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AN ANALYSIS OF THE EFFECT OF PATIENT ACTIVATION EDUCATION PROGRAMS

The University of Oklahoma PH.D. 1983

THE UNIVERSITY OF OKLAHOMA

GRADUATE COLLEGE

AN ANALYSIS OF THE EFFECT OF PATIENT ACTIVATION EDUCATION PROGRAMS

A DISSERTATION

SUBMITTED TO THE GRADUATE FACULTY

in partial fulfillment of the requirements for the

degree of

DOCTOR OF PHILOSOPHY

BY

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Norman, Oklahoma

1983

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PATIENT ACTIVATION EDUCATIONAL PROGRAMS

APPROVED BY

DISSERTATION COMMITTEE

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TO MY FAMILY

my wife April for her emotional and
intellectual support
my sons Colin and Ian for their
understanding and playing
my parents who have always been
with me

ACKNOWLEDGEMENTS

My sincere appreciation goes to all the members of my dissertation committee. Dr. Lloyd Korhonen, my chairman, has guided me through the labarynth of my doctoral efforts. Dr. Donald Udell has always been ready to provide emotional inspiration. Dr. Thomas Wiggins has demanded much and given equally. Dr. Paul Kleine and Dr. Patrick Hart have been especially helpful in questioning the research methods.

I would also like to thank Dr. John Pulliam who provided support and guidance in the early part of my doctoral efforts. Dr. Robert Hill was most instrumental in my final selection of a topic and provided me with many resources.

Special thanks are due Dr. Richard Johns whose supportiveness and contributions are warmly remembered. Jean Kelsey has also contributed her research expertise and friendship.

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CHAPTER I

INTRODUCTION

Health education is a field covering a broad spectrum of programs and it is currently receiving much attention. This study treats a particular type of educational program that falls somewhere in the middle of the spectrum, the area of medical self-help, and looks at the long term effect upon the participants. This chapter is divided into four parts that serve to introduce the study. The first section provides a general look at the background of the problem. Second is a brief statement of the purpose behind this study. The third section defines the problem and states the hypotheses. Finally, there is a brief definition of terms.

Background of the Problem

Medical self-help activities in the United States are as old as the country itself. Dr. William Buchan's Domestic Medicine; or the Family Physician, published in 1774, is reported to have been popular and well-received (Ozonoff and Ozonoff, 1977). Such books were often referred to as "the family physician" because in many cases they were all that was available in terms of medical resources. They were not only first aid, but often the only aid. Now in the 1970's

and 1980's there is a surge of interest in the area of self-care, whether or not medical resources are available, and an abundance of related literature (Ferguson, 1980; Lowen, A. and Lowen, L., 1977; Masters and Houston, 1978; Kirschmann, 1973; Roberts, Tinker, Kemper, 1976). Ozonoff and Ozonoff (1977) describe the situation as follows:

> Medical self-help literature is over-flowing the book stores. While such books have always sold well in this land of the self-reliant and home of the self-medicators, there were periods when the undependable state of medicine suggested that the "family physician" might be of more significance than that of a mere publishing fashion. We seem to be in the midst of one of those periods now. (p. 7)

The written word is not, however, the only visible sign of this interest in self-care. An inspection of the credit or non-credit program of any college or university, or at any of the multitude of community education offerings, will show similar interest. Courses abound in yoga, stress management, nutrition, aerobics and related topics. Even the television industry is involved. Program titles from cable television guides include: Human Sexuality, Medical Marvels, Medicine and You, Healthline, and more.

The type of courses offered vary from the rather extreme elements of self-care where the medical professional is viewed as an adversary to the more traditional approach of patient education. In most settings patient education is concerned with people under medical care for a particular problem and focuses on their understanding of the problem so that they comply with the medical professional's orders or prescriptions. For example, dieticians or nutritionists are often involved in educational efforts related to diabetes. A person diagnosed by a physician as being diabetic is referred to the dietician for "counseling". The patient then receives information regarding the nature of the disease, what they can do in terms of diet to help the situation, and may even receive a prescribed

diet. The education is illness oriented and medically dominated.

Kemper (1980) describes a continuum of educational focus ranging from problem oriented patient education programs to those oriented toward positive health or wellness. The diabetes example described the problem oriented program. Yoga, massage, meditation and even astrology are some of the programs that may be found on the self-care side of the spectrum.

There is one area on the middle of this continuum that has experienced a great amount of popularity and interest along with the increase in the self-care literature. Kemper refers to this area as "basic medical self-care". In Kemper's paradigm "...medical self-care is distinguished from patient education and most self-help programs because it generally occurs in anticipation of health problems. Medical self-care stresses how to recognize common problems, what to do when they occur, and when and where to seek appropriate help." (p. 64) This is the area that intends to create a working partnership between the medical professional and the lay person, and to increase the lay person's knowledge and skill base in the basics of self-care (Samuels, Bennett, 1973; Harlen, S. and de Lisser, S.P., 1981; Johnson, T., 1975).

This partnership approach is easier to describe than to name. Johns (1981) refers to the confusion regarding the proper naming of health education activities and suggests that the naming process be given more emphasis to ensure accuracy. The name, he suggests, should be descriptive of the actual intent and focus of the course. In this study the name used to describe this area of self-care and medical-lay partnership is the "activated patient". This title accurately describes the concept. Through the use of the term "patient" to imply the medical-lay relationship and "activated" to describe the assertive, self-care responsibility of the lay person. It is also the title that was most often used to

describe the courses that are examined in this study.

There is another rationale for the use of the activated patient title, and that is its relationship to the existing state of health in this and other developed nations, and the needs that such a program can address. Whereas mortality was due primarily to infectious diseases in the early 1900's, and for all known history until then, there is a definite change in the past twenty years (Surgeon General's Report, 1979; Lalonde, 1974; Lawson and Batch, 1981). Now the major killers are chronic diseases related to life-style factors. That is to say that we are killing ourselves.

The response to this dominance of life-style killers has been briefly described in the opening paragraphs of this section. Literature, radio and television programming, and educational activities of all sorts have been developed and presented to the public. These efforts at educating the public have received support from physicians, some of whom write or develop the programs, and various governmental and business programs (Health Maintenance Organization Act, 1973; Lehmann, 1979; Ferguson, 1980; Levinson, 1975).

The Activated Patient course was developed by a physician, Keith Sehnert, with Federal grant assistance (DHEW, 1976). It was intended to create a partnership between patients and medical professionals. The lay person would learn some basics of self-care and would learn to use and work better with medical professionals. The consumer would improve his/her self-care abilities and information level, and would also save on medical expenses. The physician would benefit from a better informed and more involved patient. The physician would also have more time for patients who might be at higher risk and could utilize his/her full talents.

The courses analyzed in this study were held in the Oklahoma County

area between July 1, 1978, and June 30, 1980. They were based on Sehnert's model of the activated patient. The classes dealt with such topics as: taking responsibility for ones own health care, listening to your own body, common illnesses, coping, the medicine chest, dental health and nutrition. This program was to help close the gap existing between current medical practice and medical and consumer needs.

There is, however, another gap that exists. This is the difference between faith in health education and affirmation of the results. Educational programs often terminate with some form of class evaluation, but long term effects are rarely tested. It is this gap that is confronted in this study.

Statement of Purpose

The purpose of this research is to examine the effect of a two year series of educational programs based on Sehnert's concept of the activated patient. Given the proliferation of interest in the broad area of health education it is important to attempt to make some judgments regarding those educational programs, and it is feasible to do so in a program such as the Activated Patient where the curriculum is defined (DHEW, 1976).

The wide spread interest in health education has not lead to equally extensive research. Though most programs have an end-of-class evaluation, few, if any, go beyond that. The major work examining studies of health education (Little, 1976, p. 25) suggested that no long term program follow-up exists. Information regarding the effect of these educational events must be gathered if there is to be sound justification for their continued proliferation and emphasis.

Statement of the Problem

The problem addressed in this research is: Have participants in Activated Patient classes increased their basic self-care knowledge or altered their self-care behavior and their relationships with medical professionals.

Hypotheses

The hypotheses to be tested originated in certain research questions. Those hypotheses are presented following the questions that preceeded them.

1. Do participants from Activated Patient classes demonstrate greater knowledge of medical self care than non-participants?

   H1 Participants do not rate significantly higher on the Activated Patient Questionnaire than non-participants.

2. Do participants from Activated Patient classes exhibit behavior indicative of the activiated patient concept?

   H2 Participants do not rate significantly higher on the Activated Patient Illness Report Check-list than non-participants.

3. Do participants from Activated Patient classes demonstrate greater knowledge of medical self care when characterized by age?

   H3 There is no significant difference between participants associated with age on the Activated Patient Questionnaire.

4. Do participants from Activated Patient classes behave differently when characterized by age?

   H4 There is no significant difference between participants associated with age on the Activated Patient Illness Report Check-list.

Additional data were generated as the interview process proceeded. This allowed for utilization of qualitative information emerging during the research process.

Definition of Terms

The following definitions were used in the study:

Activated patient: Concept used by Sehnert to describe a partnership between medical professionals and clients in which the client is seen as active, competent and responsible.

Patient education: Refers to educational activities, whether group or individualized, in which the content is specifically oriented to a particular disease or health concern of an individual.

Self-care (self-help): Refers to those aspects of health maintenance or improvement that are in the hands of the individual, such as habit control. This tends to be a broad term and may range from "medical self-care" indicating a respect for the existing medical profession to a strong denial of traditional Western medicine.

Wellness: A concept that focuses on high levels of well being and self-actualization, both the maintenance of and promotion of health.

Medical professional: As used in this paper refers to those specifically trained as M.D.'s, Nurses, Dentists, Pharmacists, Nurse Practitioners or Physician Assistants.

Alternative health care: This refers to the usage on non-traditional Western medical care including anything from Chiropractic to Shiatsu to dietary therapies, etc. What must be noted is that the client may still be very passive in some of these methodologies.

CHAPTER II

REVIEW OF LITERATURE

The results of health education programs have been studied. Some areas, such as patient education, have been researched a great deal more extensively than other areas of health education. Regardless of the particular focus of health education there is need for continued research, especially in the area of patient activation programs.

This chapter is divided into four sections. The first reviews the basic state of health as a basis for the interest in health education. The second section examines the efforts made in evaluating health education programs. The third part presents a brief look at theoretical considerations from education and the assumptions as related to this particular area of study. Finally, there is a brief review of the Activated Patient program that is the focus of this research effort, and the results of the end of class evaluations.

Health Education: A Recognized Need

The most significant summary of the state of health in the United States came from the Surgeon General's Report (1979) entitled Healthy People. The historical review of health points to a drastic change in types of disease. Acute infectious diseases declined dramatically in the first half of the 20th century. "While death from the major acute infectious diseases plummeted

between 1900 and 1970, the proportion of mortality from major chronic diseases, such as heart disease, cancer and stroke, increased more than 250 percent." (p. vii)

Joseph Califano, then Secretary of the Department of Health, Education and Welfare, stressed in the report that the emphasis for dealing with these new afflictions should be on prevention rather than on treatment after contraction of the disease. He stated:

> "I can compress what we have learned about the causes of these modern killers in three summarizing sentences: We are killing ourselves by our own careless habits. We are killing ourselves by carelessly polluting the environment. We are killing ourselves by permitting harmful social conditions to persist..." (p. viii)

Again, as emphasis to the preventive focus: "...you, the individual, can do more for your own health and well-being than any doctor, any hospital, any drug, any exotic medical device." (p. viii) The diseases that are doing the most harm today are to a large extent preventable or avoidable given ones basic genetic make-up.

The Canadian government also recognized similar problems, and in their 1974 publication, A New Perspective on the Health of Canadians, they introduced a concept that is utilized in the U.S. Surgeon General's report. They viewed all causes of death as having four contributing elements:

- inadequacies in the existing health care system;
- behavioral factors or unhealthy lifestyles;
- environmental hazards;
- human biological factors.

Using this framework the U.S. Surgeon General's report suggested "that as much as half of U.S. mortality in 1976 was due to unhealthy behavior or life-style; 20 percent to environmental factors; 20 percent to human biological factors; and only 10 percent to inadequacies in health care." (p. 9) They continued with an important statement in relation to the function of health education: "Lifestyle

factors should be amenable to change by individuals who understand and are given support in their attempts to change." (p. 9) This did not deny the need for continued efforts in the area of infectious disease, but it did indicate the necessity for change in emphasis.

In an article entitled "Beyond Health Care, Creating a Healthy Future" (1982), Trevor Hancock attempted to describe a futuristic scenario of health care. He suggested that the emphasis in health care will be in the "soft-health-path approach". That approach will include: a focus on prevention, a de-emphasis on the role of the physician and increased emphasis on community health para-professionals, and instruction in basic self-care skills to all people. What he suggested as a future scenario is apparently already in the making, and he was not alone in this vision of the change in the health industry.

Snyder (1982), in a recent issue of "The Futurist", provided a brief description of the past, the present and the future of health care direction.

> For treating infectious diseases, a reactive approach — administering drugs — was appropriate. Today's illnesses, however, call for preventive health care. Medical science is now in the midst of making this switch.
>
> In the year 2000 we will be paying almost as much attention to prevention — studying and anticipating problems that could happen in order to keep them from happening — as we currently do to treatment..." (p. 26)

A major tool in this change process, he suggested, is the health hazard appraisal process. This involves a life-style assessment and, with some particular systems, specific suggestions for health maintenance and improvement. The suggestions here and in the Surgeon General's report were for the medical and lay communities to focus on life-style improvement. Though it was no where suggested that behavior change would be easy, especially when one is constantly bombarded by a mass media advertising campaign supporting many unhealthy

habits, it is possible. It would take both education and support of the individual attempting to make any such changes for health improvement or maintenance.

It should not be imagined that the need for health education is just another American fad. Other nations with similar life-style have identified the same need and have developed similar programs. As mentioned earlier the Canadian government recognized the need and set a useful framework that was adopted in the U.S. Lawson and Batch (1981) described the need for such health education programs in Australian communities to counter the "...current burden of premature mortality, sickness and disability." (p. 119) Even the specific diseases they enumerated are similar: cardiovascular disease, obesity, lung cancer, and hypertension. The concern is real and wide spread.

In Finland, The North Kareli Project had similar aims as the Australian effort mentioned above. The aims of the program were "...to improve detection and control of hypertension, to reduce smoking, and to promote diets lower in saturated fat and higher in vegetables and low-fat products." (McAlister, et al, 1982, p. 43) A high cardiovascular disease rate was the precipitation of the project as it has been for much of medical self-care activities in the United States.

The growing interest in health education per se has been visible in a number of major U.S. governmental activities and plans, and was directly related to the needs regarding healthy life-styles. The National Health Planning and Resources Development Act of 1974, P.L. 93-641 declared health education as one of the national priorities for health promotion. In a similar vein the Health Maintenance Organization Act of 1973, P.L. 93-222 required educational services for the purpose of teaching the contribution that each individual can make to the maintenance of his own health. The Department of Health, Education and

Welfare in its "Forward Plan for Health FY 1977-1981" has also called for an emphasis in education for the purpose of disease prevention. Another specific concern of the plan was the development of effective methods for teaching health education.

The insurance industry has also shown an interest in the area of health and patient education. They appear to be heading towards reimbursement programs for health education programs. In the Blue Cross Associations 1974 "White Paper on Patient Health Education" they recommended the development of policies that would support such programs. Minnesota Mutual Life has taken another approach by offering a wellness program to their own employees. They have not been alone in their efforts as other private industries have made similar commitments to employee health. Minnesota Mutual's program included: periodic health testing, blood pressure monitoring, first-aid instruction, a weight control program, stress management and other topics.

The health care industry itself has shown concern for health education beyond what existed in the form of patient education. The American Society for Healthcare Education and Training (Melton, 1982), a special unit within the American Hospital Association, has taken a significant stand supporting health education. In 1977 they passed a resolution recognzing "the fact that health maintenance is an individual responsibility and that the health care system can assist consumers by sponsoring health education and promotion activities." (p. 11) Though the impact of the resolution may be difficult to determine it was an important recognition on the part of some health care professionals that the consumer is a responsible partner. It is this partner relationship that now deserves some attention.

There is, then, this other aspect of need for health education. This is

the need related to the consumer-provider relationship. Ozonoff and Ozonoff (1977), in their examination of causes for the surge of interest in self-care literature, indicated that some authors presented "basic questions of whether the doctor-patient relationship as it is now constituted does not have an inherently exploitative character, or even more broadly, whether there are not certain adverse cultural and social consequences in the increasing medicalization of daily life." (p. 9)

In a major sociological examination of the rise of the medical profession, Starr (1982) cited numerous examples of efforts to form an elite. The elitist formation intended to protect the public, and also to protect the profession. The public was to be protected from the quackery that did exist in the middle and late parts of the nineteenth century. The professional was to be assured status and an income by the development of such things as a long training program, specialized language, and legal sanctions regarding the healing arts.

Parsons (1970) refered to a concept he calls the "competence gap". It is a highly descriptive image of the wide disparity between doctor and patient. The years of schooling and apprenticeship involved in becoming a medical doctor are perceived by many lay persons as awesome and the medical professional in general becomes untouchable, both admired and feared for the extensive knowledge they possess about our bodies. Waitzkin and Waterman (1974) suggested that this basic asymmetry promoted stratification and professional dominance. As a means to developing a more humane system, they suggested narrowing the competence gap so that "patient's participation in therapeutic decision making would be based on truly informed consent." (p. 116) As with the basic life-style issues, we are again facing an educational task of a large and difficult nature. Another description of the relationship between medical professional and lay person indicated that lay

individuals have lost their autonomy in the relationship. Illich (1976) refered to this process as the "medicalization" of daily life. This medicalization involved the surrendering of major human events, birth and death among them, to the medical profession. The process then alienated the individual from him or herself. The lay person thus became subservient to and dependent upon the one that was supposed to be serving him/her.

"In organizing medical services for ambulatory patients those planning them often forget the patient in the desire to provide all the personnel and equipment that is considered to be necessary for adequate scientific care." Pratt, Seligmann and Reader (1957, p. 1277) began their examination of physicians' perspectives of patients medical information level with the preceding statement. They went on to suggest that the relationship between physician and patient was a "give-and-take between two human beings." (p. 1277) That relationship was effected by a variety of factors. It was this relationship, this interchange, and the effectiveness of such that is fundamental in evaluating the adequacy of medical care.

Two findings of their study are relevant here. First, they found that though patients showed little overt effort to obtain more information than what their physician gave, "there appeared to be an unformulated, latent desire for more information among the majority." (p. 1283) They also found that patients who were given thorough explanations were more cooperative with the physician and the treatment than others. The concern for the adequacy and the importance of the patient-client relationship has existed for some time, as this study illustrates, but that concern has become more fervent in recent years.

Kemper (1980) presented another perspective. "It is inappropriate for a person who is expected to be in full charge of 96% of his or her health problems to

be completely submissive, compliant and non-functional when a health professional enters the picture. Consumers must develop confidence in their new roles as the primary decision-makers for family health." (p. 64) The pragmatics of the situation mandated the necessity for a change in the relationship regardless of perspective.

Bille (1980) provided a brief summary of various studies indicating a deficiency in the medical-lay relationship. In terms of specific illnesses he cited reports that indicated that patients do want to learn about their illnesses, and he continued: "Other studies indicate that nearly half of all hospital patients are discharged without having all their doubts allayed and questions answered." (p. 256) Whatever the reason for the above it is a gap that should be closed if we are to improve the delivery of health care, and self-care.

A survey conducted by Kane, Parsons and Associates, Inc. (1982) in Oklahoma and in the U.S. in general showed similarities to the studies summarized by Bille above. When asked to express agreement or disagreement sixty-two percent of U.S. respondents and sixty-five percent of Oklahoma respondents agreed that "People are beginning to lose faith in doctors." Fifty-five percent of U.S. respondents and forty-nine percent from Oklahoma agreed that "Doctors usually explain things well to their patients." In fact, of the twelve questions related to the public image of physicians the most favorable response was eighty-one percent who agreed their personal physician was available in an emergency. Though the interpretation of these results by Kane, Parsons and Associates seemed to be very positive there was a definite gap between what was and what might be hoped for the best.

In an article entitled "The New American Dream", Yankelovich and Lefkowitz (1980) reported a decline in U.S. opinion regarding the medical

institution. In 1966 they reported that seventy-three percent of the population felt a great deal of confidence in the medical institution as opposed to only thirty-three percent in 1979. Though this was a significant change in attitude one can also hope that it will bring about positive changes in behavior. Indeed, some medical professionals are supportive of changes that will improve the relationship. Dr. Leslie Huffman, Jr., president of the American Academy of Family Physicians presented the following picture (Ferguson, 1980): "One of the most exciting things that's going to happen in the next 10 years will be the increasing involvement of patients in their own health care." (p. 13) If that is to come to pass there will have to be educational programs that can provide information in self-care and consumer relations, and that will offer support to the individual for whatever positive behavioral changes they may seek to make. Those programs must, however, be examined in terms of their effect. An examination of current evaluation literature follows.

Health Education: A Perspective on Effectiveness

The "Forward Plan for Health FY 1977-1981" (DHEW) not only indicated a need for emphasis in education for the purpose of disease prevention, but it also called for further effort in the area of research of such programs. That research should be directed towards factors involved in modifying individual life-style and about ways of affecting health practitioner behavior. It further suggested that emphasis must be placed on behavior, not just on cognitive learnings.

Rothman and Byrne (1981) in a review of research in the area of health education with children and adolescents made the following comment:

> Common approaches have attempted to teach sound habits related to, for example, nutrition, safety, hygiene, physical activity, and more recently smoking and the use of drugs.

> These approaches have been justified with reference to a generally accepted belief in the 'desirability' of such teaching and reinforced by declarations of major bodies such as UNESCO. (p. 85)

As their review made clear the 'desirability' and the effectiveness of such programs were not necessarily coherent. In a review of one anti-smoking program they refered to research that showed a positive impact with children, but a lessening of that impact as those children reached adolescence. Their conclusions did not judge the efficiency of educational programs in health, but strongly pointed to the need for continued research. They seemed to be calling for some nationally accepted paradigm within which to place the existing "ad hoc" research while they lamented that no such paradigm exists.

Another call for research recently appeared in an article related to the continuing education of public health professionals themselves. In a statement that echoed the DHEW report cited above, Dual, Nichols and Glanz (1980) declared:

> It is not enough to assure that new facts have been learned; it is not even sufficient to know that new skills have been acquired. What is crucial to the success of our continuing education efforts today is that the skills are used. (p. 19)

This expressed a particular view of education which suggested that learning must be followed by some behavioral change. Certainly this was a perspective that seemed to run throughout most of the literature reviewed in the discussion of the need for health education. It was not enough for someone to quote the Surgeon General's warning on the side of a cigarette package. If the educational program had been successful the behavior would have changed.

In 1972 the Maryland Consumer Health Education Demonstration Project attempted to unite the resources of the Extension Service of the University of Maryland and the University Medical Center. The main program purpose was to influence the adolescent population towards preventive health care

behavior using health education as a primary method. Their definition of health education gave a perspective on their expectations of the program:

> Health education is concerned with people and their health behavior. It is an educational process through which people increase their understanding or change their ways of thinking or actions as a result of exposure to new experiences. (Wang, Reiter, Lentz, Whaples, 1975, p. 451)

They reported finding "manifestations" that the program did affect "a) development of understanding of the Community Pediatric Center by consumers, b) development of skills for movement through that system by consumers, and c) establishment of behavior patterns necessary to maintain optimum health by consumers." (p. 453) Their expectation of behavioral change or thought process change was not, however, completely realized in their findings. The time period "did not allow sufficient time to conduct a systematic evaluation." (p. 453)

The short term evaluation cited above and the limitations of such were not unique. Sehnert's own study of his proto-type patient activation course was limited to a one-year period and yielded varying results.

The positive results from Schnert's (1977) study indicated that activated patients: (1) demonstrated significantly more confidence in their self-care activities, (2) that their medical self-care skills were greater than controls, (3) that their eating habits were significantly better, (4) they were more likely to treat acute problems themselves and utilize medical professionals for chronic problems, and (5) they were more likely to use a variety of resources for health care. However, in regards to the issue of reducing doctors visits and health care expenses, major concerns of his study, the results were less than positive. He found no significant difference between the control group and the activated patient group in overall doctor visits, use of drugs, and medical tests. There was, therefore, no reduction in overall costs. Finally, there was no difference in the

percentage of "appropriate" or "inappropriate" visits to a health professional.

Another major study produced a similar mixture of results. Fretwell (1977) used a revision of Sehnert's "Activated Patient Course for the Elderly" comparing an experimental group with controls over a three month period. He found no significant difference in self-responsibility for personal health care using the Health Activation Inventory (a psychological test constructed expressly for his study). Fretwell's study of the revised course did show improvement in cognitive performance, as had Sehnert's courses. It showed no significant effect on certain specific areas of self-confidence in dealing with medical professionals or on attitude towards ones own health status. The data were mixed.

Fretwell did report that "there was significantly more movement of the participants on the reliance on self-reliance on doctors continuum: the participants were doing much reassessment as to their degree of self-reliance in handling health problems." (p. 103) He remained somewhat confused, however, regarding the mixed results and especially the difference between the qualitative and the quantitative data.

> The anecdotal data indicated that the participants gained more than was actually measured by the quantitative instrumentation. The incongruence of subjective and objective data underscores the task that researchers concerned with assessing the efficiency of health education have of developing more precise instruments which will eventually be able to transform visible gains to documented ones. (p. 103)

There has been some research that may explain some of the confusion that was cited in Fretwell's study. Sehnert's book How To Be Your Own Doctor Sometime (1975) and Take Care of Yourself by Vickery and Fries (1977) are two of the most widely used books as texts for Activated Patient courses. Both used logical explanations of common diseases and emergencies for potential patients to determine whether to contact a medical professional or not. Vickery and Fries

(1977) used medical algorithms to lead the participant through a process of decision-making leading to "home treatment" or a medical visit, or consult. For instance, in dealing with a cough the question was asked: "Is the cough producing large amounts of thick, fowl smelling, yellow or greenish sputum?" If the answer was "yes" you were directed "See physician today". If the response was "no" you were directed to another question that directed you, according to your response, to see a physician or to apply a given home treatment. (p. 121)

The concept and use of algorithms was both useful and practical, but Berg and LoGerfo (1979) have suggested that the literal interpretation of the algorithms may be a problem in certain cases. In a study directly related to Vickery and Fries Take Care of Yourself, they reported: "The data in this study, however, indicate that strict adherence to several of the algorithms would have increased rather than decreased physician visits in the observed population." (p. 536) While recognizing limitations in their own study they suggested the cause for their findings to be related to a tendency on the part of medical professionals to "over-recommend" utilization of medical services based upon symptoms. In other words, it was possible that participants might have received mixed messages regarding self-care and the use of the medical system. Though they did not confront this issue in any depth it may help to explain some of the mixed results as reported both by Sehnert and Fretwell.

Numerous studies have shown the positive impact of more specific disease related patient education programs. (See for example: Miller and Goldstein, 1972; Rosenberg, 1971; Roccella, 1976; Inui, Yourtee, Williamson, 1976) However, no such impact studies provided clear information regarding any aspect of the activated patient courses being conducted in many forms and formats throughout this country. Other countries seem to be ahead of us in terms of

comprehensiveness of programs (those that directly involve health education, media, screening and other interventions) and impact studies (Lawson and Batch, 1981; McAlister, et al, 1982). But even in those studies that were five or more years after program implementation, they suggested that follow-up needs to be even longer.

Kemper (1980) summarized the current conditions of evaluation in the self-care arena and offered an explanation for that condition. "Although subjective evaluations are positive and plentiful, few objective research studies have been completed on how self-care programs impact clinic utilization or overall morbidity." (p. 67) He presented three causes for the scarcity of this research: 1) the difficulty of valid statistical monitoring of families medical care over a period of time, 2) the lack of consistency in self-care education programs, and 3) the lack of substantial funding for such research.

The Arthur D. Little study (1976) entitled "A Survey of Consumer Health Education Programs" provides another picture of the state of the art. In the introduction it stated: "While consumer health education has received much attention of late, spurred by statements that it presents a cost-conscious and efficacious use of the nation's health resources, we found that much work needs to be done in the field before such statements can be fully accepted and a federal consumer health education policy is adopted." (p. 3) It was also found that the impact of such programs has been demonstrated on short-term basis only, and not on the long-term. One reason offered for that finding was that very few health education programs have been in existence for a long period of time. Even then, there seem to be few indications that impact measurements were planned beyond three to four months. "Long-term evaluation for these programs would mean that long after the program had terminated, an evaluation would still need

to be in operation. We have not found a single program in which such a circumstance pertains." (p. 25) In the conclusions the call was for continued research into the long-term effects of such programs. This study will respond to that call.

Theoretical Considerations - The Activated Patient

The radical change in illness patterns from infectious diseases to chronic illness has demanded that the traditional approach to coping with illness be changed. The rising cost of medical care has caused both consumers and medical professionals to look at potential changes. In the medical sector this emphasis on the individual has been incorporated into medical care protocols (Crawford, 1977; Hamilton, 1975; Ryan, 1971; Vayda, 1978). In the consumer arena the emphasis has been on the individual's life-style. Responses to the given situation have been diverse and many. A major type of response has been that of education.

A philosophical perspective of adult education would indicate that an educational response was appropriate. Knowles defined adult education as a process of individual growth. The aim was "helping individuals to liberate themselves from whatever shackels and deficiencies prevent them from fulfilling themselves." (1975, p. 238) This approach was not limited to academic or vocational efforts alone, but included all areas of learning.

Though perspectives differed in education the general theme remained the same. Sworder (1955) summarized the role of adult education well: "The emphasis of adult education must be on learning and problem-solving rather than on mere information, recreation, or social activities." (p. 135) He added: "Adult education is planned to meet the immediate and continuing educational needs of

adults in the solving of problems that they face now as citizens." (p. 136)

The existing situation in the area of health, and the philosophical base of adult education have been merged together in the application of educational processes. They formed the basis for a course originally referred to as "Health Activation for Senior Citizens". The purpose of that course was to provide consumers with the opportunity to increase skills and understanding in dealing with personal health and in relating to the existing medical system. According to Sehnert (1972), the originator of the course, the individual was to become "an active participant in his own health care rather than assuming the passive role". (p. 409)

The emphasis was on what the individual could do as an active partner with medical professionals. The goals that Sehnert (1977) set for participants in the course adequately demonstrated his orientation: (The participants will...)

1. Accept more responsibility for their own care and that of their family;
2. Have learned skills of observation, description, and handling common illnesses, injuries, and emergencies;
3. Have increased their basic knowledge about health problems;
4. Have learned how to use health care resources, services, insurance, medications, more economically and appropriately. (p. 42)

These goals were the basis of the activated patient concept. While it is clear that he was not describing the traditional doctor-patient role it is important to note that he was not advocating a withdrawal from participation in the medical system. The suggestion was rather an "informed partnership".

Sehnert's course was taken as a model for a series of classes held in Oklahoma County and vacinity between July 1, 1978, and June 30, 1980. The program was designed to train laypersons in the basics of medical self-care based on Sehnert's activated patient model. It was sponsored by the University of Oklahoma Department of Community Medicine and used professional medical

personnel and lay persons to facilitate the classes. Each course was twenty hours in length and utilized a course facilitator, a Physician Associate (P.A.) instructor supervisor, and one small group facilitator (P.A. student, second year medical student or medical staff) per each 5 or 6 participants. Techniques utilized in the class included short lectures, small group discussion, and hands-on skill practice. Reading materials were supplied for each topic.

The course topics were varied. There were ten topics which dealt either with the issue of consumer-provider relations or with medical self-care. The following is a list of the session headings (see Appendix B for more detail):

-"Listening to Your Body"
-"Common Illnesses"
-"Medical Conditions and Emergencies"
-"How to Choose and Use Your Doctor"
-"Consumer Facts on Dental, Eye and Foot Care"
-"Coping"
-"Your Medicine Chest: Friend or Foe"
-"Taking Care of Your Body with Diet"

In all classes a book was provided as a major text in addition to special hand-outs. These books contained and utilized the concept of medical algorithms which, though not a separate topic, was referenced in many sessions.

The Activated Patient Courses

The courses were held in a variety of settings. In some cases the sponsors were medical sites with a majority of the participants were clients of the center. Some settings were residential complexes for senior citizens. Other sites had a more limited relation with participants such as the library which offered only a location and supportive publicity.

The first year of the program there were five classes in five parts of the county area. Three of the classes were open to senior citizens and two to

younger adults. The facilitators and instructors for these classes were all associated directly with the grant project or the University of Oklahoma Health Science Center.

The second program year was set up to offer two Patient Activation programs at six sites for a total of twelve classes. The first series was coordinated and managed by project staff. Those courses served as training projects for on-site coordinators in each location. After additional training each on-site coordinator was to offer a second series. Two classes of the second series were cancelled so that the final total was ten classes.

End of Class Evaluations

The initial evaluation of the Oklahoma City classes was limited to the pre-test/post-test format. It attempted to measure skills and information gain of participants through a written test and through skill performance and evaluation. It did not attempt to measure any long term effect. What follows is a brief look at the initial results to serve as background.

Though not statistically analyzed changes were measured by means of a pre and post-test. First year results were charted in terms of correct responses on paper and pencil and practical tests. A majority of participants scored above 75% correct on the post tests. Second year results were graphed and divided into two categories: classes held by the Department of Community Medicine (DCM), and classes directed by On-Site Coordinators trained by the DCM staff. The graphs also distinguished three areas: knowledge of normal vital sign measures, knowledge of proper procedures for taking vital signs and accuracy, and knowledge base anticipating health behavior. In all cases the post test showed a gain. The least mean gain was a 6% pre to post-test gain in the

knowledge of normal vital sign measures related to blood pressure.

What is lacking in these evaluations, as elsewhere, is a long term perspective. Speaking towards the general state of the art in activated patient type programs, Lehmann (1979, p. 426) defined a critical issue in health as the "real and lasting changes in behavior". This paper treats the issue of long term cognitive and behavioral effect of Activated Patient classes.

CHAPTER III

METHODOLOGY

Population and Sampling

The population was considered to include all Activated Patient participants. The sample for this particular study was drawn from those persons who were participants in the Activated Patient courses in the Oklahoma City area. There were 165 people who were accepted into the program and who completed the course. To ensure power at the 90% confidence level 103 of the participants were randomly selected. Forty-seven of those were successfully contacted for a response rate of 45%. The younger the participant the more difficult they were to contact. A majority of respondants were in the fifty-five and older category. This age group comprised a majority of the original group of participants and graduates (see Appendex G).

The control group was formed post hoc and consisted of forty-seven persons nominated by the original site sponsors or program sponsors of the various classes. This was the same process that was utilized for the initial classes. The sponsoring agencies were asked to nominate people who would benefit from an Activated Patient program if another were offered. They were offered access to the final results of the study if they so desired. The use of the same sponsors as nominators ensured similarity between the control and the participants in all basic

demographic measures (ie. age, income, geographic location, relationship to course sponsor, and race).

There were some difficulties in the selection of the control group because there were no initial plans for a long-term study. The original groups were put through a screening process after nomination by the sponsoring agency. That problem was not, however, as serious as it might initially sound. First, there were few people who expressed interest in the class that were not actually accepted into the program. The screening was more an inclusive process than an exclusive one. Second, the interviewers that did the screening were using four criteria, only one of which was objective. The first three criteria were that participants would: 1) have an understanding of the nature of the course, 2) demonstrate the capability to learn and use the material, and 3) be able to benefit from the information received. The one objective criteria, the one that participants had to sign a contract agreeing to, was that they demonstrate a willingness to make a commitment to attend all the sessions (see Appendix A). A review of the program records revealed that a majority of the rejections were due to lack of transportation or scheduling problems. Rejections were not due to any supposed personality characteristics.

There were two other factors that did represent dissimilarities in the control group. Mortality and mobility effected the experimental group and who was available for the study. The two younger age groups proved more difficult to contact than the older group due to mobility factors. The older group was altered some by mortality factors. The control group was not effected by these factors. It was believed, however, that utilizing recommendations from the sponsoring agencies for the control group did provide a group that was essentially comparable for the purposes of this study, though it was not a "matched" group.

Instruments

There were two instruments used in the data gathering phase of this study. The Patient Activation Questionnaire (PAQ) (see Appendix E) and the Activated Patient Illness Report Checklist (APIRC) (see Appendix D) were both developed specifically for this study. An extensive search of the literature failed to reveal an existing instrument that related to the long term effect of the type of program that was the interest of this study. Part of the problem, as has been discussed earlier, was that there has been little work done in the study of the impact of health care education programs beyond compliance studies related to patient education. Fretwell's Health Activation Inventory (1977) dealt with the concept of patient activation and was well documented in terms of content validity. However, it dealt only with the domain of attitude, and did not address itself to the goals of increased cognitive and behavioral dimensions. In order to examine those dimensions in reference to the patient activation concept the two new forms were developed.

The Patient Activation Questionnaire and the Activated Patient Illness Report Checklist were developed using a Manual (Ingraham, 1980) written after the courses terminated with the intent of facilitating replication. They relate to the specific learning objectives of the classes held in the Oklahoma City area and to the overall objectives of the activated patient concept. The instruments were developed utilizing materials from the manual for replication and Sehnert's materials (1975). Context and content validity were established using each of the project staff from the original program. In addition to the project staff, a researcher from the Activated Patient pilot project conducted in Oklahoma City and a physician who had been involved in the pilot program and who had some

activated patient graduates as patients, were also involved in the validation process (see Appendix F for list of reviewers). This group of experts were asked to critique and to respond to the two instruments. Questions or criteria that received inconsistent responses or that were deemed outside of actual course content by half of the reviewers were deleted. The instruments were then pilot tested with a group from the pilot program to again check validity.

Reliability was tested using a split-half formula. Every other response formed one group, and the others formed the comparison. Using a Pearson R correlation formula the internal reliability was .26 for the PAQ and .16 for the APIRC. A Pearson R correlation was also used to correlate scores on the PAQ and the APIRC. This resulted in a .31 correlation. Though internal reliability is not established within this study, reliability over time still needs to be tested. There were no figures available on other similar instruments for reliability overtime.

Procedure

The two instruments were used in an interview setting. The interviews were conducted by two interviewers, working separately, both utilizing in the same procedure. Participants, and non-participants (those who were recommended by the sponsoring groups) were initially contacted by phone or in some cases in person to see if they would agree to the interview. There were none that were contacted that refused an interview. In a few cases the interview was conducted by phone if the individual indicated that a personal visit was not acceptable. Individuals were told that all information identifying them with the data was confidential, and were told that the purpose of the study was to see what

impact the classes might have had. The APIRC was used first in order to not offer any cues that might be present in the PAQ.

The protocol for the checklist part of the interview was essentially open-ended. The individual was asked to report on two of their most recent illnesses within the past year, and to detail as much information as they could remember about the illness and how they dealt with it. They were asked how they knew they had a problem, what they did, and how did they know what to do. After their description, the interviewer simply reviewed what had been heard with the individual to check the data. They were not directed beyond that. The APIRC was then scored wherever the individual had actually mentioned doing one of the items on the checklist.

The interview process was carried out over a three month period. The time elapsed since participants had completed the course ranged from four and one half years to two and one half years. No distinction was made regarding the completion date of the participants as the numbers were too low to allow for significant analysis.

Statistical Design

An effort was made to gather both quantitative and qualitative data. The APIRC required the interviewer to interpret what they heard and then to score the instrument. The PAQ consisted mainly of a test of their knowledge of basic material for the Activated Patient program, but it also contained two open-ended questions. The open-ended questions were analyzed using a content analysis process.

A packaged computer program, Statistical Analysis System (SAS), was used in the analysis of the quantitative data. The primary statistics utilized were

Analysis of Variance (ANOVA) and Two-Way Analysis of Variance to test the difference between the means of the different groups on both the PAQ and the APIRC.

The two instruments were first scored manually. They were then separated into two groups, the participants and the non-participants. The qualitative material was then reviewed for any perceived categories or grouping of responses. Once those categories were formulated a summary was done which resulted in some alteration of the initial categories. Those findings and the interpretation of such are reported in the next chapter.

CHAPTER IV

ANALYSIS OF DATA

This chapter is divided into three sections. The first describes the two major processes that took place in the analysis of data. The second part describes the actual findings of the study and includes the tables describing the statistical part of the analysis. The final section summarizes the results as they relate specifically to the hypotheses.

Stages of Analysis

The analysis of the data from the interviews took place in two parts. The quantitative and qualitative materials were separated and the actual analysis of the qualitative took place before the quantitative in order to avoid potential prejudice regarding results of the qualitative.

The responses to the open-ended questions were studied using a content analysis process. Once those categories were established the material was then summarized by category in order to clarify any trends within the responses. The final phase of this part of the analysis was an examination for any apparent differences or similarities between the responses of participants and non-participants in the Activated Patient classes.

The quantitative material was analyzed after the qualitative had already been summarized and analyzed. Each of the instruments were scored separately.

A simple summary table was utilized to organize the initial results and to also serve as a scan for any relationships or results that had not been previously hypothesized (see Appendix H for Means and Standard Deviation Table). The data were then transferred to a computer for statistical analysis.

The Statistical Analysis System (SAS) was chosen as being the most appropriate and convenient language to utilize. Analysis of Variance (ANOVA) and a Two-Way Analysis of Variance using the General Linear Model were both used. The standard ANOVA was used where there were balanced groups for the analysis of two hypotheses. The General Linear Model function of SAS was utilized where a Two-Way ANOVA was desired but the data were not balanced. The General Linear Model, Type III Sum of Squares performed the function of a Two-Way ANOVA with unbalanced groups.

Results

The results of the analysis are reported in the same order in which the analysis took place. That is, the qualitative findings are reported first and the quantitative results are reported last, leading directly into the test of hypotheses.

There were two open-ended questions used on the Patient Activation Questionnaire. They were intended to gather more qualitative material related to the activated patient concept. The first question was concerned with the perception of good health, and the second with the lay-professional relationship. Responses to the questions were studied and then categorized according to the course content and to the content of the responses themselves.

The first question was, "What does being in good health mean to you?" Three categories emerged from the responses: first, what the patient does,

second, specific references to body signs, and finally the feelings or effect mentioned. Age differences were not apparent in the responses. Both groups, participants and non-participants, responded in the area of patient activities with similar comments. According to them, persons in good health eat right, they exercise, they rest, and they maintain a positive attitude. The above responses are reported in order of greatest to least frequency. All of those elements are items that were discussed in the classes. They are also areas of great public interest and media discussion in recent years.

There was one notable difference in responses in the category of patient activities for good health. Non-participants mentioned the use of regular check-ups one in eight times, while participants did not mention it at all. The use of regular check-ups was not encouraged in the Activated Patient program. There were certain conditions where a specific exam or exams may be suggested, but the regular check-up was not seen as having great value. Participants appeared to have heard this message as evidenced by the lack of reference to the regular check-up.

The second category that emerged related to the frequency of reference to actual body signs, e.g., temperature, blood pressure. Though this was an area of instruction in the Activated Patient courses, there was no difference between participants and non-participants evidenced in the reporting of what good health meant to them. Only a few people in either group mentioned specific body signs. Most respondants made no specific referral to a body sign. The things that were mentioned in order of frequency were: normal blood pressure, good teeth, appropriate weight, and normal pulse. There did appear to be a relationship between the mention of a particular body sign and the presence of ill health related to the body sign mentioned by the respondant (ie. someone

with high blood pressure makes reference to blood pressure).

Both participants and non-participants described good health as being represented by a general, non-specific "feeling good". This was the largest response in the positive mode. Most responses, however, were negatively framed. That is, a majority of respondants spoke of the absence of some negative characteristic such as "not having high blood pressure", "not having to go to the hospital". It might be inferred that in a disease oriented, medical model this is the predominant language option. People simply do not have a "healthy" vocabulary. The only difference that appeared was that a small number of participants made specific references to "wanting to live longer". The significance of this response, however, was unclear.

The question was also asked, "What does it mean to you to have a good relationship with a medical professional?" Responses to this question were reviewed for categories and three were selected. The first was the doctor's behavior, the second was the patient's behavior, and the third was the general characteristics of the relationship, the interaction. As with the previous question regarding good health there were no signs of differences between age groups. The description of the doctor's behavior yielded no apparent differences between the participant group and the non-participants. Though lacking specificity the predominant responses were descriptive of behaviors rather than traits. In order of frequency of response the participants and non-participants indicated that as part of a good working relationship physicians would: give thorough exams, spend time with the patient, appear knowledgable and share information, and would speak in lay terms.

There was a definite difference between participants and non-

participants in the description of patient behavior. In fact, only one participant had a response that fell into this category as opposed to eleven of the non-participants. The non-participants' descriptions of patient behavior included four activities, all of which were part of the Activated Patient curriculum: listen to the physician, ask questions, describe your symptoms fully, and follow the physician's instructions. It may be that participants integrated these concepts and that they therefore did not sort out patient behavior.

The category of characteristics of the relationship showed no differences between the two groups. The word that both groups used the most was "confidence" to describe the relationship. When requested to go beyond that word most respondants made reference to communications. A healthy relationship between physician and lay persons should demonstrate communications on both sides that is characterized by honesty, understanding, openness, and directness.

The qualitative data indicated more similarities between participants and non-participants than it did difference. The perception of good health showed similarities in terms of patient behavior though participants did not mention regular check-ups. Specific body signs were mentioned when the individual had some immediate need to be conscious of it. The language of good health for both groups indicated a negative framework as they spoke of the absence of disease. Both groups described the relation with the medical professional as being a shared process characterized by openness and trust, and inclusive of professional behavior. The main difference was the lack of reference to patient behavior by participants while non-participants did mention it.

The first part of the quantitative data that was analyzed was the relationship between participation in the Activated Patient class and the score on the PAQ. Power of the ANOVA for all the analyses was calculated at .70 using an

alpha of .05, a .25 SD effect size, and with the sample size of 47 per cell. The ANOVA summary in Table 1 presents the results of that analysis. There is a significant difference in the score on the PAQ between those who attended the classes and those who did not. This added support to some of the earlier short-term evaluations that did demonstrate a difference in the level of information (Fretwell, 1977).

Table 1 ANOVA Summary Table For Comparing Participant And Non-Participant Scores On The PAQ

Source	df	SS	MS	F
Between	1	78.68	78.68	17.7*
Within	92	409.06	4.45	
Total	93	487.74		

*Significant at the .05 level.

The APIRC scores were analyzed following the same process as the PAQ scores. The results of that analysis are in Table 2. There was no statistically significant difference between participants and non-participants in this review of activated patient behavior. This was similar to findings both of Fretwell (1977) and Sehnert (1977). Fretwell suggested that despite the lack of significant behavioral differences found with his formal instruments there was anecdotal information that appeared to suggest there was a difference. The qualitative data discussed earlier in this chapter also suggested a difference though opposite of Fretwell's. This apparent difference was worth noting and will be discussed in the final chapter.

Table 2 ANOVA Summary Table For Comparing Participant And Non-Participant Scores On The APIRC

Source	df	SS	MS	F
Between	1	2.09	2.09	.50
Within	92	383.32	4.17	
Total	93	385.40		

The sample for this study was demographically homogenous in many ways. The main difference in the initial group of participants was the age factor. The question then became whether or not age had an impact on their learnings. Neither the initial sample nor the group that was found for completing the interview process were balanced in terms of age group so a Two-Way ANOVA for unbalanced groups was conducted. The two independent variables were arranged in a 2 X 3 factorial design. The first variable was that of participation and non-participation in the Activated Patient class. The age group was the second independent variable. It was divided into persons thirty-five years of age and under, those between thirty-six through fifty-four, and those fifty-five and older. Table 3 summarizes the results as they relate to the score on the PAQ. There appeared to be no difference sorting out age as a factor. Nor was there any statistically significant difference regarding the interaction of the two variables. As previously found in Table 1, there was a difference when participation was considered.

Table 3 Two-Way ANOVA Summary Table For Comparing Participation And Age Variables With PAQ Scores

Source	df	SS	MS	F
Age	2	17.82		2.07
Participation	1	53.39	(21.62)	12.38*
Interaction	2	10.63		1.23
Error	88	379.63	4.31	
Total	93	487.74		

*Significant at the .05 level.

The same 2 X 3 factorial design was used with the analysis of the APIRC. No statistically significant differences were found in any of the factors considered. In the review of literature there was no indication that age factors had been sorted out though programs were often aimed at populations that could be sorted by age, ie., school age and senior citizen. The results of this analysis are reported in Table 4.

Table 4 Two-Way ANOVA Summary Table For Comparing Participation And Age Variables With APIRC Scores

Source	df	SS	MS	F
Age	2	8.92		1.09
Participation	1	3.94	(5.02)	.96
Interaction	2	12.52		1.53
Error	88	360.32	4.09	
Total	93	385.40		

Test of Hypotheses

Statement of Hypotheses:

H1 Participants did not rate significantly higher on the Patient Activation Questionnaire than non-participants.

The result of the Analysis of Variance was statistically significant at the .05 level. The null hypotheses was, therefore, rejected so that a difference between the two groups was recognized.

H2 Participants did not rate significantly higher on the Activated Patient Illness Report Checklist than non-participants.

The Analysis of Variance was not statistically significant at the .05 level and the hypotheses was not rejected.

H3 There was no significant difference between participants associated with age on the Patient Activation Questionnaire.

The Analysis of Variance was not statistically significant at the .05 level and the hypotheses was not rejected.

H4 There was no significant difference between participants associated with age on the Activated Patient Illness Report Checklist.

The Analysis of Variance was not statistically significant at the .05 level and the hypotheses is not rejected.

The study postulated four null hypotheses. One of the four was rejected suggesting a difference between participants and non-participants on the cognitive oriented questionnaire. The qualitative data that were gathered suggested more similarities than differences between the participants and non-participants.

CHAPTER V

SUMMARY, CONCLUSIONS, AND RECOMMENDATIONS

Summary

The purpose of this study was to investigate the effect of a two year series of educational programs based on Dr. Keith Sehnert's concept of the activated patient. This was a longitudinal study examining the impact of the program after a period of three to five years had elapsed since the end of the classes. Two instruments were used to gather cognitive and behavioral data and to collect responses to open-ended questions.

The study sample consisted of a group randomly selected from a list of class participants and from a similar group drawn in the Spring of 1983 from the initial program sites. The non-participant group was obtained in the same fashion as the initial group of participants. There were a total of forty-seven individuals in each group. Only twenty-two of the total number of those interviewed were thirty-five years of age or under. Sixteen were between the ages of thirty-six through fifty-four, while the majority, fifty-six, were fifty-five and over. This is proportionally similar to the initial group of participants. Only eight were men. The racial mixture was almost balanced, as it was with the initial group, with fifty-five Caucasians and thirty-nine Blacks. Educationally, the groups were similar with 67% having high-school or less, 18% had some college, and only 10% had college degrees. 5% either did not know or would not say what their

educational background was.

Individual interviews were conducted in person when possible, and by phone when that was the form of contact preferred by the interviewee. Data from the interviews were then analyzed in two major stages. The qualitative material was summarized first for each interview. Quantitative data were then analyzed with the aid of the Statistical Analysis System package. ANOVA and Two-way ANOVA were both utilized.

Discussion and Conclusion

Health education is a popular and necessary activity given what we know of the life-style factor of many of today's major diseases. Health education material abounds in many forms, but the effect of that material is of an untested nature (Little, 1976). It was the purpose of this study to take a given curriculum, the Activated Patient course developed by Keith Sehnert, M.D., and look at the effect it had had on participants three to five years after they had completed the course. It was hypothesized that there would be no difference between participants and non-participants in performance on the two instruments, and that age would not be an important factor. The results showed that on an information oriented test, the Patient Activation Questionnaire, participants did score significantly better, but the other null-hypotheses were not rejected.

This study indicates that the Activated Patient course does produce some long term cognitive differences in participants. The findings here confirm the short term findings of both Sehnert (1977) and Fretwell (1977). This is an important factor in the development of the activated patient concept or in terms of any health education efforts. The individual must have the necessary information to perform as an activated patient.

There appears to be a significant difference between participants and non-participants that, though undefined, needs to be noted. Fretwell (1977) made reference to the anecdotal difference he encountered between his participants and non-participants in the area of self-reporting. His participants reported feeling better about themselves and experiencing themselves as more assertive and active in their health care. This study showed the reverse in the qualitative aspect. That is, the participants did not mention activated patient qualities in reference to the patient-medical professional relationship while non-participants did. This might mean that participants have progressed to the point where activated patient concepts are well internalized and exist beneath a conscious level or it might imply that they have rejected the concept now that they have experienced it. Whatever the true nature of the difference between participants and non-participants it does appear that there are qualitative differences that remain to be defined and quantified if possible.

The lack of a statistically significant difference on the Patient Activation Illness Report Checklist suggests that there is no difference in terms of behavior. This is also similar to findings by Fretwell (1977) and Sehnert (1977), but as with both of those studies the qualitative reports from participants is positive and indicative of some difference. One might surmise that either the instruments examining behavior are inappropriate or not finely tuned enough to detect the difference, or that this is a phenomenon inherent in the self-reporting process. If the end result of Activated Patient programs is to be behavioral change then the issue of altering the class must be addressed.

The theoretical considerations emphasized the importance of need and an educational response to the need. The Activated Patient course has provided one response to that need. The fact that it was not demonstrated to have been

more effective suggests certain weaknesses. These weaknesses may have been in the design of the study. As was mentioned earlier there were difficulties in the post hoc nature of the design. The lack of a theoretical base that extends beyond program development is an important concern also. There is no learning theory base other than an implied formula that information leads to behavioral change. Not one of the presentors or programers involved in these classes was trained in the field of education. Though the courses went beyond the simple transmission of information the program lacked a framework that would have been useful in dealing with a complex need.

It must also be noted that while there is a great deal of discussion of self care and wellness in the public today there is also a constant barrage of material to the contrary. Advertising for nutritionally worthless foods and drinks, cigarettes, and unhealthy life style characteristics are visible and audible in many aspects of daily living. To assume that a single program will be a causal factor in life style change may be too much to expect.

The study also indicates that there are many similarities between the participants and non-participants that suggests an activated patient like-mindedness. Responses to the idea of good health were similar as were the characteristics of a good lay-professional relationship. Both of these elements of the activated patient concept are also components of the general thrust in health education via all the media sources. This like-mindedness may be the reason for the lack of a perceived behavioral difference between the two groups. The emphasis on qualities similar to those within the curriculum of the Activated Patient is so strong that the perceivable effect may be limited to a few special pieces of data brought forth in the classes.

Limitations

There are four primary limitations to the study, two of which might be easily corrected in future studies with proper planning and the other that might be managed in some fashion. The first limitation was the ad hoc nature of the control group. Here, as with so many other health education programs, there was no planned follow-up. When the program ended there was a hope that it would be replicated, but no built in long-term evaluation was planned. This is a weakness not only in the strategies of the planners, but also in the minds of the program funding sources, often Federal, who anticipate replication or termination yet show little interest in follow-up funding that goes beyond the bounds of the conventional three or five year limit to program funding.

The second limitation concerns the demographics of the groups. While every effort was made to develop a control group that would be similiar, there were difficulties as mentioned earlier (mortality and mobility being primary among them). It was also impossible to balance the groups for the two-way ANOVA. This was accommodated by use of the General Linear Model available through SAS, but it would have been preferred to have balanced groups. It is also possible that the sample is not representative of the population.

The instruments may have been a source of error. The PAQ and the APIRC have not been tested overtime. The low split-half correlation value may indicate a problem in the instrumens. While the PAQ showed a variation in scores the APIRC showed little variation and produced scores so low that it is suspected to not have been sensitive enough to detect variation (Mean = 4.5, SD = 2.0). This may be a fault of the instrument or the interview process that was passive reflective. An interview process that was more like the PAQ might enhance the sensitivity of the APIRC.

The final limitation is a general one in the area of health education. This is the factor related to the current boom of information and programming in this area. An idea or a particular concept that might one moment be peculiar to a certain curriculum may become public domain within months due to the media interest in this area. Though this may be a positive factor in coping with new issues and problems, it also makes it difficult to say that X is related to your program when X is available and seen by people every day. Though this difficulty can not be totally eliminated it might somehow be incorporated in the study or the program. Some of the programs from other countries made media campaigns part of their efforts to cope with the problems they were confronting. Thus, rather than an unaccountable variable, that factor became a controlled part of the program.

Recommendations

There are a number of recommendations that emerge from this study. The first echos the study by Little (1976) and calls for continuing research of a long-term nature in the area of health education. Despite the difficulties inherent in funding, effectively sorting out variables, and planning for such a project, there needs to be continued research not just for the purpose of justifying the interest in education or terminating it, but for the reassessment and alteration of such programs to enhance their impact.

More research of a qualitative nature should be implemented in order to determine the meaning of the apparent conflict between quantitative results and anecdotal data. There may be some clues within this area as to how to alter programs to make them more effective.

Replications of this study would be useful to affirm the findings and to test the reliability of the instruments. It is also recommended that competencies be developed to clearly define the desired results of the Activated Patient program and other health education efforts.

The idea of using competencies to describe the activated patient comes from an educational perspective. One general criticism of most health education programs, including the Activated Patient, is the absence of educators in the total process. Many programs are developed by well meaning technical experts with little or no knowledge of educational process. Their thinking appears to be that it's "the facts" that count and that "anyone can teach". It is suggested here that trained educators should be involved for the development of objectives and competencies, design of the overall event, technique or process development, and for follow-up evaluation. This combination of technical and educational expertise has a greater chance for creating and implementing effective educational programs.

The final recommendation is of a programmatic nature as well as a research concern. In order to manage the media as a variable, and in order to utilize media as a component of the educational process, it is suggested that health education be developed in a more comprehensive fashion as in the projects reported by Lawson and Blatch (1981) and McAlister, et al (1982). The program described by McAlister, et al in Finland involved the enhancement of preventive service, dissemination of information via a variety of media sources as well as through community meetings, educational events, interventions coordinated through existing community groups, and environmental changes including efforts to increase the availability of healthy products (ie, low-fat foodstuffs) and healthy environments (ie, restrictions on smoking in public places). The program

presented by Lawson and Blatch was less comprehensive, though still more so than what exists within the United States. This Australian program included events for parents of young children, television programs, a project within the schools, a variety of health education programs for adults and efforts to work with professional groups also. These programs serve as good examples of comprehensive efforts that should be adopted here if we are to see significant changes. The classroom activity would ideally exist within a framework that would help the individual in his/her efforts toward patient activation.

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APPENDIX A

COURSE INFORMATION

TITLE: "How to be Your Own Doctor, Sometimes"

TIME: 1:30pm to 3:30pm, Monday and Thursday

DATES: September 24, 1979 to October 25, 1979

LOCATION: South East Area Health Center
745 SE 26th
Oklahoma City, Oklahoma

SPONSORS: University of Oklahoma Health Sciences Center
Department of Community Medicine and Ambulatory Health Care Consortium

PURPOSE: The course will teach you:

1. how to take more responsibility for your health and for the health of others close to you;
2. to learn how to observe, describe and treat common illnesses, injuries, conditions, and emergencies;
3. basic knowledge of common health conditions; and
4. how to use health care services, insurance and medications more appropriately, more effectively and more economically.

****

By my signature below I indicate that I understand:

1. that this class is being provided at no cost to me and upon completing the course I will be able to keep the textbook and handouts provided for my use during the sessions; and

2. that I will be expected to attend all of the sessions and participate in the evaluation of the course which will include a personal interview soon after the beginning of the classes and several activities during the classes designed to find out how much I have learned.

SIGNATURE_____

DATE_____

OUHSC REPRESENTATIVE_____

***Wear something with loose sleeves to the first class so you can practice blood pressure taking.

APPENDIX B

UNIVERSITY OF OKLAHOMA HEALTH SCIENCES CENTER

SOUTHEAST HEALTH CENTER

Monday, Sept. 24th: "Responsibility for Your Own Health Care: Concepts on Prevention and Medical Self-Help"

The objectives of this session will include getting to know each other, understanding what it means to be an "activated patient", becoming familiar with medical terms and medical instruments, and learning what will be included in the remainder of the course.

Thursday, Sept. 27th: "Listening to Your Body"

Through role playing and active participation the students will develop the ability to interpret and respond to the messages their body is sending about its state of health. This session centers around becoming skillful at specific descriptions of these messages.

Monday, Oct. 1st: "Common Illnesses"

Dealing with the illnesses most relevant to the group discussion will include identification and reporting of common illnesses. Self-help skills pertaining to them will be discussed and learned.

Thursday, Oct. 4th: "Medical Conditions and Emergencies"

Geared to an understanding of what to do in certain medical situations, this session will deal with emergencies encountered most frequently in the group assembled.

Monday, Oct. 8th: "Coping"

This session will deal with the relationship between emotions and physical health. Students will learn coping behaviors, and discussion will focus on the kind of situations which require coping.

Thursday, Oct. 11th: "Your Medicine Chest: Friend or Foe"

With the help of the course instructors, students will gain a better understanding of their medicines, learn to identify those over-the-counter medicines which they should keep on hand, and discuss such important issues as "shelf-life", storage, labeling and disposal -- as well as receive useful tips for getting the most out of their "medicine dollar."

Monday, Oct. 15th: "Field Trip"

Thursday, Oct. 18th: "How to Choose and Use Your Doctor -- and Make the Health System Work for You"

Through group interaction this session seeks to assist the participant in learning how to find a doctor, identify the characteristics of an ideal doctor and learn to use one more effectively. Health consumer protection and patient's rights will also be covered.

Monday, Oct. 22nd: "Consumer Facts on Dental, Eye and Foot Care"

This session concentrates on Dental Health; emphasizing local availability of dental, eye and foot care services.

Thursday, Oct. 25th: "Taking Care of Your Body with Diet"

This session will span the field of nutrition from recognizing the dangers of improper diet to practical tips on food preparation. This final session will also include evaluation of the participants knowledge of the course content.

APPENDIX C

OBJECTIVES OF SELF CARE INSTRUCTION

The totality of this particular self care model is designed to help the participant:

TAKE BETTER CARE OF THEIRSELF
WHENEVER IT IS APPROPRIATE.

GET BETTER HEALTH CARE FROM OTHERS
WHENEVER IT IS APPROPRIATE.

In order to accomplish this the modules are arranged around the following specific objectives:

1. To develop a working knowledge of medical terminology and reading prescriptions.
2. To learn how to take vital signs (pulse, temperature, respiration, blood pressure).
3. To learn the normal average ranges of vital sign measurements.
4. To become skillful in the specific description of body messages.
5. To develop an ability to interpret messages the body is sending about its state of health.
6. To identify common illnesses and medical conditions to make determinations of whether outside medical help is required or if self care is appropriate.
7. To develop self help skills pertaining to common illnesses and medical conditions.
8. To develop the ability to respond appropriately to medical emergencies.
9. To develop skills to be an effective, efficient consumer and purchaser of pharmacy products and health services.
10. To develop an understanding of how to use physicians and pharmacists more efficiently.
11. To gain an understanding of shelf life, storage, labeling and disposal of medicines.

12. To recognize the interrelationship between emotional reactions and physical health.
13. To understand the concept of coping and identify coping behaviors.
14. To develop self help skills related to coping.
15. To understand the preventative aspect of self examination and the importance of early detection in relation to diagnosis and treatment of disease.
16. To learn the self examination techniques for early oral, breast and testicular cancer detection.
17. To recognize the dangers of poor diet.
18. To learn the few generally accepted "nutritional" truths and accept diet as requiring individual variations.
19. To learn how to find a doctor or health professional suited to you.
20. To identify strategies for health consumer protection.

APPENDIX D

Activated Patient Illness Report Checklist

	DESCRIBE EPISODE 1	2
ECONOMICS		
Asked for generic		
Used generic		
Used OTC		
Used book before visit		
Used call before visit		
Saw Doc when appropriate		
SELF TREATMENT/DOCTORS VISIT		
Return visit to Doctor as prescribed		
Return visit to medical professional as prescribed		
Made referral visit		
Used appropriate first aid		
Used algorithm		
Used non-medical resource		
Described symptoms to medical professional		
Asked questions of Doctor when wanted to		
Got questions answered during visit		
Treat acute problems themselves		
Utilize Doctors for chronic problems		
Took medicine as prescribed		
USE OF VITAL SIGNS		
Described body signs		
Described temperature		
Described blood pressure		
Described pulse		
Described respiration		

COMMENTS:

Age: 35 under_____

35-55_____

55 over_____

Sex: M_____ F_____

Ethnic: C____ B____ NA____ H____

Residential: _____ _____
Yes No

In the past year how many, if any:

A. health related classes have you attended _____

B. health related books have you read _____

C. health related TV programs have you watched _____

APPENDIX E

Patient Activation Questionnaire

1. The normal adult's average pulse rate is:
   - A. 50
   - B. 72
   - C. 92

2. If an adult male aged 50 has a regular blood pressure reading of 170/105 he
   - A. has a medical problem
   - B. is in excellent health
   - C. is in OK health for his age

3. A child had hot coffee spilled on his back. You should
   - A. apply ointment
   - B. apply a wet, cold cloth
   - C. apply butter

4. You cut yourself accidently. Bright red blood is spurting from the wound. You should first
   - A. apply direct pressure
   - B. tie a turnequet
   - C. clean the wound with water

5. When you visit a physician you should
   - A. only respond to their questions
   - B. come with a list of symptoms
   - C. never ask questions

6. When looking for a physician or medical clinic the most important thing is to find
   - A. someone cheap
   - B. someone you're confident about
   - C. someone close to where you live

7. Your neighbor comes to you feeling very depressed. Your most important helping tool is
   - A. non-judgemental listening
   - B. de-caffinated coffee
   - C. telling them a similar story from your life

8. Psychosomatic illnesses
   - A. are never as serious as other illnesses
   - B. are just in your head
   - C. may be as serious as any other illness

9. In general, antibiotics should be taken
   - A. until the symptoms disappear
   - B. until you have taken the full prescription
   - C. as soon as a cold starts

10. The main advantage in dealing with only one pharmacy is that they will
    - A. know what you're taking and watch for possible harmful interactions
    - B. be more likely to give you discounts
    - C. give you what you want even without a prescription

11. Brown sugar is
    - A. easier to digest than white sugar
    - B. the same as white sugar but colored
    - C. better for you than white

12. People diagnosed with high blood pressure are usually advised to
    - A. to take vigorous exercise immediately
    - B. decrease their salt intake
    - C. increase salt intake but to decrease fats

13. If you notice a raised area, a lump or a bump in you mouth you should
    - A. call a dentist or doctor immediately
    - B. gargle with salt water
    - C. watch it for two weeks and then see a dentist/ doctor if it's still there

14. Flossing your teeth is only important when you
    - A. have something stuck between them
    - B. have a meeting to go to
    - C. for regular dental care

15. Otitis means
    - A. a pain in the neck
    - B. swelling of the ear drum
    - C. a red rash

16. What does being in good health mean to you?

17. What does/would it mean to you to have a good relationship/partnership with a medical professional?

APPENDIX F

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APPENDIX G

PARTICIPANT DEMOGRAPHICS - AGE

35 & under	60
36 - 54	32
55 & over	84
unknown	15

APPENDIX H

MEANS and STANDARD DEVIATION Summary Table

	PAQ				APIRC			
	Total	Age			Total	Age		
		18-35	36-54	55+		18-35	36-54	55+
Participants								
(N)	(47)	(9)	(5)	(33)	(47)	(9)	(5)	(33)
M	12.12	12.11	12.80	12.06	4.68	4.60	5.60	4.54
SD	1.80	2.14	1.92	1.74	1.62	1.65	1.81	1.60
Non-Participants								
(N)	(47)	(13)	(11)	(23)	(47)	(13)	(11)	(23)
M	9.90	11.30	10.63	9.56	4.45	5.38	3.90	4.13
SD	3.04	2.39	1.80	2.44	2.35	2.29	2.02	2.49
TOTAL(N)	(94)	(22)	(16)	(56)	(94)	(22)	(16)	(56)