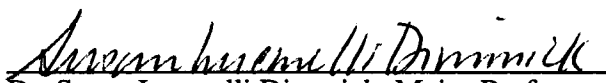


To the Graduate Council:

I am submitting herewith a thesis written by Micaela Brown entitled, "Masters of the Balancing Act: How Adults With Chronic Conditions Make Decisions About Professional Medical Advice." I have examined the final copy of this thesis for form and content and recommend that it be accepted in partial fulfillment of the requirements for the degree of Master of Science, with a major in Communications.


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Dean of the Graduate School

**Masters of the Balancing Act:
How Adults With Chronic Conditions Make
Decisions About Professional Medical Advice**

**A Thesis
Presented for the
Master of Science Degree
The University of Tennessee, Knoxville**

**Micaela Brown
December 1998**

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ABSTRACT

Nearly three-quarters of all the money spent on health care each year is directed toward the treatment and management of chronic illnesses. Half of all Americans have at least one chronic condition, and that number is growing as the chronically ill have an extended life span and as the entire population becomes increasingly older. Health care providers say that compliance with medication and preventive health care recommendations is a critical factor in managing chronic illness. Chronically ill patients, on the other hand, view compliance issues very differently. This inductive analysis of the words of the chronically ill who talked about their decision to follow or not follow health care advice indicated that the newly diagnosed are likely to follow advice. However, for individuals who have had at least some experience managing their chronic illness, findings showed that they were less likely to "follow" health care advice and to try instead to collaborate with health care professionals on an equal basis. If they met with resistance to collaboration, many chronically ill made health care decisions independently of their providers' recommendations. The chronically ill progressed through developmental stages of dealing with chronic illness and initiated processes of prioritizing, researching and evaluating, and experimenting to become experts about their illnesses. These findings have implications for health campaign planners and health care providers who wish to encourage the use of preventive health treatments such as vaccines or to change health behaviors.

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CHAPTER ONE

Introduction

Half of all Americans have at least one chronic health condition. A study in the Journal of the American Medical Association found that 90 million people live with a long-term disease or impairment, and this population accounts for nearly three-fourths of all the money spent on health care each year — about \$7 billion. The treatment of chronic conditions have substantial economic costs, too. Annual morbidity costs, the costs each year as a result of work-loss days due to illness, amounted to \$73 billion in 1991. Mortality costs of those with chronic conditions totaled \$161 billion annually (Hoffman, Rice, & Sung, 1996).

And the numbers are growing. The same study predicts that by the year 2050, there will be 167 million Americans with a chronic health condition. The increase is because of an extended life span for the entire population, including those with chronic conditions, which refers to both chronic diseases and impairments. Advances in medical technology, improved lifestyles, and better medical care have resulted in continued growth in the number of people with chronic conditions.

One of the biggest challenges for health insurance companies and health care providers is to manage the cost of long-term treatment for chronic conditions. This is difficult because the current health care system supports the resolution of acute conditions over management of long-term conditions (Hoffman et al., 1996). Insurance companies and providers must search for ways to reduce costs for the chronically ill.

One of the ways to reduce the cost to all participants in the process of health care delivery — patient, doctor, insurance company — is to encourage the use of preventive health services. Preventive health services are measures which are taken to prevent health problems or to diagnose a health problem early. This includes services such as cancer screening, health education and vaccinations.

Two of the most preventable complications that result in high morbidity and mortality for the chronically ill are influenza and pneumonia. Statistics from the Centers for Disease Control (CDC, 1997) show that more than 36,000 influenza-related deaths occur each year during flu season and thousands more become seriously ill. The same report says that during an average flu season hospitals see a quadrupling of their admissions.

A companion disease of the flu, pneumonia, is the leading cause of illness and death among the elderly and people with certain chronic illnesses. Pneumonia accounts for approximately 40,000 deaths each year (CDC, 1997). In Tennessee, for example, 34 out of 100,000 people died from pneumonia during the 1991 flu season (Robert Wood Johnson Foundation, 1995). There are approximately 500,000 reported cases of pneumonia and 7 million cases of inner ear infections each year as a result of the pneumococcal bacteria.

In response, in 1991 the CDC collaborated with more than 300 national health organizations to establish national health objectives for the year 2000. One objective of Healthy People 2000 is to have 60% of those adults who are at high-risk for influenza- and pneumonia-related illnesses vaccinated (U.S. Public Health Service, 1991).

Since 1991 national vaccination rates for those aged 65 and older have increased substantially, from 23% in 1985 to 55% in 1994. Yet vaccination rates for the chronically ill under age 65 are still very low, less than 30% (CDC, 1997). This is despite that fact that research shows that the majority of patients recommended to have the vaccines are aware of the vaccines and their availability (Nichol, Lofgren, & Gapinski, 1992; Nichol, MacDonald, & Hauge, 1996; O'Connor, Pennie, & Dales, 1996).

One possible explanation for the higher vaccination rate in those aged 65 and above is that they typically have a higher rate of compliance:

Clinicians, discouraged by what they perceive to be patient unwillingness to respond to advice about changes in behavior and health practices, may be heartened to find that they have a receptive audience in the elderly ... the elderly, as indicated by a growing number of reports, may now be regarded as the segment of the population most likely to engage in healthy behaviors. (Lavizzo-Mourey & Diserens, 1990, p. 831)

Research also shows that a health care provider's recommendation to get a flu or pneumonia vaccine — in-person or in writing — is a powerful influence on the elderly (Fiebach & Viscoli, 1991; Gianino, Corazzini, Tseng, & Richardson, 1996; Nichol et al., 1996; Nichol et al., 1992; and Pearson & Thompson, 1994).

An important question regarding the vaccination status of chronically ill adults is why the lowest vaccination rates persist in the “younger” group, those aged 18-64. Blue Cross/Blue Shield of Chattanooga recently asked for help regarding this question for their influenza and pneumonia vaccination initiative:

To meet the Healthy People 2000 goal of immunizing 60% of the high risk population, BlueCare organized an Adult Immunization Campaign. ... Our 1998 Adult Immunization Campaign needs to target our members' perceptions of the flu and pneumonia vaccine. ... How to disseminate this information (regarding vaccine benefits) to our members will be the challenge. (see Appendix A, Letter From BC/BS)

This researcher agreed to help Blue Cross Blue Shield of Tennessee (BC/BST) in its Adult Immunization Campaign by conducting research about the phenomenon of chronic illness and how it relates to a decision to follow or not follow medical advice.

Purpose

The purpose of this study is to discover and describe how participants' experiences of chronic illness relates to a decision to follow or not follow professional medical advice. Findings will be used to advise BC/BST about how to encourage more use of immunizations against flu and pneumonia among the chronically ill aged 18-64. The advice should be grounded in an understanding of what being chronically ill means in terms of a decision to follow or not follow health care advice. This puts such a decision in the context of chronic illness and will lead to a greater understanding of why chronically ill people make the health care choices that they do about flu and pneumonia vaccinations.

Definition of chronic illness

A chronic illness is defined as any illness, condition or disability that requires ongoing medical care over a period of years (Robert Wood Johnson Foundation, 1995). This includes diseases and conditions that have unknown causes and changing symptoms such as TMJ (disease of the temporomandibular joint), lupus and chronic fatigue syndrome.

It is important to note that some researchers, such as Conrad (1987), make a distinction between chronic *disease* and chronic *illness*. He says the difference is that illness is a social and psychological feeling that is a result of a disease. For example, one can be sick or ill, but not have a disease. Similarly, disease can be present in a body without the person being or feeling ill or sick. For the purposes of this study, I will interchangeably refer to chronic disease, chronic illness, and chronic condition as the same in order to avoid semantic confusion. In this study, these terms represent the presence of disease or disability that requires long-term medical care.

Possible implications: Individuals with chronic illnesses

Chronically ill adults may have several reasons for not getting flu and pneumonia vaccinations. One reason is that they may not attend to persuasive messages like the older chronically ill population does. There may be a sense of physical strength and resilience among those aged 18-64 that is lacking in the elderly. Therefore, this group might be less likely to attend to preventive health messages.

Another possible explanation for a decision to receive a vaccine is the matter of priorities. For example, if one is already seriously ill or incapacitated and he or she is also a parent, taking the time to get a flu or pneumonia shot might not be worth the time. It might be easier for the chronically ill in these situations to possibly get the flu or pneumonia because they are incapacitated already. Therefore, even if they had the flu, they would not lose any time at home with their children.

Experience with previous flu or pneumonia vaccines also might influence a decision to get another one among the chronically ill. For example, if an individual got the

flu in spite of having had a flu shot, he or she might not be willing to receive one again because the value of doing so is not apparent. The flu vaccine doesn't prevent all strains of flu, so to many chronically ill adults, it may seem pointless to receive one. It is also possible that some individuals believe the vaccine actually causes the flu. There is a need to understand why chronically ill adults receive or do not receive flu and pneumonia vaccines.

Possible implications: Health care providers

A survey of more 1,000 primary care physicians (Valente et al., 1986) found that most physicians (97%) believe they should engage in health promoting practices with patients and most (90%) say they are the person most responsible for health information dissemination in their office (Lavizzo-Mourey & Diserens, 1990). The same study found that clinicians frequently cite time constraints as a reason for not living up to their own expectations about their health promoting role.

In addition to time constraints, it is possible that health care providers do not receive enough information and training regarding the dissemination of vaccine information. If they do not have enough knowledge or support, they may be less inclined to promote the use of the vaccine.

There may be other reasons that physicians and health care providers are unable to influence patients, including chronically ill adults. One is that they might be communicating health information, such as flu and pneumonia vaccine benefits, in ways that do not resonate with the chronically ill.

Understanding how the chronically ill come to a decision to accept or not accept professional medical advice is needed. Health providers will be more successful at persuading chronically ill patients to follow medical advice if they have an understanding of what it is like to be chronically ill and how patients with chronic illnesses make health decisions.

CHAPTER TWO

Literature Review

The purpose of the following literature review is to identify research approaches and central findings related to the area of interest — how the chronically ill come to decisions about professional medical advice. This literature review casts the topic area within the larger body of research, including the quantitative and qualitative literature. Identification of main themes will be used to place the findings of this study within the ongoing dialogue in the literature. Because this is a qualitative study that seeks to discover explanations and themes emerging from the data, identification of themes or areas of concern in the literature does not imply that this is what will be found in this study.

The quantitative health behavior tradition

The overarching theory behind quantitative health behavior studies is that attitudes, beliefs and knowledge can be measured. The overall goal of these studies is behavior prediction (Ajzen & Fishbein, 1980). For example, social psychologist Marshall Becker and his colleagues developed a predictive model called the Health Belief Model that explained and predicted patients' health behaviors (1974). The primary variables in Becker's model were beliefs and cues to action. Beliefs included perceptions, such as the perceived benefit of taking an action or the perceived seriousness of a condition. Cues to action were actions or events that would "trigger" an "appropriate action" or desired behavior in the patient (p. 5). By measuring patients' beliefs and cues to action, Becker postulated that you could predict the patients' behaviors, or "likelihood of action" (p. 7).

Predicting behaviors or "likelihood of action" are often used to manipulate health behavior changes. For example, researchers often try to change patients' perceptions of the benefits of a preventive treatment, like the flu vaccine, by giving them information that contradicts patients' perceptions. In health research this is referred to as clinical intervention. Behavior change by patients, such as receipt of a flu or pneumonia vaccine, is seen as the goal of interventions and the ideal behavior of the patients.

The decision to accept professional medical advice, such as receipt of a vaccine, is most often referred to as "compliance" in the research literature. The notion of compliance has been the focus of numerous studies: A 1988 study, Medical Compliance As An Ideology, counted more than 4,000 English language research articles on the topic of medical compliance (Trostle).

This study examined the body of quantitative literature between 1988-1998 for factors associated with patient receipt of flu or pneumonia vaccines. The review was limited to quantitative research studies that used participants who were recommended to have the flu and pneumonia vaccines, namely those aged 65 and over and chronically ill adults under age 65. Research articles were collected by database searching in major health and science databases like MEDLINE, HealthSTAR, CINAHL, PAIS International, PsycINFO, SERLINE, and Social Sciences Abstracts.

Table 2.1 lists all of the quantitative studies and their central findings used in this literature review. In total, 19 studies were found.

Approaches in the literature

Most quantitative studies surveyed patients using a Likert-type scale to measure knowledge and attitudes about pneumonia, influenza and their respective vaccines and side effects. Demographic and cohort variables, such as age, sex, marital status, race, and health status, also were analyzed.

Patient survey data were collected usually from mailed questionnaires or from a convenience sample. A common setting or source of participants was outpatient clinics. Other settings for gathering data were managed care centers, public teaching hospitals, primary care centers, HMOs, and doctors' offices.

A few quantitative studies examined the health care provider's role in vaccination of high-risk patients. These studies evaluated health care providers' knowledge and beliefs regarding the influenza and pneumonia vaccines and how this relates to their recommending and administering the vaccine. For instance, McKinney and Barnas (1989) questioned whether physician's attitudes, knowledge, or perceived side

Table 2.1 Studies Used In the Quantitative Literature Review

YEAR	TITLE/SOURCE	CENTRAL FINDINGS
1988	Influenza Vaccination: A Comparison of Two Outreach Strategies. Gerace, T., & Sangster, J. <u>Family Medicine</u> , 20(1), 43-45.	no significant difference between telephone or mailed reminders to get flu vaccine
1988	Vaccination of High-Risk Patients for Influenza: A Comparison of Telephone and Mail Reminder Methods. Brimberry, R. <u>Journal of Family Practice</u> , 26(4), 397-400.	telephone reminder group had significantly better vaccination rate than mailed reminders, but both increased rate overall
1989	Influenza Immunization in the Elderly: Knowledge and Attitudes Do Not Explain Physician Behavior. McKinney, P., & Bamas, G. <u>American Journal of Public Health</u> , 79(10), 1422-1424.	physician's perceived incidence of severe side effects or estimates of vaccine efficacy were not associated with physician offering vaccine
1991	Improving Influenza Vaccination Rates for High-Risk Inpatients. Nichol, K. <u>The American Journal of Medicine</u> , 91, 584-588.	76% of elderly participants discharged from a VA were vaccinated - rates did not vary significantly within high risk subgroups.
1991	Estimation of Outpatient Risk Characteristics and Influenza Vaccination Status: Validation of A Self-Administered Questionnaire. Nichol, K., Korn, J., & Baum, P. <u>American Journal of Preventive Medicine</u> , 7(4), 199-203.	positive correlation between receipt of vaccine and patient satisfaction
1991	Patient Acceptance of Influenza Vaccination. Fiebach, N., & Viscoli, C. <u>The American Journal of Medicine</u> , 91, 393-400.	- No significant correlation between patient receipt of vaccine and demographic variables or medical diagnoses - significant correlation between patients' receipt of vaccine and perceptions that the medical provider wanted them to have one

Table 2.1 Studies Used In the Quantitative Literature Review (continued)

1992	Do Knowledge and Attitudes about Influenza and its Immunization Affect the Likelihood of Obtaining Immunization? Gené, et al. <u>Family Practice Research Journal</u> , 12(1), 61-73.	• previous receipt of flu shot is positively associated with receipt of another • immunization effectiveness and fear associated with getting shot showed small correlation with those patients who did not receive vaccine
1992	Influenza Vaccination: Knowledge, Attitudes, and Behavior Among High-Risk Outpatients. Nichol, K., Lofgren, R., & Gapinski, J. <u>Archives of Internal Medicine</u> , 152, 106-110.	• knowledge not positively associated with receipt of vaccine • Intention to follow a nurse's or doctor's recommendation for flu shot positively associated with receipt of vaccine • difficulty in coming into the medical center was negatively associated with receipt of vaccine • experience of previous side effects was negatively associated with receipt of the vaccine
1993	Improving Influenza Vaccine Coverage in At-Risk Groups: Good Intentions Are Not Enough. Litt, J. & Lake, P. <u>The Medical Journal of Australia</u> , 159(8), 542-547.	• negative patient attitudes was associated with non-receipt of vaccine • lack of an integrated organizational approach was associated with non-receipt of vaccine
1994	Improving Compliance with Immunization in the Older Adult: Results of a Randomized Cohort Study. Herman, C., Speroff, T., & Cebul, R. <u>Journal of the American Geriatrics Society</u> , 42, 1154-1159.	• standing orders for administration of vaccine and patient education improved vaccine receipt more than patient education alone
1994	Evaluation of Group Health Cooperative of Puget Sound's Senior Influenza Immunization Program. Pearson, D. & Thompson, R. <u>Public Health Reports</u> , 109(4), 571-578.	• vaccine compliance was associated positively with previous immunizations and the belief that 'my doctor wants me to get a shot' • vaccine compliance was negatively associated with fear of adverse reaction and belief that the vaccine is ineffective

Table 2.1 Studies Used In the Quantitative Literature Review (continued)

1995	Influenza Vaccine Use Among an Elderly Population in a Community Intervention. Ohmit, S., Furumoto-Dawson, A. , Monto, A., & Fasano, N. <u>American Journal of Preventive Medicine</u> , 11(4), 271-276.	• intervention program had a statistically significant impact on increasing the likelihood of immunization • positive association between existence of certain chronic health conditions and receipt of vaccine • negative association between smokers and receipt of vaccine
1995	Influenza Vaccination in the Elderly. Ganguly, R., & Webster, T. <u>Journal of Investigative Clinical Immunology</u> , 5(2), 73-77.	• fear of side-effects and shots positively associated with non-receipt of vaccine • physician's advice to get vaccine and patient's knowledge of it were positively associated with receipt of vaccine
1995	A study of patient satisfaction and adherence to preventive practice guidelines. Weingarten et al., <u>The American Journal of Medicine</u> , 99, 590-596.	• patients who were offered preventive care including immunizations were more satisfied with their medical care than those who did not
1996	Factors Associated with Influenza and Pneumococcal Vaccination Behavior Among High-Risk Adults. Nichol, K., MacDonald, R., Hauge, M. <u>Journal of General Internal Medicine</u> , 11, 673-677.	• health care providers' recommendations to get vaccine was positively associated with patient receipt of vaccines • patient's positive attitude toward immunization was positively associated with patient receipt of vaccines • Smoking was negatively associated with receipt of the flu vaccine
1996	Factors Affecting Influenza Vaccination Among Attendees at a Senior Center. Gianino, C., Corazzini, K, Tseng, W., Richardson, J. <u>Maryland Medical Journal</u> , 45(1), 27-32.	• 86% said they had received flu vaccine • vaccinated seniors were more likely to believe susceptibility to influenza than nonvaccinated seniors • physician recommendation to get flu shot positively associated with receipt of vaccine

Table 2.1 Studies Used In the Quantitative Literature Review (continued)

1996	Framing Effects on Expectations, Decisions, and Side Effects Experienced: The Case of Influenza Immunization. O'Connor, A., Pennie, R., & Dales, R. <u>Journal of Clinical Epidemiology</u> , 49(11), 1271-1276.	• framing of the flu vaccine in a positive or negative way had no influence on vaccine receipt
1997	Compliance with Influenza Vaccination: Its Relation with Epidemiologic and Sociopsychological Factors. van Essen, G., Kuyvenhoven, M., & de Melker, R. <u>Archives of Family Medicine</u> , 6, 157-162.	• age older than 50 years was positively associated with receipt of vaccine • multiple indication for vaccine was positively associated with receipt of vaccine • type of at-risk diagnosis was not positively associated with receipt of vaccine • belief in the absence of side effects and in the efficacy of the vaccine is positively associated with vaccine receipt
1997	Delivery of Vaccines to Adults: Correlations Between Physician Knowledge and Patient Variables. Hershey, C., & Karuza, J. <u>American Journal of Medical Quality</u> , 12(3), 143-150.	• pneumococcal, tetanus, and flu vaccines are offered at varying rates • lack of provider knowledge was most apparent with pneumococcal vaccine • provider's ambivalence regarding the scientific basis and/or clinical importance was most apparent with flu vaccine

effects and efficacy of the vaccine accounted for variation in the rate of vaccine administration. They found that they could not detect an association between physicians' knowledge and attitudes of the vaccine's efficacy or side effects and their vaccination practices. Overall, patients' knowledge, beliefs, and behavior regarding the flu and pneumonia vaccines were the primary focus of quantitative studies.

Another quantitative strategy to discover and account for patients' vaccine receipt was to evaluate the efficacy of intervention measures. Efficacy almost always referred to the receipt of the vaccine by the individual, and not to other measures, such as the amount of knowledge acquired from the intervention. Intervention measures were patient

vaccine reminders and education systems. One study evaluated vaccine education interventions of physicians and nurses (Herman, et al., 1994).

Interpersonal communication processes were not often addressed in the literature. A few studies did refer to doctor-patient interpersonal communication in their discussions and analyses of their findings. For example, Pearson and Thompson (1994) suggested that one factor in the use of preventive services is the setting in which communication takes place and the amount of time allowed for the communication:

These visits are often brief and characterized by a full agenda of provider- and patient-initiated discussion topics. The crowded agenda may result in immunization messages not being fully 'transmitted' by the provider or 'received' by the enrollee. Therefore, it may be that for this population, printed materials, either in the form of recruitment letters or magazine articles, are more effective communication strategies to increase vaccine compliance. (p. 576)

Similarly, group and organizational health communication were not frequently examined. Only one study examined organizational health communication and vaccine receipt. Litt and Lake (1993) found that the health organization's lack of an integrated, systematic approach toward vaccination of high-risk patients was associated with those patients not receiving the vaccine.

In summary, the most frequent approach of quantitative research is to examine isolated factors of vaccine receipt among high-risk patients. Quantitative studies use the researchers' set of measurements, or their instruments, to define and measure patient attitudes, beliefs and knowledge. Most often, receipt of the vaccine is seen as the desired behavior of patients and those that receive the vaccine are called "compliant. "

Vaccine compliance was called by other names in the literature. Examples include "vaccination behavior" (Gianino et al., 1996; Nichol et al., 1992; Nichol et al., 1996), "vaccine acceptance" (Fiebach & Viscoli, 1991), and "adherence" (Weingarten, et al., 1995). What they have in common are the assumptions that health communication is a one-way message delivery system and that the patient's role in whether or not to act on the information is mostly passive and one-dimensional. Stimson's (1974) critique of compliance studies describes this well: "The ideal that is

presented is that the patient should obey or comply with what the doctor says. It is an ideal of the patient as a passive and obedient recipient of medical instructions" (p. 99).

Findings in the literature

What emerged from the examination of the quantitative literature is that a few psychological variables demonstrated a correlation with the vaccination status of patients. For example, a fear of adverse side effects and a belief that the vaccine didn't work was found in several studies (Ganguly & Webster, 1995; Gené et al., 1992; Nichol et al., 1996; Nichol et al., 1992; Pearson & Thompson, 1994).

The strongest psychological factor associated with the receipt of the flu or pneumonia vaccine was the patient's perceptions of the health provider's recommendation. The literature showed that patients' perception that their health care provider wants them to have the flu or pneumonia vaccine was strongly associated with receipt of the vaccine (Fiebach & Viscoli, 1991; Nichol et al., 1992; Pearson & Thompson, 1994).

Patient knowledge about the vaccine and its availability did not appear to be a factor in the receipt of a flu or pneumonia vaccine (Nichol et al., 1992). The literature also showed that the type of high-risk condition, or illness, was not a factor in the receipt of flu and pneumonia vaccines (van Essen et al., 1997; Fiebach & Viscoli, 1991; Nichol, 1991).

Most studies found that intervention measures do increase vaccine rates among high-risk groups (Brimberry, 1988; Gerace & Sangster, 1988; Herman et al., 1994; Ohmit, Furumoto-Dawson, Monto, & Fasano, 1995; Pearson & Thompson, 1994).

However, the studies showed conflicting findings on the most effective intervention method. For example, Gerace and Sangster (1988) found no significant difference between patient telephone or mailed reminders to get the flu vaccine. In contrast, another study found that patient telephone reminders resulted in a significantly higher vaccination rate (Brimberry, 1988).

What is not found in the literature is a description of how high-risk adults make decisions about vaccine receipt in the context of having a chronic illness. Certainly such variables as "fear of side effects" have been demonstrated as a factor in vaccine non-receipt of the high-risk and chronically ill participants. However, they have not demonstrated that they are the sole reason for non-receipt of the vaccine.

In addition, the literature did not provide insight into the "noncompliant" participant, and so the question remains, what makes people follow medical advice or not? Not much has changed in quantitative health research over the years. The following are excerpts of early compliance studies (Stimson, 1974, p. 99):

Several authors have attempted to correlate environmental, educational, and socio-economic factors and patient characteristics with uncooperativeness. This study could show no relationship. (Maddock, 1967)

It must be emphasized that it has not proved possible to identify an uncooperative type. (Porter, 1969)

Health communication studies

Another type of research that examines compliance issues is health communication. Health communication is a relatively newer strand of research within the communication research discipline (Kreps, O'Hair, & Clowers, 1994). Health communication has no overarching theory that guides its research. Lievrouw (1994) reviewed current health communication texts on practice and theory and came to the same conclusion: "[R]egarding theory, it is clear that the predominant approach in health communication up to now has been the application of existing theoretical frameworks, not the development of new concepts and principles" (p. 98).

According to health communication researchers Pettegrew and Logan (1987), the reasons for the lack of theoretical coherence are: The health care context is very different from the social context because it is more hierarchical and institutionalized; there is a vast range of communication phenomena to study; and communication has been studied from the points of views of other disciplines.

Despite this lack of guiding theory, health communication is distinguished by two aspects. First, studies in health communication are predominantly applied research (Sharf, 1993, Lievrouw, 1994). Second, the focus of all health communication research is the role of human interaction in health care and the health of the individual. Health communication researchers Kreps and Thornton (1992) describe the common beliefs of health communication studies:

We believe human communication performs an important role in the delivery of health care and the promotion of health. Health care providers depend on their abilities to communicate effectively with their clients and co-workers to accomplish their jobs. Health care consumers depend on their abilities to communicate effectively with health care providers and representatives of the health care system to acquire the best possible health care. ... In fact, we contend that all people depend on their abilities to communicate to maintain their health and to help others maintain health. (p. viii)

Health communication falls under the umbrella of the communication research discipline. It uses communication theories and the language of communication research to examine human interaction. For example, health communication examines the levels of communication: intrapersonal, interpersonal, small group, and organizational levels (Kreps & Thornton, 1992). It treats communication as an ongoing, dynamic process whereby people "simultaneously send and receive messages on many different levels" (p. 19). Like communication research, health communication research employs both quantitative and qualitative approaches.

The focus of this study is how chronically ill individuals make decisions about health care advice. Health communication is an important aspect of this inquiry. For example, it was mentioned in this study that the reasons for patients' decisions about vaccines might depend on the way the doctor communicates the information.

A review of the literature did not find any health communication studies that examined communication variables and patient receipt of vaccines, or that inquired into how chronically ill individuals make decisions to follow or not follow medical advice.

However, Kreps (1988), and Lievrouw (1994) found that issues of compliance and doctor-patient communication were examined in health communication studies. Kreps

aggregated and categorized the findings into five areas: (a) low levels of patient compliance have been linked to the failure to establish effective provider/patient communication relationships; (b) miscommunication and misinformation in health care have been related to inaccurate interpersonal interpretations, and ineffective and manipulative messages strategies; (c) insensitivity in health care has been related to low levels of interpersonal respect and attempts for relational control; (d) unrealistic and unfulfilled patient stereotypes have been linked to cultural stereotypes, misinterpretations of relational needs, and inflexible relational role performances; and (e) dissatisfaction and health care by both providers and consumers have been tied to failures to express interpersonal empathy and to issues of relational dominance (p. 346-347).

While the findings focus on compliance and communication “problems” that could lead to noncompliance, this does not explain how patients come to decisions about medical advice, from patients’ perspectives. Sharf (1993) says that the reason there is a lack of “patient-centered” studies is that health communication research has tended to focus on three main areas: doctor-patient communication, health information dissemination, and social support. Like empirical studies, most health communication studies that examine the discourse processes in health care focus on health outcomes, such as patient satisfaction. Lievrouw (1994) found that the reason outcomes are the primary focus of health communication research is because the research takes an interventionist approach. Outcomes are “offered as the main justification for conducting health communication in the first place” (p. 95). Recommendations for future research in health communication are inquiries into the context, complexity and consequences of health communication processes, not just health outcomes (Sharf, 1993).

Qualitative studies

Like empirical research, qualitative research strives to understand phenomena, such as patient receipt or non receipt of vaccines. However, in qualitative research, understanding is from the individual participant’s perspective and is of primary importance.

Behavioral prediction can be a result of understanding, but it is not the purpose or intention of qualitative research.

The existing qualitative health literature on receipt of flu and pneumonia vaccines by chronically ill adults is non-existent (this is demonstrated in Chapter Three). However, qualitative literature examining *the experience* of being chronically ill is small but growing. The following literature review discusses the history and development of qualitative research studies that focus on the chronic illness experience. It attempts to elucidate primary research approaches and place them within their historical context. After examining the history and development of the literature, major themes or areas of concern in the literature will be examined. The main themes are the processes, meanings and contexts of living with a chronic illness.

History of qualitative health research

Qualitative health research emerged from sociology and is relatively new compared to quantitative research. Changes during the '60s and '70s in the U.S. cultural and social environment resulted in a counter-revolution in medicine whereby the patient, not the disease, became the focus (Conrad, 1987, Gerhardt, 1990). Sociologists began to devote more time to asking questions about illness/wellness from the patients' perspectives.

According to Gerhardt (1990), the first qualitative study that attempted to understand illness was by the sociologist Anselm Strauss in the 1960s. He attempted to understand the life management of the dying based on his emerging grounded theory. The methods in grounded theory research require the individual's account of a phenomenon, in his or her own words. Grounded theory analysis generates an inductive theory about a substantive area that is grounded in the data. Later, Strauss and his colleague, Glaser, advanced grounded theory into a methodology that attempted to understand illness as a time-related phenomenon and from the actor's point of view, with the theory or understanding emerging from the data.

The body of grounded theory research on the chronically ill mainly consists of describing the *processes* inherent in managing a chronic disease (Jenson & Allen, 1994). For example, Corbin and Strauss (1987) interviewed chronically ill patients and used their biographies to learn about their concepts of self, body and performance over time. They found that two of the processes of learning to cope with a chronic illness is a redefinition of identity and a "biographical recasting," or rewriting of personal history. According to Corbin and Strauss, understanding these processes leads to a deeper understanding of the chronic illness experience:

An inescapable implication is this: to help those who suffer from severe chronic illness — even the most realistic and resolute need some help in this regard — requires that anyone who works with them has an awareness of the kinds of biographical processes that are going on "in them" ... the professionals usually do not have deep information about what the chronically ill person is struggling with. (p. 279)

Similar research has followed the work of Glaser and Strauss in the '60s to describe chronic illness. Nyhlin, Lithner, and Norberg (1987), Charmaz (1991) and others have studied the management styles of the chronically ill from a grounded theory perspective. Grounded theory studies comprise a substantial portion of the qualitative literature.

In the '70s, phenomenology replaced grounded theory as the dominant paradigm of medical sociology and is an important influence on qualitative health research today (Gerhardt, 1990). Phenomenology strives to elucidate the "essential objects and relationships of society" and the "taken-for-granted" normalization processes (Lindlof, 1995, p. 35). Like grounded theory, phenomenology acknowledges the existence of multiple subjective realities. Jensen and Allen's (1994) synthesis of qualitative studies found that the phenomenological literature on chronic illness mostly attempts to describe the *meanings* that illness has for the chronically ill.

At the same time phenomenology was the dominant paradigm guiding qualitative research, ethnomethodology emerged. Ethnomethodology took phenomenology's idea of subjective realities one step further by striving to disclose the subjectivities that people

had in common, referred to as *intersubjectivities*. These enable us to communicate and understand one another across different realities. One of the main tenets of ethnomethodology is that the patient's "rationality" and health-related behavior is a result of the patient theorizing about his or her illness (Gerhardt, 1990).

As a method, ethnomethodology is different from grounded theory because the data lie in the participants "doing" in the natural environment — the conversational encounters between "actors" rather than the dialogue from interviews. Most ethnomethodological research involves analysis of dialogue and conversation by direct observation (Lindlof, 1995). Its influence on social medicine resulted in rigorous analyses of doctor-patient conversations. For example, in Going to See the Doctor, Stimson and Webb (1974) "focused on the patient's autonomy accounting for non-compliance as well as staged impression management during communication with the doctor" (Gerhardt, 1990, p. 1154). The body of literature between 1980 and 1998 shows few true ethnomethodological studies of the chronically ill.

A subcategory of ethnomethodology is narrative analysis (Gerhardt, 1990). Narrative analysis is a method that treats the patient's accounts of chronic illness as narrative stories. It is derived from linguistic analysis of literature and "philosophical notions of causality" (Gerhardt, 1990, p. 1155). Its basic tenet is that events are communicated through storytelling, and storytelling is a useful product for analyzing processes of reality construction (Lindlof, 1995). It owes to ethnomethodology the idea of "indexicality of accounts", which means that stories are indices of behavior and explanations that serve to legitimate one another. Rationality of the accounts are found by attending to the taken-for-granted aspects of everyday, mundane life.

Examination of the literature demonstrates that researchers are mainly using narrative analysis as a method of data collection in the form of tape-recorded oral narratives and that it is not for theory-driven data analysis. Thus, the findings are similar to the ethnomethodological accounts in that patient's rationality and health-related behavior is a result of the patient theorizing about his or her illness through the narrative.

A few researchers have argued that people are universally and innately storytellers or "homo narrans," and narrative analysis should be thought of as a different world view altogether, a new theory (Fisher, 1984, 1985). Several researchers have recommended narrative analysis of health care phenomena including aspects of the chronic illness experience (Kreps & Thornton, 1992, Pettegrew & Logan, 1987, & Sharf, 1993).

Ethnography, or the ethnographic account, is a naturalistic mode of inquiry that uses quantitative and qualitative methods, depending on the researcher. Traditionally, ethnography strives for a holistic and complete description of cultural membership in addition to phenomena. "Thickness" is a key term used to describe it because it attempts to describe all aspects of "a culture's material existence, social system, and collective beliefs and experiences" (Lindlof, 1995, p. 20). Therefore, ethnographic findings are highly detailed ("thick") characterizations that include analyses of participants' friends and families. For example, Peyrot, McMurry & Hedges (1987) examined 21 adult diabetics *and* their spouses to determine the role of personal and professional (medical) knowledge of diabetics and their spouses in diabetes regimen management. There are a very small number of studies on chronic illness (less than 10) whose method of inquiry is an ethnographic account of illness (Gerhardt, 1990).

Gerhardt (1990) introduces a newer line of thought on chronic illness using qualitative evidence. She calls it biographical research. Biographical research is a method of data collection in which the individual writes his or her own biography, or "personal narrative." Personal narratives are then analyzed by the researcher using a variety of methods such as thematic analysis. Biographical studies have in common the idea of the individual's dramatic engagement in the world. Dramatic engagement is the ability to create or convey feelings of drama and emotion. One of the ideas that emerges from these studies is that the chronically ill have social "careers" or roles (Gerhardt, 1990). For example, Robinson (1990) examined and analyzed the life stories of people with multiple

sclerosis using their written, autobiographical narratives. One participant described the new role that he or she had chosen for himself:

I have become a very determined person and a very positive thinker ... I have also started to go out and meet new people and begin my life again. I am determined that no one will think there is anything wrong with me. (p. 1180)

Major concepts that emerge from Gerhardt's analysis are that different chronic illnesses have similar social realities in terms of a change in social status (e.g. from stigma) and that patients neutralize this change in status in a process called normalization. Normalization involves processes such as redefinition of identity and narrative reconstruction.

The next section summarizes the major themes or strands of research in the qualitative literature. The themes are processes, meanings and contexts found in the experiences of the chronically ill.

Themes in qualitative health research

Researchers Jensen & Allen (1994) conducted an extensive aggregation and synthesis of qualitative research on wellness-illness experiences. Their synthesis included studies of the chronically ill. Their findings and categories are consistent with what was found in the literature review. Their categorizations will be used to describe the central themes found in the literature review. Identification of themes or areas of concern does not imply that this is what will be found in this study.

Processes

Processes are defined as the "work of living" with disease. These are the developmental processes that the chronically ill go through in day-to-day living with the illness.

- *Comprehending:* When individuals are diagnosed with a chronic illness, they are often faced with uncertainty and ambiguity regarding their condition. This precipitates a search for knowledge and understanding. One participant described the process: "The brain wants to make order out of what happens to us. It wants

to have [the] experience make sense, no matter what kind of mental gymnastics we have to go through" (Garro, 1994, p.779).

- *Managing*: Describes the process of coping with changes once individuals are drawn into the "work of living" with their condition. Managing is a process of relinquishing control or taking control as necessary to restore balance. For some, balancing between letting go of control and taking control is like "walking a fine line" (Nyhlin et al., 1987, p. 62).
- *Belonging*: The chronically ill often have to redefine and reestablish their interpersonal relationships because the relationship is altered by the presence of illness. For example, one individual described the change in her spouse: "My husband finds it very difficult to accept sickness in any form, which doesn't make it easy. ... You know, I always did everything. I think he's resentful that I'm not able to anymore" (Dick, 1984, p. 145). When a relationship becomes too negative, one participant gave the following advice: "[Y]ou stay away from downers, people who are down in the mouth for no reason. Cut them off. Even if it means dissolving a friendship" (Nekolaichuk, 1990, p. 143).
- *Normalizing*: When health is altered, the chronically ill's roles change. There is a struggle to redefine their place in the world. For some, the process of normalizing includes aspects of disclosure regarding their illness: "Yeah, everybody at work knows. ... I don't make a big issue out of it. I make sure somebody knows 'just in case.' It would be stupid not to tell somebody" (Price, 1988, p. 150).
- *Valuing*: Living with the illness or doing the "work of living" for the chronically ill means not being able to realize former goals or hopes. Illness disruptions can reduce meaning in living. In order to cope, priorities and values change. Through the work of living with the disease and valuing new things, life becomes meaningful again. One participant said, "To be honest with you, [physical functioning] isn't that important, because you can find ways around it. For me, being able to function mentally is more important" (Stuifbergen & Rogers, 1997, p. 9).

Meaning

The second major theme in qualitative research is the meanings that are inherent in living with a chronic illness. The meanings are descriptions of the dynamic emotional states of the chronically ill that are dependent upon their physical states.

- *Abiding vitality*: This describes vacillating between feeling vigorous and feeling run-down. Having energy means feeling healthy and sound. The chronically ill have limits in their energy and vitality, and as one said, "Right now I feel fine, my lupus is not active, but I am not cured and I don't know how long this feeling will last; days, months, years" (Labrie, 1987, p. 98).
- *Transitional harmony*: This describes the feeling of harmony and contentedness despite a constant state of vigilance over the illness. When disruption occurs, such as feeling worse, uncertainty takes over. "You have this underlying feeling that something is going to get you. Which you kinda sweep back all the time. I made it today, maybe I can make it tomorrow, maybe I'll make it the next day" (Peyrot et al., 1997, p. 140).
- *Rhythmical connectedness*: This refers to feeling whole and connected with the world when feeling good, and feeling disconnected and alienated when feeling bad. One chronically ill individual explained the process of rhythmical connectedness as, "you become more aware of the world around you and the people around you and what they're going through" (Nekolaichuk, 1990, p. 163).
- *Unfolding fulfillment*: Elucidates the feeling that some chronically ill have that life is a challenge and worth participating in. The amount of effort doesn't matter to these chronically ill, they feel useful and effective. When they feel hopeless or defeated by their disease, they don't have a sense of worth or competence. One chronically ill individual described her strategy for maintaining a sense of unfolding fulfillment; "I have the philosophy that although it is a horrid disease, you have to work your life around it ... you have to live your life the best way you can" (Labrie, 1987, p. 52-53).
- *Active optimism*: This describes feeling motivated and in control when well and feeling overwhelmed and controlled when sick. For one individual, living with the illness has

given her active optimism; "Life has taught me always to come back and to never give up" (Nyhlín et al., 1987, p. 63).

- *Reflective transformation:* This means that for some chronically ill individuals, disease can be a stimulus to live. There is an openness to change and one can "embrace vulnerability" as well as possibilities. As one individual put it, "I wouldn't say there are good things about it [having diabetes] but I think some good things can come out of it" (Michael, 1996, p. 263).

Context

The third major theme of qualitative health studies is context. This refers to the individuals' interrelationships with their bodies, their selves, their environment, and others while they are doing the work of living with the disease.

- *Being in a body:* Being in a body describes the taken-for-granted feeling of good health. For example, one individual asked, "whatever had happened to the bouncy me?" (Kelly & Dickinson, 1997, p. 271). For the chronically ill, their bodies change and subsequently they are confronted by their bodies. Sometimes there is mistrust of the body because it acts unpredictably.
- *Being in space:* This refers to feeling as if one's body is merged with the environment and existence is taken for granted. When individuals are confronted with illness, the surrounding environment seems limited to them. Existence is no longer taken for granted after they have faced their mortality:

I faced up to death, mean, OK, yeah if I die I'd accept that now. I don't know many people my age [who] go through that, or have y'know come to a point where it's just right there, y'know. (Kelly & Dickinson, 1997, p. 260)

- *Being in time:* This describes the relationship of time and the chronically ill. For some individuals it can represent an endless struggle or chances of survival. For many, time is a precious commodity. "I am not counting on growing old. Maybe I have another ten years to live, which is too short" (Nyhlín et al., 1987, p. 63).

- *Being in relationships:* This means that lives are not lived in isolation of one another. "One lives embedded in groups, roles and norms" (Jensen & Allen, p. 360). With illness, lives and relationships are disrupted and altered. Some chronically ill experience a loss of identity as well. As their bodies change, so do their abilities and roles. They often have an increased awareness of their strengths and limitations. One individual who reduced her work hours reflects on the time she worked more: "And they're competing and competing and rushing, sometimes I get very jealous of the way they hustle, and I think, wait a minute, do I really want to live like that? No, I really don't" (Brooks & Matson, 1987, p. 89).

Summary

The body of quantitative research focuses on specific personality, knowledge, or experiential variables to explain why chronically ill adults receive or don't receive the flu and pneumonia vaccine. The results demonstrate that there is a substantial number of the chronically ill who know about the existence of the flu and pneumonia vaccines. These studies also show that a health provider's recommendation to get vaccinated is a strong influence on the elderly. Empirical studies demonstrate a small correlation between expectations of, or attitudes about, the efficacy and side effects of the vaccines and receipt of the vaccine.

In quantitative studies, vaccine non-receipt by high risk individuals is considered to be a negative reflection on either the patient, the doctor, the relationship between the two, or the organizational structure of the company administering the health care. Criticism is not necessarily unwarranted. Certainly, there can be improvement in communication between patient and provider, and in the administrative structure of health care organizations. Similarly, striving to improve the immunization rate of high risk patients through behavioral understanding and manipulation is not necessarily bad.

However, it is important to know something about the individual or group you are trying to change. If there is not understanding of their experience, or what it is like to walk in their shoes, then attempts at behavior changes may be unsuccessful. This is

demonstrated by the persistent low vaccination rates among high-risk adults despite interventions targeted “at them.” Patients’ accounts of chronic illness experience, including making health decisions, is completely missing in the quantitative literature.

Similarly, quantitative research does not examine vaccine non-receipt in terms of a positive decision from the individual’s perspective. Put another way, the person’s own good reasons for not getting vaccinated are not explored. “Good reasons” are defined in Practical Reasoning and Human Affairs as “those elements that provide warrants for accepting or adhering to the advice fostered by any form of communication that can be considered rhetorical” (Fisher, 1986, p. 100). Fisher says that the elements that provide good warrants for accepting advice include the relevance, fact, consequence, consistency and value of the advice. Excluding individuals’ reasons for not getting vaccinated negates the possibility that chronically ill individuals are making constructive decisions to not receive a vaccine.

Health communication studies demonstrate the importance of communication processes in communicating about health. They provide an alternative way of looking at non-compliance by examining it in the context of communication practices. Many health communication studies’ investigations into illness are similar to quantitative investigations because they focus on health outcomes, such as receipt of the vaccine, rather than the processes, contexts, complexities and consequences of coming to a decision about health care advice.

Health communication research, like quantitative research, subordinates the patients’ needs to those of the health care provider. Subsequently, the patient’s reasons for making health care decisions are often excluded. This results in studies that assume the health decision-making power primarily belongs to the health care provider:

Paradoxically, however, “negotiation” and “collaboration” between patient and providers often favor the provider. ... very few [health] communication studies presume to question systematically the social relationships, institutional arrangements, and assumptions that support a provider’s privileged claim in the first place. Without an examination of the conditions or warrants for the privileged knowledge claim, “collaboration” becomes a mechanism for more provider control. (Lievrouw, 1994, p. 96)

Health communication studies typically exclude an analysis of what being chronically ill means from the patient's perspective. Therefore, understanding what it is like to be chronically ill and how it relates to the decision-making process is limited to an external perspective. Often this perspective is from the health care provider and the researcher.

Qualitative studies have given researchers more information about the experience of being chronically ill from the point of view of the person with the illness. For example, we know some of the processes of learning to live with a chronic illness, how they see themselves, and what the experience means to them. Qualitative studies also have shed light on some of the processes of managing a chronic illness over time. In these studies successful management of the illness is evaluated and judged by the individual with the condition, not by the health care provider.

Qualitative studies have not explicitly inquired about vaccine receipt by chronically ill individuals. However, many did examine the medical regimens of chronically ill individuals and their relationships with health care providers. Some qualitative studies also examined chronic illness from a longitudinal perspective. In short, these examinations of chronic illness contained descriptions of how individuals with chronic condition came to a decision to follow or not follow professional medical advice.

CHAPTER THREE

Methods

This study used a qualitative approach to discover how the individual's experience of chronic illness related to a decision to follow or not follow professional medical advice. The qualitative approach was chosen because it is congruent with the purpose of the study and the types of questions being asked. This study seeks an emic perspective of chronic illness — it seeks meaning, experience, and perception from the participants' points of view. It seeks a more contextual and holistic understanding of how chronically ill individuals make decisions about medical advice. It seeks to provide the researcher an interactive role whereby she can guide the analytic process as insights or understandings emerge (Morse, 1992).

Theoretical perspective

A social constructivist world-view or paradigm guided this research. Social constructivism posits that "realities [emphasis in the original] exist in the form of multiple mental constructions" (Guba, 1990, p. 27). Facts are value and theory-laden. Therefore there cannot be a completely objective existence. Methodologically, the constructivist elicits and refines individual constructions of reality (depicting them as realistically as possible) and at the same time, compares and contrasts these constructions. The goal is to generate one or a few constructions "on which there is substantial consensus." Investigations about the phenomenon of interest (chronic illness and how it relates to following health care advice) are new and relatively scarce. However, an analysis of the research studies that focused on chronic illness can generate new insights about chronic illness and decisions about professional medical advice. Also, such an analysis can tell us if there is substantial consensus about the topic of interest or not.

Definitions

High risk and **at risk** are used in this study to describe groups at high risk for influenza and/or pneumonia complications, as defined by the CDC (1997). These groups include:

1. Residents of nursing homes and chronic-care facilities
2. Adults and children who have chronic disorders of the pulmonary or cardiovascular system, including asthma and cardiovascular disease
3. Adults and children who have required regular medical follow-up or hospitalization during the preceding year because of:
 - chronic metabolic diseases (e.g. diabetes mellitus)
 - renal dysfunction (e.g. cirrhosis)
 - hemoglobinopathies (e.g. sickle cell disease or splenectomy)
 - immunosuppression (e.g. from leukemia, HIV and cancer treatments)
4. Children and teenagers who are receiving long-term aspirin therapy (and would therefore be at risk for developing Reye's syndrome)
5. Women who will be in the second or third trimester of pregnancy during the influenza season.

For the purposes of this study, chronically ill and at-risk adults up to 65 years old will be examined. CDC statistics estimate the number of high risk people between ages 2 and 65 to be 31 million and growing (1997, p. 2).

Influenza or flu is a contagious viral infection of the respiratory system, with symptoms of fever, myalgia, sore throat and a dry cough. Unlike other respiratory infections, such as a cold, it can cause severe malaise lasting several days or sometimes weeks (CDC, 1997). In high-risk patients, including the chronically ill, this can more easily result in pneumonia, a lethal bacterial infection that is highly resistant to antibiotics.

Pneumonia (*streptococcus pneumoniae*) infection is the leading cause of illness in young children, and causes illness and death among the elderly and high risk patients. Pneumonia causes an estimated 40,000 deaths annually in the United States.

Approximately half of these could have been prevented with the use of the pneumonia vaccine.

Pneumonia and influenza vaccines have different vaccination schedules. Standard influenza vaccinations occur once a year during pre-flu season, which usually is between September and mid-November.

The pneumonia vaccine schedule is slightly more complicated. According to the CDC (1997), people should receive the vaccine only once or twice in a lifetime. Patients age 65 or older should be vaccinated once. If their first vaccination occurred before the age of 65 and was at least five years ago, they should be revaccinated.

The high risk population aged 2-64 years do not need to revaccinate until age 65 or older. The exception for this group are those have anatomic asplenia that is a result of diseases, such as sickle cell anemia. These individuals age 10 years or older should be revaccinated every five years. Children ages 2-10 should be revaccinated every three years.

Limitations

Initially this study will focus on chronically ill adults aged 18-64. This excludes chronically ill children, teens and young adults because this group is more dependent on other adults; therefore, this group could have a dramatically different experience of utilization of vaccinations and other medical services.

This study will confine itself to the chronically ill and their experience of illness, medical advice and treatment. This leaves out a detailed description of other phenomena of day-to-day living with chronic illness such as managing personal relationships or how they choose to disclose their illnesses.

Last, this study uses participant excerpts from other studies. Therefore, all of the primary data are not available for analysis. It is possible that context and information will be lost in the analysis of words that have been pre-selected. It is also possible that this study loses context and information because of the inability to analyze words that have

been excluded from the original studies. However, the studies selected for analysis contained ample data on the phenomenon of interest.

Significance of the study

This study added to the scholarly research and literature in the field of qualitative health behavior and communications because it focused on a less common aspect of chronic illness experience, how being chronically ill affects a decision to follow or not follow health care advice. It analyzed and described the understandings that emerged from the participants own words. Most importantly, it attempted to improve the practice of health care intervention and communication by bringing the context of chronic illness and medical advice to light.

Data collection

Data collection and analysis in qualitative studies are a reflexive and reciprocal process. Therefore, this collection of research studies has changed over time. Similarly, it is important to note that the subsequent description of how the research was collected and analyzed is not to be interpreted as a literal, linear model. The purpose of describing data collection and analysis is to provide a general outline that can be replicated. A primary goal of qualitative research is to preserve the individual's account of a phenomenon. Therefore, "Actual talk, gesture, and other social action are the raw material of analysis" (Lindlof, 1995, p. 21). The method used in this study was an inductive analysis of actual talk found in qualitative studies in the form of participant excerpts. An inductive analysis is a systematic approach to discover recurring patterns, themes and categories that are grounded in the data. The analyst also looks for natural variations among these patterns (Patton, 1990).

This study examined the body of qualitative literature between 1980-1998 that focuses on the individual's experience of chronic illness and how it related to a decision to follow or not follow professional medical advice. This time frame was chosen because (1) an initial data search showed very few studies on the topic of interest before 1980, and (2) this study sought to examine a more recent body of literature.

Criteria for selection of the studies to be used in analysis: First, participants in the research had to be between the ages of 18-64 and have at least one chronic condition. This study made two exceptions where the age range of the study went over the age of 65. However the majority of the population in these two studies was between 18-65, and so they were included.

Next, the study had to exhibit the characteristics of a good qualitative study. According to qualitative health researcher Madeleine Leininger, a good qualitative study meets the following six criteria (Morse, 1994):

- *Credibility of the findings.* The findings seem believable and true to the people being studied. Participants can recognize and identify with the major findings. If the study solicited feedback from participants, it was included in the analysis.
- *Confirmability of the data.* How researchers have periodically, throughout their study, confirmed what they have seen or heard in process of data collection. For example, in the interview process it is important for the researcher to confirm what he or she has heard the participant say, and where the emphasis, or importance of the words lie.
- *Meaning-in-context data analysis.* This means that the researcher puts the meaning, or the analysis, in context of the participants' "total situation ... the totality of their lived experiences." (p. 106).
- *Recurrent patterning.* The data or analysis contains repeated expressions, experiences, events or activities that substantiate the findings.
- *Saturation.* Describes complete immersion into the phenomenon of interest. This means that the researcher finds no further explanation, interpretation or description of the phenomenon of interest by the participants of the study. Saturation does not mean that there are not alternative explanations or interpretations in other data sets or from other participants. It just means the researcher has exhausted the data set at hand.

- *Transferability of the findings.* This refers to whether the findings can be put into another similar context or situation. For example, if the findings of a study could be applied to another chronic illness, then it demonstrated transferability of the findings.

Once the criteria were determined, an initial search was conducted. Research articles were collected by database searching in NASW Clinical Register, MEDLINE, HealthSTAR, CINAHL, PAIS International, PsycINFO, SERLINE on Silver Platter, Social Sciences Abstracts, sociofile, Social Work Abstracts, Mental Measurements Yearbook and Dissertation Abstracts. Each electronic search employed the same databases and the same period of time, 1980-1998.

Many search phrases were used and in many combinations. For example, some of the first terms searched were "chronically ill adult (or chronic diseases) and vaccination or immunization," "preventive care and chronic diseases," "factors in influenza and/or pneumonia vaccine receipt," "acceptance or barriers of vaccine," and "adult immunization and chronic illness." The initial search yielded several quantitative studies on chronically ill individuals and vaccines. However, no qualitative research that studied how chronically ill individuals come to a decision to receive a vaccine was discovered. Therefore, the search terms "qualitative studies," was added. This yielded more results.

Next, specific qualitative research terms were added. For example, the terms "ethnomethodology or grounded theory or narrative theory or descriptive study" were searched in conjunction with "chronically ill adult (or chronic diseases) and vaccination or immunization," and with "preventive care and chronic diseases." This search string yielded several studies. The term "utilization of preventive care" was broadened to "medical care utilization" and "medical advice utilization." This also yielded several qualitative studies.

Another database search method used in this study was to conduct a database search in specific journals and periodicals that are indexed in a database such as MEDLINE. For example, after finding some articles that fit the criteria of this study in the Journal of Holistic Nursing and Social Science and Medicine, the search terms were used

with the title of the journals during a database search. This was another successful data collection method.

As studies were found, search terms that provided successful results were derived from the database search findings and in the text of specific studies. For example, the term “illness narrative” was found in one study and subsequently used in a database search. Similarly, the references and bibliographies of studies provided additional studies that fit the criteria for analysis.

Both published and unpublished studies (such as theses and dissertations) were used. The rationale for including unpublished studies is that they frequently contained more raw data — the participants’ own words — than did published studies.

In addition, studies conducted in other countries were included. Although a different economic and cultural health care system might affect the results, certain aspects of having a chronic illness and deciding to follow or not follow medical advice may be universal, and the differences, if any, might provide new insight.

Data exclusion

Articles, theses and dissertations that did not contain accounts of how chronic illness related to a decision to follow or not follow professional medical advice were excluded. For example, a recent examination of asthma patients and their perspectives about medication and chronic illness initially appeared to fit the data collection criteria (Adams, Pill, & Jones, 1997). However, upon closer examination it proved to contain scarce information on how having a chronic illness specifically influenced them to follow or not follow medical advice. Instead, the article examined ways that asthma patients come to terms with and manage their disease. These asthmatics were grouped into categories, such as deniers and accepters. While this type of study provides useful insight into the varying ways people handle their disease, it does not provide clear insight into their decision to follow or not follow medical advice (see Appendix B for a complete list of the qualitative studies that were found by database searching).

Studies selected for analysis

A total of 23 studies were found from the data collection process. Based on the above criteria, excerpts from a total of 12 studies were selected for analysis. Table 3.1 lists the studies used in the analysis of how chronically ill individuals come to a decision to follow or not follow medical advice.

Data analysis

The researcher and a second coder analyzed the data in order to ensure that the data set was exhausted for all explanations of the phenomena of interest. The second coder was the major professor of the researcher. The unit of analysis were the words of participants in studies that examined chronic illness and decisions about health care advice. All excerpts of the participants' own words were highlighted (for examples of participants' excerpts see Appendix C). This included quotes, longer narratives, and answers to questions. The participants' words were read through once, without taking notes. Because this study attempted to describe phenomena from the participants' perspectives, care was taken to ensure that the original researchers' findings and interpretations were not included in the analysis. The following question guided the analysis: How might having a chronic illness affect the decision to follow or not follow professional health care advice?

Excerpts were coded using inductive analysis. The excerpts were read again, and indigenous and sensitizing terms and concepts were identified. According to Patton (1990), "a good place to begin inductive analysis is elucidation of key phrases or terms ..." (p. 390). Indigenous terms are those phrases and definitions used by the participants. Sensitizing terms are those terms that the researcher imposes. For example, an expression often used by participants to describe "coming to terms" with an illness (a sensitizing term) is "handling it" (an indigenous term).

Next, themes and patterns, or how the indigenous concepts fit together were teased out. Similarities and differences among the categories were noted and used to

Table 3.1. Studies Used in Inductive Analysis

Title	Source	Chronic Condition(s) of Participants	Participant Characteristics/ Type of Study
Managing Multiple Sclerosis	Brooks & Matson (1987)	multiple sclerosis	N=19, ages 22-73*, 8 men and 11 women, most married, time since diagnosis: one year to 9 years/ grounded theory study
The Other Side of Illness: A View From Inside the Chronic Illness Experience	Dick (1984)	kidney disease, rheumatoid arthritis, multiple sclerosis, and lupus erythmatosis	N=22, ages 28-71**, 8 men and 14 women/ naturalistic inquiry study
Factors Influencing the Attitudes Held By Women With Type II Diabetes: A Qualitative Study	Dietrich (1996)	diabetes	N=6, ages 37-65, all women, time since diagnosis: 5 weeks to 40 years/ naturalistic inquiry study
Narrative Representations of Chronic Illness Experience: Cultural Models of Illness, Mind, and Body in Stories Concerning TMJ***	Garro (1994)	TMJ disease***	N=32, 27 women and 5 men, ages 23-65/ narrative analysis study
The Narrative Self In Autobiographical Accounts of Illness	Kelly & Dickinson (1997)	ulcerative colitis	N=2, one man and one woman, both aged 29, both have had ileostemies****/ narrative analysis study
Lupus: Managing a Complex, Chronic Disability	Labrie (1987)	lupus erythmatosis	N=36, ages 22-50, men and women, some married/ grounded theory study
Learning To Live With Uncertainty: The Role of Hope and Medication Compliance In Chronic Illness	Nekolaichuk (1990)	rheumatoid arthritis, epilepsy, migraines, hypertension, chronic renal failure, breast cancer with metastases, cancer of the cervix and uterus, Hodgkin's lymphoma, and diabetes	N=8, ages 21-65, 4 men and 4 women, Time since diagnosis: one to 29 years, number of illnesses per individual was one to 4/ grounded theory study

Table 3.1. Studies Used in Inductive Analysis (continued)

Experience of Being Diabetic: "It is Up to Oneself to Manage"	Nyhlin, Lithner, & Norberg (1987)	diabetes	N=20, ages 23-53, 5 men and 15 women, good metabolic control of diabetes with no signs of vascular damage/ grounded theory study
Living with Diabetes: The Role of Personal and Professional Knowledge in Symptom and Regimen Management	Peyrot, McMurry, & Hedges (1987)	diabetes (diagnosis at least 3 years)	N=21, ages 26-56, men and women, all married, Caucasian participants only/ ethnographic study
Perceived Uncertainty Associated With the Management Trajectory of a Chronic Illness — Diabetes Mellitus	Price (1988)	diabetes mellitus	N=19, ages 24-53, 7 men and 12 women, single, divorced and married, time since diagnosis: 1-to-22 years, all insulin managed / grounded theory study
Health Promotion: An Essential Component of Rehabilitation For Persons With Chronic Disabling Conditions	Stuifbergen & Rogers (1997)	multiple sclerosis	N=20, ages 32-65, 15 women and 5 men, time since diagnosis: one to 19 years/ used NUD*IST software and thematic analysis
Constructive Noncompliance in Chronic Illness	Thorne (1990)	over 11 chronic diseases*****	N=77, 21 men and 56 women, ages 16-76***** /grounded theory

Notes:

N=246, 59 men and 146 women, in some studies cannot tell sex ratios. Although the majority of participants were Caucasian, several studies included African-Americans, Asians, Hispanics, and other ethnicities.

Chronic conditions that are most frequently studied: diabetes (6 out of 12 studies), multiple sclerosis (4 out of 12 studies), followed by kidney disease or renal failure (2 out of 12 studies) and lupus (2 out of 12 studies). There was only one study that examined hypertension, breast cancer, uterine and cervical cancer, Hodgkin's lymphoma, migraines, TMJ, and colitis.

* only two out of nine were age >65, so study was included

** mean age was 49, so study was included

*** TMJ = temporomandibular joint

**** ileostomy = removal of a portion of bowel that is inflamed

***** includes cardiovascular disease, inflammatory bowel, arthritis, spinal cord, multiple sclerosis, respiratory disease, and diabetes

***** majority, or over 80%, were between 21-64 so study was included

create a theme under which related ones were eventually grouped. Guba calls this looking for "recurring regularities" in the data (Patton, 1987).

Lastly, the recurring regularities were judged by their "internal homogeneity" (Patton, 1987, p. 154). Internal homogeneity means the extent to which the data that fall under a certain theme and "hold together or dovetail in a meaningful way."

Analysis and comparison of categories were made within a single study and across studies by constant comparison and evaluation. Emerging themes were collected and categorized. The themes that developed are discussed in Chapter Four, Analysis and Findings.

CHAPTER FOUR

Analysis and Findings

This study attempts to discover and describe how individuals with chronic conditions come to a decision to follow or not follow professional medical advice. Analysis of the participants' own words collected from 12 qualitative studies suggests that the chronically ill do have distinctive ways of making such decisions.

During the data analysis, a metaphor that compared the chronically ill individual to a tightrope walker developed. In this picture, the tightrope represents the challenge of balancing the need to attend to the illness and the need to participate in everyday activities. The findings of the analysis are presented with this metaphor in mind. The themes, which often took on names that fit with the tightrope metaphor, are:

Theme #1 — *Tightrope walkers* — refers to the chronically ill who find themselves in a precarious position — balancing on a tightrope.

Theme #2 — *Mastering the balancing act* — describes the processes that tightrope walkers go through to learn to live with their illness.

Theme #3 — *The safety net* — discusses the qualities of health care providers who help the tightrope walkers learn and master the balancing act. The safety net catches the tightrope walkers if they fall, helps them rebalance, and encourages them along the way.

Theme #4 — *The drag net* — highlights the aspects of health care providers and services that bring the tightrope walker down, or are weak and unsupportive when the chronically ill fall.

Theme #5 — *The invisible net* — describes nonmedical strategies that strengthen and support tightrope walkers' efforts to learn and master the balancing act. Invisible nets are much like safety nets because they help tightrope walkers balance, catch them if they fall, and encourage them along the way. These sources are often "invisible" options for health care from the perspective of professional health care providers.

Tightrope walkers

In this metaphor, diagnosis of a chronic illness often means that the participant's world changes dramatically. What becomes clear is that the chronically ill find themselves in a precarious situation, on a tightrope. If they want to survive, they have to step on the rope. At first it appears frightening to individuals. It seems nearly impossible to balance on the rope, much less walk along the length of it. Sometimes the chronically ill fall off of the rope. These are referred to as the novice tightrope walkers. Slowly, after time and experience, they become better at balancing and walking along it. After time on the rope, and practice, novice tightrope walkers become the experienced tightrope walkers and eventually, masters of the balancing act.

This is not to imply that this process of mastering the tightrope is only a matter of practice and time. The emotional, cultural, economic and social dimensions of illness combined with the unpredictable nature of the body result in a developmental process that is complicated and non-linear. For example, individuals can lose financial resources to treat their illness, or lose support from a family member on whom they relied. No matter how much time or practice they've had on the tightrope, these disturbances can diminish their confidence in their ability to balance on the rope. Charmaz (1991) highlights the varying patterns of time and illness in her longitudinal study of chronically ill patients:

Not everyone experiences a linear progression of illness. Some people define intrusive symptoms long before they have a major disruption or crisis. Thus, their illnesses start in the background of their lives and move stealthily into the foreground as they demand more attention and time. Other people catapult from an initial interruption straight into immersion in illness routines. They suffer through a crisis and then find themselves at home sick — very sick. (p.10)

Despite the complexity of living with chronic illness the data show that there is a strong difference in how decisions are made about medical advice between the newly diagnosed person and the person who has experience with living with an illness. Novice and experienced tightrope walkers also differ in how they live with the illness and react to changes over time. This will be discussed later in this chapter.

First, it is necessary to have an understanding of the basic developmental stages of learning to live with a chronic illness. Figure 4.1 outlines the three basic stages of learning to live with chronic illness. "Learning to live" with or "doing the work of" chronic illness means walking the tightrope of chronic illness every day and eventually achieving a certain level of balance and security. This figure represents the developmental stages of coming to terms with chronic illness.

It is important to note that the categories in the figure do not have fixed boundaries. Instead, the categories represent a snapshot of the general stages of learning to live with chronic illness. Walking the tightrope is a developmental process of learning and experience, and the purpose of Figure 4.1 is to demonstrate the processes within the stages. In the real world of chronic illness, the lines become blurred between the stages of development. Not every individual makes it to the final stage of the master tightrope walker. Similarly, some people who make it to the master stage could go back to the novice stage if their illness worsens, or if new health problems arise.

The time period for each stage is not fixed either. In general, it is assumed that most chronically ill leave the first stage, the stage of the novice tightrope walker, and spend the rest of his or her life in later developmental stages. This assumption is made because life for the novice is very chaotic and traumatic. It is assumed that the intensity and difficulty of this period motivates a move into the later stages of learning to live with the illness. In addition, the extended life span of chronically ill individuals indicates that many will spend the majority of their time in the later stages of living with chronic illness.

DIAGNOSIS⇒	⇐STAGE ONE⇒ Stepping onto the Rope novice tightrope walkers	⇐STAGE TWO⇐ Learning to Balance experienced tightrope walkers	⇐STAGE THREE Mastering the Balancing Act master tightrope walkers
feelings about the illness(es)	• disbelief • anger • shock • denial • fear, vulnerability • confusion	• frustration • disappointment • anger • fear • confusion	• integration • acceptance • less anger • less fear • less confusion
relationship with primary health care provider	• very dependent upon primary health care provider • sees doctor as authority figure	• becomes more independent from provider • begins to see provider as secondary support • struggle over control	• two-way information sharing, or partnership with provider • reduced reliance on provider, uses provider for maintenance
emotional and cognitive processes	• trying health regimens for the first time • learning and assimilating • worrying	• prioritizing • researching about disease, origins and treatments and evaluating them • experimenting by: -stopping medicines -testing limits -seeking nonmedical treatments -seeking advice and support from others • worrying	• still prioritizing • less researching • less experimenting • still seeking nonmedical treatments • maintaining support networks • less worrying • more accepting
degree of knowledge and experience of condition	• very little knowledge of disease • no experience	• increasing knowledge, • increasing experience	• very knowledgeable • very experienced

Figure 4.1 Learning to Live With a Chronic Condition: Tightrope Walking

The findings show that there is a difference in how chronically ill people make decisions about health care advice, depending on what stage they are in. For example, participants in stages two and three, the experienced and the master tightrope walkers, said that they could tell the difference in their relationships with health care providers between the stages. One important difference was that the patients assumed more control of their health in the later stages:

[My psychologist] asked me one time who was in control of my health, the day she took me on as a patient and I said of course the medical people. She asked me a few months later and I said I'm in control. (Nekolaichuk, 1990, p. 162)

Somewhere down along the road there's a misunderstanding started about the extent to which we as individuals are responsible for our own health. At the beginning I just assumed that my responsibility was limited to me going to the doctor's office and then following his instructions. And now I know. Now I say, OK, give them a chance, but ... if they can't come up with a plan of action that seems to flow from a diagnosis, then walk away from it. (Thorne, 1990, p. 65)

Similarly, individuals in stage two and three recognize that they have relinquished control in some areas. For example, one participant reflected on dialysis treatments and said, "[T]here is a learning process definitely ... I've learned that these things are simply the conditions of dialysis ... All of these things are just part and parcel of my condition ... and I don't jump to any conclusions until if they [side effects] persist ... (Nekolaichuk, 1990, p. 148).

The developmental stages of learning to live with a chronic illness are described in the next section. These stages emerged from an analysis of the data.

Stage one: stepping onto the rope

For those who have been recently diagnosed with a chronic illness, their life becomes like stepping onto a tightrope and these are called the novice tightrope walkers. At first, they are wobbly and insecure, and very afraid of falling off the rope. Panic, and the desire to escape, are some of the reactions to a diagnosis of a long-term illness:

The summer before I started dialysis I panicked. I will say, I panicked. That summer we were not home at all. We went everywhere. It was as if I had to do everything then. I never thought about that until just now. [pause] I haven't thought about that for a long time. But I knew it was horrible that summer. ... I'd tell him, 'Hey, I just have the feeling if we don't do it now, we'll never be able to do it

again.' ... We'd just all of a sudden decide to go somewhere, pack up, get in the car, ... Crazy, it was just running, that's what it was. (Dick, 1984, p. 111)

Some participants reported that they initially tried to ignore the illness. One said, "As I say, I was kidding myself that there was nothing wrong, y'know, but that didn't work" (Kelly & Dickinson, 1997, p. 263). Some of the chronically ill don't deny the existence of their illness but they do deny the seriousness of the illness until they are faced with the health consequences. "I took it [the diagnosis of hypertension] really lightly. I wasn't that scared at first. Then years later, ... [you] saw a few cases of your own that they had a stroke" (Nekolaichuk, 1990, p. 124).

Many of the chronically ill said that they experienced anger after the diagnosis of illness. For example, some were angry at their health care providers:

I was mad, I was just mad. I don't know, it is hard to describe. I wasn't mad at the doctor [who diagnosed her]. I was mad for one doctor not telling me or finding out. I think that was lax on his part. I was just mad, because I had to start watching what I eat and drink ... (Dietrich, 1996, p. 18)

For some chronically ill, waiting for diagnosis leaves them uncertain. One described it this way: "[I]t was hanging up [from the doctor] and not knowing. Not knowing is the rough thing to go through. The knowing isn't near as bad as the guessing ..." (Nekolaichuk, 1990, p. 129). A diagnosis brought relief to the participants who had an illness that was difficult to diagnose:

For the next few months I spent much of my time in the doctors' offices and went through test after test. They couldn't find anything wrong ... But this time he called in a specialist and within a few hours they had it vaguely diagnosed as lupus. I didn't know what lupus meant and I really didn't care. It was just such a relief to know that I wasn't going crazy; that I wasn't a hypochondriac. (Labrie, 1987, p. 63-64)

Participants with chronic migraines also said that they found life easier with a diagnosis: "[U]ntil they [the migraines] were properly diagnosed and I got support from the doctors and a clear understanding of what was going on, it was quite difficult" (Nekolaichuk, 1990, p. 121).

When the chronically ill first step onto the tightrope, falling off means doing something wrong medically, getting sicker, and possibly dying. Consequently, they are

very dependent on health care providers and insecure about their own coping and managing abilities. The chronically ill in the first stage of learning to live with a chronic illness usually follow medical advice to the letter.

They gave me this diet to follow — classic diabetic diet ... That diet is just as depressing as anything. I pretty much stuck with it for a year or two. (Peyrot, McMurry, & Hedges, 1987, p. 127)

It [illness] was like a bad dream. I thought if I followed the diet it would go away and that is why I was so obsessive in the beginning. (Price, 1988, p. 97)

Stage two: learning to balance on the rope

After individuals have had time to recover from the initial trauma and uncertainty surrounding a diagnosis, they begin to focus on managing and controlling their illness. Participants often referred to it as a long and difficult learning process: "You learn all through this period; you begin to learn about yourself ... You've got to learn a whole lot more and it's not just a thing you can just go out and grasp" (Brooks & Matson, 1987, p. 96). The chronically ill focus their energy on learning to balance and to feel better. To some participants, it seemed as if their illnesses controlled their lives:

[It] has got me so backed up against the wall, that I couldn't even, I couldn't even dare think about the future. I just got to the point where I couldn't look back and I couldn't look ahead, all I could do was just get through the day. (Garro, 1994, p. 783)

This can be a very frustrating stage because all their efforts at management may amount to little or nothing. Participants reported feeling vulnerable and doubting themselves, which caused even more distress. "They [the medications] weren't working. And I'd get panicked and I'd say, 'What's the matter with me?' And I think probably that alone would make me feel all riled up" (Nekolaichuk, 1990, p. 129). One participant questioned whether or not he was responsible for his illness:

I kept wondering around that point a few months ago, like, why aren't I getting better? I mean, I'm doing all this stuff, what's the problem here? And once again I began to doubt myself, you know, do I want to be sick? No, I don't want to be sick. (Garro, 1994, p. 780)

This is where the struggle to control the illness really begins. The chronically ill see their illnesses as a challenge, something to subdue. Some refer to it as a "fight" saying, "I am at it all the time. It is a constant battle" (Nekolaichuk, 1990, p.114).

For others, the struggle is against their own bodies:

I am totally imprisoned inside this painful body. That's why the only thing I can do is to try to get better. All I do 24 hours a day is work on my health ... (Garro, 1994, p. 783)

Some fight against the restrictions the disease has placed on their lives:

For me the most difficult part is the restrictions. Lack of freedom to adjust your schedule, and following right behind that is the dependence upon the treatment. I always felt I was the type of individual who would prefer to be independent. But now I have to be dependent upon something or someone. (Dick, 1984, p. 109)

Learning to balance on the tightrope, or to get regulated, was especially difficult for diabetics. Many of the diabetic participants reported that they had trouble "handling" their blood sugar levels. Some had difficulty with the amount of information they had to learn: "It took a little while to process all of the information and to learn new information ... I just couldn't get a handle on this thing" (Price, 1988, p. 103). They also had difficulty adjusting to different schedules:

But there are problems with the handling of diabetes. It is all right when you are at home and have regular hours. The worst is when you are on holidays. Or if you have a job that forces you to be away or to work irregular hours. (Nyhlin et al., 1987, p. 64).

Diabetics said that the difficulty in managing their disease resulted in them seeking out others with the condition. They compared and questioned their health care and providers:

'Does that mean my diabetes is better or worse than theirs?' 'Should I be doing something differently?' 'Is my doctor right about this diabetes and insulin, or is their doctor wrong?' (Price, 1988, p. 108)

Many of the participants reported difficulty in learning how to control their disease through a medical regimen, but it was most often reported by diabetics.

All of the participants in stage two, regardless of their illness, said that they evaluated their relationship with their health care providers. Several participants reflected

on their relationships with their doctors in the beginning and described them in terms of a parent and child:

Also when initially as a child [when] you had the flu, you went to the doctor, he told you to take aspirin, fluids ... and you got better. That was my experiences of a physician. This time I'd gone to the physician and he didn't fix me and he couldn't fix me. I was getting annoyed with him ... Why can't he fix this problem? (Nekolaichuk, 1990, p. 138)

[B]eing forced to do something, I don't think any of us likes to do that. It's like being reprimanded by your parents, only this is different, but it's still a reprimand ... (Dietrich, 1996, p. 18)

If I can show up good test results I am considered to be cooperative and they like me. Another thing is that I agree to suggestions that I am not convinced of and later regret ... I've a feeling that if I state my view they would consider me troublesome and dislike me. ... One has to have a lot of courage to dare to stress one's will. (Nyhlin et al., 1987, p. 65)

At this stage, the chronically ill begin to experiment with prescribed medications and treatments. Diabetic participants frequently reported that they gave up following their prescribed regimens exactly because they had trouble managing their blood sugars:

I just seemed to be going up and down and up and down [with my blood sugars]. And I got so frustrated, I said, 'Why bother?' Or I would follow my diet perfectly and I would have blood sugars of 20 or more ... If I am going to have this disease ... it had better follow a pattern. (Nekolaichuk, 1990, p. 121)

Some chronically ill said they do their own doctoring, "I think everybody sorta drifts away from it [regimen]. I started doing my own doctoring, second guessing the doctor" (Peyrot et al., 1987, p. 127).

Participants also said that they sometimes stopped their regimens when they appeared to be ineffective or "useless" to them:

I thought, 'Well I wonder what will happen if I just let this thing ride on without me taking anything' ... I knew I was ... in my case anyway, it was virtually useless. That drug y'know, em [sic], as far as keeping the episodes away. So I thought, 'Well now, you can just see what'll happen if you let this go on of its own accord ... (Kelly & Dickinson, 1997, p. 262)

The chronically ill also reported that they reduced the frequency of tests they were willing to undergo because the tests did not tell the health care providers how the patients were *feeling*:

They would like you to come in for blood work every week. I did that for a while, but when the blood work would indicate that I should be feeling bad, I would feel

fine, and when the bloodwork indicated that I should be feeling well, I would be feeling bad. So I said, what the hell. The blood work isn't really telling them anything in terms of how I feel, so I come when I feel just a little bad to make sure I won't have a flare up, but not every week. (Labrie, 1987, p. 125-126)

The data show that the participants in stage two of learning to live with the chronic illness make health care decisions that would be considered noncompliant by many health care providers. Participants reported making decisions about health care advice independently from their providers' recommendations. Participants compared, experimented with or stopped their prescribed treatments, regimens, medications and tests. Individuals with diabetes seemed to have the greatest difficulty "learning to live with it" or manage the disease. Subsequently they reported more willingness to experiment with or stop their diet and insulin regimens. Regardless of type of illness, the chronically ill in stage two are actively struggling to balance on the tightrope, or learn to live with their illness every day.

Stage three: Mastering the balancing act

Tightrope walkers eventually relax their efforts to control the disease when they learn all of the specifics of their illness and their treatment, and they come to know what to expect. One said, "the reassurance that you're more knowledgeable about it ... [makes it] less frightening" (Brooks & Matson, 1987, p. 85). Many participants said that reaching a relaxed stage was a learning process:

There is a learning process definitely ... I've learned that these things are simply the conditions of dialysis ... All of these things are just part and parcel of my condition .. and I don't jump to any conclusions until if they [reactions] persist, if they become progressive... (Nekolaichuk, 1990, p. 148)

The participants also said that they accepted less than perfect health or symptom management as part of their acceptance; "You may never be 100%, but settle for 80%, if that's all you're going to get. It's better than the zero you're at now" (Garro, 1994, p. 784).

Subsequently their primary health priority at this stage is to feel better and be comfortable:

... okay, if the disease is going to kill me in 5 to 10 years, I will live them with comfort. In other words, hope to me does not deny facts ... my hope is that within

the fact that the disease [exists], I don't want to be a burden. I don't want to be depressed ... I want to be as comfortable as can be. (Nekolaichuk, 1990, p. 118)

The master tightrope walkers also have accepted their limitations and act within their boundaries:

Satisfaction equals the difference between what you do and what you want to do ... and if you have unrealistic goals, then you are going to be very dissatisfied. ... You quietly redefine what is important to you. (Stuifbergen & Rogers, 1997, p.10)

They focus on redefining their priorities and goals. Many times their new priorities are not health-related. For some it is their family's well-being:

What is much more important than anything else is being with your family. ... Once that is right, then you can make other things right. (Stuifbergen & Rogers, 1997, p. 9)

By this stage, participants reported that they had found a physician who satisfies their needs for flexibility, willingness to experiment, and equality:

I find the best thing with him [my physician] is that he will listen to me ... I feel that when I meet with him, I have information sharing and that's great. (Nekolaichuk, 1990, p. 85)

If the chronically ill are more independent from health care providers, they might stay with a provider who acts as a peripheral support. In these situations, the doctor-patient relationship is one where "I tell him what I want and he does it — so far" (Brooks & Matson, 1987, p. 83).

Finally, expert tightrope walkers have embraced their illness and treat it as part of themselves. They have learned to live *with* the illness: "I cannot imagine having a life that belongs to me without it. It is my life — it's so ONE [emphasis in the original] at this point" (Brooks & Matson, 1987, p. 98).

The data show that expert tightrope walkers, or the chronically ill in stage three, make health care decisions based on their own experience and knowledge. Participants allow themselves to be the equals of the health care providers. They often make decisions *with* their health care provider in a two-way, information-sharing process. Analysis of the data demonstrates a difference between the stages of learning to live with a chronic illness. The following analysis elucidates the themes that emerged from the

participants' accounts of living with a chronic illness and how it related to a decision to follow or not follow health care advice. It focuses on the chronically ill in stages two and three called the "experienced" and "master" tightrope walkers. One of the central themes that emerged is the process of "learning to live with" a chronic illness, which is metaphorically referred to as learning and mastering the balancing act. The other themes that emerged were the influences on the process of learning and mastering the balancing act. They are referred to as the safety net, the drag net and the invisible net.

Learning and mastering the balancing act

Those who are not newly diagnosed with an illness have at least enough experience of living with their disease on a daily basis to begin to learn and master the balancing act. Like the metaphor of the tightrope walker, the longer they practice and work at balancing, the better they become. The difficulty for the novices is finding a balance between attending to their conditions and participating in their lives. What the experienced chronically ill demonstrate is the incorporation of the disease into their life. A chronic illness becomes part of them. Wholeness, integration, or working together are frequently the words used by chronically ill to describe the process of learning to live with their condition. Balance occurs when they don't have to choose between attending to their condition and participating in life because the two activities become one. One experienced tightrope walker said it this way:

The problem is we're trying to be so intellectual that we make everything so separate and dry and classify it, but there is a connection to everything and you just can't go separate things. ...if you go with the approach that you are a whole unit and you are embraced as such, then you can start to heal. (Garro, 1994, p. 785)

The chronically ill work very hard to reach the point of living with their illness from day to day:

I make incredible calculations all of the time. There is a constant back burner going about how everything is going to affect [me] diabetically. I usually give a pat answer to a question like hers, but instead I gave her a specific answer to what I was doing now. I said, 'Well today I swam this much, and I knew we were not going to have dinner until late, but I didn't want my blood sugar to go up, so I took a couple of units then,' ... and she just looked at me and said 'oh my God!' And I said, 'I'm always going through these calculations.' (Price, 1988, p. 131-132)

What it puts on me is a responsibility for taking charge of my own health: being aware of what's happening to my body, any patterns that are happening, when they're happening, and then having an idea about what to do. (Thorne, 1990, p. 65)

Once they do find that balance, the chronically ill become experts about their disease. Often they know more about it than do their physicians. The chronically ill said that they have put more time and energy into thinking about, researching and living with illness. Therefore, they are confident in their ability to access and evaluate health care advice:

But I know more than he [doctor] does. Right after I was diagnosed I gained 20 pounds in one week. He didn't know about multiple injections . . . (Price, 1988, p. 74)

And to be honest, I feel that I'm more well informed than many doctors about my condition. And I just feel better about myself doing that. (Nekolaichuk, 1990, p. 142)

I had discovered by reading materials that I was supposed to be doing thus and so ... and I asked him and ... he slipped up on so many things, I knew he was a counterfeit ... (Brooks & Matson, 1987, p. 85)

I knew all along the radiation wouldn't work. All I probably got out of the radiation is kidney damage. (Labrie, 1987, p. 61)

This experience and expertise in managing their own illness results in the patient assuming complete control over their health care:

At this point I don't believe it is possible to manage diabetes by having your doctor control it. (Price, 1988, p. 149)

You do a little researching on yourself. I always say that the doctor in Boston doesn't tell me how I am, I tell him how I am [emphasis in the original]. It's that kind of thing. You are sort of on equal status with him because each case is so individual that it's whatever is best for you. (Dick, 1984, p. 115)

But I consider myself intelligent enough to know when to cut or add [the insulin dosage] and I put more thought into it than he does. (Peyrot et al., 1987, p. 129)

Yes, they don't know anything about this disease. They're just guessing half the time. I've read everything I can get my hands on and I figure I have a 50-50 chance either way, so I am going to do it my way and they're not going to use me as a guinea pig. (Labrie, 1987, p. 124)

Basically we have a contract. So he [the doctor] knows that I'm someone who feels assured enough or safe enough that I'm willing to bargain, that I'm no longer a pushover. And probably he sees me as a reasonably intelligent person who's willing to take responsibility. (Thorne, 1990, p. 66)

From the findings, it is clear that the chronically ill are often more knowledgeable and experienced about their illnesses and conditions. This includes knowledge about the origins of the conditions, treatments, medications, and what works to make them feel better. The following is a description of the processes that lead to learning to live with a chronic illness or master the balancing act. The processes are prioritizing, comparing and evaluating, and experimenting. How these affect a decision to follow or not follow professional medical advice also is discussed.

Prioritizing

Chronically ill individuals frequently order their time around what's most important to them. This helps them live with their condition, or walk the tightrope. They focus on what is important and what areas of their life will get the most attention.

Participants reported that they had to change their expectations. "I don't think there is a perfect anymore" (Price, 1988, p. 134). They also changed their expectations about what they could accomplish:

Satisfaction equals the difference between what you do and what you want to do ... and if you have unrealistic goals, then you are going to be very dissatisfied. ... You quietly redefine what is important to you. (Stuifbergen & Rogers, 1997, p.10)

One of the priorities that the chronically ill reevaluate is their health status. And interestingly, they are often willing to settle for less than perfect health:

[Y]ou may never be 100%, but settle for 80%, if that's all you're going to get. It's better than the zero you're at now. (Garro, 1994, p. 784)

And some of the aggravation that I gave myself was looking for 100% health. And you have to have a certain degree of acceptance I feel because at this present time, and I think so many of us in my support group feel this way, that we can have a certain degree of health but we may not have 100%. As soon as you accept that ... then I think you're a bit more relaxed about it. (Nekolaichuk, 1990, p. 145)

For the chronically ill, prioritizing also means finding out what is most important and what they want to focus on. Often being functional or comfortable is more important than "100% health":

For almost four years I've been enjoying a good quality of life and ... I've learned that I can live with the disease and still be functional, productive and of value to other people. (Stuifbergen & Rogers, 1997, p. 11)

[I]f the disease is going to kill me in 5 to 10 years, I will live them with comfort. (Nekolaichuk, 1990, p. 118)

For others, it is their family and their children who get top priority:

[I want to] be there for their [childrens'] emotional needs, you know, and their physical needs. To me, that's more important than me at this point. Making sure that they grow up and have a normal life. ... Mama's already been through this, so hey, let's get you through this. That's what's important to me. (Stuifbergen & Rogers, 1997, p. 9)

I don't want ... to become ill to the extent of being a burden on somebody. To my family. (Nekolaichuk, 1990, p. 119)

What does not seem to be very important to the experienced tightrope walker, or the individual who has learned to live with his or her condition, is the reality of diminishing abilities. While they don't want to be incapacitated to the point of being a burden to their families, they are willing to accept some physical and cognitive limitations:

[even] my organizational abilities are not the same as previously. But again, I accept that too. I mean, my limits, the threshold of my limits is shorter a bit. But within that I try to cope and accept it. ... I see that as a process [losing organizational abilities] that is going to happen and if I can control it I would have controlled it. In other words, I have to accept it. (Nekolaichuk, 1990, p. 96)

I don't overdo. That's a luxury I don't have. (Brooks & Matson, 1987, p. 97)

[I thought]... just maybe I would reach this independence. I never did, but that's not important. I still keep trying. That is the important thing for anyone who is a victim of a long-term illness, — trying, day after day ... (Dick, 1984, p. 114)

Researching and evaluating

Individuals with chronic illnesses are constantly seeking information and evaluating the information that they get. They often know more about their condition, treatments or managing symptoms than their physician because of their own experience and self-education. Part of the evaluation process includes comparing. They compare the pros and the cons, the risks versus the benefits, and the value of health information, services and treatments.

Is it worth the consequence? I have to really think constantly, constantly about the consequences. (Garro, 1994, p. 784)

I don't take medications just like that. With any new medication I have to go and read the CPS [textbook on medications] and the details about it. Ask the doctor about it, get back to him and say, 'Look there might be this side effect or this interaction with that drug.' I'll say, 'What do you think?' ... I feel that I have control over medicating myself too ... In fact many times I'm given a medicine and I don't take it at all, after I read about it, until I see my doctor the next time. Or I'll phone him ... So I am active in taking care of myself in terms of my medication treatment. (Nekolaichuk, 1990, p. 178)

I was getting really fat. I knew it was the medication ... I cut down on the prednisone. They told me to take 30 milligrams, but I cut it down to 5 milligrams. They got mad and told me I shouldn't change it myself like that, but my hair started to grow back and I lost all that weight. (Labrie, 1987, p. 123)

The data show that evaluating side effects of medications is an important influence on a decision to follow or not follow medical advice regarding medication:

It's my body and I want to know what drugs are going into it and what the side effects will be. And I feel much better knowing that. And then I can make an educated decision on whether or not I want to try that. (Nekolaichuk, 1990, p. 79)

I don't want to be sick, and I don't need to take these pills because I know they'll damage my immune system. They might help me in the short term but in the long term they won't help me. And that bottle's still sitting unopened on my shelf. (Thorne, 1990, p. 64)

I don't like to take shots but I'm not quite ready to die, so I make a compromise — I won't do everything that they tell me to do. I'd rather have less time, but I would rather do some things in order to gain some [time] ... The doctor wanted me to try an insulin pump. I am not willing to do that. ... If I can't LIVE, [emphasis in the original] then I don't want to live. (Peyrot et al., 1987, p. 136)

Experimenting

Chronically ill adults are often willing to try new treatments. They also are willing to stop any form of medical care with which they are dissatisfied. They are willing to experiment with regimens they have had for some time. They become experts about their condition through trial and error, by finding what works and what doesn't work for them.

I was always, anytime I went to the doctor's office there, I'd try and grab that new medical [journal] — trying to read the new ones or watch anything new on blood pressure. And I was always game to them to experiment with anything that came along ... To hit the right one. (Nekolaichuk, 1990, p. 72)

When the doctor changed my insulin around, I thought that this wasn't working. Then I realized that this is a game! And you have to play around with it, but he didn't give me the freedom to change it around at first. I thought his word was law and that he knew what he was doing. (Price, 1988, p. 103)

You're not always wise to do things without medical advice. But what I did then though was, bearing in mind the dangers, ... I looked at alternative therapies ... I looked-up in the library because I thought, 'Well you really can't tell the doctors,' ah, y'know, 'what to do or not to do, should I try this or that?', because I had asked one doctor, y'know, 'Is there no other? ... Have you not got anything in your research?', y'know, 'that could point to a cause', y'know, and he said, 'No.' So I thought, 'Well, they'll maybe go and maybe experiment'. I don't think they do, they don't like experimenting unless there's a real clinical reason for doing so. (Kelly & Dickinson, 1997, p. 265)

Chronically ill individuals have said that finding the balance, or learning to walk the tightrope, *necessitates* experimentation and trial and error:

Diabetes is a game. Like walking down the white line on a Nevada highway, but you don't know how wide the road is ... you are never sure... on one side is high blood sugar and on the other is low blood sugar. What I've learned is to make my own little off-white line and it may fall somewhere near the definite highway mark and sometimes it doesn't, but you have to be comfortable either way. I believe somebody has to feel as rotten or as good as they can before they can come right out in the middle. (Price, 1988, p. 122-123)

Learning to live with a chronic illness requires prioritizing, researching and evaluating, and experimenting. Chronically ill individuals sometimes need help from professional health care providers. However, participants said that there is a distinct difference in the quality of health advice and treatment among health care professionals. For many chronically ill, health advice and services are as different as night and day. This is distinguished by a positive support system, referred to as the safety net, and a negative support system, called the drag net. The following is a description of the components of the safety net and the drag net, and how that affects a decision to follow or not follow medical advice.

The safety net

The safety net represents the health provider who helps chronically ill adults through their journey or walk across the tightrope. The supportive provider is also a cheerleader on the ground, helping patients stay balanced and on the tightrope by providing feedback on how they are doing. When the chronically fall off the tightrope, they are caught and supported by the safety net. Falling off the rope means getting sicker or feeling worse. Some individuals fall off the rope because experimentation with their

regimens has been unsuccessful. Other patients become inured to their routine and skip certain parts of it. For whatever reason they become sicker or feel worse, patients said they expect and need the safety net.

The supportive health provider

The supportive health provider pays attention to where his or her patient is at. Metaphorically, he or she stands with the net below and moves the net with the patient as they walk the tightrope. The supportive health provider's actions give a sense of confidence and security to the chronically ill because they know that their provider is doing his or her best for them and is supportive. The health care provider takes in information from the patient, such as 'a little more to the left with the net,' and acts on that information, trusting what the patient says. Similarly, the supportive health care provider gives feedback from his or her position: 'This is what I can see from down here.' This communication process was described by chronically ill patients as a reciprocal process: "... it became a two-way process. I do my share and he [doctor] does his share ... " (Nekolaichuk, 1990, p. 111).

Participants in this study described a "supportive" health provider as one they trust, one who recognizes their efforts, and one who genuinely cares for their well-being.

The following excerpts describe the issue of trust that is a source of support for the tightrope walker. Trust is referred to as a feeling that is a result of the provider's honesty as well as his or her medical expertise:

It's very valuable for me that he will sometimes say, 'Well I haven't heard of this. Or this is new to me.' I can trust him then, because I know that he's being very honest. (Nekolaichuk, 1990, p. 84)

It gives you a great feeling of confidence. He's always on top of it, and I feel I was fortunate to have him as a doctor. He knows how I feel. (Dick, 1984, p. 121)

Chronically ill individuals also want encouragement and recognition of their efforts:

He talked to me a lot, and he would say, 'When you are on dialysis, you are going to feel better. You're not going to feel like this all the time.' He made me talk to people who were on dialysis. ... He continually encouraged me, and told me that this was not going to last, that I would feel better. And what he was saying was

true. And he'd talk to my husband and tell him the same thing. So he was a big factor as far as encouragement and moral support. He continues to be. And he's the type of doctor who looks at the patient as a total person, emotionally and physically. (Dick, 1984, p. 122-123)

He made me feel so good about myself and he made me feel like 'keep trying!' ... just by recognizing the effort I was making. (Price, 1988, p. 148)

Finally, the chronically ill said that they are deeply appreciative of the health care providers who have demonstrated sincere empathy for their patients:

He [doctor] is very into family medicine and family care and he just wants to make sure that things are going well. I think he is somebody I can talk to. (Dick, 1984, p. 129)

At the beginning my doctor got me through it (taking injections) and he was willing to treat me as an outpatient because I had no money or insurance. I know now that he didn't know much about diabetes, but he was really supportive. I see him about once a year now. (Price, 1988, p. 149)

For tightrope walkers, trust, recognition, and empathy are essential components of the safety net. "One of the problems that we find in the support group is people not being satisfied with what's happening with their doctor. And when they do find a good physician they can talk to, it really lifts their spirits. It makes such a difference." (Nekolaichuk, 1990, p. 143)

Without trust, honesty, and a sincere interest in their welfare, health care providers are not providing the kind of support their patients say they need.

The flexible health provider

Safety nets have to be strong, but in order to perform correctly, they must be flexible. The net must have spring and give when patients fall. Also, the net must move with patients as they walk along the tightrope. If the net stays in one place, such as where the tightrope walkers begin, then health care providers will not be a useful safety net. This means health care providers must be flexible in their advice and treatments to adapt to the changing needs of their patients. Participants described the actions of flexible providers:

They have tried to adjust the treatment to fit my lifestyle because of the type of business I'm in ... (Peyrot et al., 1987, p. 135)

He'll find out about it [new treatments]. Also, if he finds something new, which he always does try ... he's very good at just talking to me about what's new in the market and what he's heard recently. (Nekolaichuk, 1990, p. 85)

[Medications] That's the one area where a layman has to totally depend on the medical profession. And I was very fortunate, from my rheumatoid people, to my cancer people, who would phone me at home and say, there is something new out. I want you to try it. (Nekolaichuk, 1990, p. 112)

The drag net

Chronically ill individuals often refer to health care providers who bring them down, emotionally and physically. While these health care providers may give the appearance of being a supportive net, they have many characteristics that have the opposite effect.

Participants frequently suggested avoiding or leaving the drag nets:

If you're not working together with your doctor, get a different doctor because you don't want anybody hanging onto you that brings you down. You fight to stay up and they bring you down, where are you? (Nekolaichuk, 1990, p. 110)

The drag net represents the aspects of health care providers that act as a negative force on the tightrope walker and are described next.

The health provider that leaves information out

This describes health care providers who leave important information out regarding the possible symptoms, management or treatment of the chronic condition. This causes physical and emotional harm to the tightrope walker. For the chronically ill, it is like a hole in the net they can't see, until after they've fallen.

I didn't know that until I had the flu. Nobody ever told me that. Nobody ever told me that if I was running a temperature or had an infection that my blood sugar would go high. (Peyrot et al., 1987, p. 118)

At first I was on these pills and no one had explained to me about the reactions, when it did happen I wasn't sure what I was feeling. I had read about the symptoms but actually feeling the shaking, that really bothered me. (Price, 1988, p. 96)

Things just got, went from bad to worse, my eyes sort of looked as if I was looking through polythene [sic]. And the pain. ...Cos [sic] I went to get my eyes tested and I got these glasses. And then the pain in one of my eyes, you wouldn't believe. I had to go up to casualty, and they just put me in the eye clinic. And then just by chance he said, 'Do you have any stomach problems...' And I said, 'well actually, I'm waiting to go have an ileostomy' and he said, 'Oh that's what it is, your eye is connected with your bowel, you'll find that once you have had the operation that t the chances ... (Kelly & Dickinson, 1997, p. 258)

The chronically ill find that some physicians don't tell them directly what their treatment will be, nor do they provide instructions:

[T]he doctor never came to explain it to me and so, when my husband told me, he said, we have to take the needle home. I said, 'We do?' And I didn't know how to give myself a shot ... (Dietrich, 1996, p. 18)

In addition to leaving out information out about symptoms and treatments, physicians frequently omit information about sexuality and 'private' subjects:

My mate ... should he approach me or should he avoid me sexually? ... The physician or the health care system provides nothing in the realm of sexuality information for the lupus patient. (Labrie, 1987, p. 38)

Some participants feel that the doctor just doesn't take the time to tell them important information in-person. Sometimes it seems as if they are just pointing the patients toward pamphlets:

The neurologist confirmed the diagnosis and said, 'I really don't know much about MS, But I think there are some brochures in the waiting room.' Right then I decided that I was going to have to educate myself about this disease. (Stuifbergen & Rogers, 1997, p.13)

I've gotten pamphlets and stuff but it just tells you about your diet and your exercise and infections, but it doesn't explain why and how and all this ... (Dietrich, 1996, p. 21)

They don't tell you anything when you come. I still don't know what lupus is?[sic] ... No one takes the time to explain and that just makes me mad. (Labrie, 1987, p. 125)

I just wish doctors themselves were more clued in so they could themselves help ... educate the public. I mean they've got the pamphlets in their office, but that's not enough. ...they should be told the possible side effects. That's a major concern now ad days. ... Now it's a major concern. (Nekolaichuk, 1990, p. 125)

Lastly, some participants find the physician's way of communicating health information to be lacking in and of itself:

If doctors would explain what this illness is, in an encouraging way, that you can help yourself ... and it can be lived with. If doctors would do this, I think it would help a lot. Explain how this illness can affect things, one way or another ... It's educating people in a positive way. (Dick, 1984, p. 124)

Not getting enough information, the right kind of information, or having information presented negatively can cause emotional and physical harm to the patient. This can lead to distrust in the health care provider and an unwillingness to participate in a treatment. For

the chronically ill individual, that potential results in the following decisions to not follow health care advice:

So then I went back to another doctor at the clinic and he looked at the report, the same report, and said it's not all that bad, I don't understand why they put you on a diet at all, and so I quit that diet right there ... (Dietrich, 1996, p.19)

I don't know anything about lupus, that's why I stopped coming here for appointments for awhile ... They don't explain anything, they always have conferences with a lot of doctors asking me questions, but they don't tell me anything. (Labrie, 1987, p. 95)

The controlling health provider

Chronically ill individuals, or tightrope walkers, like health providers to be supportive, but not rigid and controlling. It is very important to chronically ill individuals that they maintain control over their body and medical treatments. Health care providers who are controllers do not move the net as the patient moves. Subsequently, they can be a hindrance to the chronically ill:

If I can show up good test results I am considered to be cooperative and they like me. Another thing is that I agree to suggestions that I am not convinced of and later regret ... I've a feeling that if I state my view they would consider me troublesome and dislike me. ... One has to have a lot of courage to dare to stress one's will. (Nyhlén et al., 1987, p. 65)

I don't think she (the doctor) really listened to me; I think she was so involved with her method that she just wanted to use it and that it wasn't applicable didn't really matter. (Thorne, 1990, p. 65)

[G]etting strapped with having a certain routine ... I felt a lot more free before I became a diabetic, able to do what I wanted, when I wanted, and not having to worry about it. ... You feel kinda trapped into having a strict routine. (Peyrot et al., 1987, p. 133)

Well I got angry only to a point, because he'd [the doctor] probably throw me out. Because I needed him more than he needed me, or at least I thought so at the time. (Dick, 1984, p. 80)

The fight for control can be frustrating for both patients and providers. Often it forces the providers and patients into relationships in which they are not working together or collaborating on the health of the patients. The data show that this struggle often results in the patients asserting complete control over health care choices:

I tell him what I want and he does it — so far. I feel like sending him a bill. (Brooks & Matson, 1987, p. 83)

I am not going to sit at the phone and wait for his phone calls to tell me to make the changes that I am fully capable of making on my own. I am not going to live like that. I've always handled my insulin and I am going to continue to do that. (Peyrot et al., 1987, p. 129)

Nothing will happen to me without my consent. And nothing will happen to me without my believing in it. (Thorne, 1990, p. 63)

Yes, they don't know anything about this disease. They're just guessing half the time. I've read everything I can get my hands on and I figure I have a 50-50 chance either way, so I am going to do it my way and they're not going to use me as a guinea pig. (Labrie, 1987, p. 124)

It is my body. It depends on my own will whether I will manage. Nobody else can do anything about it. If I don't want [it], it won't help even if everybody else wants me to do something. (Nyhlin et al., 1987, p. 62)

The disconfirming health care provider

This kind of health care professional disconfirms the tightrope walker's needs, fears, complaints and pains. Cissna and Sieburg (1981) describe disconfirming communication as communication that fails to acknowledge others, uses impersonal language, shifts the focus of the conversation to something tangential, and uses demeaning or disparaging remarks. Disconfirming behavior conveys the feeling to the listener that he or she does not exist. It can be psychologically damaging. Disconfirming health care providers communicate that they don't believe, trust, or legitimate the chronically ill's experiences. When providers relate this way to their patients, it can destroy trust and confidence in the individual's ability to balance and walk on the tightrope. It can also result in the patient choosing a different doctor or alternative sources of support.

The following are examples of health care providers who don't believe the existence of the illness in the individual:

They had labeled me a neurotic. I began to perceive myself as one. I still suffer from the destructive professional attitudes of the physicians during these years. I needed so much to define my problems or at least to have someone grapple for a definition with me. (Labrie, 1987, p. 47-48)

You'll hear this from a lot of TMJ sufferers who go to dentists or doctors and they start asking your psychological history. You know, like, have you been particularly under stress about anything? And so they kind of turn it on you in a way, by saying it's all stress related and it's like you're causing it yourself. (Garro, 1994, p. 780)

There are instances where the physician does not believe that the participant is following a regimen, or taking medicine, or performing a regimen in the way that he or she prescribed:

My doctor has called me a liar ... He would swear that I was doing the things that I wasn't supposed to be doing and wasn't doing the things that I was supposed to be doing ... He used to tell me 'You're wasting your time and I'm wasting your money.' (Peyrot et al., 1987, p. 125)

Another participant said she had to prove that she had trouble taking a medicine:

I had to prove why I was choking on it [the medication] ... That's what life is with me, I got to prove everything. Just don't take my word. I got to prove to you why I can't take it. (Nekolaichuk, 1990, p. 129)

Many of the participants simply wanted acknowledgment of their discomfort or side effects. In these instances, it appeared as if their uncomfortableness was of no importance. Rather, completing the medical procedure or figuring out a regimen took precedence over the patient's comfort:

I really don't think they understand how ill you are when they put you through [colonoscopy]. I mean they don't realize what having diarrhoea [spelling in the original] all the time, and the way you suffer like that ... I have a fear of that machine [X-ray and barium enema]. Dr. McEwan said it was silly, but it's not. I hate not having my feet firmly [on the ground] ... I had a colonoscopy done with just a valium injection [which is the normal way of doing the procedure] and they say I fight all their anesthetics. And I was wide awake. And it was really just as well they weren't saying anything untoward because I did turn around in the middle [of the procedure] and say, 'When am I supposed to fall asleep?' (Kelly & Dickinson, 1997, p. 258)

In the beginning I was having a lot of headaches and I was worried about them. When I tried to tell my doctor he said 'I'm not worried about a headache, we need to look at how to adjust your insulin!' I thought the headaches might be from the blood sugar. I just needed to have them acknowledged as a part of me ... just acknowledgment, that is the word! (Price, 1988, p. 148)

Finally, there are physicians who are condescending to their patients:

There are also bad physicians, who just, unfortunately I feel that women are often not taken as seriously ... A lot of people in my experience have had that type of visit with a physician, where because they're a woman, because the majority of people in my group are women, have been patted on the head so to speak. Condescended to. (Nekolaichuk, 1990, p. 148)

Doctors try to categorize diabetics. They have this book, and try to go back to the theory. But everybody's different. Like the doctor that I had before [who said] 'I know that you're doing this stuff wrong,' and I wasn't. I honestly wasn't. [But] that

wasn't in his book or otherwise my blood sugar wouldn't be like that. (Peyrot et al., 1987, p. 123)

Experienced and master tightrope walkers, or the chronically ill in stage two and three, reported that they respond quickly and assertively to disconfirming health care providers by walking away:

[I]f things don't start falling together in a reasonable length of time ... then walk away from it and just cope on your own. Cope with it as best as you can. But don't allow your whole life to go to pieces. (Thorne, 1990, p. 65)

When the chronically ill encounter drag nets, or negative health care providers, they will be more inclined to seek other sources of support. This result is similar to the processes of researching, evaluating and experimenting in that the chronically ill look elsewhere for help in order to find what works best for them. The following section describes the different kinds of alternative sources that they turn to.

The invisible net

The invisible net is a support system that also helps the patient maintain balance, catches them if they fall, helps them get back on the tightrope and then helps them walk across it. The net is similar to the safety net in its enabling and helpful function to the tightrope walker. It is called an invisible net because traditional biomedical, or Western medicine, does not recognize the existence or efficacy of alternative forms of healing, therapy and support. Examples of alternative health sources and therapy include financial stability, humor, family support, working, one's own personality or will, support groups, meditation, and "listening" to their bodies. While some health providers might not see the value of such alternative therapies, the support it provides is very clear to the tightrope walkers. The following are some examples.

Some participants saw that "sound economics" was strong medicine:

And I have patients lying beside me [in the hospital] dying. And I can guarantee you, if they had won the lottery, they would be alive today. The worry of that debt killed them ... So I am telling you, sound economics is a strong medicine. (Nekolaichuk, 1990, p. 167)

Some said, "Working is medicine to me" (Nekolaichuk, 1990, p. 167). In addition, the chronically ill often rely on their personalities or "character" to help them manage:

Now I have to learn to use my strength of character as a drug. ... In this way I am able to manage, which is due more to my strength of character than to the insulin injections. (Nyhlén et al., 1987, p. 62-63)

For others, humor provides a “shot in the arm” that helps medicine work better:

Humor is the adrenaline of medicine — there is no question — humor is the adrenaline of medicine. (Nekolaichuk, 1990, p. 167)

The chronically ill often know the impact that their personal relationships have on their reactions to treatments:

Again, you have to have the support of your husband and family in every way. If you don't I would not have reacted as well to dialysis. I would not have as good treatment. Because we have people here in the dialysis unit like that. You know they're not getting the support and it makes a real difference in how they react, in how their treatments go, and how they feel. (Dick, 1984, p. 151)

A strong character, positive attitude, and strength of will were attributed to being able to go on. “It is really keeping the positive mind to deal with it. Whatever comes into my life, just really keeping the mind to just really go on” (Stuifbergen & Rogers, 1997, p. 13).

Several of the chronically ill found that joining a support group was an important source of health information as well as a source of friends:

I started my own [support] group. And we have a very tight group ... We are very close and very, very supportive of one another. We can call each other at any time. We exchange medical information. And we give each other a lot of common sense advice. (Nekolaichuk, 1990, p. 82)

Another invisible net or source of support for the participants was their body's innate wisdom. They found that when they attended to the pain in their bodies that “all of a sudden things were working.” They also said that when they ignored stopped listening to their bodies it had an impact on their health:

And the further you get away from listening to your body with your mind, and taxing your body, the more your body's going to protest and the more of your health you'll lose until finally you'll be flat on your back. (Garro, 1994, p. 785).

What the data show is that the chronically ill turn to alternative forms of health care therapies and information. This is because experienced and expert tightrope walkers are willing to experiment. The chronically ill also have higher standards for their relationships with their health care provider. Instead of expecting an authority figure, such as in stage

one, they want an equal, information-sharing partnership. When health care providers fail to live up to the expectations of the participants they will look elsewhere for health care support. For example, participants said that family relationships and working provided therapeutic value to their health. The chronically ill also found practical information and “wisdom” from support groups and from inside their bodies.

Summary

There is little doubt that the developmental stages of learning to live with the disease influence how the chronically ill make health care decisions. The chronically ill in the initial stage, or the novice tightrope walkers, are the most likely to make health care decisions based on providers’ recommendations. The experienced and master tightrope walkers come to decisions about health care advice independently from health care providers’ recommendations. This is because they are experts in “doing the work” of chronic illness.

The data show that the processes in stages two and three of “doing the work” further elucidate how the chronically ill come to decisions to follow or not follow medical advice. These processes were reported by all the participants, regardless of the type of illness they had. In general, their efforts at prioritizing, researching and evaluating, and experimenting result in health care decisions based on their research and experiences, not on those of the health care providers’. Despite this, the chronically ill reported that providers still had an impact on their health care experiences — positive or negative.

There was variation in the frequency and duration of the experimentation process among the participants. Specifically, diabetics said they experimented with their regimens more often than chronically ill with other types of illnesses. They also reported that it took a long time to find their balance and consequently they spent a longer period of time experimenting with their regimen. The complexity of the regimen and the difficulty in “controlling” their blood sugars were reported to be the primary reasons for their extended experimentation.

The process of researching and evaluating health care and health information was also a strong influence on participants making health care decisions independently from their providers' recommendations. For instance, some chronically ill reported that when they considered following prescribed regimens exactly or taking certain medications that it was not worth it to them.

The process of prioritizing seemed to play less of a role in how individuals' come to a decision to follow or not follow health care advice. However, it did influence their health standards. Often, the experienced and expert tightrope walkers settled for less than perfect health. Prioritizing can mean that the chronically ill sometimes ignore health care advice.

Finally, the chronically ill reported variation in the quality of support they received from health care providers while doing the work of chronic illness, or learning to live with it. Some participants described having a supportive health care provider who participated in an equal, information-sharing relationship with them. These relationships fostered more of a willingness to share control of the decision-making process by both patient and provider. The chronically ill said that the safety nets, or supportive health care providers, had the qualities of being trustworthy, supportive and flexible.

Other participants said that they have had experiences with negative health providers or drag nets. The qualities of the drag net were described by the chronically ill as health care professionals who omit information and exhibit controlling and disconfirming behaviors towards them. The participants experiences with the drag net made them very appreciative of doctors who acted as safety nets. Some participants remained with their drag net, but only under the condition of their absolute control of health care decisions. The most frequent reaction to drag nets was to find another doctor and seek alternative sources of support.

The chronically ill actively seek alternative forms of support, referred to as the invisible net. The invisible net was a source of comfort, healing and information, much like

the safety net. These alternative therapies and information sources were as different as the participants in the study.

Health care providers and researchers must face several issues in order to understand how the chronically ill make decisions about health care advice and how they can be successful at clinical interventions. Ignoring these issues, such as a patients own good reasons for making decisions about health care, will perpetuate the misunderstandings between providers and patients regarding health care choices. It may also interfere with health intervention measures, such as an adult immunization campaign.

Chapter Five

Discussion and Implications

Discussion

This analysis proceeded under the assumptions inherent in a social constructivist world view. Social constructivism posits that realities are constructions of the individual's mental framework and experiences. Therefore, methodologically, this study has attempted to elicit individual constructions of reality and to find a few constructions on which there is substantial consensus. The area of interest was chronic illness and how it related to decision-making about health care advice. What emerged from an inductive analysis of the participants' words was that decision-making about health care advice is made in the context of living *with* their illness and their relationships with health care providers. True to a qualitative study, these findings were not presupposed by the researcher and subsequently tested. Instead, these findings emerged from the data.

This study systematically sought to meet the criteria of a good qualitative study (refer to Chapter three for the criteria). Credibility of the findings, confirmability of the data and meaning in-context could not be tested because access to the participants was not possible. However, the studies selected for analysis met these criteria.

Throughout the analysis, recurring themes and patterns emerged from the indigenous concepts and led to theme development. For example, several participants referred to accepting less than "100% health". Another recurring pattern was the participants' description of experimenting with regimens as a "willingness to try new things". The concept of settling for less than 100% health fell under the process of prioritizing, and the "willingness to try new things" fit under the process of experimenting. Both prioritizing and experimenting fell under the general theme of processes inherent in learning to master the balancing act or learning to live with chronic illness. Both are examples of the internal homogeneity of this study.

Similarly, this analysis exhausted the data set until all explanations, interpretations and descriptions of the phenomena of interest were found. The data set, the participants' words, were analyzed at least five times by the researcher and the second coder.

Another characteristic of a good study is whether or not the findings would retain their explanatory power under other similar contexts. This study demonstrates transferability of the findings because it included participants with at least 20 different chronic conditions. Therefore, the findings are probably applicable to many different types of chronic illnesses. For instance, a lupus patient and an asthmatic would go through similar developmental stages in learning to live with his or her illness.

The overarching metaphor of the balancing act developed from participants' descriptions of learning to live with a chronic illness. For example, some said learning to live with a chronic illness is like "walking a fine line," which indicates the notion of balance. Others described a constant vigilance over every step they took. "I have to really think constantly, constantly about the consequences." As in balancing on the tightrope, there are definite health consequences for the chronically ill if they are not observant of their bodies and their regimen.

The idea of the tightrope walker implies the precariousness and danger that the newly diagnosed feel initially. Master tightrope walkers exhibit a more relaxed attitude about their ability to balance. Experienced balancers often report that their body and mind work together as one. The chronically ill also learn to live *with* the disease, instead of apart from it. When this happens, balancing becomes easier and more natural for them.

There are three stages of learning to master the balancing act. The first stage is comprised of participants who are newly diagnosed. These chronically ill individuals experience greater uncertainty and self-doubt than those in the later stages. The analysis found that this group would be more likely to make health care decisions based on their doctors' recommendations. The second stage is characterized by a tremendous output of energy and effort by the chronically ill as they try to balance and learn to live with their illness. Frequently they struggle for control, whether it's over the restrictions the illness has

put on them, against the illness itself, or against their health care providers. This stage is also unique because the chronically ill undergo a growth spurt. They absorb large amounts of information about their illness, treatments and side effects, and alternative therapies. They learn how their particular side effects, symptoms and illness progression compare with others that have the same condition. The third stage of learning to master the balancing act is different from the second in that the chronically ill have relaxed their efforts because they are now experts about their illnesses. There is less struggle for control and more acceptance and incorporation of illness into daily life.

The chronically ill attain balance through the cognitive and emotional strategies of prioritizing, researching and evaluating, and experimenting. Prioritizing helps them focus on the most important tasks. In the beginning, the priority is usually just balancing, but over time as they gain experience, the priorities shift to other areas, such as family and work. Researching and evaluating are steps the chronically ill take to empower themselves regarding their health. This process helps them regain a sense of control and purpose. They tailor their medical care to fit their needs best. In many cases, the chronically ill gain insight or information about treatments that the health care providers lack. Another way the chronically ill learn is by experimentation. Trial and error, or as one participant said, "by guess and by golly," is an effective way for them to gain information about their illness, and more specifically, what medical treatments or regimens work for them. Because the natural sciences, including medicine, are inexact sciences, no two people respond the same way to medications or treatments. Similarly, no two people with the same disease experience the exact same illness trajectory. Therefore, in many cases, experimentation without their providers' guidance is the quickest way to find out what works for them.

This study found that health care providers play a role in helping the chronically ill maintain balance. However, the providers' role becomes more limited in the later stages because they become more of a back-up rather than a primary source of help. Specifically, providers either help the chronically ill attain balance quicker and easier by being supportive and flexible, or they hinder them by leaving information out, trying to

control them, or disconfirming them. Ideally, the chronically ill seek the safety net, or the supportive, flexible health care provider. They want recognition for their expertise and seek “two-way information sharing.” Often the chronically ill will leave the providers who “bring them down.” A few stay with the negative health care providers, but in these instances, they do not allow them to act as a drag net. Instead, the chronically ill reduce the impact and input of these kinds of providers. Communication becomes a one-way process in which the patient tells the doctor what they want.

This analysis found that the chronically ill seek and use alternative sources of support and health care advice or therapies. This was referred to as the invisible net by the analyst. It differs from the safety net and the drag net mainly because it represents the health care choices of the chronically ill, not of the providers. The invisible net demonstrates the control that the individuals take over their health care because *they* seek out the support, information and therapies rather than the provider telling them what they should use. These alternative sources of support are not readily recognized or highly valued in the traditional health care community. Examples include “body listening”, humor, and spending time with family. In some cases, the invisible net directly conflicts with what the provider has recommended. For example, for some chronically ill, having financial security is a priority and a source of therapy, so they return to work despite their doctor’s advice not to do so.

There are currently very few studies that examine chronic illness in terms of making health care decisions. The studies that do exist frame the issue in terms of compliance. Therefore, this study adds to the body of literature on chronic illness by providing an understanding of *how* the chronically ill make decisions about professional medical advice. This study brings to light the specific processes and developmental stages in health care decision-making by the chronically ill.

The findings in this study support the themes in qualitative literature. The literature shows that are three major themes in qualitative research: processes, context and meaning in chronic illness. This study’s processes of prioritizing, researching and

evaluating, and experimenting are similar to the processes of comprehending, normalizing and managing found in the literature. However, the findings in this study provide more detailed information on how the chronically ill comprehend, normalize and manage. For example, prioritization helps the chronically ill manage by reducing time-consuming activities that are no longer important to them. This study also elucidates an important process not frequently found in the literature, experimentation. Experimentation is important because it explains why some chronically ill decide not to follow traditional health care advice and casts such a decision in a positive light. Experimentation can be a constructive step for the chronically ill because it helps them find the regimen, treatment, or source of support that is best for them, from their lived experience.

The findings in this study also support the meaning and context of living with chronic illness that is found in the literature. For instance, the meaning of transitional harmony (as in 'I feel fine now but it could change at any time') and the context of being in time (such as 'I may only have 5 years') also were found in this study. Meaning and context are important for understanding what it is like to be chronically ill and what it means for the individual.

Recommendations for Blue Cross/Blue Shield of Tennessee

BlueCare, a subsidiary of BC/BS of Tennessee, is in the second phase of its Adult Immunization Campaign. The objective is to increase the immunization rates of its high risk clients to 60% in accordance with the Healthy People 2000 goal.

The chronically ill in this study who are in stage one of learning to live with chronic illness said that they followed their health care providers' advice. Therefore, for this group, a physician reminder letter that tells them to suggest the influenza and pneumonia vaccines to their chronically ill patients probably would help increase vaccination rates. The challenge would be to ascertain a general time frame that represents the first stage for the newly diagnosed. The data from this study suggest that the chronically ill are in stage one from initial diagnosis to a year or two after. BC/BST or the physicians could determine which of their clients are in the initial stage by examination of medical records for the date

of diagnosis. Overall, the clients or patients in stage one probably represent the smallest population of high risk adults; therefore, one possible strategy would be to focus on the chronically ill in stages two and three.

The chronically ill in stages two and three often make health care choices based on their own priorities, research, and experiences. They said that they sought information on their own and from alternative sources, such as medical journals and support groups. Frequently they compared and evaluated the information that they received in order to weigh the risks versus the benefits of a therapy, medication or treatment. Specifically with medications, the chronically ill said that they wanted to know all of the possible side effects. They also said that they didn't want their hopes raised only to be let down in terms of treatments and medicines. For example, if a vaccine has a 20% chance of not working, they would want to know that as well as the side effects. The following recommendations to increase the vaccination rates of chronically ill adults are the following:

1. Target the message and medium to the developmental stage of chronic illness. Use client data, such as the date of the original diagnosis, to determine the likelihood of being in stages one, two, or three. If this is not available, an examination of the patient record for self-reported behaviors could be done. For example, if the provider has made a note that his or her patient is experimenting with their regimens, or if the provider reports "noncompliance," that's a good sign that a patient is in stage two or three.

2. Use language and appeals that correspond to the developmental stages. For example, tell the chronically ill in stage two that the vaccines would support them in *their* efforts to maintain balance or independence during the flu season. Another example would be to suggest that they take control of their health and ask about the vaccines. They might be told to not let the flu control them during flu season. Include information about the side effects and efficacy of the vaccines. For example, tell them that they will recover more quickly and feel better (not 100% or perfect) if they have had a vaccine and get the flu anyway. The chronically ill can understand fairly complicated risk information in the second and third stages.

3. Acknowledge that the chronically ill in stages two and three need to prioritize, research and evaluate, and experiment in order to master the balancing act. For example, use the information-seeking behavior of the chronically ill. Put vaccine messages or information in areas or in a medium that they use, such as web sites, medical libraries, and medical journals. Use support groups to diffuse information.

4. Adopt the characteristic language of the safety net or supportive health care provider. For example, tell the chronically ill that the vaccines are a source of support and tell them that their efforts at finding balance or managing regimens are recognized. Commend them for managing their disease. Likewise, avoid the language and qualities of the drag net. Avoid messages that disconfirm the patient. For example, do not tell them that "despite of what you heard, the flu shot doesn't cause the flu." Don't leave the pertinent information out, such as efficacy and side effects. Don't use condescending or overly simplistic language. Finally, avoid messages that tell the chronically ill what to do or that seem directing and controlling, such as "See your doctor now about the flu vaccine."

5. Acknowledge that the chronically ill seek alternative forms of support, or invisible nets. Use this understanding to give or target vaccine messages to these alternative resources. For example, give the information to the leaders of support groups for the chronically ill and use the language of the chronically ill. Another strategy would be to acknowledge alternative sources of support in the message directly targeted to the chronically ill. For example, say, "You might be able to find an extra boost from a flu vaccine like you do from your kids."

In a recent telephone conversation with Julie Wilson, clinical project manager of Blue Cross Blue Shield of Tennessee, the current strategies for the Adult Immunization Campaign were discussed (July, 1998). Ms. Wilson said that BC/BST currently used three main strategies to reach its high-risk population: The first was direct mail of postcard reminders. The second was an article in the member newsletter. The third was a pre-recorded telephone "hold" message that plays when clients are placed on hold. The limitations of current methods also were discussed in this conversation. First, roughly half

of the direct mailings are returned because BC/BST's clients are a "highly mobile group," and because they sometimes think that they are receiving a bill. Second, the article in the member newsletter seemed to be the most effective approach, but BC/BST does not have statistics to support that. Third, the pre-recorded "hold" message has too many barriers to message delivery and receipt. For example, not every client calls BC/BST, and not every person who calls is placed on hold.

It is suggested that BC/BST could improve its immunization rates of adults aged 18-64 by following the previous list of recommendations. In addition, the direct mail reminders and "hold" messages for the chronically ill in stages two and three of learning to live with a chronic illness are not recommended. However, the direct mail reminders and telephone hold messages would be more effective for the chronically ill who are in the first stage, or the novice tightrope walkers, and in the elderly, aged 65 and over.

The data show that the chronically ill are active information-seekers and users (as opposed to being passive receivers and nonusers) despite income and education levels. Therefore, it is suggested that BC/BST put vaccine messages and information in places where the chronically ill look so that its clients can find the information themselves. Participants in this study reported using medical journals and textbooks, libraries and support groups as sources of information.

The member newsletter might be an effective strategy to alert or stimulate interest in the topic of flu and pneumonia vaccines. The chronically ill in stages two and three likely would seek other sources for vaccine information once they had an interest in it. Therefore, an article in a newsletter could provide sources for them to go to, such as articles in the Journal of the American Medical Association, or to web sites that give accurate information on vaccines and the chronically ill. It is important that these sources provide information regarding the side effects and efficacy of the vaccines because the chronically ill said that is what they wanted to know. They also demonstrated that they could understand fairly complicated risk information. A good example of information about vaccine efficacy and risks that the chronically ill would use is found in the vaccine inserts. Inserts typically list

efficacy rates, side effects, which people are indicated to have it, and sources for more information (see Appendix F for a pneumococcal vaccine insert).

Another strategy would be to give vaccine information to pharmacists, who are often a primary source of health care information for patients. The chronically ill in stage one, or the newly diagnosed, are highly influenced by professional health care advice and a pharmacist intervention could work well for them. For the chronically ill in the later stages, particularly stage three, they may be seeing a pharmacist more often than a doctor because they are making health care choices independently of their doctor, but they still rely on a prescription. Pharmacist training and education in the pre-flu season could be an effective intervention for the chronically ill in all stages.

Areas for future research

This study looked at health decision-making as it relates directly to chronic illness. It is assumed in these recommendations that decisions about preventive health care advice might follow similar patterns. Whether preventive care advice is considered differently by the chronically ill should be investigated directly.

Because there are no qualitative research studies that investigate decisions to obtain or not obtain flu and pneumonia vaccines by high-risk chronically ill adults, a study should be initiated.

This study could not determine if there was a difference between men and women in decision-making about health care advice because the words of the participants were often not attributed to men or women. It would be helpful to know if such a difference exists.

These areas of research are necessary in order to meet the goal of Healthy People 2000 and BC/BST to increase vaccination rates of chronically ill adults under age 65. It is recommended that future studies take a qualitative approach in the areas of interest in order to gain insight and answers directly from the chronically ill. For example, focus groups and depth interviewing would be useful tools for asking the chronically ill these kinds of questions.

The role the pharmacist plays in the management of a chronic illness in adults under age 65 needs to be examined. It is possible that the chronically ill have greater trust or reliance on these health care professionals.

Finally, another area that merits investigation is from a macro perspective. It would be interesting to know whether or not the type of health care system, such as Canada's system and the U.S.'s market-driven system, relates to the chronically ill and decisions about health care advice. This study analyzed the words of patients in Canada, Australia, Sweden and the United Kingdom in addition to the U.S. There was no difference between these countries in how their chronically ill made decisions to follow or not follow health care advice, but it is possible that there might be a difference in vaccine receipt. For example, some countries might have widespread standing orders to vaccinate adults at high-risk for flu or pneumonia.

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APPENDICES

Appendix A: Letter from Blue Cross/Blue Shield of Tennessee



BlueCare

Influenza and Pneumococcal Vaccination Initiative

BlueCare BCBST

Julie Humble Wilson, RN, MSN, CCRN

Jennifer Atterton, MSS

BlueCare is a TennCareSM managed care organization (MCO) product of BlueCross BlueShield of Tennessee which uses the primary care gatekeeper model. The TennCareSM program was designed to provide managed health care services for the Medicaid eligible, the uninsured and the uninsurable. BlueCare has approximately 600,000 members, 2000 primary care managers (PCMs), 4000 specialty providers, and 112 hospitals throughout the state of Tennessee.

To meet the Healthy People 2000 goal of immunizing 60% of the high risk population, BlueCare organized an Adult Immunization Campaign. To identify which members were considered high-risk, we reviewed claims/ encounter data from January 01, 1994 to June 30, 1997 for specific ICD9 codes determined by the Health Employer Plan Data Information Set (HEDIS). The review of claims revealed 227,933 current BlueCare members to be high-risk. From this list, 147,007 members, for which BlueCare is the primary payor, were sent letters explaining their potential risks for flu and its complications and the value of immunization. In addition, 1421 Primary Care Managers were sent a packet which included the Advisory Committee on Immunization Practices' (ACIP) guidelines, BlueCare's reimbursement schedule for vaccinations, and a list of their members who had been identified as high-risk.

Appendix A: Letter from Blue Cross/Blue Shield (continued)



BlueCare

BlueCare p.2

Other components of the campaign included contracting with a home health agency to provide flu clinics for our members; placing an immunization article in the member newsletter; printing promotional slogans on provider and member mailings; and playing pre-recorded messages on the phone lines.

In 1996, before the described interventions, only 7% of members 65 years and older with BlueCare as the primary payor, had claims filed for an influenza vaccination, and only 1% for pneumococcal. In April 1998, we will evaluate the effectiveness of our interventions by reviewing claims/ encounter data for the 147,007 members, to determine the percentage who were vaccinated against flu and pneumonia.

Our 1998 Adult Immunization Campaign needs to target our members' perceptions of the flu and pneumonia vaccine. Member education should include the access and availability of immunization, the benefits, and the benign effects of the vaccine. How to disseminate this information to our members will be the challenge.

**Appendix B: Qualitative studies found in database search
(Note: Studies used in analysis are in bold)**

Author	Title/Source	Participant Characteristics	Reason for Exclusion
Adams, S., Pill, R., & Jones, A. (1997)	Medication, chronic illness and identity : The perspective of people with asthma. <u>Social Science and Medicine</u> , 45(2), 189-201.	N= 30, 14 women, 16 men, ages 19-57, asthma, diagnosis two-22 years,	It contained little regarding illness and decision to follow or not follow medical advice
Brooks, N. A., & Matson, R. R. (1987)	Managing multiple sclerosis. Research In the Sociology of Health Care , 6, 73-106.	N=19, ages 22-73, 8 men and 11 women, some diagnosed within past year, some diagnosed for 4-9 years, most married	
Charmaz, K. (1987)	Struggling for a self: Identity levels of the chronically ill. <u>Research in the Sociology of Health Care</u> , 6, 283-321.	N= 85, ages 20-91 years, men and women, cardiovascular diseases, diabetes, lupus erythematosus, and multiple sclerosis	It contained little regarding illness and decision to follow or not follow medical advice
Corbin, J., & Strauss, A. L. (1987)	Accompaniments of chronic illness: changes in body, self, biography and biographical time. <u>Research in the Sociology of Health Care</u> , 6, 249-281.	N=30, all married, cardiac disease, cancer, stroke, diabetes, some are paraplegic or quadriplegic, ages not determined	It contained little regarding illness and decision to follow or not follow medical advice
Dick, P. S. (1984)	<u>The other side of illness: A view from inside the chronic illness experience.</u> Unpublished doctoral dissertation.	N=22, 8 males, 14 women, ages 28-71 (mean age 49), most were married, 5 had kidney disease, 5 had rheumatoid arthritis, 8 had multiple sclerosis, 4 had lupus erythematosus,	

Appendix B: Qualitative studies found in database search (continued)

Dietrich, U. C. (1996)	Factors influencing the attitudes held by women with type II diabetes: a qualitative study. <u>Patient Education and Counseling</u> , 29, 13-23.	N=6, ages 37-65, diabetes, women only, diagnosis 5 weeks to 40 years	
Fallsberg, M. (1991)	<u>Reflections on medicines and medication: A qualitative analysis among people on long-term drug regimens</u> . Unpublished doctoral dissertation, University of Linköping, Sweden.	N=90, ages 50-80, with the majority ages 61-80, conditions: asthma, high blood pressure, and chronic pain	Doesn't meet age criteria
Ferrell, B. R. & Dow, K. H. (1996)	Portraits of cancer survivorship: a glimpse through the lens of survivors' eyes. <u>Cancer Practice</u> , 4(2), 76-80.	no data for number of participants, and sex, all cancer patients,	Cannot discern if it meets age criteria
Forsyth, G. L., Delaney, K. D., & Gresham, M. L. (1984)	Vying for a winning position: management style of the chronically ill. <u>Research in Nursing and Health</u> , 7, 181-188.	N=50, ages 29-85, MS, arthritis, Parkinsonism, COPD, and varied neurological diseases	Doesn't meet age criteria
Garro, L. C. (1994)	Narrative representations of chronic illness experience: mind, and body in stories concerning the temporomandibular joint (TMJ) <u>Social Science and Medicine</u> , 38(6), 775-778.	N=32, 27 women and 5 men, ages 23-65 chronic TMJ disease	
Kelly, M. P., Dickinson, H. (1997)	The narrative self in of illness. <u>The Sociological Review</u> , 254-278.	N=2, both age 29, a man and a woman, both have ulcerative & colitis	

Appendix B: Qualitative studies found in database search (continued)

Labrie, V. Y. (1987)	<u>Lupus: Managing a complex chronic disability.</u> Unpublished doctoral dissertation.	N=36, ages 22-50, lupus, men and women, some married	
Mapes, D. L. (1991)	<u>Self-management compliance and quality of life in chronic hemodialysis patients.</u> Unpublished doctoral dissertation, University of California, San Francisco.	N=114, 54 females and 60 males, ages 26-87, many ethnicities but mostly white, and all chronic hemodialysis patients	Mostly quantitative research no participant excerpts doesn't meet age criteria
Michael, S. R. (1996)	Integrating chronic illness into one's life: A phenomenological inquiry. <u>Journal of Holistic Nursing</u> , 14(3), 251-267	N=17, ages 21-75, all Caucasian, 3 men and 14 women, diabetes mellitus, coronary artery disease, rheumatoid arthritis, COPD and asthma	Doesn't meet age criteria
Nekolaichuk, C. L. (1990)	<u>Learning to live with uncertainty: The role of hope and medication compliance in chronic illness.</u> Unpublished master's thesis.	N=8, ages 21-65, 4 men and 4 women, diseases: rheumatoid arthritis, epilepsy, migraines, hypertension, chronic renal failure, breast cancer with metastases, cancer of the uterus and cervix, polymyalgia rheumatica, osteoporosis, Hodgkin's lymphoma and diabetes. Number of illnesses per individual ranged from one to four. Time since diagnosis ranged from one to 29 years	
Nyhlén, K.T., Lithner, F., & Norberg, A. (1987)	Experience of being diabetic: "It is up to oneself to manage." <u>Scandinavian Journal of Caring Sciences</u> , 1(2): 59-67.	N=20, ages 23-53, men and women, diabetes with good metabolic control and no signs of vascular damage	
Peyrot, M., McMurry, J. F., & Hedges, R. (1987)	<u>Living with diabetes: The role of personal and professional knowledge in symptom and regimen management. Research in the Sociology of Health Care</u> , 6, 107-146	N=21, ages 26-56, all married, male and female, all insulin-managed diabetics	

Appendix B: Qualitative studies found in database search (continued)

Price, M. J. (1988)	<u>Perceived uncertainty associated with the management trajectory of a chronic illness — diabetes mellitus.</u> Unpublished doctoral dissertation	N=19, ages 24-53, 7 men and 12 women, single, divorced and married, all insulin-managed diabetics, time since diagnosis was 1-22 years with the average being 7.3 years	
Robinson, I. (1990)	Personal narratives, social careers and medial courses: Analysing life trajectories in autobiographies of people with multiple sclerosis. <u>Social Science and Medicine</u> , 30(11), 1173-1186.	N=50, ages and sex not listed, multiple sclerosis, narrative analysis	Cannot discern if it meets age criteria
Stuitfbergen, A. & Rogers, S. (1997)	Health promotion: An essential component of rehabilitation for persons with chronic disabling conditions. <u>Advances In Nursing Science</u> , 19(4), 1-20.	N=20, ages 32-65, 15 women and 5 men, all had multiple sclerosis, years since diagnosis ranged from one to 19	
Thomas, B. L. (1988)	<u>Compliance in context: an exploratory study of chronic obstructive pulmonary disease from the interactional perspective.</u> Unpublished doctoral dissertation.	N=4, ages 61-68, 2 males, 2 females, COPD, interpretive interactionism	Not enough excerpts doesn't meet age criteria
Thorne, S. E. (1990)	<u>Constructive noncompliance in chronic illness. Holistic Nursing Practice</u> , 5(1), 62-69.	N=77, women and men, ages 16-76 (80% are between 26-65)	
Wainwright, S. P. (1997)	Transcending chronic liver disease: a qualitative study. <u>Journal of Clinical Nursing</u> 6, 43-53	N=10, ages not listed, sexes not listed, chronic liver disease	Cannot discern if it meets age criteria

Appendix C: Examples of participant excerpts

regarded not as models of how people act, but rather as ideological models of how people are believed to act. To take Good's suggestion one step further, these theories can be considered to derive from the cultural model. This model of what is expected to happen when someone is ill also contains rudimentary information about treatment and healing. Even when actual illness events bear little resemblance to the cultural model, the model serves as a backdrop for recognizing and comprehending variation and complexity.

The illness histories recounted in the interviews contrast significantly with the simplified world of the cultural model [33]. These are stories of individuals who unsuccessfully seek care and effective treatment. Those who told them were aware that their narratives did not fit the expected pattern [34]:

It's pretty disconcerting, you know, I was brought up like any other good American. If there's something wrong you go to the doctor and he tells you what it is and you can label it, you can take a pill and you get better. That's the way God intended. What's this crap? It... it was not the way. I never heard of anything like this (Paul, 36 years old).

I was sort of back on my old, my old beliefs that I could find some type of miracle cure. I could find something that was going to, something to say, here it is, that's what's wrong with you. We're going to do this, make a correction here, and do this and that. Maybe it's not an operation, maybe there's something else he's gonna suggest, but it's gonna be the, the end of the line. I won't worry about this business anymore (Brian, 28).

It was so long not knowing, not getting it all together and thinking I was going crazy. Then, all of a sudden, we got it all together, all these phantom pains and aches and sores and teeth and jaws, all boiled down to these three letters—TMJ. It was like we finally found out what was wrong with me, now, let's get it fixed. How long does it take to fix it? Well, we may never fix it. That did it... The whole world changed. I just felt like I didn't belong here anymore. I wasn't normal anymore (Nora, 44).

And I guess I figured it (TMJ) was like, you know, gum disease or something. I mean they would take care of it. I had no idea it was as complex, as difficult to understand, and as intractable to treat. I thought it was like the sinus infection. They give you some antibiotics. It goes away. I still believed that treatment worked (Gail, 37).

As pointed out earlier, overall, the stories are complex, with most extending over a number of years. While the onset could sometimes be identified, for others it was insidious, developing slowly over time. Once the decision to seek help is made, it is not a simple matter of consulting someone, being diagnosed and accepting treatment. More commonly, numerous consultations with different practitioners were reported, both prior to and after receiving a diagnosis of TMJ. Often, there was a period when the individual's claim to be ill was not validated by a diagnosis from a medical practitioner, causing difficulties in the workplace and sometimes at home. For those interviewed, improvement was only variably linked with treatment. Many received various diagnoses and were prescribed treatments which did not lead to improved health. The inability on the part of the practitioner

to identify anything wrong was often accompanied by an implication that the problem was basically of a psychological nature. A striking characteristic of a number of these stories is perseverance in seeking treatment and relief from pain and dysfunction. Additional features of the stories told are sketched below.

The way individuals generally reconstructed their illness histories followed a similar outline. The stories typically start by establishing the genesis of the illness as understood from the perspective of the present [35]. Thus, past events are often given different interpretations than they had when they happened. Two different patterns of establishing the genesis occurred. For the first, a precipitating factor or cause was identified, although other events might be seen as contributory. For example, one man who saw his TMJ as basically the result of an automobile accident, explained:

It just deteriorated and degenerated over the years... It's like you start with a little nip in something and it gets worse and worse (Tim, m, 25).

For those 25 individuals who identified a primary cause, each went on to describe a period which covered the genesis to the realization that the physical symptoms are a major disruption in the person's life. This could be as short as a few days or as long as many years.

In the second pattern, no event was singled out as the genesis, although one or two might be given more salience in the narrative than others. These persons would point to multiple possible causes that led to the development of TMJ over time. As in the first group, a growing awareness that there was something seriously wrong was commonly reported.

After establishing the genesis, the illness histories turned to two themes, the search for diagnosis and the search for effective treatment. While individuals may have sought help prior to recognizing that the problem is a major one, the search for diagnosis assumes a different character after this realization. Before, the pain and/or dysfunction remained, to a great extent, in the background of the individual's life. After, the illness takes on more significance in the individual's life and the search for diagnosis and treatment intensifies.

The search for diagnosis ends when the individual comes to think that their problems can be understood, at least partially, as TMJ. Sometimes this occurs when TMJ is first diagnosed, sometimes later after other possibilities are explored and rejected. Slightly over half of those interviewed consulted four or fewer practitioners before being diagnosed with TMJ, but others often saw a number of different practitioners, and were usually either given alternative diagnoses or told there was nothing physically wrong. This frequently led to such things as feelings of disenchant-

Appendix C: Examples of participant excerpts (continued)

The seriousness of the illness or the severity of the symptoms may also influence the uncertainty, that is, the less serious the problem and the less severe the symptoms, the lower the degree of uncertainty. Some participants did not initially view their illness as being serious, partly because their symptoms were minimal.

When it [the diabetes] started it wasn't that serious.....it was not serious, made to me serious, when it was first diagnosed.....Until now all the disease I had to me was problem that has to be coped with. But it did not really show that this problem was serious. That if you slack a little bit it could be dangerous later on.

And I took it [the diagnosis of hypertension] really lightly. I wasn't that scared at first. Then years later, you start getting more exposed to the media and telling you what it's really all about. And saw a few cases of your own that they had a stroke. And the thing is anytime you hear about somebody having a stroke, did he have high blood pressure? You always want to combine them.....As you get older there's more concern I mean. Concern. Let's not joke around with it. This is serious.

For others, the seriousness of the illness was manifested in the severity of symptoms.

And it took two weeks to diagnose it [sudden onset of massive pain] and that is two weeks without one minute's sleep because it is just massive pain.

Profile of or stigma attached to the illness. The profile or stigma of the illness may affect the degree of uncertainty. For example, some illnesses, such as cancer, have a high degree of fear associated with them, which may add to the uncertainty of the situation.

So many people when you're dealing with cancer - I don't know what other diseases, but when you're dealing with cancer - the first thing when they hear the word cancer, they throw their arms up in the air. It should be renamed. It should have a different

Appendix C: Examples of participant excerpts (continued)

name.....I've seen people sit in the aisle ways at [the hospital] women who would probably be their first visit over there, or they've been diagnosed for having cancer Crying. Crying pitifully.....They get dreadfully scared.....But it is a scary one. It should be renamed. Should find a funny name for it.

Two things are the worst part of medicine - one is worry that you have accommodated your family, if you are a man, and the other is the word cancer. Even you don't say it. Everybody is afraid to say cancer. I haven't got leprosy, I have got cancer. But they will avoid you. They will go on the other side of the street. They will go around you because - not that they don't love you - they are just petrified of that word cancer and they shouldn't be, but they are.

Other illnesses may contribute to the uncertainty of the situation due to their low profile and the lack of public awareness and knowledge regarding the illness process. This is reflected in the comments of two of the participants.

There needs to be more recognition of this [migraines] as being an illness or condition. There needs to be more information given out to people.

I kept ending up in the emergency ward. What am I doing here again?.....Between that and my parents confronting him [my physician], a combination of the two, he says you got epilepsy.....If somebody walks up to you and says you got epilepsy. What is it?.....What is it? Is it like leprosy? Am I gonna fall apart or what?

I just wish that doctors themselves were more clued in so they could themselves help this association [support group] educate the public. I mean they've got the pamphlets in their office, but that's not enough. I mean if somebody has a head injury or a cut or whatever, they should be told the possible effects. That's a major concern now a days. Now it is. Now it's a major concern.

Appendix C: Examples of participant excerpts (continued)

him with multiple symptoms of other illness and extreme fatigue. The key factor is for the physician to listen to the patient's medical history along with the laboratory tests. This is the way toward a definitive diagnosis. It becomes a "patient/physician participatory process." Only through in-depth sensitive and informed discussions with the patient about the pattern of symptoms will an accurate diagnosis take place.

Lupus awareness affects personal relationships with family, friends and general acquaintances. There are two central themes from the patient's perspective, in regard to this lack of awareness about lupus: one is that they have an illness or disorder that other people do not understand, and two, this lack of understanding and information is the basic source of negative and ignorant reactions by other people. Claudia explains this reaction:

The startling and difficult thing about lupus is so many people don't have the slightest idea what having this disease means. I have had people ask, 'Can I catch it' from simply being in the same room with me, or 'should I eat out of utensils that you have eaten out of.' This is ridiculous, lupus is not contagious (Labrie interview, 1984).

The core of the disease trajectory of lupus relates to the psychosocial issues that are necessary for the management of the illness

Appendix D: Example of vaccine reminder letter to provider



**BlueCrossBlueShield
of Connecticut**

A Member of the Blue Cross and Blue Shield
Association, an Association of Independent
Blue Cross and Blue Shield Plans

370 Bassett Road
North Haven, Connecticut 06473-4201
203/239-4911



September 1996

Dear Dr.:

As part of our ongoing efforts to promote high quality health care and service to our members, we are pleased to introduce you to our new flu prevention program. This program was created for high risk members in our BlueCare Health Plan and Constitution HealthCare programs. Its intent is to provide members with information about the flu and the importance of protecting against the flu by getting an annual flu shot.

The flu prevention program has been evaluated and endorsed by the Blue Cross & Blue Shield of Connecticut Primary Care Council, an advisory group of primary care physicians. Our goal in creating the flu prevention program is to help our members stay well by increasing our influenza vaccination rate for older adults and for members with chronic high risk conditions. We also hope to use the flu prevention program, with its emphasis on the flu vaccine, as a foundation for expanding our adult immunization program.

We will be sending the enclosed brochure to our health plan members in the following high risk groups:

- 65 years of age or older
- Adults and children with chronic disorders of the pulmonary or cardiovascular systems, including children with asthma
- Adults and children with chronic metabolic diseases, including diabetes mellitus, renal dysfunction, hemoglobinopathies, or immunosuppression

Specifically, using this criteria we have identified patients in your practice who will be sent the flu prevention materials beginning September 26, 1996 (please review the attached list).

In addition to this letter, we are sending you a supply of the enclosed brochure *"The Flu Season is Coming. Are You Ready?"* We invite you to share these brochures with appropriate patients in your practice.

As with all of our clinical programs, your feedback is always welcome.

Sincerely,

Vice President, Medical Policy and Chief Medical Officer

Appendix E: Example of vaccine reminder letter to client



**BlueCross BlueShield
of Connecticut**

A Member of the Blue Cross and Blue Shield
Association, an Association of Independent
Blue Cross and Blue Shield Plans

370 Bassett Road
North Haven, Connecticut 06473-4201
203/239-4911



September 1996

Dear Member:

The flu season is coming. Are you ready?

Each year 25 to 50 million Americans will suffer from fever, chills, headaches, sore throats, muscle aches, sneezing and runny noses. For most people, plenty of bed rest, lots of fluids and some acetaminophen or aspirin is all that's needed to conquer the flu. But, for older adults and people with chronic medical conditions, the flu and its complications pose a greater danger.

Our commitment at Blue Cross & Blue Shield of Connecticut is to keep you healthy. As part of this commitment we are pleased to introduce you to our flu prevention program, designed especially for our over-65 members and members with chronic medical conditions enrolled in our BlueCare Health Plan and Constitution HealthCare programs. The flu prevention program provides information about the flu and the importance of protecting against the flu by getting an annual flu shot. As you may already know, your health plan provides benefits for flu shots.

We encourage you to discuss getting a flu shot with your primary care physician. This relatively painless procedure is your best protection against the flu this season. The enclosed brochure has an appointment reminder card to help you remember to schedule and keep your flu shot appointment.

We hope the information in this packet will help you get ready for the upcoming flu season.

Sincerely,

Senior Clinical Quality Specialist

Appendix F: Pneumococcal Vaccine Insert

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Directions for Use of the LEDERJECT Disposable Syringe

1. Twist the plunger rod clockwise to be sure the rod is secure to rubber plunger base.
2. Hold needle shield in place with index finger and thumb of one hand while, with the other thumb, exert light pressure on plunger rod until the plunger base has been freed and demonstrates slight movement when pressure is applied.
3. Grasp the rubber needle shield at its base, twist and pull to remove.

To prevent needle stick injuries, needles should not be recapped, purposely bent, or broken by hand.

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PRIOR TO ADMINISTRATION OF THIS VACCINE, HEALTH CARE PERSONNEL SHOULD OBTAIN THE PARENT, GUARDIAN, OR ADULT PATIENT OF THE BENEFITARY'S PERMISSION TO ADMINISTER THE VACCINE.

RISKS AND RISKS OF IMMUNIZATION WITH PNEUMOCOCCAL VACCINE

Category C: Animal reproduction studies have not been conducted with PNU-IMUNE 23. It is also not known whether PNU-IMUNE 23 can cause fetal harm when administered to a pregnant woman or affect reproduction capacity. PNU-IMUNE 23 is not recommended for use in pregnant women.

It is not known whether the drug is excreted in human milk. Because many drugs are excreted in human milk, caution should be exercised when PNU-IMUNE 23 is administered to a nursing woman.

ADVERSE REACTIONS

Pneumococcal Vaccine Polyvalent PNU-IMUNE 23 is associated with a relatively low incidence of adverse reactions. The adverse reactions observed in clinical studies were of short duration and not serious.

In a study of 32 individuals who received PNU-IMUNE 23, 23 (72%) experienced local reaction characterized by soreness at the injection site within 3 days after immunization.¹⁹

Low grade fever (less than 37.8°C [100°F]) and mild myalgia occur occasionally and are usually confined to the 24 hour period following immunization. Rash and arthralgia have been reported infrequently.

Although rare, fever over 38.9°C (102°F) and marked local swelling have been reported with pneumococcal polysaccharide vaccine. Rash, urticaria, arthritis, arthralgia, and anemia have been reported rarely.

Patients with otherwise stable renal, hepatic, or hematologic purpura have, on rare occasions, experienced a relapse of thrombocytopenic purpura 2 to 14 days after immunization, and lasting up to 2 weeks.²⁰

Reactions of greater severity, or extent are unusual. Rarely, anaphylactoid reactions have been reported.

Temporal association of neurological disorders, such as paresthesias and acute radiculoneuropathy, including Guillain-Barré syndrome, have been reported following parenteral injections of biological products including pneumococcal vaccine.

DOSEAGE AND ADMINISTRATION

The immunization schedule consists of a single 0.5 mL dose given intramuscularly in a single dose. Intramuscular administration should be avoided. Do not inject intravenously.

Parenteral drug products should be inspected visually for particulate matter and discoloration prior to administration (see DESCRIPTION).

Before injection, the skin at the injection site should be cleansed with a suitable antiseptic. After removal of the needle, aspirate to help avoid inadvertent injection into a blood vessel.

Simultaneous Administration with Other Vaccines

Many patients who receive pneumococcal vaccine should also be immunized with influenza vaccine which may be given simultaneously at a different site. In contrast to pneumococcal vaccine, influenza vaccine is recommended annually.²¹

Reimmunization

The incidence of local reactions after reimmunization were found to be more severe than after initial immunization when the interval between immunizations was 13 months.²² Reports of reimmunization after longer intervals in children and adults, including a large group of elderly persons reimmunized at least 4 years after primary immunization, suggest a similar incidence of such reactions.²³ The immunization Practices Advisory Committee (ACIP) recommendations regarding reimmunization are as follows: Persons who receive the 14-valent vaccine should not routinely be reimmunized with the 23-valent vaccine. However, reimmunization with 23-valent vaccine should be strongly considered for persons who received the 14-valent vaccine if they are at highest risk of fatal pneumococcal infection (eg, asplenic patients). Reimmunization should be carefully considered for adults at highest risk who received the 23-valent vaccine 10 years before and for those shown to have a rapid decline in antibody levels (eg, patients with nephrotic syndrome, renal failure, or transplant patients). Reimmunization should be carefully considered after 3 to 5 years for children with nephrotic syndrome, asplenia, or sickle cell anemia who would be 10 years old or younger at the time of reimmunization.²⁴

HOW SUPPLIED

PNU-IMUNE 23 is supplied as follows:

NDC 0005-2309-31 2.5 mL Vial, for use with syringe only.

NDC 0005-2309-33 5 x 1 mL Dose (0.5 mL) LEDERJECT Disposable Syringes.

STORAGE

DO NOT FREEZE. STORE REFRIGERATED, AWAY FROM FREEZER COMPARTMENT AT 2°C to 8°C (36°F to 46°F).



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