels of
communication with physicians. What is especially important about this program is that it is aimed at a population that derives much of its health care from hospital clinics and emergency rooms.

References
Fahey, J.L.: Self-management educational programs for childhood asthma. Los Angeles, June 11–12, 1981 (reprints available upon request from Dr. Goldstein).