1998

Patient empowerment and chronic care: an exploration of the patient perspective

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Recommended Citation
Morgan, Lisa Ann, "Patient empowerment and chronic care: an exploration of the patient perspective" (1998). *Master's Theses*. 1708.
DOI: https://doi.org/10.31979/etd.pc83-2rwv
https://scholarworks.sjsu.edu/etd_theses/1708

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PATIENT EMPOWERMENT AND CHRONIC CARE: AN EXPLORATION OF THE PATIENT PERSPECTIVE

A Thesis

Presented to

The Faculty of the Department of Health Science

San Jose State University

In Partial Fulfillment

of the Requirements for the Degree

Master of Public Health

by

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August 1998

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ABSTRACT

PATIENT EMPOWERMENT AND CHRONIC CARE: AN EXPLORATION OF THE PATIENT PERSPECTIVE

by Lisa A. Morgan

This exploratory qualitative study investigates patients' perspectives on patient empowerment as it relates to their ability to self-manage their chronic conditions. Specifically, this research explores the perspectives of arthritis patients receiving health services during a period of historical change in the health care system. Twenty-three people were interviewed in order to learn about their experiences, opinions, and advice regarding patient empowerment, self-management, and chronic health care.

The study reveals that patients primarily understand patient empowerment in terms of empowering or disempowering experiences in their relationships with their physicians. A physician's communication skills and treatment approach may ultimately influence a patient's ability to successfully self-manage. In addition, patients with chronic conditions desire a health care system that supports partnering patient-physician relationships. These findings are particularly important at a time when the health care delivery system is undergoing changes that may place this relationship at risk.

ACKNOWLEDGEMENTS

This research is dedicated to the twenty-three individuals who came forward to share a part of themselves in order to help others. You are strong, insightful, and dedicated to taking on the daily challenges of managing your health, negotiating the health care system, and being all that you can be. You have taught me about chronic conditions, about health care, and about life. You inspire and challenge those around you. You are role models to all.

I would especially like to acknowledge my husband, Dan, whose endless support, thoughtful insights, and incredible belief in my abilities gave me the courage to see this research through. You continuously inspire me to grow, personally and professionally. There is no greater gift. Thank you for having the capacity to care so much for me.

I would like to thank those individuals whose patience, wisdom, love, and humor made this work possible.

To my parents, who have nurtured my ability to really listen to what other people have to say, to always strive for what is in my heart, and to believe in myself. Thank you for giving me the tools and the vision to make my dreams happen.

To my friends, Misha and Teeger, whose constant affection and cat-like humor provided many excuses to take breaks and made the long days of writing endurable.

And finally, to my advisors. Your patience, encouragement, wisdom, and faith in me are irreplaceable. You have touched my life in lasting ways. You are teachers of academia and you are teachers of life. Thank you for your inspiration.

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CHAPTER 1

INTRODUCTION

Chronic illness is a compelling example of the challenges we face in addressing social problems and in giving care. It produces human problems of major lifelong consequence and affects our use of the health care system (Cotler, 1996). Due to the long term nature of chronic conditions, a partnership between patients and their health care providers is crucial to the individual's ability to manage her or his health and illness. People with chronic diseases currently face the challenge of self-management in a health care system that is not only designed for acute conditions, but is also changing dramatically and rapidly. Indeed, the transformation of American health services into a system of managed care raises questions about the ability of the system to provide empowering patient care for individuals with chronic conditions.

The purpose of this study was to explore patients' perspectives on patient empowerment as it relates to their ability to self-manage their chronic conditions. Specifically, this qualitative research investigated the perspectives of arthritis patients receiving health services during a period of historical change in the health care system. The primary goal of this study was to bring forward the perspectives of patients who have unique and invaluable knowledge of the challenges and successes of chronic disease self-management. The ultimate goal of this research was to stimulate health professionals and key decision makers to acknowledge, understand, and incorporate patient perspectives as care is provided and policies are created which affect the lives of people with chronic conditions.

Statement of the Problem

Our nation has witnessed a profound change in the nature of common illnesses. Advances in research, medical care, and technology over much of this century have allowed us to survive acute medical traumas and continue to live with certain diseases and conditions. As a result, many previously fatal situations have been transformed into chronic conditions (Sandy & Gibson, 1996). We are now surviving more often and living longer.

This increase in individual longevity allows chronic conditions such as hypertension, HIV, asthma, diabetes, arthritis, and stroke to affect more Americans than ever before (Hays et al. 1994). Indeed, nearly 40 million Americans have a chronic condition (Sandy & Gibson, 1996). Furthermore, chronic conditions account for nearly 80% of all medical expenses (Fox & Fama, 1996).

Arthritis, one of the most prevalent chronic conditions, affects one in three Americans in their lifetime (National Institute of Health [NIH], 1988). Arthritis accounts for the largest proportion, 41%, of new pain symptoms reported to physicians (NIH). By 2020, the estimated number of persons with arthritis is projected to increase by 57% (Centers for Disease Control [CDC], 1994). Activity limitations associated with arthritis will increase by 66% (CDC, 1994).

Chronic conditions, such as arthritis, require an extraordinarily high level of individual responsibility for successful day-to-day living (Clark et al. 1991). Although the initial medical diagnosis may be the result of an acute episode, people with chronic conditions live, not cured but stabilized, in a life outside the health care institution. There they must begin or continue to manage their conditions by themselves. Quality of life for the individual is very much dependent upon how well she or he is able to self-manage the condition on a daily basis.

The struggle to self-manage a chronic condition involves not only the individual, but the family, caregivers, the health care system, and the community. In order to successfully self-manage a chronic condition, the patient often relies on his or her own knowledge and skills, support from others, and access to good health care. The health care system, in particular, may positively contribute to an individual's ability to self-manage by providing a range of services and products. Medical care, patient education, psychosocial support, and skill building are all vital to a patient's physical, mental, and social well-being.

That state of complete physical, mental, and social well-being, and not merely the absence of disease, is the World Health Organization's (WHO) definition of health (World Health Organization [WHO], 1978). Patient empowerment is understood as essential to the self-management and thus overall health of the patient with a chronic condition.

Empowerment is a term defined in a multitude of ways within a multitude of situations. Rappaport (1985) defines empowerment as a sense of control over one's life in personality, cognition, and motivation. It is a process ability that we all have, one that takes on different forms in different people and different contexts. Merzel (1991) discusses empowerment by claiming that through the process of empowerment, individuals are liberated from helplessness to make their own decisions and implement them to the fullest extent possible. Immerman (1991) states that empowerment is a process of learning to obtain the knowledge we need, becoming more effective in utilizing existing systems, and transcending those systems wherever possible by taking responsibility for our own needs. Finally, Wallerstein (1992), from a social ecology perspective, defines empowerment as a social action process that promotes participation of people, organizations, and communities towards the goals of increased individual and community control, political efficacy, improved quality of community life, and social justice.

Taking into account the WHO definition of health and the range of definitions of empowerment, patient empowerment for a person with a chronic condition may be defined as the ability of the patient to experience a sense of control over his or her condition that liberates him or her to self-manage in order to maintain a certain degree of physical, mental, and social well-being. Environments, such as those created by health care organizations, have a unique ability to foster individual empowerment.

Health care that fosters patient empowerment can be referred to as empowering patient care. Empowering patient care may consist of a variety of services and a style of care that empower patients by developing their sense of control over their conditions. Empowering health care is essential to the long term health and well-being of patients with chronic conditions. A health care system that is able to provide empowering patient care has the opportunity to enhance the health and quality of life of its patients.

The existing health care system in the United States is not particularly responsive to individuals living with a chronic condition (Corbin & Strauss, 1988; Lorig, 1993). The current preventive and curative models in health care are not well suited to a population whose conditions are present and continue to linger (Rood, 1996). Care for chronic conditions often falls through the cracks, being addressed by neither the public health nor the medical care system (Lorig, 1996).

Managed care, for decades an interesting experiment, is now poised to dominate the nation's health care delivery system. More than 90% of the employed population now receives care from some form of "managed" health care system (Sandy & Gibson, 1996). Research indicates that the health maintenance organization (HMO), a specific type of managed care configuration, has not yet fully capitalized on the opportunity to improve care for people with chronic conditions (Sandy & Gibson).

Wagner, Austin, and Korff (1996) argue that in order for managed care organizations to provide effective and efficient care for people with chronic conditions, they must empower patients to take responsibility for the management of their conditions. The high cost of chronic illness, due in part to poor management of chronic conditions, and the importance of having healthy and satisfied members make it essential that these organizations explore and evaluate methods to provide empowering patient care.

Patient input is an invaluable resource for investigating and defining the concept of patient empowerment, and eventually developing the most effective empowering systems. However, due to the swift pace of health care reform, there has been little time for listening to the perspectives of patients. Despite the wealth of information supplied by quantitative studies examining discrete components of self-management, managed care, and patient care, the patient's perspective appears to be a missing link.

The transformation of our health care system will have profound effects on people with chronic conditions. Amidst this institutional change, health care must continually strive to empower patients with chronic conditions, so that patients, providers, and the system itself benefit. Acknowledging, understanding, and incorporating patients' perspectives on empowerment into the care that is provided and the policy decisions that are made is an important part of that effort. If we fail to bring forth the patient's voice we will sacrifice valuable information that might seriously limit the success of our reforms. It is vital that we listen to patients with chronic conditions as we design care that strives to empower them to take charge of their own health.

Objectives and Questions

This research was designed to meet the following objectives:

1. To explore patients' perspectives on patient empowerment, including sources, barriers, and empowering experiences related to their ability to self-manage their arthritis.
2. To generate data about how patients perceive the health care system to be empowering people with arthritis, and desired characteristics of environments that empower patients to self-manage their arthritis.
3. To stimulate health professionals and key decision makers, most importantly those associated with managed care, to acknowledge, understand, and incorporate the

perspectives of patients as care is provided and policies are created that affect the lives of people with chronic conditions.

4. To contribute to the current discussions of the nature and organization of our health care system as it pertains to chronic care.

This research was designed to address the following questions:

1. What are arthritis patients' perspectives on patient empowerment, including sources, barriers, and empowering experiences, related to their ability to self-manage their arthritis?
2. Within the context of their health care, what are arthritis patients' experiences with empowerment or disempowerment, related to their ability to self-manage their arthritis?
3. What specific types of care do arthritis patients believe would help empower them to self-manage their arthritis?

Methodology

The framework for this study is based upon the concept of empowerment. Empowerment is a term that has been interpreted in various ways, defined by a multitude of terms, and applied to a range of situations. The use of the concept of empowerment in the field of patient care is limited. It has more typically been applied to communities struggling to overcome adverse social situations (McKnight, 1997; Wallerstein, 1992).

People with chronic conditions may be viewed as a community struggling to accept and successfully self-manage the physical, mental, and social aspects of their lives.

This community is intimately involved with the health care system. Investigating the concept of empowerment as it relates to this community, in their terms and in light of their experiences, gives yet another view of empowerment. This crucial perspective may be applied to the development and reform of chronic care systems.

This exploratory qualitative study utilized personal interviews to gather arthritis patients' perspectives on patient empowerment as it relates to their ability to self-manage their chronic conditions. The sample consisted of twenty-three participants who have arthritis and had participated in one of the Arthritis Foundation's Arthritis Self-Management Programs (ASMPs) within Santa Clara and San Mateo Counties. Participants had a diagnosis of at least one of the following common types of arthritis: osteoarthritis, rheumatoid arthritis, fibromyalgia, or lupus. The researcher recruited participants from ASMPs following a brief announcement describing the purpose and methods of the study and the role of participants.

Attempts were made to include in the sample approximately five people from each of the following age groups: 30-49, 50-69, and 70-90. Attempts were also made to equally represent sex and common types of arthritis, however, no specific numbers were required. A wide range of ethnicities were sought for the sample, however, there also were no specific numbers of ethnic group members required for this study.

Interviews were approximately one hour in length and were held at a place and time most convenient to each interviewee. Participants were asked to complete a short demographic intake questionnaire at the beginning of the interview. This questionnaire collected basic demographic information, arthritis diagnoses, and information pertaining to self-management, health status, and patient satisfaction. Participants were then led through a series of questions designed to facilitate discussion of their experiences, perceptions, and opinions regarding the relationships between patient empowerment, self-management, and their health care.

No pre-determined variables within this study were tested for statistical significance. Rather, participants, through their comments, generated their own themes and patterns around the issue of patient empowerment. Likewise, the names of specific health care providers were confidential as the purpose of this study was not to evaluate or compare specific organizations.

Each interview was audio taped and transcribed into written text. Content analysis identified emergent themes, patterns, and trends within the text that were common across individuals. In reporting the results, emphasis was on common themes, patterns, and trends rather than correlations between responses and particular situations of those interviewed.

At the time of the interview, each study participant received a written thank you note, ten dollars, and a selection of arthritis educational and resource materials. A final closure to this study involved those who contributed. Each participant was invited to attend a pasta dinner at a selected location. This occasion was organized and financed by the researcher. All participants also received a second written thank you note at that time, regardless of their presence at the dinner. At the dinner, the researcher presented a summary of the study results and distributed copies of the final paper. It was a time for giving back to those who shared so much of themselves.

Definitions

The following conceptual definitions were used in the framework for this study:

Empowerment	A sense of control over one's life in personality, cognition, and motivation, a process ability that we all have, one that takes on different forms in different people and different contexts (Rappaport, 1985).
Disempowerment	The lack of control over one's life.
Managed Care	Organizational arrangements that seek to alter treatment practices so that care of acceptable quality can be provided at lower cost (Mechanic & Schlesinger, 1996).
Chronic Condition	Long term conditions that encompass diseases; injuries with long sequelae; and prolonged structural, sensory, and communication abnormalities (Sandy & Gibson, 1996).
Self-Management	The mastering of the following three related categories of activities: (a) sufficient knowledge about one's condition and its treatment to make informed decisions about one's care, (b) performance of activities aimed at management of the condition, (c) application of skills necessary for maintaining adequate psychosocial functioning (Clark et al., 1991).

Limitations

Three key limitations emerged during the design and activities of this research: the composition of the final sample, the absence of the evaluation of individual health care providers and plans, and the difficulty of exploring the concept of empowerment. These limitations are important to note when applying the findings beyond this specific study.

This study used a purposive sampling strategy to recruit individuals who had arthritis and held a basic level of knowledge about the principles of self-management. This selection process created a sampling bias towards people more familiar with the concepts being explored. It may also have limited the sample to empowered patients, or individuals who were successfully managing their chronic conditions. The perspectives of those without these resources or experiences would add important dimensions to these results.

Another limitation of this study is in the demographics of the final participants. The final sample consisted primarily of highly educated, financially stable, Caucasian women. Their opinions and experiences may differ significantly from the responses one might receive from male participants, those with less education or financial resources, people of different ethnic backgrounds, or a combination of any of these. By design, the sample was drawn from individuals living in the San Francisco Bay Area, which may also limit generalizeability of the findings.

Individual health care providers and plans were not evaluated in this study, leaving the reader unable to draw conclusions about specific types of health care organizations or systems. The ultimate goal of this research was to identify common opinions and experiences of those involved with health care in general, with an eye to the relevance of the data in the current transition to managed care. However, it would be interesting to know which health care organizations are able to provide particularly empowering patient care.

Finally, as expressed by numerous experienced researchers, empowerment is a complex and difficult concept to explore (Funnell et.al. 1991; Israel, Checkoway, Schulz, & Zimmerman, 1994; Labonte, 1994; Wallerstein, 1992). Despite this reality, the researcher made the assumption that participants would be able to discuss freely and critically their perspectives regarding empowerment. Remarkably, participants were indeed aware of this concept and had the ability to share their opinions about what it means to them. They also had the ability to relate their experiences, both within their personal lives and their health care, to the meanings they had assigned to empowerment.

Significance

This study is significant for several reasons. First, it represents perspectives of a key group of patients. The population of people with chronic conditions continues to grow, and our health care system continues to undergo reform. If we are going to create a system that empowers the people it serves, the need for patient input is crucial. The information presented in this study specifically represents the perspectives, opinions, and experiences of a particular group of people living with a chronic disease. Their comments bring to our attention the issues that are most significant to them, and most likely, to others living with chronic conditions.

Second, these participants' interpretations, experiences, and opinions regarding empowerment not only add to our understanding of the concept of empowerment, but also reveal its relevance to patients, and even more so, to patients with chronic conditions. Empowerment is a complex term, one that has always been difficult to research. Major contributions have been made by research within the broad areas of health education, health promotion, social justice, and advocacy. Understanding the meaning of this concept, through the words of patients, only brings us closer to identifying the factors that facilitate the empowerment of the people we are trying to help.

Third, and most important, these results remind us of the powerful nature of the relationships between patients and health care providers, specifically physicians. Patients do not expect to be empowered by the people who care for them. However, individuals can be positively influenced by an empowering environment or an empowering relationship. As told by this research, relationships with health care providers, physicians in particular, can be very empowering, or disempowering, for patients.

People with chronic conditions are intimately and inextricably involved with the health care system. They depend, not always by choice, upon health care providers for a variety of reasons. For those of us either practicing in health care or designing health care systems, it is easy and almost second nature to focus on designing the most appropriate clinical pathways of care, prescribing the most effective medications, or creating the most up-to-date patient education materials and programs to help our patients manage their health. The patients in this study have confirmed that classes, educational materials, and medications are important. However, they have also shown the value they place on one simple aspect of their care: the relationships they have with their physicians.

Finally, these patients have brought to our attention several key issues relevant to the decisions being made within health care reform. These issues concern individual choice, relationships with physicians, and access to alternative care. These three key issues are particularly relevant to people living with chronic conditions, and were discussed by study participants within the context of empowering patient care. Participants' insight into these issues offers valuable guidance to service providers and decision makers. As the future of our health care system continues to take shape, while at the same time serving more and more people with chronic conditions, the integration of patient input remains crucial to designing the most appropriate and effective empowering patient care.

CHAPTER 2

LITERATURE REVIEW

The literature on health care, chronic disease, self-management, and patient empowerment provides an overview of the current state of health care, the prevalence and nature of chronic disease, the daily challenges people with chronic conditions face in trying to manage their health, and finally, the significance of empowering patient care.

Health Care and Reform

Health care is in a state of crisis and reform. The dramatic expansion of medical technology, the infinite needs of a growing population, and the soaring costs of medical care have transformed the humanitarian social service of health care into a corporate enterprise (Thorne, 1993). Health care has traditionally been organized around the most expensive professionals, the most technologically oriented services, and an enthusiasm for curative procedures.

As a result, the United States (U.S.) health care system, in particular, is now changing rapidly, dominated mainly by the shift from fee-for-service to managed care. Despite the failure to legislate comprehensive health system reform at the federal level, the health care system is being reformed, largely through powerful market forces. Even in the absence of national legislation, the emergence of managed care as the predominant force in the health care system is virtually assured in the U.S. (Brook, Kamberg, & McGlynn, 1996).

The transition to a managed care health system has been largely driven by the desire of employers, insurance companies, and the public to control soaring health care costs (Brook et al., 1996). It was estimated that a combination of over-priced and unnecessary treatments, combined with a huge health care bureaucracy, were costing the nation $200 billion a year - money that could be productively redirected to pay for health care for the uninsured ("How Good," 1996). It was believed that managed care could offer at least the potential to deliver good medical care efficiently and cost-effectively ("How Good").

The Clinton health care plan, introduced in 1993, proposed a system of "managed competition" to put health care in a framework that would both control costs and ensure high quality treatment. Writing in *Time* magazine, former Surgeon General C. Everett Koop suggests that, in the minds of many Americans, the campaign for health care reform ended in 1994 when Congress rejected the President's plan (Koop, 1996). The plan collapsed under the prediction that managed care would limit Americans' choice of doctors and restrict their access to care ("How Good," 1996).

Ironically, in the last several years, market forces have shifted American medicine dramatically in the direction of managed care. Over 50 million people, approximately 20% of all Americans, are currently enrolled in managed care organizations (MCOs). Eleven managed care plans have at least 100,000 members. Predictions indicate that 40% to 65% of the population will be enrolled in managed care plans in five years (Brook et al., 1996).

In its simplest form, managed care is an attempt to lower the nation's medical bill by putting an end to the American way of health care - a costly approach that has included unlimited tests; treatments on demand; multiple visits to specialists; emphasis on expensive, high-tech procedures; long hospital stays; and unrestricted choice of doctors ("How Good," 1996). Examples of MCOs include: health maintenance organizations (HMOs), individual practice associations (IPAs), preferred provider organizations (PPOs), and point-of-service (POS) plans (Miller & Luft, 1994).

Physician practice is what is managed in managed care. Therefore, managed care refers to organizational arrangements that seek to alter treatment practices so that care of acceptable quality can be provided at lower cost. This is accomplished through capitation, selective financial incentives for physicians and patients, gatekeeper arrangements or other factors constraining treatment and referral practices, and utilization review, including the use of protocols and practice standards (Mechanic & Schlesinger, 1996).

Koop (1996) asserts that the original impetus for managed care actually came from physicians who wanted the freedom to treat their patients without being worried about the ability of patients to pay for each visit, test, or procedure. In the early MCOs, cost containment was an unexpected benefit, not the primary purpose. Since then, in many cases, managed care has lived up to those ideals by paying far more attention to preventive care, by standardizing medical practices to produce better outcomes, and by eliminating many unnecessary tests and procedures. However, many rapidly proliferating MCOs seem to be interested firstly in managing costs and only secondarily in maintaining health. When profit, not health, is the objective, it may pose a threat to the health care system.

The transition to managed care has involved the entire health care system. Patients, providers, and health care organizations have experienced both positive and negative aspects of managed care. Patients, in particular, are having to negotiate a system that, due to its rapid evolution, they have had little time to understand and little time in which to be a part of crucial decision making. The patients with the most intimate relationship with the health care system, who are being challenged by its current approach to medical care, are those with chronic conditions.

Contrary to belief, MCOs do attract significant numbers of people with chronic conditions (Fox & Fama, 1996). Recent analyses suggest that among the employed insured population, MCOs have the same proportion of persons with chronic conditions as the fee-for-service system, however, they have not fully capitalized on the opportunity to improve care for this population (Sandy & Gibson, 1996).

The goals of managed care and the high cost of chronic care make it crucial that these organizations examine ways to provide improved care for this population. For example, the cost of diabetes and comorbidities can range as high as 15% of total health plan costs. Because the enrollment of people with chronic conditions is likely to increase, and chronic care is such a high price item, MCOs will need to evaluate the quality of care they are providing (Sandy & Gibson, 1996).

The impact of managed care upon patients has been tremendous. Through the influence of managed care, the U.S. health care system is requiring patients to take greater responsibility for their own health, including both prevention and wellness and self-management of existing conditions. A part of this responsibility involves patients becoming personal advocates for their own care. Due to the nature of chronic illness, a condition that already requires a great deal of self-management on behalf of the patient and family, the expectations put upon patients with chronic conditions will be greatest.

Care for people with chronic conditions requires a chronic care perspective. In a competitive market, plans that are effective and efficient in delivering care for people with chronic conditions will prevail (Fox & Fama, 1996; Sandy & Gibson, 1996; Wagner et al., 1996). Most importantly, millions of people living with chronic conditions will be able to rely on a health care system that provides quality care, carefully designed to meet their unique needs and enable them to successfully meet the challenges of self-management.

Chronic Disease

Chronic diseases are the major causes of death, disability, and medical expenditures in the U.S. (Centers for Disease Control [CDC], 1997). Almost 100 million people have one or more chronic conditions, and over 40 million people are limited in their daily activities by chronic conditions (Institute for Health and Aging [IHA], 1996). It is projected that in the year 2020, 134 million people will have chronic conditions (IHA).

Chronic conditions are long term conditions that encompass diseases; injuries with long sequelae; and prolonged structural, sensory, and communication abnormalities (Sandy & Gibson, 1996). Chronic condition is a general term that includes chronic illnesses and impairments. Conditions such as AIDS, arthritis, diabetes, and heart disease are considered chronic illnesses with the presence of long term symptoms. Conditions such as cerebral palsy, head injuries, and spinal cord injuries are considered impairments, either caused by a developmental disability or an injury (IHA, 1996). Having more than one chronic condition, referred to as comorbidity, is also common. In fact, 44% of persons with chronic conditions have more than one chronic condition to manage (Hoffman, Rice, & Sung, 1996).

Not only do chronic conditions manifest themselves in both physical and mental impairments, but they also emerge both at birth and throughout the life span. Although the elderly have a higher percentage of persons with chronic illness - 88% with at least one chronic condition - chronic conditions are prevalent in all age groups (Hoffman et al., 1996). In 1987, 25% of children (aged 17 and younger), 35% of young adults (18 to 44), and 68% of middle-aged adults (45 to 64) had at least one chronic condition (Gage, 1996).

In spite of broad public awareness among all age groups of specific life threatening diseases such as cancer and heart disease, chronic conditions account for three out of every four deaths in the U.S. collectively (IHA, 1996). We are also seeing increases in morbidity rates for heart disease, asthma, diabetes, arthritis, and other chronic diseases (Rothenberg & Koplan, 1990). Today, people over the age of 65 carry an average burden of approximately two chronic conditions (Lorig, 1993). In fact, chronic disease accounts for 90% of all morbidity and 80% of all mortality (Scott & Robertson, 1996).

The prevalence of chronic conditions in the late 20th century is due to several factors, notably the changing nature of illness and increasing longevity. Earlier in this century, it was uncertain whether an encounter with the health care system increased or decreased the odds of survival. The problems of the early 20th century were primarily acute diseases such as infections or communicable diseases that usually resulted in death

(Lorig, 1996). With the exception of AIDS, tuberculosis, and pneumonia, Americans today rarely die from infectious diseases (IHA, 1996).

Today, modern medicine creates spectacular successes on a daily basis. One of the byproducts of this capability, however, is the transformation of many acute diseases and situations into chronic illnesses. Advanced medical knowledge - screening, treatments, surgical interventions, and pharmaceuticals - has prolonged the lives of many people with disabling chronic conditions, and increased the number of survivors of traumatic injury (IHA, 1996).

In addition to the changing nature of illness, improvements in diet, sanitation, and medical care have resulted in increased life expectancies for Americans. Since 1960, the life expectancy of a woman at age 65 has increased 17.7% (Cassel, Rudberg, & Olshansky, 1992). The total population is aging, and the fastest growth rate is in the over-85 population, which is the population most vulnerable to chronic conditions (Sandy & Gibson, 1996). Since 1960, the elderly population has grown from 16.6 million to 32.8 million (Hoffman et al., 1996).

In addition, the baby boomer generation, now entering its fifties, will soon swell the over-65 population to record levels, with a corresponding increase in the prevalence of chronic conditions (IHA, 1996). The risk of disability increases with age. Among seniors 65 to 74 years of age, 6% are disabled (Scott & Robertson, 1996). Among those 75 to 84 years of age, 13% are disabled (Scott & Robertson). And, among those 85 years of age and older, 40% are disabled (Scott & Robertson). Older Americans, those most vulnerable to chronic conditions, are a population that is living longer and growing faster than ever before.

Due to the ever increasing prevalence of people with chronic conditions and the nature of chronic care, the economic cost of chronic care is staggering. Chronic care costs make up the largest share of health care dollars spent in the U.S. Seventy percent of the $612 billion spent on direct medical costs for personal health care in 1990, an estimated $425 billion, can be attributed to persons with chronic conditions (IHA, 1996). Another estimate credits a near 80% of all medical expenses to the cost of chronic care (Fox & Fama, 1996).

In 1987, annual health care costs for persons with chronic conditions averaged $3,074 compared with $817 for persons with only acute conditions. Persons with more than one chronic condition spent $4,672 per year compared with $1,829 for persons with only one chronic condition (Hoffman et al., 1996). Over half of all emergency room visits and over 70% of visits to health professionals other than physicians are made by people with chronic conditions (Hoffman et al.). This population also accounts for nearly 7 in every 10 hospital admissions, 80% of hospital days, and 96% of all home care visits (Hoffman et al.).

As mentioned previously, morbidity and mortality rates are exceptionally high for people with chronic conditions. The resulting economic costs are remarkable. Morbidity costs in 1990 as a result of work-loss days due to chronic conditions amounted to 4.5 million years of productivity loss at a cost of $73 billion (Hoffman et al., 1996). Deaths due to chronic conditions in 1990 totaled more than three quarters of all deaths in the

U.S., with the loss to the economy amounting to $161 billion (Hoffman et al.). Adding indirect costs, in terms of lost productivity, brings the cost of chronic conditions to $659 billion (IHA, 1996).

The high cost of chronic illness is a result of the complexities of living with a chronic condition and caring for those with chronic conditions. A chronic disease affects the individual, family, the health care system, and the community at a level far beyond what one is accustomed to with an acute disease. For those with chronic conditions, striving for optimal health is an enormous challenge. For those caring for people with chronic conditions, it is a frontier with much to be explored.

In order for the health care system to effectively care for the patient with a chronic condition, providers and health care plans must understand the paradigm in which chronic care exists. Chronic care requires a different perspective than acute care, the model under which our health care system has been operating for over one hundred years.

Lorig (1996) outlines several differences between acute and chronic conditions that affect the lifestyle of the individual and the type of care required. The onset and duration in an acute disease are abrupt and limited, whereas with a chronic disease the onset is gradual and the duration is lengthy and indefinite. The cause of an acute disease is usually singular and concrete, with the diagnosis and prognosis being commonly accurate. A chronic disease exhibits multivariate causations that often change over time, with the diagnosis often uncertain and the prognosis obscure.

In addition to the uncertainty surrounding the diagnosis and prognosis of chronic conditions, there is the commonly indecisive nature of treatments and their outcomes

(Lorig, 1996). For example, technological interventions such as laboratory testing, medications, and surgery are usually effective for acute diseases. For chronic conditions, however, such interventions are usually indecisive. In the case of an acute disease, the outcomes of various treatments are most often a cure, along with a return to normal health. In the case of a chronic disease, there is no cure.

Chronic Disease Self-Management

The nature of a chronic illness requires patients to take on a certain level of responsibility for managing their condition. People with chronic conditions are attempting to meet the challenges of self-managing their conditions, aside from the additional expectations the health care system has put upon them.

There is accumulating evidence of the effectiveness of self-management in having a major positive impact on health status, both physical and psychological (Clark et al., 1991). Self-management has been described as the daily tasks a person must undertake to control or reduce the impact of disease on physical health status, and to cope with psychosocial problems either generated or exacerbated by the disease. It has been discussed in terms of self-regulation, the process by which an individual attempts to control personal, behavioral, and environmental factors, outlined by Bandura (1986) as determinants of human behavior, in order to reach a goal. Individuals who are more self-regulating regarding their health will, theoretically, gain more control over the manageable aspects of their disease (Clark et al.).

Corbin and Strauss (1988) suggest three types of work involved in living with a chronic disease: (a) the work necessitated by the disease, such as taking medications, visiting health professionals, and exercising; (b) the work of maintaining everyday life, such as employment, chores, family responsibilities, social contacts, and hobbies; and (c) the emotional work required by an individual to deal with feelings of frustration, anger, and depression often resulting from an altered view of the future.

Similarly, Clark and colleagues (1991) define successful self-management as the mastering of three related areas. First, patients must be knowledgeable about their conditions and its treatment in order to make informed decisions about their care. Second, patients must perform certain activities for the management of their condition, such as healthy eating or exercising. Third, patients must apply skills necessary for maintaining adequate psychosocial functioning. Lorig (1993) summarizes these tasks by defining self-management as the learning and practicing of skills necessary to carry on an active and emotionally satisfying life in the face of a chronic condition.

As the prevalence of chronic illness has escalated, and the issues of health resource constraint have grown, the identification of efficient and effective ways to involve patients and families in decision making and self-management has become necessary (Giloth, 1990; Ruzicki, 1990). For example, as hospital stays have shortened drastically, health care providers have had to depend upon their patients to self-manage by providing their own care at home (Ruzicki). It has become clear that health care providers cannot care for their patients alone, and that patients themselves have a major role to play.

Although the medical model has helped patients with a large proportion of the work necessitated by the disease, a key area of self-management, other areas are lacking in attention, making this model of care often insufficient. Public health models, focusing primarily on primary and secondary prevention, and medical models, focusing primarily on the acute aspect of care, rarely address the important issue of helping patients overcome the emotional aspects of their condition and maintain positive life roles (Lorig, 1996).

It is recognized that current methods of training health professionals and the culture and structure of the usual medical practice often contribute to deficiencies in the care of patients with chronic conditions (Wagner et al., 1996). Our health care system, now becoming primarily one of managed care, is geared to react to acute illness and urgent care. These deficiencies in the delivery of routine care for people with chronic conditions result in overall reduced quality of care due to delays in the detection of complications or declines in health status, inadequately managed psychosocial distress, and poor self-management by the patient (Wagner et al.). Chronic care models must address all of the challenges patients face in trying to self-manage.

Health care for individuals with chronic conditions may be evaluated in a variety of ways. Quantitative studies measuring various interventions and predictors of health have dominated the literature on chronic disease, self-management, and health outcomes. Predictors of optimal health are a complicated web of interrelated factors such as patient satisfaction, patient control, compliance, personal health beliefs, and self-efficacy. The doctor-patient relationship has been studied extensively for its key role in influencing many of those factors (Anderson & Zimmerman, 1993). In addition, predictors such as compliance, beliefs, and self-efficacy have been studied autonomously for their impact on self-management and overall health, demonstrating how their effect may be completely independent of any interaction with a health care provider (Hays et al., 1994).

In this era of health care reform, and in light of the growing prevalence of chronic conditions, their unique traits, and their tremendous impact on individuals and society, it is essential that our health care system adopt a chronic care perspective. Wagner and colleagues (1996) believe that high-quality medical care for chronic illnesses must achieve three objectives. First, it must deliver interventions (evaluations and treatment, medical and psychosocial) that have been shown by rigorous evidence to be effective. Next, it must provide information, support, and resources to assist patients in self-management tasks. Third, and finally, it must empower patients to take responsibility for the management of their condition.

Promoting Chronic Disease Self-Management - Models of Care

There are philosophies of care and a variety of health care models that have been proposed, developed, and examined with the ultimate goal of establishing standards that will improve the quality of care for people with chronic conditions. Several of these models and philosophies are discussed below, as they support the movement in health care towards requiring and enabling patients with chronic disease to become successful self-managers.

Self-Management Model

Lorig (1996) describes a self-management model of care that assists patients in gaining skills and most importantly, in gaining the confidence to apply these skills on a day-to-day basis. This model also supports patients with changing roles and changing emotions. The three most distinguishing features of the self-management model are (a) dealing with the consequences of the chronic condition, not the physiological disease; (b) being concerned with problem solving, decision making, and patient confidence, rather than prescription and adherence; and (c) placing patients and health professionals in partnership relationships, with the key to full partnership being continual patient-health professional communication.

An example of how this model has been applied within health education is the patient education self-management program. Self-management programs allow participants to make informed choices, adopt new perspectives and generic skills that can be applied to new problems as they arise, practice new health behaviors, and maintain or regain emotional stability (Lorig, 1993). Criteria for these programs include: content focused on patients' perceived needs, practice and feedback of new skills, attention to emotional and role management, use of techniques to increase patients' self-efficacy, and emphasis on patients' active roles in the doctor-patient relationship (Lorig, 1996).

The theoretical basis for the success of these programs is the enhanced self-efficacy of the participants. Self-efficacy is defined as one's belief that he or she can accomplish a specific behavior or cognitive state (Bandura, 1986). In the case of a chronic illness, it may be referred to as having a sense of control over the condition.

The ASMP is a 12 hour course for people with arthritis designed to improve self-management skills and thus improve health status and decrease health care utilization. This program has proven to enhance self-efficacy and illustrate a correlation between changes in self-efficacy and changes in health status (Lenker, Lorig, & Gallagher, 1984). Self-efficacy enhancing strategies of skills mastery, modeling, reinterpretation of symptoms, and persuasion are incorporated into the program. In a four year longitudinal study of the effects of the ASMP, self-efficacy, pain levels, and physician visits were significantly improved (Lorig, Mazonson, & Holman, 1993).

In experimental studies, manipulations of self-efficacy have proven consistently powerful in initiating and maintaining change, supporting Bandura's assertion that efficacy expectations reflect a person's perceived, rather than actual, capabilities, and that it is these perceptions, not one's true abilities, that often influence behavior (Strecher, DeVellis, Becker, & Rosenstock, 1986). Indeed, the commonalties identified in self-managing chronic conditions suggest that becoming a better self-manager is linked less to learning facts about a particular condition (Clark et al., 1991) and taking on certain behaviors (Lorig, 1993), and more to learning how to set goals, organize resources, implement problem-solving strategies, and believe in one's ability to carry out certain actions.

Chronic Care Delivery Systems

Suber (1996) describes an ideal system for managing chronic care that incorporates aspects of the self-management model. It is a virtually integrated system for medical and social treatment, responsive to patients' needs and preferences. Care should be patient-focused, recognizing the patient as the primary care manager. Suber lists the following imperatives for chronic care management, which are an expansion of the requirements set forth by the National Chronic Care Consortium in the 1995 *Issue Brief: The Elements of Integrated Care Management.* To achieve integrated chronic care management, the health care delivery system must (a) integrate health and social services across many provider settings, (b) implement methods for identifying those who are at high risk of disability progression and high-cost care, (c) use treatment protocols or extended care pathways to monitor care and improve outcomes, (d) use interdisciplinary care teams to meet complex care needs, (e) emphasize prevention to avoid or delay disability and decline, (f) provide person-centered care for shared decision making, and (g) integrate acute and long-term care through aligned financial incentives.

Person-centered, or patient-centered, care is a key imperative for promoting self-management of chronic conditions. Patient-centered care means helping people living with a chronic condition make informed choices to maximize their quality of life (Coles, 1995). The role of the professional is to facilitate, to ensure that patients take responsibility for the self-management of their condition (Coles). A patient-centered approach is especially important in chronic disease in that so much of the management of the condition is dependent on (a) the patient's understanding of the self-care instructions and the consequences of not adhering to medical recommendations, (b) the patient's willingness to participate in shared decision-making regarding his or her care, and (c) the patient's confidence in his or her ability to self-manage (Suber, 1996).

The core component of patient-centered care is recognition of the patient as an equal partner in decision making. This requires providing the patient with access to all information regarding his or her condition, with the needed education and support on how to use the information. Examples of this type of care include: participation of the patient and family members in treatment planning, self-help support groups, and health education classes designed to reinforce self-care and self-sufficiency (Suber, 1996).

Sandy and Gibson (1996) describe a similar system for optimal chronic care delivery. Several examples of the discrepancies within the acute care model are also given. Care is usually very fragmented with patients seeing multiple specialty physicians, and no one physician is responsible for overseeing the patient's entire care requirements. Types of care that enhance patient self-management, such as patient education and active participation in care, are limited. Better service delivery systems for chronic care focus on integration of services and patient-centered care.

Effective models of care for populations of people with chronic conditions, according to Sandy and Gibson (1996), include the following features: (a) integration of primary and specialty care, (b) integration of medical care with home- and community-based services, (c) integration of patient and family perspectives into the care process, (d) emphasis on functional status and quality of life, and (e) delivering care in multidisciplinary care teams. Reflecting upon the various proposed models of chronic care, it is apparent that building self-efficacy, providing patient-centered care, and focusing on integrated care delivery systems are key requirements for quality chronic care, including care that supports individual self-management.

Fox and Fama (1996) outline several differences between acute and chronic conditions that provide yet another look at the complexities of chronic care and self-management. These highlight aspects of the previously discussed models of care. The underlying objective in acute care is to cure, whereas in chronic care it is the relief of symptoms and the ability to adapt to illness. The elements of care may be purely physical in acute care, whereas they almost always include a psychological component in chronic care. The medical professionals are often the caregivers in acute care. In chronic care, the patient is responsible for daily management, therefore, patients and family members are partners with health professionals. Finally, the need for patient empowerment is determined to be moderate in acute care, whereas in chronic care it is absolutely essential.

Empowering Patient Education

Patient empowerment is the guiding philosophy of the Michigan Diabetes Research and Training Center Education Committee (Funnell et al., 1991). This committee has adopted a philosophy of empowerment to guide the development of their diabetes education programs. This philosophy is based upon the following ideas: (a) successful diabetes self-management requires that patients be able to make informed choices and decisions that will help achieve their goals; (b) knowledge and experience are required, as is the ability to take responsibility for one's own care; and (c) people have an inherent drive towards health and growth, and patients have the right to have the power to control their own health behavior. Therefore, the purpose of education should be to provide a combination of knowledge, skills, and enhanced self-awareness regarding values, needs, and goals so that patients can use this power to act in their own self-interest.

Empowering patients has the ability to affect more than specific health behaviors. It has the potential to expand resources in other personal and social areas and promote overall health (Wallerstein & Bernstein, 1988). Funnell and colleagues (1991) define empowerment as the "discovery and development of one's inherent capacity to be responsible for one's own life" (Funnell et al., p. 37). They define patient empowerment as an outcome, more than a strategy to help people make behavior changes to comply with recommended treatment plans. Patients are empowered "when they have the knowledge, skills, attitudes, and self-awareness necessary to influence their own behavior and that of others in order to improve the quality of their lives" (Funnell et al., p. 38).

Funnell and colleagues (1991) compare traditional and empowering educational models, emphasizing that empowering patient education differs significantly from traditional views in that it empowers patients to deal with their diabetes in a biopsychosocial context versus persuading them to comply with treatment regimens in order to improve their physical status. If empowerment is the desired outcome, then patient education programs become "a process designed to improve the quality of life of patients by enabling them to take charge of their health through recognition and promotion of individual strengths, informed choices, and personal goals" (Funnell et al., p. 38).

Patient Empowerment

The concept of empowerment has been explored, defined, practiced, and evaluated by diverse individuals, at various levels of practice, in a variety of contexts. Recently, empowerment has become a buzzword in the fields of health education and social welfare policy in the U.S. (Merzel, 1991). The term has been operationalized on multiple levels of analysis, such as the individual, organizational, and community levels discussed by Israel, Checkoway, Schulz, and Zimmerman (1994). It has been discussed as a process (Wallerstein, 1992), a relationship (Labonte, 1994), and a sense of self (Zarillo, 1991). It has been expressed at the level of feelings, at the level of ideas about self-worth, at the level of being able to make a difference in the world around us, and even at the level of something spiritual (Rappaport, 1985).

Despite the popularity of the term, there are weaknesses in empowerment as a concept. It has been referred to as a term that is overused, difficult to grasp, and lacking in clarity. Guttmacher and Leeds (1991) describe such weaknesses as "the unresolvable lack of clarity in its definition, problems with the power component of empowerment as an overriding concept, a failure to acknowledge and attempt to have an impact on real power, and the context-dependent nature of the concept" (Guttmacher & Leeds, p. 7). Israel and colleagues (1994) point out that despite the breadth of literature on the topic, there are still competing definitions and a lack of clarity on its relationship to health, its measurement, and its application and conceptualization in practice.

The meanings of empowerment are vast and diverse, with a wide variety of definitions and assumptions surrounding the term. Depending upon one's culture, personal experiences, and current life situation, the interpretations of empowerment may vary drastically from person to person and place to place. Tina Zarillo, Director of Women's Survival Space, a shelter for battered women in New York City, defines empowerment as a "strong, positive sense of self" believing that "you can't be empowered until you know who you are, and accept yourself, and love yourself, and connect with the ability to nurture yourself" (Immerman, 1991, p.15).

It is important to remember that "you can't empower someone else" (Immerman, 1991, p. 16), argues Allison Jucha, one of the educators of the Women's Health Education Project (WHEP). WHEP facilitates self-empowerment of women by helping them to obtain the knowledge they need, enabling them to more effectively utilize the health care system, and to transcend the system wherever possible by taking responsibility for their own needs. Jucha states "you can keep offering and offering and offering the information, support, resources, alternatives, groups, organizations, phone numbers, ideas - whatever it is - that they can choose from and thereby support them in their self-empowerment" (Immerman, p. 16).

Gwen Braxton, Director of the New York Black Women's Health Project, expands on this notion (Braxton, 1991). She believes we are all born powerful and we can reclaim that power by exercising it. Most importantly, she believes that assisting others in reclaiming their power involves doing "whatever is necessary for them to make the best decisions they can make for themselves. This means that you and I have to accept that they might not make the decision that we want. They will make mistakes despite our advice and learn from their mistakes" (Braxton, p. 10).

This theme emerged from a forum, sponsored by Health/PAC, designed to discuss the meanings of empowerment in public health. Forum participants critiqued traditional health education models that emphasize compliance with predetermined standards of behavior and ignore the full context of the lives of people. Participants also agreed that empowerment is not intended to be a tool to achieve increasing compliance with professionally accepted standards. Instead, empowerment was viewed as a means of resisting the passive and dehumanizing patient and client roles engendered by the social service and health care systems (Merzel, 1991).

Funnel and colleagues (1991) support this perspective in their comments regarding empowering patient education. Some patients may prefer a more prescriptive approach. In these circumstances, patients are choosing to transfer the power back to the health professional, or in a sense, empowering the professional to make the decisions. An empowerment philosophy would respect a patient's desire to transfer power back to the professional.

Health, educational, and psychological services are frequently seen as one-way transactions, in which relatively passive patients or clients are helped by authorities and experts (Guttmacher & Leeds, 1991). However helpful the relationship between the professional and the client, there is always the risk of fostering dependence that eventually hinders the client's independence (Guttmacher & Leeds). In a sense, this dependence could be referred to as a negative side effect of a treatment, or iatrogenesis, as discussed by Rappaport (1985). Illich (1976) has extended the concept of iatrogenesis, which is most well developed in the field of clinical medicine, to include social iatrogenic effects.

He believes the negative effects of medicine are those created by a medical bureaucracy that increases stress and dependence while reducing individual choice and self care. He believes this has a negative impact on individuals by depriving them of control over their own bodies.

Rappaport (1985) supports these views by claiming that much of the way the helping professions function in our culture creates iatrogenic effects. The language of helping itself, developed in both a medical and business context, suggests that we are dependent on experts. He believes if we are to make it possible for people to have access to alternative ways of handling their problems, we need to provide people with a vocabulary and set of ideas that communicates something about their own ability to help themselves. In other words, Rappaport proposes, we need a language for helping that communicates the powerful force for change contained within ourselves, our significant others, and our communities.

McKnight (1997) in his discussion of the designs, capacities, and appropriate uses of health systems and communities, outlines four values that he believes are reflections of situations in which health professionals have had a positive impact upon the health system and thus the community. These values are stated in terms of community organizing for health, however, they can easily be applied within the more formal context of the health care system.

First, the health professionals respect the wisdom of citizens. Second, they have useful health information for citizens. They share that information in understandable forms, where they are not the source of analysis or solutions, but instead are mobilizing the power of the citizens to develop and implement solutions. Third, health professionals use their capacities, skills, contacts, and resources to strengthen the power of citizens. And finally, health professionals escape the ideology of the medical model (McKnight, 1997).

This fourth value outlined by McKnight (1997), escaping the ideology of the medical model, is one that is particularly pertinent within the context of chronic care. McKnight points out that the medical model tends to carry a negative assumption that what is important about a person is his or her injury, disease, or deficiency. The able, skilled, and capable person is not the focus of the medical model. He states in reference to community building, "Communities are built by one-legged carpenters. Medical systems are built on the missing leg" (McKnight, 1997, p. 24). In other words, community building, health promotion professionals invert the medical model, focusing on capacities rather than needs and deficiencies (McKnight & Kretzmann, 1990). Focusing on the capacities of people with chronic conditions is an approach somewhat foreign to health professionals working within health care systems, who, for the most part, are deeply entrenched in the medical model approach to patient care.

Health care systems are communities that can be described in terms of individuals and organizations. Empowerment within this system can be discussed at the individual, organizational, and community levels (Israel et al., 1994). Individual or psychological empowerment refers to an individual's ability to make decisions and have control over his or her personal life. It is similar to other constructs, such as self-efficacy, and combines personal efficacy and competence, a sense of mastery and control, and a process of participation to influence decisions. Psychosocial literature supports the variable of control as an important health-enhancer (Wallerstein, 1992). In the context of people with chronic conditions, an individual who is challenged by the complex aspects of self-management might experience a sense of control over his or her condition, and thus better health, if empowered.

Organizational empowerment, on the other hand, is discussed in terms of the organization empowering individuals as part of the organizational process (Israel et al., 1994). Zimmerman (1985) suggests that organizations can be empowering because they can provide environments for individuals to feel in control of their own lives, or in the case of people with chronic conditions, their own health. In the case of the medical care system, organizations such as MCOs, hospitals, and ambulatory medical centers, have a unique ability to provide empowering environments.

An empowered community is one in which both individuals and organizations collectively apply their skills and resources to meet each other's needs (Israel et al., 1994). Quality of life in the community is enhanced through support, conflict resolution, and increased influence and control. A prominent and growing community within the health care system is the community of people with chronic conditions. These individuals are attempting to self-manage their conditions by seeking out medical care, education, and support from medical establishments or organizations. In turn, many of these organizations, or systems, are attempting to provide the knowledge and skills necessary for their patients to become better self-managers.

As welcome as these developments may be, crucial questions regarding the purpose and outcomes of patient empowerment within health care remain. Patients may in fact be gaining knowledge and skills, but are they empowered? If patients are in fact empowered to manage their health, is it for the benefit of the patient or for the health care organization? Braxton (1991) touches upon the latter by stating that if an organization wants to empower its clients to fulfill certain objectives, for example in this case, complying with prescribed self-management tasks, that is not true empowerment. The organization benefits by meeting its objectives, however, individuals may or may not feel in control of their health.

Various authors have clearly stated the need for empowering patient care for people with chronic conditions. Chronic conditions are compelling examples of the limitations we experience in addressing social problems and giving care. Like many social disorders, such conditions are slow in onset and completely affect our lives, our selves, our ability to function, our family, our work, our recreation, and our use of the health care system (Cotler, 1996). Wagner and colleagues (1996) describe one of three objectives for high-quality medical care for chronic illness as empowering patients to take responsibility for the management of their condition. Fox and Fama (1996) declare the need for patient empowerment in chronic care to be absolutely essential.

The growth of managed care raises crucial questions regarding the concept of patient empowerment. Because managed care emphasizes cost-effectiveness and measured outcomes, it may challenge the integration of such a philosophy. In the long run, is patient empowerment cost-effective? Do managed care systems allow the development of empowering systems for patients? Is the empowerment of patients just a means for shifting responsibilities to the patient to achieve cost-effectiveness? Would MCOs promote the empowerment of patients for the benefit of the organization, such as meeting outcome goals, or for the real benefit of the patient?

Prior to the challenge of exploring the previous questions presented by managed care, lies the initial challenge of exploring the concept of patient empowerment itself. Over the years, there has been limited discussion of this term within the context of the medical model. Because it has been said that patient empowerment is especially important in chronic care, it is crucial that the concept be more fully explored, both within the context of chronic care and by people with chronic conditions.

Qualitative research in the areas of clinical care and chronic illness is limited. However, the qualitative studies that have been completed have produced results of significant discovery. Thorne (1993), in her extensive research of the experiences of people with chronic illness, states that one cannot completely understand these experiences without understanding the situations these people encounter in the health care system. Thorne has utilized qualitative exploratory research to gain the perspectives of people with chronic conditions in order to truly understand their experiences of living with a chronic illness and their interactions with the health care system.

One significant qualitative study investigating patients' perspectives about their health care revealed that patients' concerns usually fall into seven dimensions of care (Delbanco, 1992). These dimensions are above and beyond the primary biomedical aspects of clinical management. They include respect for patient's values, preferences, and needs; communication and education; coordination and integration of care; physical comfort; emotional support and alleviation of fears and anxieties; involvement of family and friends; and continuity and transition. As Sobel (1995) points out, simply providing medical care that ignores the psychosocial determinants of health compromises the prospect of improving health.

When patients are given the opportunity to speak, they touch upon crucial, yet often forgotten, aspects of care. Delbanco (1992) supports research that includes the patient's perspective as he argues that outcome studies evaluating the quality of chronic care should include reports from patients on their perceptions of their care. He believes this is especially important for the chronically ill, as they may be at particular risk for poor communication with their providers. Exploring the concept of individual patient empowerment from the patient's perspective is not only an appropriate means for understanding this term in the context of the health care system, but also a necessary means for listening to patients during this period of dramatic health care reform.

Conclusion

People with chronic illnesses are negotiating a health care system in which they are being asked to take on greater responsibility for managing their condition, and their overall health. Chronic conditions already require a high degree of patient responsibility for quality of life. If our evolving health care system, one that is caring for more and more people with chronic conditions, expects these patients to fulfill such a role, it must be prepared to listen, and most importantly incorporate their needs and values into the care that it provides. Understanding the empowering and disempowering experiences of patients with chronic conditions within the health care system will allow health care providers and decision makers to gain insight into the elements of empowering care. It is these empowering elements, described simply in patients' terms, that may then be built upon.

CHAPTER 3

METHODOLOGY

The purpose of this study was to explore patients' perspectives on empowerment as it relates to their ability to self-manage their chronic condition. Specifically, this research investigated the perspectives of arthritis patients receiving health services during a period of historical change in the health care system. The primary goal of this study was to bring forward the perspectives of patients who have unique and invaluable knowledge of the challenges and successes of self-management, in their personal lives and within the health care system. The ultimate goal of this study was to stimulate health professionals and key decision makers to acknowledge, understand, and incorporate patient perspectives as policies are created and care is provided that have an impact on the lives of people with chronic conditions.

Research Objectives and Questions

This research was designed to meet the following objectives:

1. To explore patients' perspectives on patient empowerment, including sources, barriers, and empowering experiences related to their ability to self-manage their arthritis.
2. To generate data about how patients perceive the health care system to be empowering people with arthritis, and desired characteristics of environments that empower patients to self-manage their arthritis.

3. To stimulate health professionals and key decision makers, most importantly those associated with managed care, to acknowledge, understand, and incorporate the perspectives of patients as care is provided and policies are created that affect the lives of people with chronic conditions.
4. To contribute to the current discussions of the nature and organization of our health care system as it pertains to chronic care.

This research was designed to address the following questions:

1. What are arthritis patients' perspectives on patient empowerment, including sources, barriers, and empowering experiences, related to their ability to self-manage their arthritis?
2. Within the context of their health care, what are arthritis patients' experiences with empowerment or disempowerment, related to their ability to self-manage their arthritis?
3. What specific types of care do arthritis patients believe would help empower them to self-manage their arthritis?

Definitions

The following operational definitions were used in the framework of this study:

Chronic Condition	In this study, a chronic condition was identified as any one of the following self-reported types of arthritis: osteoarthritis, rheumatoid arthritis, fibromyalgia, and lupus.

Self-Management	In this study, self-management was defined by the interviewees. Self-management was discussed in terms of activities performed, personal attitudes, and coping skills.
Patient	In this study, the term patient was identified as someone with either osteoarthritis, rheumatoid arthritis, fibromyalgia, or lupus who was receiving health care services.
Health Care	In this study, health care was identified as any aspect of the health care system including relationships with providers, direct clinical services, education, materials, insurance coverage, and access.
Policymakers	In this study, policymakers were identified as local politicians and people in Congress making decisions that determine health care policy.
Empowerment	In this study, empowerment was defined by the interviewees. Definitions were expressed in terms of opinions, experiences, and feelings.
Disempowerment	In this study, disempowerment was defined by the interviewees. Definitions were expressed in terms of opinions, experiences, and feelings.

Empowering Research

Throughout this study, the researcher made a conscious effort to create an empowering environment for all participants. The researcher valued, heard, and respected participants, while allowing them to guide all aspects of the study.

Research Design

The study used qualitative methods to explore patients' perspectives on patient empowerment as it relates to their ability to self-manage their chronic conditions. The overall research design was exploratory, descriptive, and interactive. The researcher was committed to an approach that would respect individuals' input and honor the value of their experiences.

Data collection consisted of personal interviews with twenty-three people with chronic conditions. Specifically, this research investigated the perspectives of people with arthritis who had recently participated in an ASMP and who were currently receiving health care services.

Interviews were conducted in person, at a time and place indicated as most comfortable for the participant. At the time of the interview, each person received ten dollars, a selection of arthritis educational and resource materials, and a written thank you note.

The final closure to this study involved those who contributed. Each participant was invited to attend a pasta dinner provided by the researcher. All participants also received a second written thank you note after the event, regardless of their presence at the dinner. At the dinner, the researcher presented a summary of the study results and distributed copies of the final paper. Results were mailed to those people unable to attend the dinner. It was a time of giving back to those who had shared a part of themselves.

Assumptions

The assumptions underlying the topic of this research included:

1. Quality of life for people with chronic conditions is very much dependent upon how well they are able to self-manage their condition and their overall health.
2. The health care system, influenced by managed care, is asking patients to take on more responsibility for their own health, including prevention and wellness and self-management of chronic conditions.
3. People with chronic conditions benefit from health care that builds self-management skills by providing empowering environments for patients.
4. People with chronic conditions are receiving inadequate health care from a system primarily designed to manage acute conditions. Specifically, the majority of health care organizations are not providing empowering patient care for people with chronic conditions.
5. Health care organizations are designing models of care for people with chronic conditions that are not incorporating patients' perspectives.

The assumptions underlying the methods of this research included:

1. An exploratory qualitative study utilizing personal interviews would be an appropriate method to gather patients' perspectives regarding empowering patient care.
2. Participants from local ASMPs would make a particularly valuable contribution to an exploration of empowerment and self-management, due to their experiences with self-management and the health care system.
3. The researcher would be able to interview 25 participants from ASMPs who were currently receiving health care services.
4. The researcher would be able to interview 25 participants representing both sexes, various age groups, ethnicities, and cultures.
5. A mix of open-ended and shorter questions would facilitate patients' exploration of their own experiences with minimal intervention from the researcher.
6. Participants would be able to discuss empowerment, both from a personal perspective and within the context of their health care, while critically reviewing their health care.
7. Keeping in mind the nature of qualitative research, the researcher would make sure to notice and manage her own reactions to participant experiences in such a way that they would not affect the content or quality of the data.
8. The self-management capabilities of people with chronic conditions will be enhanced and thus the quality of their lives improved, if health care organizations incorporate patients' perspectives into the design of empowering patient care.

Population and Sample

Participants

Participants were recruited from ASMPs in Santa Clara and San Mateo Counties, California. This program is offered by the Arthritis Foundation and the Stanford Arthritis Center. The decision to interview people with arthritis who had participated in an ASMP was made for several reasons.

The arthritis population was selected for this study for several reasons. First, arthritis is easily identifiable as a common type of chronic condition. Secondly, it has a significant and growing presence as a condition to be managed within our health care system. And finally, the researcher's familiarity and experience with this population (the researcher has cared for arthritis patients for seven years as a Physical Therapist, and has worked with this population during her graduate studies) was considered an asset in recruitment, data collection, and data analysis.

The decision to select participants from local ASMPs was based upon accessibility, the researcher's experience with this specific population, and most importantly, the researcher's sense that this population could make a particularly valuable contribution to an exploration of empowerment and self-management. The ASMP participants are generally a group of people that have begun to explore opportunities for improving the quality of their lives. They have often had a multitude of experiences with the health care system and self-management of their condition. They are open and willing to share their experiences, and have definite opinions about these experiences. They tend to communicate passionately, yet objectively, about their feelings, perceptions, and successes and failures with self-management and the health care system. They are a community of people with great potential to be heard and to be a part of a greater level of change.

Sampling

Participants were recruited from ASMPs in Santa Clara County and San Mateo County, California. The sampling goal was 25. Both the Arthritis Foundation and the Stanford Patient Education Research Center gave prior approval for the researcher to recruit participants from these programs. Approval from the San Jose State University Human Subjects-Institutional Review Board was obtained before recruiting subjects and collecting data.

Leaders facilitating currently running ASMPs were contacted by telephone. A list of current programs with leader names was provided by the Stanford Patient Education Research Center. Leaders were informed of the research and asked if they would be willing to allocate 5-10 minutes of their program time for study recruitment. The specific date and time for recruitment was determined by the leader. All program leaders contacted were interested in providing time for study recruitment.

The researcher presented the study over a three month period at five different programs. Purpose and significance of the study, parameters, role of the participants, role of the researcher, and processes for interviews, data analysis, and dissemination of the results were discussed. The researcher emphasized confidentiality, the right to withdraw from the study at any time, and the final process for sharing results with participants. It was also made clear that the decision to participate would not affect their relationship with the ASMP.

After presenting the study, a sign-up list was distributed to collect names of interested persons. The researcher's name and telephone number was left with all those interested. The researcher informed interested persons she would be contacting them by phone to explain the study in further detail and answer any of their questions.

A purposive sample, selected according to age, type of arthritis, sex, and ethnicity was initially intended. Twenty-six people expressed interest in being interviewed. Because this number was near the sampling goal, the researcher decided to interview all 26, regardless of demographics. Individuals were contacted by telephone to review the study in more detail, confirm interest, and arrange a date, time, and location for the interview. To be included in the sample, persons had to have a diagnosis of at least one of the following common types of arthritis: osteoarthritis, rheumatoid arthritis, fibromyalgia, or lupus. Diagnoses were self-reported.

At the time of the interview, informed consent was emphasized to all participants. The researcher explained that participation was completely voluntary and that one may refuse to participate in the study or any part of the study at any time. The researcher explained the purpose of the study again and reviewed the informed consent form (see Appendix A), previously signed by the researcher. Participants were asked to sign the form and keep it for their records.

Data Collection Methods and Instruments

Instrument Development

The intake questionnaire and interview guideline were developed by the researcher using a variety of resources and input. The intake questionnaire (see Appendix B) was used to demographically describe the study sample; determine type of health care; and obtain information about perceived health status, satisfaction with health care, and perceived self-efficacy to manage a chronic condition. The interview guideline (see Appendix C) was used to explore the primary questions of this research.

The intake questionnaire included categorical questions about age, ethnicity, gender, educational level, and type of arthritis. Type of health care coverage was determined through the use of two questions that confirmed whether or not the person was covered by managed care. Questions about perceived health status, satisfaction with health care, and perceived self-efficacy to manage a disease, were taken from various standardized outcome measures and surveys (Lorig et al., 1996). All information was self-reported.

Content and style of this questionnaire was developed and revised through the input and professional advise of several respected researchers in the field. Advisors from patient education and self-management, qualitative research, public health, geriatrics, and health service research were consulted at various points. A pilot questionnaire was pre-tested by two individuals with chronic conditions and managed care health plans who are acquaintances of the researcher.

The interview guideline consisted of a series of questions designed to meet the objectives of the research. This guideline was also developed and revised with the professional advise of the previous experts. There were several warm-up questions and several closure questions. Questions were broad and open-ended. The interview guideline was designed with the idea that each interview would continue to shape the content and style of the questions and possibly influence the omitting or adding of questions.

One pilot interview was conducted in order to finalize the format and style of the interview guideline and familiarize the researcher with the interview process. An acquaintance of the researcher, who has a chronic condition and a managed care health plan, was interviewed using the guideline. This interview was taped and transcribed. Based upon the experience of this interview and the information received, revisions were made to the guideline and certain interview procedures were refined. Input from the pilots, the researcher, and professional consultants was key in the process of finalizing both research instruments and the overall interview process.

Data Collection

Each participant was interviewed one time. Most interviews were conducted at the home of the participant, with only one taking place at the individual's place of work. The length of each interview was between 45 minutes and 2 hours. Each participant received compensation of ten dollars for participation in the study, a variety of resource materials, and a written thank you note. All interviews were audio taped and transcribed by the researcher. All audio tapes, intake questionnaires, interview notes, and consent forms were kept in a locked file cabinet in the researcher's home.

The purpose of the study, and, most importantly, the significance of the individual's input were discussed with the participant before beginning the interview. The process of how the information would eventually be communicated was presented, with time allowed for any questions to be answered. In addition, anywhere from 10 to 20 minutes was spent talking informally before the interview began. It was important to the researcher to spend time with each participant before the interview, getting to know him or her, reemphasizing the important contribution about to be made, and thanking him or her for taking the opportunity to be interviewed. This allowed both the researcher and the participant time to become comfortable and prepared.

Participants were asked to read and sign the consent form and complete the intake questionnaire at the beginning of the interview. They were given an overall description of the type of questions that would be asked and the format for the interview. They were reminded that the interview would be recorded in addition to the researcher taking notes. Specifically, participants were asked to share however little or much information with which they were comfortable. They were also asked that if at any point during the interview they were sharing something they did not want repeated, or they simply needed a break, to notify the researcher.

The interview itself consisted of the researcher leading the participants through a series of questions in the interview guideline. The guideline was not always followed in the same order, nor were the questions always phrased in the same manner. Additional probing questions may have been asked when clarification of a response was needed or when further depth, detail, or nuance was desired. The researcher remained sensitive to the needs of each person by pacing the questions and introducing the questions in a comfortable manner. Due to the exploratory nature of this research, it was the participant who actually guided the flow of the interview, the choice of questions, and the degree to which concepts were explored in depth.

At the completion of the interview questions, participants were asked if there was anything else they would like to share that was not covered in the interview, or if there were any questions to which they would like to return. Once participants were satisfied with ending the questioning, the recorder was turned off and the formal aspect of the interview considered complete. They were told if there was anything else they would like to share to feel free to contact the researcher at home.

Closing the interview often took 10 to 15 minutes. This time was spent talking informally and thanking the participant once again for sharing his or her time and contributing in such a unique and important manner. At this time, the researcher gave each person a variety of arthritis educational materials and resources, reviewing each one briefly, answering any questions, and making any recommendations for follow-up based upon issues that arose during the interview. A written thank you note was sent by mail several days after the interview to show final appreciation and comment on the value of the interview.

It was the primary intent of the researcher to make sure each participant was comfortable during the interview and felt a sense of purpose from the process. All efforts were taken before, during, and after the interview to meet the needs of the participants, encourage them to guide the process, and show appreciation for their unique contribution. It was hoped participants would recognize the significance of their input, having had the opportunity to share their experiences and wisdom in an environment where their comments were heard, respected, and valued.

Data Analysis

Data were collected and analyzed in an ongoing and reflective manner during five months of interviewing. To begin the analytical process, a nearly full transcription of the pilot interview was completed in order to identify key areas of inquiry. These areas were charted in a format designed to facilitate the transcription and data analysis process for future interviews (see Appendix D). Using this chart, information transcribed from interviews was easily sorted into the appropriate area of inquiry and finally grouped with similar data from other interviews. The use of the computer facilitated simple modification of categories or data assignment as needed during the analysis.

Data collection and analysis occurred concurrently. As each interview was transcribed, content analysis revealed core themes. This allowed the researcher to recognize areas that required further probing during future interviews in order to gain greater depth and insight. This method also allowed the identification of areas that did not need as much emphasis. It became evident to the researcher, over time, that certain questions and their responses were the heart of the data. These questions eventually became the focus of the final content analysis.

Once all interviews were transcribed into the charts, key areas of inquiry were highlighted in order to easily identify three critical categories: (a) questions pertaining to patients' personal perspectives regarding empowerment, (b) questions pertaining to patients' experiences with empowerment within the health care system, and (c) questions asking for advice patients would give to others. These categories were reviewed in order to gain general impressions about the data and notice emerging themes.

Patterns of responses to key questions were distinguished by noting significant words and phrases that were common across a majority of participants. As responses were categorized, the researcher recorded separately the common themes that arose. Identifying themes for each question involved both reading responses to key questions and reading throughout the interview transcription. Reviewing the entire transcription gave the researcher a feel for the tone of the interview, and an opportunity to include pertinent information that related to key questions, yet was maybe located in different sections of the interview.

The transformation of themes into a text that guides the reader and reveals the insights of the participants included a review of qualitative literature, critiques from experts in the field, and feedback from other graduate students conducting research. Familiarity with the techniques qualitative researchers use to report results in the literature gave structure to the text from beginning to end. Expert advice from three readers guided the process of accurate and meaningful reporting. And finally, feedback from other researchers helped to ensure that the results were reported in an easily discernable manner.

Validity and Reliability

The researcher was committed to a process that would bring forward valid and reliable findings. Validity was addressed through several measures. A constant comparative methodology was used for data collection and analysis. As a result, as the researcher gained a greater understanding of the content and the interview process, she naturally became more sensitive to the listening and probing required to facilitate personal accounts. This established a continual process of gaining greater specificity and depth of response from each succeeding interview. In addition, all interviews were designed to allow the interviewee as much security and comfort as possible so that she or he would feel comfortable in providing honest information. Each interview occurred at a place designated by the participant and took as long as she or he desired. The researcher took great effort to establish rapport with each person prior to asking difficult questions, by spending time talking informally and discussing warm-up questions. And finally, when constructing probes for gaining greater depth and specificity, the researcher made a point to balance the process with respect for each individual's privacy.

Reliability was controlled through several methods. All interviews were completed by the researcher. Interviewing took place over a concentrated five month period. All interviews were transcribed within a two week period, with the majority transcribed prior to convening the next interview. And finally, the same interview format was used for all interviews, including similar probes and follow-up questions. These measures assured reliable results.

CHAPTER 4

RESULTS

This exploratory study revealed the perspectives of patients with chronic conditions. Participants shared personal information about themselves, their experiences within the health care system, and their opinions about empowerment and empowering patient care.

Final Sample

The final sample consisted of 23 participants. Twenty-four people expressed interest in being interviewed, however, one person became ill over the course of the study and had to withdraw. Participants ranged in age from 35 to 86. More than half were over 60; the mean age was 65. All but one were female; three males had signed up to be interviewed during the initial recruitment period, however, two eventually declined. The mean years of completed education was 13, with total years ranging from 8 to 16 or more. Twenty-two of the 23 participants were Caucasian. One participant was Hispanic.

The most prevalent type of arthritis among participants was osteoarthritis. Seventeen had osteoarthritis, seven had rheumatoid arthritis, three had lupus, and one had fibromyalgia. The average number of years since arthritis was diagnosed was five, with a range of two to eight years. Eight of the participants had been living with arthritis for over ten years. When asked to rate their overall health, the average response was fair (2) on a five-point scale of poor (1) to excellent (5).

Seventeen of the 23 participants had some form of managed care as their health care coverage. Almost one third of all participants, managed care or not, had been with their current health care plan for over 10 years. When asked to rate the quality of health care with their current insurance, the average response was good (3) on a five-point scale of poor (1) to excellent (5).

Findings

Empowerment and Self-Management

Participants were asked several open-ended questions about empowerment. As can be seen in Figure 1, several core themes emerged around the following issues: empowerment and what it means to people living with a chronic condition, empowerment and self-management, and disempowerment and self-management.

Figure 1

Empowerment and Self-Management: Common Themes

Empowerment: What it Means to People with Chronic Conditions
Ability
Control
Feelings

Self-Managing a Chronic Disease: Empowering Themes
Others
Attitude
Ability
Knowledge
Faith

Self-Managing a Chronic Disease: Disempowering Themes
Others
Attitude
Inability

Empowerment

Three major themes emerged from discussions with patients about what it means for them to be empowered: (a) ability, (b) control, and (c) feelings. The most common response was "being able". When patients talked about having the ability to do things there was often a great sense of pride that accompanied their descriptions. As one woman's explanation illustrates,

> You are able to do something. You feel that you are able to do something. When you talk about empowerment…it really means removing obstacles so you can do what you feel like doing, really. Makes you feel wonderful. You can cope. You can do things You can make changes…facilitate change that will be able to help you.

Another woman described this simply and clearly as "being able to do the things I need and want to." One patient explained it as, "knowing that I have the energy and the resources to do what I need to do… able to do what I need to do." One woman who had struggled with arthritis since the birth of her first child, over 40 years ago, gave her perspective on empowerment as, "when you can do anything you want to attain." The following person related the concept directly to her health by saying, "It is the ability to pursue the health you need and read up on things that are bothering you."

A second theme that emerged from patients' perspectives on empowerment was "being in control". As seen in Table 1 below , this concept was reflected in various contexts. Patients made it clear that being in control of their lives, particular situations, and themselves were key components of feeling empowered.

Table 1

Being in Control: Quotes from People with Chronic Conditions

Participant	Being in control
Participant #1	To have control....dominion over my life.
Participant #2	To take control of your situation.
Participant #3	I'm in control!
Participant #4	To be in control.
Participant #5	To be in full charge. To be in ultimate charge!

Note. The numbered participants in this table do not correlate with numbered participants in other tables.

A majority of the participants expressed their perceptions of empowerment in terms of feelings. These patients passionately described how it feels to be empowered. As they shared their perceptions they often smiled, laughed, or even sat tall as if to portray their own personal strength and pride. As one woman described, "It is to feel respected and important and like I know what I'm doing." Another patient explained, "It feels like freedom...the confidence and power to be who I want to be." Another woman smiled as she stated her feelings: "It feels like being in a non-victim place, a healthy, emotional place." Another patient described her feelings of empowerment as, "not feeling labeled and knowing your own worth."

In addition to expressing personal ideas of what it means to be empowered, a few informants gave their opinion about how one becomes empowered. The following account gives the perception that empowerment is internally derived: "God gives it to everyone. I think everybody has it, but they have to bring it up from within themselves." Another participant described the process as one that is bestowed: "It is when somebody gives me the power, or gives me the information so I can be empowered."

Empowerment to Self-Manage

There were five common themes that emerged when talking with patients about what empowers them to self-manage: (a) others, (b) attitude, (c) ability, (d) knowledge, and (e) faith. The discussions involved both factors external to themselves and factors internal and personal. The two most prevalent themes were others and personal attitude.

The people that patients referred to when discussing the impact that others have in their lives fell into three categories: those who understand and treat them in certain ways, those who are role models, and those who give them a sense of purpose in life. Almost every person mentioned family and friends, including spouses, children, and long term friendships, when talking about how they have been treated. Words such as understanding, supportive, and accepting came forth from the stories individuals shared. Family and friends who respect them, accept them for who they are, and treat them as an equal were mentioned repeatedly as empowering people in their lives. One person said this well when she claimed, "You just want to be treated like everybody else, as an equal and respected, not fussed over."

Sharing and problem solving were discussed as activities that occurred most often between people experiencing similar situations, especially between those with chronic conditions. Classes, community activities, or support groups were empowering environments for many people. The importance of interacting with people in similar situations was made very clear. As one woman said with much enthusiasm, "Groups are very empowering!" Another person's experience illustrated the effect of groups:

> Listening to other people who have problems much worse then yours and what they did to overcome that. Listening to that kind of makes you feel not so sorry for yourself, and you think, well gee, they got along with these things. Makes you think, well you can try a little harder or do a little more of this exercise. It's very inspiring.

There were role models who influenced individuals' actions and attitudes and inspired them to do more than they thought capable. One person touched upon this as she described her parents and grandparents as role models for how she approaches each day: "They had a strong purpose in life and they were always looking forward to tomorrow." Another person mentioned the positive effect her parents and grandparents had as role models when she stated that, "they were always doing the best job they could do."

Finally, there was a strong sense of purpose in life that evolved from a variety of associations with others. One person explained, "Taking care of my grandchildren is empowering. They need me." Another who volunteers daily at a local school said, "The kids at school all give me a sense of purpose. Working at the school has helped me the most. The kids really need me. Without them I would not get up in the morning."

Attitude was most frequently discussed when individuals shared their personal means of empowerment. As seen in Figure 2, the multitude of words, thoughts, and actions that came forth illustrate the range of examples that comprise one's attitude and the importance of attitude for these particular people.

Figure 2

Empowering Attitudes: Comments from Patients

Empowering Attitudes

Discipline
Motivation
Optimism
Desire to be long living and healthy
Good feeling of self-worth
Philosophy in life
Not afraid to challenge my condition
Not being afraid
Responsibility
Decisiveness
Try not to worry
Can do it myself
Strong will
Try not to let things get me down.

One person discussed attitude in terms of her desire to be independent. She stated, "I empower myself. My desire to take care of myself and not rely on anyone else. I have to be independent. I am always trying to prove myself." Another described attitude as a philosophy of life: "I make my own reality. I'm responsible. Ten percent of life is what happens to you. Ninety percent is what you do about it." One woman described her attitude as, "knowing that I can always do more. There's always another step, another place to be. Ya just have to know what it is and work towards it." Another explained attitude in terms of personal motivation:

> It is the motivation to do what you want to do. Somebody calls you up to do something or go someplace. That motivates you. And it really empowers you, it really does. The desire to participate. You could just be sitting in your rocking chair, but if someone calls you and asks you to do something, that really helps.

In addition to attitude, simply having the ability to do things was mentioned as being very empowering for people with chronic conditions. "It is empowering to be able to do your work; the ability to use your abilities," claimed one individual. Included in this discussion was often the aspect of being pain free. As one 49 year old woman's comments illustrate, "Feeling good is empowering. To be free of pain. Wow!" She continues to work full time, fulfilling a demanding role in a large corporation, despite dealing with painful rheumatoid arthritis.

Having knowledge about their condition and the health care system was also frequently mentioned as being very empowering. Patients felt that knowing what they are dealing with, what to expect, how to handle it, and where to go for help, are crucial to having peace of mind. Several discussed this in terms of wanting to learn. One person expressed it this way: "Learning is very empowering. Asking a lot of questions. It helps you to be strong about questioning and demanding things with your health care." Another patient said, "I like to learn about things, so I can use what I've got as long as I can." Many patients simply stated that knowledge was empowering, without going into details about how one becomes knowledgeable.

And finally, faith, sometimes phrased in terms of religion or spirituality, was spoken of often. Many patients appeared to have a deep, internal faith that they could manage, that things would work out, and that life isn't too bad. Frequently, within a conversation about faith, nature, music, relaxation, and meditation were mentioned. All of these personal aspects of individual's lives were referred to as ways people gain strength to manage their health.

Disempowerment

Participants discussed what things did not help them, or disempowered them, in managing their conditions. Common sources of disempowerment were (a) others, (b) attitude, and (c) inability.

The actions and judgements of other people were the most freely discussed disempowering aspects of peoples' lives. Being criticized, being unaccepted, and being completely overprotected were a few examples. As one person's account illustrates,

> Criticism that you are overreacting. Judgments about you from other people. When people don't quite understand. They say what's wrong with you? You look alright. They'll say, why can't you help with this? You don't really want to go into it and a lot of people think you just don't want to participate. Absolutely affects a persons ability to self-manage.

Another person expressed the power that others have:

> People who want to protect you are disempowering. People who are not accepting. I cry, avoid them. I desire to be accepted, so as not to embarrass them. People are more apt to disempower me than anything else. Everything else is pretty taken care of.

Personal attitude was mentioned often as one of the most disempowering aspects of living with a chronic condition. The absence of several of the key factors previously noted as empowering, such as optimism, were noted as being disempowering. Worrying and setting limits on oneself were particularly mentioned. As one woman stated emphatically when asked about disempowerment, "It's when people put limits on you and most importantly, when you limit yourself. When you are not willing to take a chance."

Finally, inability was usually expressed in terms of decreased functioning, pain, limitations, or the feelings one has when unable to accomplish something. One person discussed a disempowering aspect of inability as the process of realizing personal limitations: "Recognizing and realizing all the things I can't do is disempowering… due to pain, discomfort, fatigue. There are a lot of things I used to do that I don't do, and have learned that I shouldn't do." Another patient expressed frustration with the environment and its lack of accessibility for people with chronic conditions: "Limitations and restrictions of devices and things in our environment that are not suitable for a person with limitations or a disability are disempowering." One woman discussed her own reaction to her limitations and its disempowering effect over time: "When I can't do something myself, I am very embarrassed. It limits me doing some things. Curtails what I would or could do."

Empowerment and Health Care

When patients were asked about empowering or disempowering aspects of their health care, a variety of experiences, opinions, and feelings were shared within the following themes: provider relationships, choice, accessibility, and knowledge (see Figure 3). Many involve elements of direct patient care, while others address broad issues that exist at the organizational level of health care.

Figure 3

Empowerment and Health Care: Common Themes

Empowering Health Care
Patient-Physician Relationship
Choice
Accessibility
Knowledge

Disempowering Health Care
Patient-Physician Relationship
Choice
Accessibility

Empowering Health Care

Four themes emerged from discussions with patients regarding their experiences with empowering health care: (a) partnering patient-physician relationships, (b) choice, (c) accessibility, and (d) knowledge. The most prevalent area of discussion centered around the relationships between patients and their physicians. Patients focused primarily on their relationships with their physicians, both primary care physicians and specialists. However, other health care providers were mentioned occasionally, such as therapists, nurses, and social workers.

Patient-Physician relationship. When patients discussed empowering aspects of their relationships with physicians they frequently mentioned either the physician's personality or attitude, communication skills, or treatment approach. Participants used the following words to describe their physicians' empowering personality characteristics: encouraging, comfortable, understanding, interested, respectful, kind, calm, supportive, hopeful, believing, caring, and patient. Empowering communication skills were consistently explained in terms of a single characteristic; the physician's ability to listen to the patient. And finally, being flexible and thorough, providing choices, and partnering with patients were empowering characteristics of a physician's treatment approach.

The following experiences and opinions reflect the many words and phrases used to express the empowering aspects of relationships with physicians. As one person's story illustrates,

> A doctor I had ... we had a nice relationship. She suggested things. Had a lot of personal interest in me. I'm not just someone who's going to come in and leave real quick. She likes to sit and talk about things, and is not prejudice or bias about you who are. That's really encouraging. It is really encouraging to have your doctor listen. It's encouraging when you have someone who is interested and wants to listen, asks questions... really wants to help you out.

Another patient, who had seen many physicians over a period of years, described one in particular that she found to be very empowering:

> There's interest in my well-being. He walks me out to the waiting area. He's very supportive and caring...and very patient. Listens, ya know. Takes time with me - 45 minutes! Never have done that before. Another doctor is knowledgeable and I trust him, but he doesn't listen ...he's fast. I'm in and out in 15 minutes. I get no personal interest from him. He prescribes things for me and he's out the door. This is very important to be empowered ... to be into me personally ... asking what are you feeling and, what do you think about it. He gives me choices. This makes a big difference in how you feel towards your illness or handicap. You feel so much more at ease, not embarrassed or guilty for taking up time. Makes me feel like I can do more. A physician with knowledge is not enough. There are times in your life when you need to let your doctor know things. Empathy and listening are important.

The following quotes are a variety of the empowering experiences shared by patients:

> My doctor doesn't spend a lot of time with you, but has a way of speaking directly to you. So even though not a lot of time, he handles it with such finesse. Wonderful communication. Makes good use of the time and has good eye contact and listening skills. Relationships with providers are the most important thing in health care.
>
> I have a good doctor. She is so thorough. She is so thorough. She's very focused. She never seems like she's in a hurry. She hears you. She follows up and listens. Makes patients feel important.
>
> My doctor's mind set. It's positive. He assumes I know what I'm doing and respects me. He will say, 'What do you want me to do and what can I do to help?' He's opening the door for me to be in control. It's the attitude. I'm not a case. I'm a human being.
>
> My doctor communicates a sense of hope. He always listens. I think it allows you to have more confidence and trust in your doctor. You know they are willing and interested in helping. Kind of decreases your fears.
>
> My doctor is very nice. Very respectful. Looks out for me. Always believes everything I say. Always sends me to someone else if needed. He's kind, gentle, and smart, and ... a good listener. He remembers me and things about me very well.

The interpersonal skills and treatment approaches of physicians who provide empowering environments for their patients are evident throughout the words of these patients.

Choice. Choice and accessibility were also referred to as empowering aspects of patient care. Choice was most commonly discussed here in terms of referrals to other providers, alternative care, and classes or community programs. If patients were given the opportunity to seek additional care or education, they felt they were not only being presented with choices, but also supported and encouraged in pursuing them. As one person stated, "I have a good doctor. He knows what to do and refers me to others if needed or if I want to see others." Another said, "My primary doctor is so willing to recommend someone else. Really gives me choices." Another patient declared, "Being able to get referrals as needed. In my doctor's office they have a full time lady...that is her full time job - just getting referrals."

Access. Access was discussed in terms of the following: good communication within the system; the ability to access various services, such as the pharmacy or classes; and good health care coverage. One patient noted, "I have the ability to leave messages and they are returned within 24 hours." A similar comment regarding phone use was, "Getting calls back from my doctor. If I have a question he will always call me back. I think that immediate feedback is just powerful."

The same patient who said she felt that relationships with providers were one of the most important means for empowering care, also claimed the importance of having good communication with the system. She stated, "Getting through the phones faster and having phone refills available with the pharmacy are great. Accessibility is very empowering." Another patient supported the need for accessible services: "Everything is in the same place. Last HMO I had, I had to go everywhere for everything. Now I have an easy pharmacy. I can call in, pick-up, have mailed, or delivered my prescriptions."

Many patients mentioned their health care coverage as being empowering in that it allows them to access health care. One person reflected upon this by saying, "It gives you piece of mind to know that you have coverage." Another patient responded when asked about empowering health care by saying, "Good coverage. I am seen when I need to be seen."

Knowledge. Finally, having knowledge, imparted through the education received within their health care, was mentioned by many as being empowering. Knowledge about their conditions allowed patients to have a greater understanding of what to do to self-manage, what to expect, and how to work with providers to get questions answered and personal needs met. The following means of education were mentioned: mailings, including newsletters and magazines; information supplied with prescriptions to explain medications; classes; literature given at appointments; lists of medications that are covered by a health plan; lists of specialists and other providers within a health plan; and one-on-one education provided by health care providers.

Disempowering Health Care

Three themes emerged from discussions with patients regarding their experiences with disempowering health care: (a) poor patient-physician relationships, (b) lack of choice, and (c) lack of accessibility. Patients who had such experiences exhibited genuine dissatisfaction with the disempowering effects upon themselves and their ability to more successfully manage their health.

Patient-Physician relationship. As with the discussion of empowering health care, the conversations about disempowerment centered around the patient-physician relationship. Again, patients focused primarily on their relationships with their physicians, both primary care physicians and specialists, however, occasionally other health care providers were mentioned.

Disempowering aspects of patients' relationships with physicians were similar to those of empowering relationships: the physician's personality or attitude, communication skills, and treatment approach. Disempowering personalities were described using the following words: unresponsive, disinterested, uncaring, unsympathetic, disrespectful, critical, intimidating, discouraging, and rude. Disempowering communication skills were consistently explained in terms of the physician's inability to listen to the patient, exactly the opposite of what patients found to be empowering. And finally, a physician's treatment approach of not being flexible, not providing and supporting choices, and not partnering with patients was discussed as disempowering, exactly opposite of the approach patients believe to be empowering.

In describing disempowering aspects of their physicians' personalities and communication skills, patients commonly expressed frustration, disappointment, and anger. One patient described her physician's personality as unresponsive: "It's hard on your self-esteem with an unresponsive doctor…with the doctor's disinterest in listening to you." Another person noted, "My doctor doesn't explain a lot to me. And he's not a great listener." Patients often feel like they are not taken seriously, as portrayed by this patient:

> Doctors - some are so uncaring, unsympathetic, disrespectful, critical. They're not always acknowledging your situation. Makes you feel like you're there cuz you just want to get out of something. They make fun of it. It's rude. It's disempowering.

A similar experience supported this view:

> I had a really bad physician before, and I couldn't change for a year. It was horrible. He always made me feel like I was a little old lady that didn't know a darn thing about what I was talking about.

Another patient mentioned feeling intimidated:

> The comments and interactions with my doctor don't appear to be empowering, based upon my impression of what empowering would be. I was usually intimidated instead - by the communication processes, decisions, tone of voice.

In addition to personality and communication skills, patients felt that the physician's treatment approach could be very disempowering. Characteristics of disempowering treatment approaches included if the physician spent little time with patients, did not support their investigation into alternative care, offered little follow-up, or treated them from what they often termed, "a very narrow perspective". As one patient's account illustrates,

> My doctor just prescribes medicine for me. Spend so little time with me. He don't listen very well. Just prescribes medicine and then the nurse brings the prescription and that's it. There is no follow-up from any last visits. I have to bring up everything.

Patients also mentioned the fact that even if their physician was knowledgeable and trustworthy, they felt their care was not empowering if the physician's treatment approach was not supportive. They believe that even knowledgeable and trustworthy providers can be very disempowering. This particular patient's description of her physician testifies to this:

> My physician was talking around me. Didn't listen. Made me feel guilty. It was always a very short examination with terrible bedside manner. She's a good diagnostician, but I really don't want my health care in her hands. Doesn't talk to me about self-managing at all.

Another person's experience with her physician illustrates a similar situation:

> I respect his knowledge, but I feel like he's in a test tube. He's very narrow, like he has blinders on. When I asked about a water arthritis class, he says, "no you don't need that." I don't understand. He walks in a room and I'm sitting up on a bench. He doesn't see me trying to move, trying to put my clothes on. He doesn't see the difficulty in my life. He always says, "so what do you want?" And the standard thing is "so what do you want to do?" And it's always only about my medication.

Lack of choice. Disempowering aspects of choice were discussed in terms of physicians sometimes not supporting patients' choices, as in the previous account, and insurance companies usually restricting choice. Patients appeared more frustrated with the restrictions placed upon them by their health insurance versus their physician, however sometimes the two were linked closely together. The following detailed account illustrates this perspective well:

> The way my physician communicates. His tone of voice. The decisions that are made and the tests that are done without explanation. It's a very intimidating process. And my insurance won't assist with any choices made outside of my doctor's recommendation. They won't cover things I know are recommended, like swimming, chiropractors, fitness, massage. I find myself getting very angry. Even to get covered for psychology, my diagnosis didn't work to continue sessions. I needed more of a diagnosis to get further visits. It would be nice to have a refresher throughout the year without having to go through a full diagnosis. You need that with chronic conditions. Again, an intimidating process. You are supposed to submit to everything they tell you to do and then if you don't you are non-compliant. Insurance companies are dictating to the doctor what kind of care will be provided. You are an outsider, just observing, and not able to participate in those decisions as a patient. But those decisions are affecting you as a patient. I am constantly reminded of the potency of the medications I take, but I don't have other choices. I have to have the doctor's agreement. He wants to see what's going on, but doesn't treat you so nice. You don't have a lot of choices.

This person's frustration with choice is purely related to her insurance company:

> I went to my same doctor once and then got a huge bill, since my doctor wasn't on the plan anymore. I didn't know. You have to play the paper game. There are a

> lot of rules, and they don't really make sense. Gets to be ridiculous. If you don't have private resources to pay for what they won't do or can't do, you're up a creek without a paddle. My doctor's hands are usually tied.

Lack of access. Just as having good access to health care was mentioned as being empowering, not having access was discussed as being very disempowering. Patients repeatedly told their stories of having to wait for appointments and fight for referrals. One person felt very strongly that being in a MCO limited her access. When she was asked about disempowerment within her health care, she gave the following response:

> My health plan - waiting for approval for procedures to happen or to see a specialist. Waiting a long time for an appointment and then spending just five minutes with you. If I want to change doctor, I will have to start all over again. A new doctor will not know me. Trying to get an appointment takes weeks. I feel like I'm second class since I am in an HMO. I think I am treated differently. They don't have enough time for me. I feel like I am treated like a second class patient. There are too many companies and too much red tape for me and for my doctor. I wish I never had to go to my doctor. The HMOs are money makers. They just don't seem to care about the patient.

Another patient expressed her frustration in regards to getting referrals:

> I feel like everything is sort of a fight. You have to have this tough edge to try to get through and get what you want. It doesn't always come easy. You're at their mercy. Ya know, will they or won't they? You can't just pick up the phone and call who you want. It affects my stress level for sure.

Empowering Patient Care

Patients were asked to share their opinions about what they believe to be empowering patient care. They were asked either what they would like to see in their health care for it to be more empowering or how they would describe patient care that is empowering. Their opinions centered around the following two issues: the patient-physician relationship and choice.

Patient-Physician Relationships

When patients discussed the empowering qualities they would like to see in the care they receive from physicians, they mentioned things such as the amount of time they have with physicians, how seriously they are taken, how well they are heard, how much education is provided, and access. One patient discussed both accessibility and time:

> I would like to be able to talk to my doctor when I like. I have to go through nurses. She determines when the message gets to the doctor. This is disempowering. Also, I would like to see more doctors with less patients. I would like to know them. They should have more time with patients. This would be less frustrating for doctors also. Maybe they wouldn't have to prescribe so many medications. So many medications are taken just because of the stress, from everything surrounding us personally.

This patient believed that education, time, and encouragement are important:

> More education. Talk and explain a little more. Spend more time with patients. It gives you more of a feeling of the doctor caring versus the money he will make. More encouragement. You would leave with more positive feelings.

Several participants specifically emphasized the amount of time they are given to spend with their physician, as one woman explained:

> I feel very sorry for doctors. They're working too hard at what they're doing. I can remember when the doctor would hardly ask you until after 20 minutes what is wrong. They would then take your blood pressure. By that time you were all calmed down. So much more comfortable. The poor guy I see now. He is so busy! It's a big difference from the past. I'm sad about it for the doctor. I think they work too hard. I can't see why everybody has to do everything so quickly. I even get interrupted. I want to say, "This is my time." It's a hard business just to get there, and when you do, you should be able to take a little time. I can see the difference in just the few years I have been with him. He used to be able to talk to me quite a bit longer than now. That I guess has happened because of the HMO.

When asked to describe empowering patient care, patients also discussed the importance of being heard and being taken seriously. Participants agreed that to feel like you have been heard is very empowering. This person expressed this as, "To feel like you have a doctor who hears what you're saying. To have a doctor that is more than just a doctor." Another expressed her opinion this way:

> I would like to talk to my doctor a little longer when I see him. I would like him to explain better and listen better. They focus on the symptoms but not what causes the problems. They are not focusing on the person at all.

This particular patient felt that the most important part of her care is to be taken seriously:

> To be taken seriously. That is the most important thing. It can eliminate sometimes months, even years, of trying to get them to pay attention to you. If I didn't keep coming back like a bad penny, I would have never gotten to this point. I would like someone who I'm comfortable with, who believes me and treats me as though I haven't lost my marbles yet.

Choice

The degree of choice that patients have, specifically, the options of care they are given and supported in pursuing, was mentioned often as something patients would like to see in their health care for it to be more empowering. Although participants did not expand on this issue with varied examples, they did make it very clear that they would like to have better coverage and support for alternative care. Patients believe strongly in the benefits of alternative care, having experienced many benefits themselves. They also feel that to be given options for managing their health is crucial to their own sense of control and confidence in managing their condition..

Advice to Physicians, Policymakers, and Patients with Chronic Conditions

Patients were asked for the advice they would give to the following groups of people: physicians, policymakers, and patients newly diagnosed with a chronic condition.

As seen in Figure 4, there were several themes that emerged from the responses to each question.

Figure 4

Advice to Physicians, Policymakers, and Patients: Common Themes

Advice to Physicians
Listen to your patients
Take your patients seriously
Offer and support choices for your patients

Advice to Policymakers
Listen to people with chronic conditions
Involve people with chronic conditions in policy decision making
Give physicians and patients more freedom to make medical decisions

Advice to Patients Newly Diagnosed with a Chronic Condition
Learn about your condition and your own health care
Find a good physician
Maintain a healthy attitude

Advice to Physicians

When patients were asked what advice they would give to physicians, three themes emerged from the data that centered around interpersonal skills and treatment approach: (a) listen to your patients; (b) take your patients seriously; and (c) offer and support choices for your patients.

Effective interpersonal skills were discussed in terms of the physician's ability to listen to the patient. Patients consistently wanted to send the message to physicians that it is crucial for them to listen to their patients. They believe that not enough physicians either take the time to listen or even have the ability to listen. One person stated very emphatically, "Be a good listener!" Another exclaimed, "Listen to your patients, everything said and everything asked!"

Advice to physicians about listening skills was often mentioned within the context of desired personality traits. As one patient said, "Be more caring. Give the feeling that you are listening to us. Have a pleasant personality. Give patients time for explaining." The following patient focused on the responsibility of the physician to provide information to patients and better prepare them: "In the beginning, provide more information about what to expect - talk more, listen more. Prepare people for what to expect." This person described good listening as being responsive: "Be responsive to your patients. The attitude of the doctor affects the attitude of the patient. It's hard to read the doctor if they're not responsive. It's demeaning and depressing if the doctor is not responsive."

The following patients reminded physicians that their medical degree does not necessarily mean they have the interpersonal skills that help empower patients. As this patient's thoughts illustrate,

> Take people seriously. Listen to your patients. I see a lot of young doctors with beautiful resumes and education, but a lot of them aren't willing to listen. Patients know when something is different with their body, I mean they've been living in it.

This person's advice supports this view:

> Make sure you are as versed in interpersonal communication skills as you can be. Know that just because you have medical knowledge and you've been to medical school does not necessarily assure you of being a good doctor. People expect communication. Unless you're able to communicate, patients aren't going to feel comfortable. Because in most cases, I don't question their level of knowledge, but I might question their level of telling me their knowledge, and that's just communication. Over time patients become disempowered. Physicians also need to be aware of who they're talking to, because different cultures have different

> ways of having knowledge given to them. They need to understand the level and how the communication goes.

Patients also believe it is extremely important for physicians to take them seriously and treat them as human beings, not just another medical case. Many of these patients felt that over the years they have not been taken seriously or respected by their physicians. They discussed the act of being taken seriously as one with the potential to create powerful results. Being taken seriously could be very empowering, could build trust, and could create hope.

Patients expressed this point from different angles. One way a physician could take a patient seriously would be to display genuine interest in the patient. As this person emphatically said, "Act interested in the person!" Another patient mentioned trust and empowerment in her statement: "Recognize us and recognize the problem. Have interest in us. This builds trust. Then it empowers you to self-manage."

The following patients' accounts illustrate the idea that patients want to be taken seriously in a manner that respects them for who they are as human beings. Patients commonly feel the dehumanizing atmosphere of health care. They have a strong desire to be seen for who they are, not just another case, but an individual with unique knowledge, experiences, and needs. The advice given by this patient reminds physicians of the complexity of caring for people with chronic conditions:

> See a patient as a patient and not one of the many cases. I would like more personal recognition from my doctor. In my outpatient care, I get very little recognition. They don't know your history, don't know your medications. They spend all this time asking you. This time could be spent with the doctor. Bottom line? I would like to see doctors spend more time with certain patients. Not all patients. Those with a broken arm or routine things don't always need it. A

> chronic condition is more deep. It is influenced by more things from the outside. For chronic conditions, people should be seen more often or longer by their doctor.

The following patient told physicians to put themselves in the place of their patients, while also recognizing the demands upon physicians: "Treat patients as human beings. Having a chronic condition does not mean an end in itself. Doesn't mean you're done for. There can always be improvement. Put yourself in our place." And finally, this person's account addresses the lives patients lead outside of the office:

> Remember that patients that come in are a person with individual complaints. Try to broaden your scope, taking in the whole person, not just the clinical study. It's not just a body sitting there. It's a person who functions in a life somewhere other than the doctor's office. They have a life beyond that. You should think, how does their problem relate to who they are and what they do the rest of their day. I think this is pretty idealistic. Take things more seriously. Even if something seems minor to you, maybe because the patient before you was so much worse, any limitation is a struggle. If they didn't learn it in medical school, which they probably didn't, there are alternatives to treatment. They all play a part, and if they all work together, things would be better.

Patients also want physicians to offer them choices and support them in pursuing choices. This was evident as patients discussed their desires to explore options of alternative care, and have their physicians assist them or at least support them in the process.

Some patients have obtained powerful results from alternative care. When asked what advice she would like to give to physicians, this person deliberately stated, "Support more alternative care!" One person with rheumatoid arthritis, who had investigated various means of therapies, including swimming and massage, felt very strongly about patients being supported to pursue alternative care. She has achieved numerous benefits from alternative care and was extremely disappointed in the lack of support she received from her physician. Her advice to physicians is, "Be more helpful with a patient exploring all forms of therapy, especially alternative therapies and ones that are different from the ones you are trained in."

Advice to Policymakers

When patients were asked what advice they would give to policymakers, or people in Congress making decisions about health care, two themes emerged from the data: (a) understand and support the needs of people with chronic conditions by listening to them, supporting their needs, and involving them in key decisions; and (b) give physicians and patients more freedom to make medical decisions.

Patients offered a variety of perspectives. The following people, who were frustrated with some of the political aspects of health care, clearly communicated their feelings. As one patient exclaimed, "Stop taking all the polls in the mail! Take time to listen to people; person to person contact. Slow down. Try to take the time to understand people." Another angrily responded, "Get real first! The bottom line is not the answer. Remember the words, health care. Getting reelected should have little to do with it. They should forget themselves and think about who they're working for." This patient declared managed care to be only out for money:

> Things are very unfair. They don't care about the people. They're out for money. We should have one law for rich and poor. They have their needs met. They don't understand. They don't know where they are headed sometimes. They should get out with the people and find out how people live. This is the trouble with a lot of HMOs. They get what is not spent on you.

Patients suggested the use of advisory boards and ombudsmen to involve people with chronic conditions. One patient with several chronic conditions, who had experienced difficult situations in the hospital trying to get her needs met, suggested the use of an ombudsman for the patient:

> Leave room for the exceptions. There should be an ombudsman for the patient. Someone to listen to your problem, be on your side, arbitrate, understand your problem. The agencies give you forms to fill out, but there is no place to tell the rest of your story. A lay person doesn't have the medical background to do this, especially as we get older. We have a different vocabulary, yet we are operating in the same world. I also see a behavior problem. Some people would never tell a doctor anything or never question. The doctor is right. The doctor is God. The patient takes all the guilt.

This patient is concerned that the people currently making health care decisions do not have a chronic condition or any medical knowledge:

> If you haven't walked in their shoes you cannot make decisions for people. The time we have in the hospital is too short. It is determined by our diagnosis. Insurance companies are determining how long we stay in the hospital. I have an ally at my hospital. You have to have an ally. He has to go through hoops to keep you in the hospital.

This patient's account illustrates the need for patients to be involved in decision making:

> The people that make the decisions of what types of benefits are available should be made by people with the chronic conditions. Maybe have them on an advisory board. We would save a lot of money by sending a patient to warm water swim therapy versus an office visit, more blood tests, or more medications that cause other damage that would then need to be counteracted. They could help the patient investigate these, particularly early on. They could be a leader rather than one retarding the process, the plan.

This person feels strongly about the need for decisions to be made by those with medical knowledge: "What happened to the way it used to be? If you needed something you just got it. Now there are so many roadblocks. Medical people should be on the board of decision makers."

Patients also had the opinion that MCOs should give physicians and patients more freedom in making medical decisions. Patients believe that physicians should have more authority and patients should have more choices. One patient gave the following advice to policymakers:

> Do not control everything. We're paying exhorbanent salaries to people who are controlling. When you get down to the bottom, what is there for actual health care? I realize we need some control, but not to the point where medical practitioners are limited by Congress as far as how they can treat their patients. I would find it very frustrating if I was a doctor or any other practitioner and had to stop to consider, is this covered, will they approve of this? I think it's kind of sad.

This patient's advice reflects the control over patients that she has experienced:

> Give as much empowerment to the members as possible to move within the groups. When you have to ask permission, it's not so much that as an adult you don't want to ask permission. To me it's more, how much time is this going to take? To know that you can step outside of your managed care plan if you or your doctor perceive that you need something a little unusual. If I were in need of an oncologist, I don't want just the next one to roll up on the rolodex. Then you feel helpless.

Previous perspectives regarding empowering patient care reflected a desire from patients to have more flexibility and choice in their health care. A majority of patients expressed the importance of being able to pursue alternative care in managing their conditions. Similarly, a common point of advice to policymakers was to support coverage for more alternative care. As this patient declared, "Everyone should have coverage for alternative care. It is often much more economically practical." Another sadly stated, "I wish there was more leeway with who I can see." And finally, a patient who has found alternative care to be very beneficial, yet has had to pay for all of it herself, gave the following advice, "Cover things like homeopathy, acupuncture, and bodywork. Things that are not invasive. Look at alternative care as a viable way of treating a patient, instead of all the pills. A lot has been proven to help."

Advice to Patients Newly Diagnosed with a Chronic Condition

When patients were asked what advice they would give to other patients newly diagnosed with a chronic condition, three themes emerged from the data: (a) learn as much as possible, as soon as possible, about your condition and your health care; (b) find a good physician; and (c) maintain a healthy attitude. By far, the most common advice that patients gave to other patients was to learn as much as possible about their own condition and their own health care.

Patients who believe it is crucial for people newly diagnosed to learn about their condition, expressed this by recommending avenues for learning. Table 2 shows the variety of responses.

Table 2

Learning About Your Condition: Advice for Patients with Chronic Conditions

Participant	Advice about learning
Participant #1	Read all you can. Don't just sit around. Do things even if it hurts. Take classes.
Participant #2	Read widely. Read a lot.
Participant #3	Go to groups, classes. It's very inspiring and empowering. No doctor could do all that. Learn a lot through books and the internet. Read.
Participant #4	Get yourself a lot of information. Read. Find out all you can. It gives you other options. Then go talk to your doctor. Then you can say, what if this, or what about that?
Participant #5	Learn as much as you can. Make lists about questions for the doctor. Take classes.
Participant #6	Get as much information as you can, as fast as you can.
Participant #7	Learn as much as you can. Ask questions.
Participant #8	Learn as much as you can. Classes and groups really help.
Participant #9	Get all the information you can. See how it fits with your life. I wish I had learned more about my condition earlier.

Note. The numbered participants in this table do not correlate with numbered participants in other tables.

Patients mentioned attending classes to learn and receive the support of others. As one person stated,

> Read as much as you can. Classes are very good. The information and group participation is a spring board to following through with things. I'm encouraged. If I want to do something good for myself, it's out there and I know how to begin. It is skill building.

Another patient gave the following advice about classes:

> It is important to have a broad idea of different peoples' conditions so you recognize there is quite an expanse of different situations. From a psychological thing, it makes you realize you're not as bad as you think you are when you look at some of the other people. You might be able to tell some people what you have done that has helped you and what might help them. Go to classes so you have some idea of what is ahead. Get involved with others. Learn from others' experiences. Some of the things they can do to help themselves will help you.

This patient offered a variety of resources for learning:

> Find out what kind of arthritis you have and as much information as you can. Use sources such as the arthritis society, magazines, the Internet, the public library, bookstores, pamphlets. Don't just stop at reading materials. There are videos and tapes. Start with your doctor and go from there. Find out resources within your community.

In addition to learning, patients believe it is crucial for people newly diagnosed with a chronic condition to find a good physician. Table 3 shows the variety of suggestions shared.

Table 3

Finding a Good Doctor: Advice for Patients with Chronic Conditions

Participant	Advice for finding a good doctor
Participant #1	Find good doctor.
Participant #2	Find a good doctor who listens.
Participant #3	Find someone who treats you like a human being.
Participant #4	Find a doctor you are comfortable talking to and one not threatened by your questions. Have good rapport.
Participant #6	Who your doctor is is key. It should be someone you can work with versus being led or just given a prescription.
Participant #7	Try to take control. Finding the right doctor is the most important.

Note. The numbered participants in this table do not correlate with numbered participants in other tables.

Finally, patients felt that having a healthy attitude is vital to one's ability to cope with a chronic condition in order to self-manage and have a better quality of life. Table 4 shows the variety of recommendations that these patients had for people just beginning to deal with their condition and the impact it has upon their lives.

Table 4

Having a Good Attitude: Advice for Patients with Chronic Conditions

Participant	Advice about attitude
Participant #1	Accept what you have. Have patience. It is an important step towards feeling better about yourself and feeling better physically.
Participant #2	It is not the end of the world. There are a lot of people just like them. There are worse things that could happen.
Participant #3	Do what you read or think is right.
Participant #4	Don't be afraid to ask questions.
Participant #5	Have a positive outlook. Have courage and willpower. Don't give up. Do the best you can with what you have.
Participant #6	Do not be afraid. Try to use your imagination to work things out so you can do them. Be stubborn. Accept help when you need it.
Participant #7	Get out and among people. Do not isolate yourself. Have hope.
Participant #8	Often we can be our best healers. Your attitude plays such a role. Positive attitudes are so important.
Participant #9	Don't give up. There may be no cure, but you can get some help.
Participant #10	Know your limits. Test your limits. Focus on what you can do as opposed to what you cannot do. Find a spiritual practice.

Note. The numbered participants in this table do not correlate with numbered participants in other tables.

Throughout the entire interview, patients were able to share their personal experiences and opinions in a manner that bring to light real individual situations of patients, while at the same time, bring forth their collective political voice. Overall, the advice these patients gave reflected not only their strong desire to be heard, respected, and involved, but also, their belief in learning and taking responsibility for their own health.

CHAPTER 5

DISCUSSION

This exploratory study revealed the individual and unique perspectives of people with chronic conditions. Participants shared personal information about themselves, their experiences within the health care system, and their opinions about empowerment and empowering patient care. They also gave their own expert recommendations about empowerment and health care to three significant groups of people: physicians, policymakers, and patients newly diagnosed with a chronic condition.

The results of this research give an inside view of what it means to people with chronic conditions to feel empowered. Participants' words reveal the empowering or disempowering aspects of the challenges they face as they manage their health. Their stories illuminate the empowering and disempowering aspects of their health care and the broader systems within which that care occurs. The opinions expressed, the experiences shared, and the advice presented create a picture that suggests the issues most important to patients in our health care system today.

Summary of Findings

When study participants were asked to discuss the concept of empowerment, the most common responses related to the idea of being able to do the things one wants to do in life. Being in control, having knowledge, and being pain free were also mentioned within the context of this discussion. The most prevalent theme, however, that all conversation eventually led to was that of having the ability to do things, or function in life. Participants said that if they are able to physically do what they want to do, need to do, or have to do to self-manage, they feel empowered. How one becomes empowered, they said, comes from within a person, although there was unanimous agreement that a person's environment may facilitate or retard the process.

When participants were asked to discuss the empowering or disempowering aspects of their lives that affect their ability to manage their health, they primarily talked about the empowering or disempowering effect of their own attitude. It was apparent from the multitude of opinions and experiences shared that these patients believe that having the right attitude can have an impact on a person's ability to self-manage a chronic condition. An empowering attitude was discussed in terms of one's desires, philosophy in life, outlook on life, and degree of self-worth.

Participants believe that one's attitude plays the primary role in either empowering or disempowering a person, however, they also feel strongly about the impact of other people. Spouses, parents, children, grandchildren, friends, grandparents, classes, community activities, volunteer work, and support groups were among the variety of examples brought forth to explain how others can have empowering effects on someone with a chronic health condition. The acceptance and understanding, the inspiration and motivation, and the support and encouragement people receive from such individuals and groups helps empower them to do the things necessary to manage their health and their lives. The sense of purpose that many of these individuals create for other people is also extremely empowering. On the other hand, the lack of acceptance and support, and the presence of criticism and judgments from others, can significantly affect some individuals' attitudes, and thus in the end, affect their ability to self-manage.

In addition to exploring the personal side of empowerment, patients were asked to discuss the relationships between their health care, empowerment, and their ability to manage their chronic condition. The most empowering or disempowering aspect of health care that patients believe plays a significant role in their process of self-management is the relationships they have with their physicians. The degree of choice and accessibility one has within their health plan was also emphasized. However, the patient-physician relationship was consistently the first issue raised and the one most deeply discussed.

Participants' descriptions of empowering patient-physician relationships can be organized into three categories: a) the physician's personality or attitude, b) the physician's communication skills, and c) the physician's treatment approach. Empowering personalities were referred to as encouraging, understanding, interested, respectful, kind, calm, supportive, hopeful, believing, caring, and patient. Empowering communication skills were explained in terms of the physician's ability to listen to the patient; a consistent theme throughout this research. Empowering qualities of a physician's treatment approach were expressed in terms of being flexible with patients, providing choices, and partnering with patients.

Similarly, participants' descriptions of disempowering patient-physician relationships can be organized into the same three categories: a) the physician's personality or attitude, b) the physician's communication skills, and c) the physician's treatment approach. Disempowering personalities of physicians were described as unresponsive, disinterested, uncaring, unsympathetic, disrespectful, critical, intimidating, and discouraging. Disempowering communication skills were consistently discussed in terms of the physician's inability to listen to the patient, exactly the opposite of what patients found to be empowering. And finally, disempowering qualities of a physician's treatment approach were expressed in terms of not being flexible, not providing and supporting choices, and not partnering with patients.

When patients were asked how they would describe empowering patient care, again their comments centered around their relationships with physicians. While having choices was also emphasized, the patient-physician relationship was the most significant aspect of this discussion. There were two issues discussed regarding empowering patient care that were not raised in the discussion of empowering patient-physician relationships: the amount of time a physician spends with the patient and whether the physician takes the patient seriously.

When patients were asked to give their advice to physicians about empowering patient care, three themes emerged from the data that coincide with previous discussions: a) develop effective interpersonal skills, most importantly, listen to your patients; b) take your patients seriously; and c) provide and support choices for your patients. It was apparent during this discussion and previous questions that patients want physicians to have positive attitudes, listen to them, take them seriously, and finally, partner with them by offering them choices.

Patients were also asked to give their advice to policymakers. They expressed hope that policymakers would understand and support the needs of people with chronic conditions by listening to them and most importantly, involving them in key decisions regarding the future of health care. They also believe that physicians and patients should be given more freedom to make medical decisions.

It is apparent that people with chronic conditions want to be heard, supported, and included in decision making by family and friends, physicians, and policymakers. It is also evident they would like to have choices in their lives and particularly in their health care, choices supported by the people providing their care and created by the people designing the systems in which their care is experienced.

Limitations

Three key limitations emerged during the design and activities of this research: the composition of the final sample, the absence of the evaluation of individual health care providers and plans, and the difficulty of exploring the concept of empowerment. These limitations are important to note when applying the findings beyond this specific study.

This study used a purposive sampling strategy to recruit individuals who had arthritis and held a basic level of knowledge about the principles of self-management. This selection process created a sampling bias towards people more familiar with the concepts being explored. It may also have limited the sample to empowered patients, or individuals who were successfully managing their chronic conditions.

These conclusions were anticipated, due to the researcher's choice to interview people who had been involved in ASMPs. As previously mentioned, the decision to interview these individuals was based upon the researcher's opinion that they were people who had enough familiarity with self-management and experience with the health care system to openly discuss empowerment within the context of their health care. It was the understanding and conclusion of the researcher that the degree of information that would be gained from such participants outweighed the degree of specificity that biased the results. The perspectives of those without these resources or experiences would add important dimensions to these results.

Another limitation of this study is in the demographics of the final participants. The final sample consisted primarily of highly educated, financially stable, Caucasian women. Their opinions and experiences may differ significantly from the responses one might receive from male participants, those with less education or financial resources, people of different ethnic backgrounds, or a combination of any of these. The final make-up of this sample was anticipated due to the often higher prevalence of females in ASMPs. In addition, by design, the sample was drawn from individuals living in the San Francisco Bay Area, which may also limit generalizeability of the findings. Outreach might have enhanced the diversity and generalizeability of the sample.

Individual health care providers and plans were not evaluated in this study, leaving the reader unable to draw conclusions about specific types of health care organizations or systems. This too was planned and anticipated. At the time of this study, managed care was in a state of great flux in the San Francisco Bay Area. The specifics of providers and plans were often difficult to decipher and individuals had often changed their source of health care several times over a course of several years. The difficulty in determining exactly what type of organization or plan an individual received care from, and then linking it to the comments of a particular individual, were beyond the scope of this study. More importantly, the objectives and overall purpose of this research did not require such methods. Rather, the ultimate goal was to identify common opinions and experiences of those involved, with an eye to the relevance of the data in the current transitions to managed care. However, it would be interesting to know which health care organizations are able to provide particularly empowering patient care.

Finally, as expressed by numerous experienced researchers, empowerment is a complex and difficult concept to explore (Funnell et.al. 1991; Israel, Checkoway, Schulz, & Zimmerman, 1994; Labonte, 1994; Wallerstein, 1992). Despite this reality, prior to collecting data, the researcher made the assumption that participants would be able to discuss freely and critically their perspectives regarding empowerment. Remarkably, participants were indeed aware of this concept and had the ability to share their opinions about what it means to them. They also had the ability to relate their experiences, both within their personal lives and their health care, to the meanings they had assigned to empowerment.

In spite of participants' ability to freely discuss empowerment, the complexity of this concept may have limited the depth of their responses. As mentioned, participants were able to discuss empowerment to a certain degree, however, their capacity to expand on their thoughts and critically evaluate the relationships between self-management, personal empowerment, and their health care was somewhat limited. The researcher understood and dealt with this issue by providing the necessary probes to facilitate depth from the participants, while at the same time, allowing participants to determine the level and context of the conversation. Despite some participants' inability to explore empowerment at a deeper level, the themes that emerged from the combination of responses from all participants were significant and powerful.

Discussion

Despite the complexity of researching the concept of empowerment, the participants in this study were able to define empowerment in their own words, and discuss what factors, both in their personal lives and their health care, empower or disempower them in managing their health. They truly enjoyed being faced with such a complex and personal question, as it gave each of them the opportunity to explore their own thoughts and feel the worth of their own contribution to research.

Feste and Anderson (1995) define empowerment as an educational process designed to help patients develop the knowledge, skills, attitudes, and degree of self-awareness necessary to effectively assume responsibility for their health-related decisions. The empowerment philosophy is based on the assumption that to be healthy, people need to have the psychosocial skills to bring about changes in their personal behavior, their social situations, and the institutions that influence their lives (Anderson et al., 1995). This philosophy claims that empowerment-based programs of psychosocial education that focus on helping patients develop their goal-setting, problem-solving, coping, and other psychosocial skills build self-efficacy and improve self-management behaviors. The work of Anderson and colleagues indicates a patient empowerment program to be an effective approach to building self-efficacy, improving attitude, and developing self-management skills in patients with diabetes.

The patients in this study have confirmed the importance and effectiveness of patient education programs in their own process of becoming successful self-managers. They have praised the empowering aspects of groups and classes, and the importance of learning. However, they have brought to our attention an additional avenue of empowerment: the patient-physician relationship. These patients have discussed the role their physicians play in empowering them to manage their health. They believe that the personality of the physician, his or her communication skills, and his or her treatment approach create either an empowering or disempowering environment, one that eventually either facilitates or complicates the course of managing one's chronic condition.

The communication skill of active listening was mentioned repeatedly as an empowering quality of any interaction between patient and physician. This was the one quality that emerged in response to several different questions, was always mentioned first, was always discussed in the most detail, and was emphasized as the most important. It is apparent that patients simply want to be heard. There is a level of understanding and respect that is portrayed by any person who truly hears another. People with chronic conditions are dealing with complex issues in their lives. They need to know that someone, in this case their physician, is listening and honoring their situation.

Benet (1996) supports these findings in her article titled, *A Portrait of Chronic Illness*, where she reminds the medical community that having facts about an illness does not guarantee behavioral changes in those who seek their services. She states,

> Cognitive knowledge does not create behavioral change. Patients need comfort and understanding as well as instruction and information. Caring must never be counterfeit. Sincere understanding gives us strength and courage in this struggle with the hardships of chronic illness and chronic pain. (Benet, p. 773-774)

Benet (1996) also mentions the importance of having respect for a patient's individual experiences. She talks about the fact that it is one thing to know about chronic disease and another to actually experience it. She believes that physicians themselves feel the need to learn how to understand and communicate with patients. Therefore, she states that in order to bring physicians to a deeper level of understanding their patients, medical training must incorporate communication and active listening skills into the curriculum.

Although listening shows respect, it is not enough, claims Benet (1996). The skill of active listening is what is needed in patient care. Once mastered, patient and physician are free to work together in creating the best treatment package. When the patient has the ability to take action in his or her own best interest, the locus of control becomes internal. Then pain decreases and patients have the strength and will to manage (Benet). The active listening skills Benet is referring to are the same active listening skills discussed by the patients in this study.

The work of Kaplan, Greenfield, and Ware (1989) also supports various findings in this study. They completed a quantitative study that assessed the effects of physician-patient interactions on the outcomes of chronic disease. This research consisted of four clinical trials conducted in various practice settings among chronically ill patients with differing sociodemographic characteristics. The findings demonstrated that better health, measured physiologically, behaviorally, or subjectively was consistently related to specific aspects of physician-patient communication. For example, more patient control and more information provided by physicians during an office visit were associated with better health.

It was interesting to the researcher that the patients in this study primarily focused on the relationship between themselves and their physician, versus discussing the role of other providers in their health care, such as nurses, therapists, or social workers. It is possible that this particular group of patients had few relationships with other providers, and therefore only emphasized the relationship with their physician. Maybe in reality, other health care providers who possess empowering communication skills could assist physicians and actually enhance patient care in the ways discussed by this study's participants. However, the participants' emphasis on the physician's communication skills suggest that even though a patient has positive relationships with other providers the patient-physician relationship may still be the most powerful, and therefore, is most central to patient care in the eyes of patients.

It is a coincidence and quite interesting that during this time of health care reform, in which the spotlight is directly on the patient-physician relationship, these patients have brought to our attention the value they place upon this relationship. They have shared the empowering and disempowering experiences they have had with physicians. They have expressed their desire to be heard, understood, and respected by physicians. Finally, they have asked physicians to listen to them and support them in pursuing personal choices.

Rarely during this research did any participants complain about the quality of their overall health care, either managed care or private. Nor was there a notable difference between the comments of people with managed care plans and those with private health care. Instead, regardless of health care coverage, patients seemed to have a general understanding and certain degree of acceptance of the inadequacies that are inherent in any large system. What patients focused on, regardless of health care coverage, were the interpersonal aspects of their care, primarily the physician's communication skills and treatment approach. They emphasized, in a variety of ways, the role physicians may play in empowering patients to manage their health.

In addition to the discussion that centered around the interpersonal role of physicians was the consistent message sent regarding the importance of both physicians and policymakers providing choices for patients. People with chronic conditions in particular are experiencing positive benefits from various forms of alternative care. Participants remarked that physicians who offered and supported them in pursuing alternative care were empowering. They described empowering patient care as care that offers choices, especially avenues for receiving alternative care. Finally, they asked that both physicians and policymakers support them in pursuing alternative care. This data mirrors larger policy discussions taking place within health care reform about choice and coverage.

It is important to note that this study sample was primarily female. Perhaps women tend to desire the personalities, communication skills, and treatment approaches emphasized, whereas men might have quite different opinions. The responses of the one male participant in this research did not differ greatly from the responses of the women, and in fact, even supported the trends that were developing. However, if more men had been interviewed, there is always the possibility that different themes would have emerged from the data.

Finally, throughout this study it has been the intent of the researcher to provide an empowering environment for all participants. The primary goal of each interview was to create a positive and rewarding experience. At the end of every conversation, participants always expressed their utmost appreciation for being interviewed. They were proud, confident, and pleased because they had been able to contribute in such a significant manner. Many participants made a point of expressing their delight that someone had taken the time to listen, hear them, and show them respect. Many admitted that they had not expected the interview to be so gratifying. The researcher even received personal notes and gifts from some participants describing how much they had enjoyed the experience. Above and beyond obtaining meaningful data, was the mission of performing empowering research.

Significance

This study is significant for several reasons. First, it represents perspectives of a key group of patients. The population of people with chronic conditions continues to grow, and our health care system continues to undergo reform. If we are going to create a system that empowers the people it serves, the need for patient input is crucial. The information presented in this study specifically represents the perspectives, opinions, and experiences of a particular group of people living with a chronic disease. Their comments bring to our attention the issues that are most significant to them, and most likely, to the millions of others living with a chronic condition.

Second, these participants' interpretations, experiences, and opinions regarding empowerment not only add to our understanding of the concept of empowerment, but also reveal its relevance to patients, and even more so, to patients with chronic conditions. Empowerment is a complex term, one that has always been difficult to research. Major contributions have been made by research within the broad areas of health education, health promotion, social justice, and advocacy. Understanding the meaning of this concept, through the words of patients, only brings us closer to identifying the factors that facilitate the empowerment of the people we are trying to help.

Third, and most important, these results remind us of the powerful nature of the relationships between patients and health care providers, specifically physicians. Patients do not expect to be empowered by the people who care for them. However, individuals can be positively influenced by an empowering environment or an empowering relationship. As told by this research, relationships with health care providers, physicians in particular, can be very empowering, or disempowering, for patients.

People with chronic conditions are intimately and inextricably involved with the health care system. They depend, not always by choice, upon health care providers for a variety of reasons. For those of us either practicing in health care or designing health care systems, it is easy and almost second nature to focus on designing the most appropriate clinical pathways of care, prescribing the most effective medications, or creating the most up-to-date patient education materials and programs to help our patients manage their health. The patients in this study have confirmed that classes, educational materials, and pain medications are important. However, they have also shown the value they place on one simple aspect of their care: the relationships they have with their physicians.

Finally, these patients have brought to our attention several key issues relevant to the decisions being made within health care reform. These issues concern individual choice, relationships with physicians, and access to alternative care. These three key issues are particularly relevant to people living with chronic conditions, and were discussed by study participants within the context of empowering patient care. Participants' insight into these issues offers valuable guidance to service providers and decision makers. As the future of our health care system continues to take shape and, at the same time, serve more and more people with chronic conditions, the integration of patient input remains crucial to designing the most appropriate and effective empowering chronic care.

Recommendations

In view of the results of this study, this researcher has the following recommendations for health education and health care practice, future research, and health care policy:

Implications for Practice

1. **Incorporate the perspectives of people with chronic conditions into the design of chronic care.** Participants in this study, all patients with chronic conditions, had keen insight, strong opinions, and practical suggestions for the changing organization

of health care services. Providers, educators, and key decision makers would do well to heed the experiences of their clients as models of care, patient education materials, and patient education programs are designed.

2. **Provide trainings for all health care providers, particularly physicians, who care for people with chronic conditions to continually resensitize them to the issues of empowering patient care.** This training could begin with medical and allied health education, continuing on through all stages of professional development. Education and training should emphasize the importance of effective communication skills, specifically active listening, and an approach that supports individual patient choice.

3. **Preserve and enhance the relationships between patients and physicians when designing new models of chronic care.** American health care is in a period of historic transition. Therefore, it is crucial to recognize the power of the patient-physician relationship in providing an empowering environment for patients, particularly when the health care system is undergoing changes that may place this relationship at risk.

4. **Consider the role that other health care providers could play in contributing to empowering patient care**. Other providers may be able to play a more prominent role in meeting the various needs of people with chronic conditions. Nurses, health educators, physical and other therapists, mental health counselors, and nutritionists might also provide opportunities for open communication and respectful partnering that patients in this study find so important.

Implications for Future Research

1. Continue to explore the concept of empowerment with people with chronic conditions. Narrow the scope of the research to focus on gaining more depth from patients' experiences with empowerment. Experiment with questions or methods that draw out more specific examples. Further develop the concepts of empowerment and disempowerment and the ways that each are operationalized in the lives of people with chronic conditions.

2. Explore the perspectives of a population of people with chronic conditions other than arthritis or with a more diverse demography. Although most people with chronic conditions face similar issues, people with diabetes, heart disease, or multiple sclerosis, for example, may have different needs of their health care system. Likewise, people of different socioeconomic status, ethnicity, culture, or age may have different needs.

3. Utilize quantitative methods to evaluate a larger, more diverse sample. The participants in this study suggest numerous areas that could be explored through quantitative analysis, such as communication skills and patient choice. The results of a quantitative study with a larger sample might then be generalizeable to the broader population of people with chronic conditions.

4. Conduct further research on the relationships between both patients and physicians, and patients and other health care providers. Further research could distill the essential elements of the relationships patients in this study found so empowering. Further research could then investigate the possibility of other health care providers playing a more prominent role in future models of empowering patient care.

5. Conduct research with physicians. Qualitative methods could be used to identify the barriers physicians perceive in their relationships with patients, and their own goals for communication and patient empowerment.

Implications for Policy

1. Actively incorporate the perspectives of patients into larger political decisions regarding health care reform. Involve people with chronic conditions in advisory roles when developing health policy. This can be done at the program, organizational, or legislative levels.

2. Put the patient-physician relationship in a prominent place on the health reform agenda. Participants in this study clearly identified communication with their physicians as a key factor in their ability to self-manage their chronic conditions. Remember the importance of this relationship as health plans and organizations are reformed.

3. Incorporate the components of patient-centered care in health system design. This perspective recognizes the patient as a partner in decision making and emphasizes the importance of relationships with a variety of supportive health care providers. Many of the components of patient-centered care are the very aspects of care patients in this study find empowering.

4. Consider the importance and benefit of alternative care for people with chronic conditions when determining regulations regarding health insurance plans. Study participants mentioned alternative care, such as Eastern medicine and nutrition therapy, as important in their ability to self-manage their chronic condition. Massage, herbal therapy, acupuncture, water exercise, and health classes are all part of the alternative care support system patients currently must pursue on their own. The long term benefits of these alternative methods may significantly enhance traditional health care, while contributing to patient empowerment, by offering patients a broader set of choices with which to manage their own care.

References

Anderson, R.M., Funnell, M.M., Butler, P.M., Arnold, M.S., Fitzgerald, J.T., & Feste, C.C. (1995, July). Patient empowerment. Diabetes Care, 18, (7), 943-949.

Anderson, L.A., & Zimmerman, M.A. (1993). Patient and physician perceptions of their relationship and patient satisfaction: A study of chronic disease management. Patient Education and Counseling, 20, 27-36.

Bandura, A. (1986). Social foundations of thought and action. Englewood Cliffs, N.J.: Prentice-Hall.

Benet, A. (1996, May). A portrait of chronic illness. American Behavioral Scientist, 39, (6), 767-776.

Braxton, G. (1991). Wellbeing is our birthright. Health/PAC Bulletin, 9-11.

Brook, R.H., Kamberg, C.J., & McGlynn, E.A. (1996, August). Health system reform and quality. Journal of the American Medical Association, 276, (6), 476-480.

Cassel, C., Rudberg, M., and Olshansky, S. (1992, Summer). The price of success: Health care in an aging society. Health Affairs, 88.

Centers for Disease Control. (1994). Arthritis prevalence and activity limitations - United States, 1990. Morbidity and Mortality Weekly Report, Vol. 43, 433-438.

Centers for Disease Control. (1997, April). Resources and priorities for chronic disease prevention and control, 1994. Morbidity and Mortality Weekly Report, Vol. 46, (13), 286-287.

Clark, N.M., Becker, M.H., Janz, N.K., Lorig, K., Rakowski, W., & Anderson, L. (1991, February). Self-management of chronic disease by older adults. Journal of Aging and Health, 3, (1), 3-27.

Coles, C. (1995). Educating the health care team. Patient Education and Counseling, 26, 239-244.

Corbin, J., & Strauss, A. (1988). Unending work and care: Managing chronic illness at home. San Francisco CA: Jossey-Bass.

Cotler, M. (1996, May). Chronic illness and current perspectives: What are the problems for patients, families, and other care givers? American Behavioral Scientist, 39, (6), 647-654.

Delbanco, T.L. (1992, March). Enriching the doctor-patient relationship by inviting the patient's perspective. Annals of Internal Medicine, 116, (5), 414-418.

Feste, C., & Anderson, R.M. (1995). Empowerment: From philosophy to practice. Patient Education and Counseling, 26, (1-3), 139-144.

Fox, P.D., & Fama, T. (1996). Managed care and chronic illness: An overview. Managed Care Quarterly, 4, (2), 1-4.

Funnell, M.M., Anderson, R.M., Arnold, M.S., Barr, P.A., Donnelly, M., Johnson, P.D., Taylor-Moon, D., & White, N.H. (1991). Empowerment: An idea whose time has come in diabetes education. The Diabetes Educator, 17, (1), 37-41.

Gage, R. (1996, November 25). The toll of chronic illness. U.S. News & World Report, 24.

Giloth, B.E. (1990). Promoting patient involvement: Educational, organizational, and environmental strategies. Patient Education and Counseling, 15, 29-38.

Guttmacher, S., & Leeds, J. (1991). Empowerment, a term in need of a politics. Health/PAC Bulletin, 7-8.

Hays, R.D., Kravitz, R.L., Mazel, R.M., Sherbourne, C.D., DiMatteo, M.R., Rogers, W.H., & Greenfield, S. (1994). The impact of patient adherence on health outcomes for patients with chronic disease in the medical outcomes study. Journal of Behavioral Medicine, 17, (4), 347-357.

Hoffman, C., Rice, D., & Sung, H. (1996, November). Persons with chronic conditions- their prevalence and costs. Journal of the American Medical Association, 276, (18), 1473-1479.

How good is your health plan? (1996, August). Consumer Reports, 61, (8), 28-42.

Illich, I. (1976). Medical nemesis: The expropriation of health. New York: Pantheon Books.

Immerman, G. (1991). Knowledge is power. Health/PAC Bulletin, 12-16.

Institute for Health and Aging. (1996, August). Chronic care in America: A 21st century challenge. Eatontown, NJ: Robert Wood Johnson Foundation Publications.

Israel, B.A., Checkoway, B., Schulz, A., & Zimmerman, M. (1994). Health education and community empowerment: Conceptualizing and measuring perceptions of individual, organizational, and community control. Health Education Quarterly, 21, (2), 149-170.

Kaplan, S.H., Greenfield, S., & Ware, J.E. (1989). Assessing the effects of physician-patient interactions on the outcomes of chronic disease. Medical Care, 27, (3), S110-S127.

Koop, C.E. (1996, Fall). Manage with care. Time, 148, (14), 69.

Labonte, R. (1994). Health promotion and empowerment: Reflections on professional practice. Health Education Quarterly, 21, (2), 253-268.

Lenker, S.L., Lorig, K., & Gallagher, D. (1984). Reasons for the lack of association between changes in health behavior and improved health status: An explanatory study. Patient Education and Counseling, 6, (2), 69-72.

Lorig, K. (1993). Self-management of chronic illness: A model for the future. Generations, 11-14.

Lorig, K. (1996, May). Chronic disease self-management. American Behavioral Scientist, 39, (6), 676-683.

Lorig, K., Mazonson, P.D., & Holman, H.R. (1993). Evidence suggesting that health education for self-management in patients with chronic arthritis has sustained health benefits while reducing health care costs. Arthritis and Rheumatism, 36, (4), 439-446.

Lorig, K., Stewart, A., Ritter, P., Gonzalez, V., Laurent, D., & Lynch, J. (1996). Outcome measures for health education and other health care intervention. Thousand Oaks, CA: Sage Publications, Inc.

McKnight, J.L. (1997). Two tools for well-being: Health systems and communities. In M. Minkler (Ed.), Community organizing and community building for health (pp. 20-25). New Brunswick, NJ: Rutgers University Press.

McKnight, J., & Kretzmann. (1990). Mapping community capacity. Center for Urban Affairs and Policy Research Report. Evanston, IL: Northwestern University.

Mechanic, D., & Schlesinger, M. (1996, June). The impact of managed care on patients' trust in medical care and their physicians. Journal of the American Medical Association, 275, (21), 1693-1697.

Merzel, C. (1991). Rethinking empowerment. Health /PAC Bulletin, 5-6.

Miller, R.H., & Luft, H.S. (1994, May). Managed care plan performance since 1980. Journal of the American Medical Association, 271, (19), 1512-1519.

National Institute of Health. (1988). On the threshold of discovery, 1988. Annual National Arthritis Advisory Board Report. (NIH Publication No. 88-1587). U.S. Department of Health and Human Services: Public Health Service.

Rappaport, J. (1985, Fall). The power of empowerment language. Social Policy, 15-21.

Rood, R.P. (1996, May). Patient and physician responsibility in the treatment of chronic illness. American Behavioral Scientist, 39, (6), 729-751.

Rothenberg, R.B., & Koplan, J.P. (1990). Chronic disease in the 1990s. Annual Review of Public Health, 2, 267-296.

Ruzicki, D.A. (1990). Promoting patient self-management in the health care system. Patient Education and Counseling, 15, 1-2.

Sandy, L.G., & Gibson, R. (1996). Managed care and chronic care: Challenges and opportunities. Managed Care Quarterly, 4, (2), 5-11.

Scott, J.C., & Robertson, B.J. (1996). Kaiser Colorado's cooperative health care clinic: A group approach to patient care. Managed Care Quarterly, 4, (3), 41-45.

Sobel, D.S. (1995). Rethinking medicine: Improving health outcomes with cost-effective psychosocial interventions. Psychosomatic Medicine, 57, 234-244.

Strecher, V.J., DeVellis, B.M., Becker, M.H., & Rosenstock, I.M. (1986). The role of self-efficacy in achieving health behavior change. Health Education Quarterly, 13, (1), 73-91.

Suber, R. (1996, May). Chronic care in ambulatory settings. American Behavioral Scientist, 39, (6), 665-675.

Thorne, S.E. (1993). Negotiating health care: The social context of chronic illness. Newbury Park, CA: Sage Publications.

Wagner, E.H., Austin, B.T., & Korff, M.V. (1996). Improving outcomes in chronic illness. Managed Care Quarterly, 4, (2), 12-25.

Wallerstein, N. (1992, January/February). Powerlessness, empowerment, and health: Implications for health promotion programs. American Journal of Health Promotion, 6, (3), 197-205.

Wallerstein, N., & Bernstein, E. (1988, Winter). Empowerment education: Freire's ideas adapted to health education. Health Education Quarterly, 15, (4), 379-394.

World Health Organization. (1978). Alma-Ata 1978, primary health care. World Health Organization Health for All, Series 1. World Health Organization, Geneva.

Zarillo, T. (1991). Empowerment and health. Health /PAC Bulletin, 1-4.

Zimmerman, M. (1985). Empowerment, perceived control, and citizen participation: A dissertation proposal. University of Illinois, Champaign-Urbana.

Appendix A

Informed Consent

Agreement to Participate in Research

Responsible Investigator: Lisa Morgan

Title of Protocol: Patient Empowerment and Chronic Care: An Exploration of the Patient Perspective

1. I have been asked to participate in a research study investigating arthritis patients' perspectives on patient empowerment, including sources, barriers, and empowering experiences related to their ability to self-manage their arthritis.
2. I will be asked to participate in a personal one-on-one interview with the researcher during which I will be asked about my perceptions, experiences, and opinions regarding patient empowerment as it relates to the self-management of my arthritis and the health care I receive. The interview will be audio taped and transcribed into written text. This approximately 1 hour interview will occur during the fall or spring of1998 at a date, time, and location that is convenient and comfortable for me.
3. There are no anticipated risks or discomforts associated with this study.
4. There are no expected discernible benefits associated with this study.
5. The results of this study may be published but no information that could identify me will be included. I will receive results of this study prior to any public dissemination.
6. Compensation for participation in this study will include arthritis educational materials and resources, $10, and a dinner hosted by the researcher.
7. Questions about any items pertaining to this research may be addressed to Lisa Morgan at (408) 261-1728. Complaints about the research may be presented to the Health Science Department Chair, Dr. Bill Washington at (408) 924-2970. Questions or complaints about the research, participants' rights, or research related injury may be presented to Serena Stanford, Ph.D., Associate Academic President for Graduate Studies and Research at (408) 924-2480.
8. No service of any kind, to which I am otherwise entitled, will be lost or jeopardized if I choose to "not participate" in the study.
9. Consent is given voluntarily. I may refuse to participate in the study or in any part of the study. If I decide to participate in the study, I am free to withdraw at any time without prejudice to my relations with San Jose State University or any other participating institutions.
10. I have received a signed and dated copy of this consent form.

- **The signature of the person on this document indicates agreement to participate in the study.**
- **The signature of the researcher on this document indicates agreement to include the above named person in the research and attestation that the person has been fully informed of his or her rights.**

Participant's Signature ______________________________ Date ___________

Investigator's Signature ______________________________ Date ___________

Appendix B

Interview Intake Questionnaire

Name ______________________ **Date** __________

Sex F M **Age** ______ **Years of Education** ______

Marital Status _______________ **Ethnicity** _______________

1. **What is your primary arthritis diagnosis?**

   ☐ Osteoarthritis
   ☐ Rheumatoid Arthritis
   ☐ Other ___________________
   ☐ Fibromyalgia
   ☐ Lupus

2. **How long have you had this type of arthritis?**

   ☐ Less than 1 year
   ☐ 1-2 years
   ☐ 3-4 years
   ☐ 5-6 years
   ☐ 6-10 years
   ☐ 10+ years

3. **Please list any secondary types of arthritis you may have and/or other chronic conditions for which you are seeking care?**

   ____

   ____

4. **Is your health insurance a managed care plan?**

   ☐ Yes ☐ No

   If yes, what is the name of your plan?

   ____

5. **Does your health insurance limit or restrict where you receive your health care?**

   ☐ Yes ☐ No

6. **How long have you been covered with your current health insurance plan?**

   ☐ Less than 1 year
   ☐ 1-2 years
   ☐ 3-4 years
   ☐ 5-6 years
   ☐ 6-10 years
   ☐ 10+ years

7. **Overall, how would you rate health care with your current health insurance?**

1	2	3	4	5
poor	fair	good	very good	excellent

8. **Having a chronic condition often means doing different tasks and activities to manage your condition. In terms of your arthritis, how confident are you that you can...**

Please circle one number.

a) Do all the things necessary to manage your condition on a regular basis?

Not at all confident									Totally Confident
1	2	3	4	5	6	7	8	9	10

b) Judge when the changes in your condition mean you should visit a doctor?

Not at all confident									Totally Confident
1	2	3	4	5	6	7	8	9	10

c) Do the different tasks and activities needed to manage your health condition so as to reduce your need to see a doctor?

Not at all confident									Totally Confident
1	2	3	4	5	6	7	8	9	10

d) Reduce the emotional distress caused by your health condition so that it does not affect your everyday life?

Not at all confident									Totally Confident
1	2	3	4	5	6	7	8	9	10

e) Do things other than just taking medication to reduce how much your condition
affects your everyday life?

Not at all confident									Totally Confident
1	2	3	4	5	6	7	8	9	10

9. **In general, would you say your health is...**

1	2	3	4	5
poor	fair	good	very good	excellent

Appendix C

Interview Guideline

Interview Guideline **Name** ________________

- Can you tell me a little about the **history of you and your arthritis**? For example - a little about you before you were diagnosed or discovered you had arthritis and now. Like the activities or things you were able to do and they type of person you were before compared to now (physically/personally).

- Lets talk now about the **things you need or want to do**. What might some of these be for you? For example these could be **daily activities or long term goals.**

- Can you tell me a little **about how you manage your arthritis** so you are either able to do these things or work towards doing these things. In otherwords, what things do you do to manage your condition - either on a daily basis, weekly, etc...? And along with that, how would you **define a self-manager**? Using your definition of a self-manager, how would you **rate yourself as a "self-manager"? Has managing been a natural role for you, or difficult? New skills?**

- So we've talked some about what you do to manage your arthritis so that you are able to work towards some of your goals, or accomplish your daily activities. Many health care organizations are saying that in order to provide quality/effective care for people with chronic conditions one thing they must do is empower their patients to manage their conditions, or provide empowering patient care. **What does it mean to you to be empowered or for something to be empowering?** (Either using their definition or mine)...

- Now I would like to ask you more specifically **what helps, enables, motivates, allows, encourages, entices you, gives you a sense of control to "self-manage".** It could be **personal things** about yourself, **things in your environment**, various **situations/experiences** - anything.

- Along that same line, **what does not help, is discouraging, is a problem, is a barrier or a road block for you in trying to self-manage** your arthritis? It could be **personal things** about yourself, **things in your environment**, various **situations/experiences** - anything.

- Now I would like to talk to you a little about your arthritis and your healthcare. First of all, the avenues in which you receive care or the things that make up your care, whether it be medical care, education, types of support, etc... may exist as a part of your health care organization (your health plan, health insurance or the place where you receive care) or may exist within the community and be things that you seek out on your own and are not associated with your health care plan, insurance, or organization. **What things do you associate with, or do, or get from the community** (lectures, support groups, libraries, fitness programs, etc...)? **What things do you associate with the care you receive from your health insurance or your health care organization** (your provider, classes, information you receive, services that are available, resources, etc...)?

- So in reflecting upon the things associated with your health insurance/care/organization, can you tell me a little about what has **helped, enabled, motivated, allowed, encouraged, given you a sense of control to "self-manage"** (experiences, big impacts)?

- Along that same line, what with your health insurance/care/organization, **has not helped, been a problem, a barrier, or a road block for you in trying to self-manage** your arthritis?

- Would you say the care you have received, your **healthcare** organization, or your insurance **has been more helpful/empowering or a problem/disempowering?**

- **What would you like to see in your healthcare** in order for it to be more helpful or empowering for you in self-managing your arthritis (type of care, services, interactions with staff, etc...)?

- The last thing I would like to ask you is...**if you could tell the following groups of people anything you like about anything we have discussed today, what would you tell them?**

  ⇒ physicians (your doctor)

  ⇒ decision makers/policy makers (Congress, people in D.C.)

  ⇒ people newly diagnosed with a chronic condition (someone with arthritis)

  ⇒ health educators (people who educate/train you to manage your arthritis)

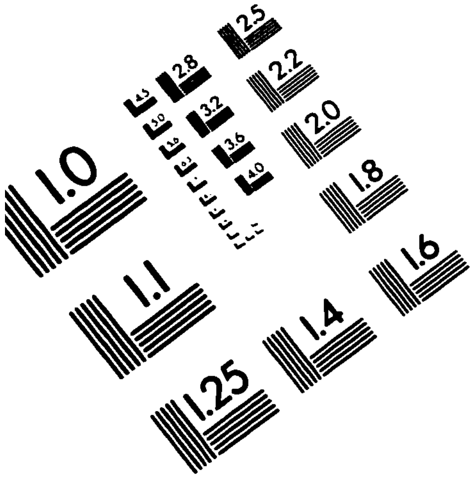
- Is there **anything else you would like to tell me about our conversation** (missed, explain further, clarify)?

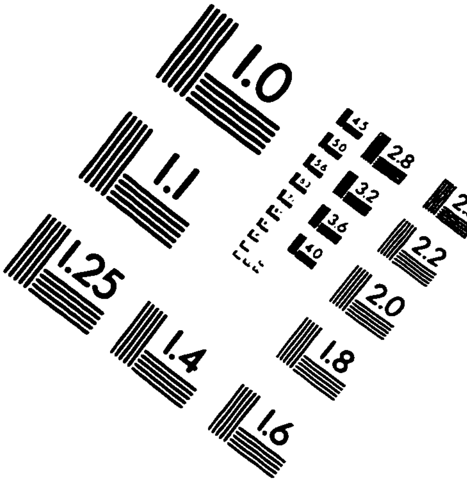
Appendix D

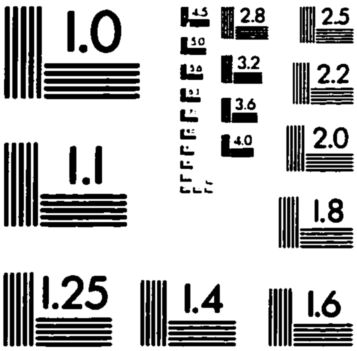
Content Analysis Chart

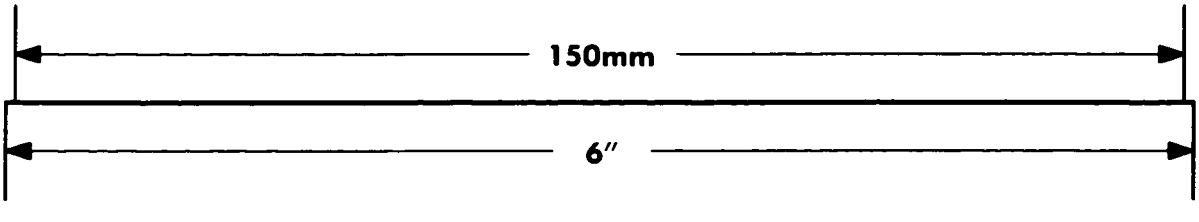
History/Self-management		**Concepts/Themes**
History of you and your arthritis/condition. - Diagnosis, Physically, Personally		
How you manage your arthritis		
Empowerment		
What does it mean to you to be empowered/for something to be empowering? Important for self-managing?		
What "helps… empowers (their definition) you to self-manage?		
What does not help… is disempowering for you to self-manage?		
Health Care		
What things do you associate with the care you receive from your health insurance or organization?		
What things have helped or empowered you to self-manage?		
What things have not helped, been disempowering for you and self-managing?		
Has your health care been more empowering or disempowering?		
What would you like to see in your health care for it to be more empowering?		
What would you tell the following groups of people?		
Physicians		
Decision/policy makers		
Newly diagnosed?		
Health educators		

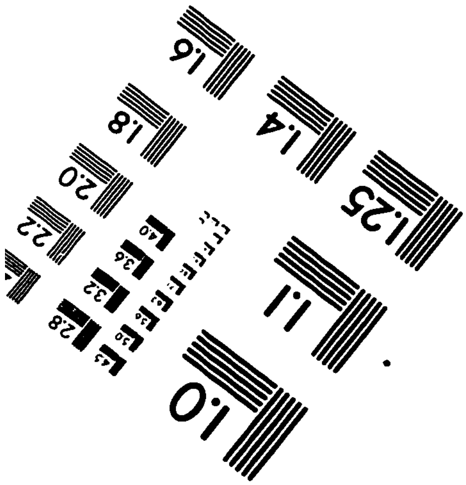
IMAGE EVALUATION TEST TARGET (QA-3)

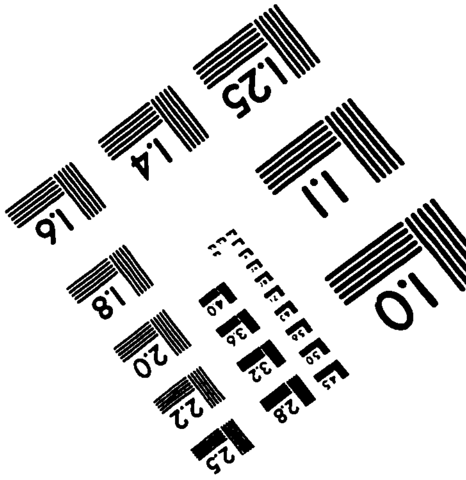












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