

FORMATION OF A GUIDEBOOK FOR PRIMARY CARE PROVIDERS
TO ACCESS SPECIFIC PRINTED CONSUMER HEALTH
INFORMATION FOR THEIR PATIENTS

by

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the requirements for the degree

of

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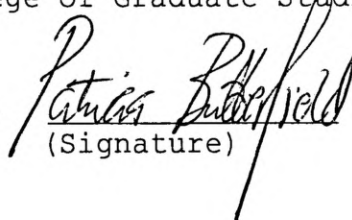
APPROVAL

of a professional project submitted by

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This professional paper has been read by each member of the professional project committee and has been found to be satisfactory regarding content, English usage, format, citations, bibliographic style, and consistency, and is ready for submission to the College of Graduate Studies.

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ABSTRACT

The volume of printed consumer health information has increased rapidly over the past decade and many primary care providers do not know how to obtain and screen the material for their patients. The purpose of this professional project was to develop a guidebook for primary care providers to access multiple printed consumer health information sources for their patients. The guidebook covered illness, wellness, and environmental health issues. The specific dimensions addressed in the guidebook included literacy level, regional issues, age-related issues, and cultural appropriateness.

Utilizing the Fieselmann Consumer Health Information Model as a framework for this project, a plan to develop the guidebook was created. The five main concepts of this model are: a) consumer health information, b) patient specific information, c) primary care specific information, d) mediating factors, and e) informed decision making. The plan to develop the guidebook, "The Primary Care Provider's Guide to Printed Consumer Health information", entailed a panel of experts to provide insight regarding specific sources of information based on their background, knowledge, and expertise. The author and the panel of experts identified and screened multiple sources that provide printed consumer health information. The sources were organized into the following three categories: wellness, illness, and environmental health. Each source was also categorized by the author as a brochure or pamphlet, Internet source, or book source with fact sheets. Each source was then classified according to information specific to cultural, regional, age, and literacy issues.

Outside the scope of this project is dissemination of the guidebook to health care providers in Gallatin County. Thus, evaluation of this guidebook will be determined by practical application.

CHAPTER 1

PURPOSE AND BACKGROUND

Purpose of the Professional Project

Patient education should be an integral component of all primary care contacts. Health education provides patients with a better understanding of their health concerns and allows patients to make informed decisions regarding their care. While approximately 37% of time during a primary care contact is devoted to patient education, it has been noted that patient retention of information is quite low (Tang & Newcomb, 1998). Without adequate retention of educational information, patients are less able to make the best choices regarding their health.

Although patient education activities are often provided in primary care settings, the patient may not be ready to learn in a clinical environment. Many patients need to be in a comfortable environment and frame of mind to be ready to learn (Redman, 1997). Often, locations outside the clinic are more conducive for the patient to learn about illnesses, wellness behaviors, or environmental

health issues. Providing patients with printed consumer health information is one approach providers can use to facilitate patient learning.

Printed consumer health information allows the patient to reexamine the information as needed in a comfortable learning environment and peaceful frame of mind.

Therefore, providing comprehensible and reliable printed health materials to the patient during a clinical visit can enhance patient education.

For health professionals to provide their patients with quality printed health materials, they must first know where to obtain them and how to identify reliable material. The volume of printed health information has increased rapidly over the past decade and many health care professionals do not know how to access, select, and screen appropriate materials. Moreover, searching the large volume of information is time consuming and not possible for most clinicians. Consequently, providing patients with appropriate printed consumer health materials is often neglected during clinical visits.

The purpose of this professional project was to develop a guidebook for primary care professionals wishing to provide printed consumer health information about

illnesses, wellness behaviors, and environmental health issues. The guidebook, "The Primary Care Provider's Guide to Printed Consumer Health Information" (see Appendix A), can assist such professionals to efficiently access affordable printed health information most suitable for their patients by identifying and screening materials using a panel of experts. The specific dimensions addressed in the guidebook included literacy level, regional issues, age-related issues, and cultural appropriateness. The significance of these specialized dimensions is addressed below in the theoretical model.

Background and Significance of the Project

For a patient to make an informed decision, the health care provider must supply them with information specific to their clinical and developmental situation. While patient specific health information may be provided, it is important to note that the final decision regarding health action belongs to the patient. The Fiesermann Consumer Health Information Model (The Fiesermann Model) was developed as the conceptual framework for this professional project and is predicated on the belief that informed patients make the best health decisions.

Conceptual Framework

The Fieselmann Model contains five concepts including:
 (a) consumer health information, (b) patient specific
 information, (c) primary care specific information, (d)
 mediating factors, and (e) informed decision-making (see
 figure 1).

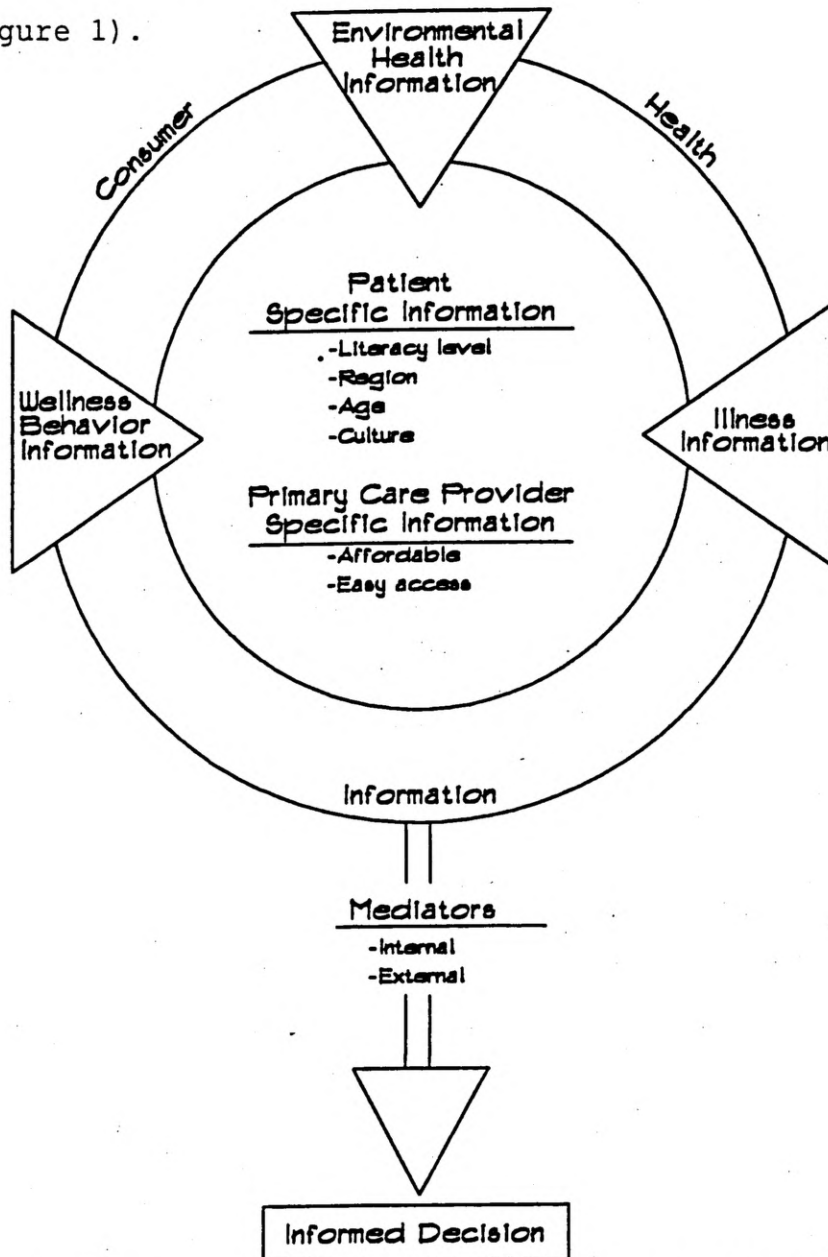


Figure 1. Fieselmann Consumer Health Information Model

The first concept is consumer health information in a primary care clinic. This includes three interacting subtopics: wellness behaviors, environmental health issues, and illness-specific information.

The second concept is patient specific information. To make an informed decision, the patient must be given information that is pertinent to their situation and background. Dimensions of this concept include appropriate literacy level, age, culture, and regional location of the patient.

Concept three is availability of material to the primary care provider. The information must be affordable and easily accessible to the health care provider.

The fourth concept addresses external or internal factors that mediate informed decision-making. An example of an external mediator may be mistrust developed between the patient and health care professional. Examples of an internal mediator include patient health beliefs, readiness, and motivation.

The final concept is based on the final possible outcome of an informed decision. Upon providing patient and provider specific consumer health information, the patient has the opportunity to make an informed decision.

The five major concepts in the model are based on the following assumptions:

1. The health care provider must provide the patient with wellness, environmental health, and illness information that is patient specific.
2. For a patient to make an informed decision, the provided information must be patient specific in regard to literacy, age, locality, and cultural background.
3. Wellness behaviors, environmental health, and illness encompass interrelating health issues.
4. Consumer materials must be affordable and easily accessible for the health care provider to furnish them to their patients.
5. Mediating factors, which may be internal or external to the patient, impact health decision-making.

The principles and assumptions from the Fieselmann Model are the guiding factors for this professional project. The background and significance of each concept from the Fieselmann Model will be addressed within the following sections. The organization follows a format of definitions supported by perspectives and discussion of each theoretical concept.

Concept a) Consumer Health Information

Conceptual Definition. "Any information that enables individuals to understand their health and make health-related decisions for themselves and their families" (Rees, 1998, p. 1).

Operational Definition. Information regarding wellness behaviors, illness-specific conditions, and environmental health issues specific for patients being seen in a primary care visit.

Perspectives on Consumer Health Information. The nation's health care system is changing. The expansion of managed care has created new information needs for patients regarding their health care choices. Consumer health information has evolved to accommodate this demand. Comprehensive health information, also referred to as consumer health information, addresses a wide variety of health topics (Rees, 1998).

Over the past several years, the quantity of consumer health information has greatly expanded. Several government agencies are involved in the generation, revision, and dissemination of consumer health information addressing specific topics. One such organization, the U.S. Department of Health and Human Services (DHHS), is

taking the following steps to enhance the quality of consumer health information. This agency has been taking a primary role in the growth of national health information that uses technology; coordinating access to consumer health information; and encouraging partnerships with other public and private organizations to extend the reach and impact of consumer health materials (Rees, 1998).

Improved organization of consumer health information may assist with informed choice promoting the patient's well-being or health (Prottie, 1989). Prottie stated that consumer health information is a significant aid in forming "decisions about health promotion, disease prevention, provision of care, monitoring, evaluation, and controlling health care resources" (Prottie, 1989, p. 26).

Subtopics of Concept a) Wellness
Behaviors, Illness, and Environmental Health

Conceptual Definition of Wellness Behavior. "A process of moving toward a greater awareness of and satisfaction from engaging in activities that move the person at any age, with others, toward fitness, good nutrition, positive relationships, stress management, a life purpose, a consistent belief system, commitment to self-care, and

environmental sensitivity and comfort" (Murray & Zentner, 1993, p. 635).

Operational Definition of Wellness Behavior. Health promotion/disease prevention or a state of soundness in body, mind, and spirit.

Conceptual Definition of Illness. "Human responses, whether by individuals or society, that place people in an imbalanced, unsustainable relationship with their environment and therefore decrease the ability to survive and to create a higher quality of life" (Edelman & Mandle, 1998, p. 13).

Operational Definition of Illness. Signs and symptoms, diagnosis, treatment, and prognosis of disease.

Conceptual Definition of Environmental Health. "Freedom from illness or injury related to exposure to toxic agents and other environmental conditions that are potentially detrimental to human health" (Pope, Synder, & Mood, 1995, p. 13).

Operational Definition of Environmental Health. Resources concerning the biologic, chemical, and physical conditions affecting the patient's area of living.

Perspectives on Wellness Behavior, Illness, and Environmental Health. Wellness behavior, illness, and

environmental health issues are three subtopics of consumer health information utilized in this project. These subtopics are important elements within the definitions of health promotion and disease prevention. O'Donnell, Bishop, & Kaplan (1997) noted that the purpose of health promotion is to improve the health of participants by promoting positive change in health behaviors and status.

Leavell and Clark (1965) developed three levels of prevention as guidelines for health professionals: primary prevention including health promotion and specific protection which precedes disease, secondary prevention including early diagnosis, prompt treatment, and disability limitation, and tertiary prevention including restoration and rehabilitation of health.

Three health promotion and disease prevention categories have been developed more recently. These categories include: health education involving optimal states of health and detection of illness, health protection which involves environmental health, and preventive health services which includes primary prevention. These categories must be integrated to increase health and social conditions in the community (Edelman & Mandle, 1998).

These categories of health education, health protection, and prevention services have three main goals defined within the "Healthy People 2000" report, a national initiative. The goals are to increase the span of a healthy life for every American, to decrease health disparities among Americans, and to achieve access to preventive services for all Americans (Edelman & Mandle, 1998). Ultimately, the goal of providing consumer health materials is to assist patients to live longer, healthier lives.

Concept b) Patient Specific Information

Conceptual Definition. Information for the individual that depends on the health-care system for diagnosis, treatment, or rehabilitation (Whitman, Graham, Gleit, and Boyd, 1992).

Operational Definition. Wellness behavior, illness, and environmental health information that relates specifically to the patient's background and addresses their age, culture, region, and literacy level.

Perspectives on Patient Specific Information. The provision of wellness, illness, and environmental health information can be enhanced if it is tailored to the

patient's health issue and demographic background.

Specific patient information includes customizing materials to the patient's concerns. Patient and health education encompasses the delivery and discussion of patient information. In this professional project, the delivery of specific or customized information is discussed in the literature review as one component of patient education.

Patient education is considered an ongoing process of diagnosis and intervention. Redman (1997) defined patient education as a patient's use of information and skills for whatever purpose is desired. The author noted that there are differences between the terms health education and patient education with the latter term referring to behavior change towards health promotion and compliance with a medical regimen.

DeAmicis (1997) stated that health education consists of assisting patients to make intelligent, informed decisions regarding their health needs. As health care professionals begin to educate their patients with consumer health information, there is an increased probability that patients will participate in health promotion and disease prevention activities.

Green and Kreuter (1990) stated that health education refers to "any combination of learning experiences designed to facilitate voluntary adaptation of behavior conducive to health" (p. 319). Health education is focused on making changes to improve health status while ensuring that patients' maintain control over their decisions and actions.

Patient education is a key component in any health care system, which allows patients to make their own decisions. Patient focused decisions are a key component in the Fieselmann Model. By providing wellness behavior, illness, and environmental health information specific to patients' needs and backgrounds, the opportunities for patients to make informed decisions increases. Four patient specific dimensions utilized in this project include regional lifestyle, culture, age, and literacy level.

The consideration of regional lifestyle is important towards the patient's quest to make an informed decision. There are multiple scales addressing urban and rural living characteristics. "A commonly agreed upon definition is that a rural community has < 2500 residents " (Bushy, 1990,

p. 29). This definition is important to note because people's lives are very different from urban to rural life.

The unique health care needs of rural dwellers are based on their occupations, differences in personalities, and health care services. "The health status of a rural community often is directly impacted by the primary economic resource of a region, such as farming, ranching, lumbering, and mining" (Bushy, 1990, p. 29). Many of these rural occupations may lead to injury or specific environmental concerns.

Often, the rural dweller defines health as the ability to work. Thus, when an occupational accident does occur, patient education should focus on getting the patient back to work. "A farmer who has lost his finger in a grain thresher several hours earlier does not have time during the harvesting season for a discussion of occupational safety" (Lee, 1998, p. 3).

Health information provided to rural individuals should also take into consideration personality differences. While every individual has their own unique personalities, ruralness has several common characteristics. Rural people are often noted to be self-reliant. "Rural dwellers are often self-reliant and resist

accepting help or services from those seen as outsiders" (Lee, 1998, p. 11). Bushy (1990) stated, "rural people are described as being more self-reliant and express greater reluctance to seek assistance from others" (p. 30).

Another common characteristic of rural residents may be reluctance to receive health care due to fear that friends, relatives, and neighbors may find out. Lack of privacy is a very important factor in receiving brochures. Maintaining privacy is a vital issue when giving and receiving brochures.

Lack of health care services in rural areas should also be noted when providing printed consumer health information. "Poverty, isolation, and limited options are often the reality of rural life for children" (Whitener, 1995, p. 217). In order to compensate for limited sources of health care, family and friends often provide care to sick individuals. "More rural families than urban families used relatives as caregivers, especially for young children" (Whitener, 1995, p. 217). This point is important to note because printed consumer health information may target such individuals.

Overall, "health care services must be tailored to suit the preferences of rural persons for family and

community help during periods of illness" (Lee, 1998, p. 15). Services and health information should be tailored to the patient's needs and the focus should include the regional location of the patient.

The second dimension of patient specific information is culture. The United States is permeated with cultural variations among a variety of racial, ethnic, and regional communities. The "Hispanic-American population is rapidly increasing and will after the turn of the century become the largest ethnic minority group in the United States" (Friedman, 1998, p. 506). Asian Americans are also one of the fastest-growing ethnic minorities in the United States. Native Americans are another diverse culture within the United States.

"It is significant to remember that the ability to work with cultural groups are dependent upon the ability to understand the group in terms of their background as they view it and not in terms of our interpretations of their background" (Clemen, 1977, p. 192).

Cultural empathy is the stated ability to understand a client's culture including the culture's assumptions, values, and patterns of thinking (Friedman, 1998). Ridley and Lingle's article (as cited in Friedman, 1998) noted that practitioners "working with families from cultures

different from their own must develop cultural empathy in order to be effective" (p. 184). Selecting printed health education materials should reflect a fundamental understanding of an individual's culture. "To understand and to be able to work efficaciously with families from cultures different from one's own, health care professionals must be aware of the unique, distinctive qualities and the variety of lifestyles, values, and structures in families' cultures" (Friedman, 1998, p. 176).

Culturally specific printed consumer health information refers to aspects of one's lifestyle, health values, and structure (including language or regional jargon). For this professional project, lifestyle included the poverty status of a culture and need for low-cost brochures or brochures that discuss inexpensive treatment suggestions.

Health values included prayer, relics, faith, herbs, and spices. "The provider's ignorance and arrogance regarding Latino's traditional beliefs and practices make families feel alienated and uncertain" (Friedman, 1998, p. 519).

"Language is a fundamental aspect of culture/ethnicity. The critical nature of language barriers also deserves mention" (Friedman, 1998, p. 177). Brochures were noted if

they are available in multiple language formats.

The third dimension of patient specific information is a patient's literacy level. "Approximately one out of every five adults in the United States cannot read or understand written health care information" (Davis, Michielutte, Askov, Williams, & Weiss, 1998, p. 613). Twenty percent of adults in the US, or about 40 million, are considered functionally illiterate meaning they read between the 3rd and 6th grade levels. "Illiteracy, a major problem facing the nation, has a direct effect on a patient's health" (Hanson-Divers, 1997, p. 56). The issue of illiteracy was important to this guidebook developed in this professional project because it addressed the importance of providing printed consumer health information that is specific to one's literacy level.

Because of the increased incidence of adults with literacy limitations, it is important for the primary care provider to become aware of the reading level of printed consumer health information provided to their patients. Many brochure companies advertise their information at the 6th grade level. Many patient information sources on the Internet are noted to average the 10th grade reading level (Graber, Kaebler, & Roller, 1999).

Patients tend not to discuss their reading level and may often be embarrassed to discuss their illiteracy.

"Relying on patients to voluntarily tell healthcare professionals of their inability to read is likely to result in missed opportunities to provide useful medication information resources" (Buck, 1998, p. 964). There are quick literacy tests that may be given to the patient, including the REALM, WRAT, and TOFHLA (Davis, et al., 1998).

Overall, it is important for primary care providers to become familiar with the patient and the patient's ability to read and comprehend written information addressing their health problems.

The last dimension of patient specific information is the age of the patient. Illness, wellness behaviors, and environmental health issues change throughout the lifespan. Many theories have been developed to describe the individual lifestyle changes through a lifespan. Erikson's eight life stages include infancy, early childhood, late childhood, early adolescence, adolescence, early adulthood, middle adulthood, and maturity. Havighurst's developmental tasks follow these stages as a framework for health promotion throughout the lifespan (Edelman & Mandle, 1998).

Health information that targets these different stages is called age-specific.

Children have specific learning needs and related health issues. Providing age-specific printed consumer health information specific for children can increase the chance of an informed decision for all family members. "An increased understanding of the child's health care needs can encourage a parent to accept recommended treatment" (Patterson, 1997, p. 48). It is important for printed consumer health information to be "at an appropriate level for the child's age" (Patterson, 1997, p. 48). Some common pediatric concepts include accidents, malignant neoplasms, and congenital anomalies (Valanis, 1999). Children also have multiple environmental health and wellness issues specific to their age. Some examples include immunizations, safety, and nutrition.

Young adults encounter different health related issues from the age of twenty-five to forty-four. The top illnesses affecting young adults include HIV (in men), accidents, heart disease, and malignant neoplasms (Valanis, 1999). Adults also have to make decisions regarding exercise, stress management, nutritional plans, and lifestyle choices such as smoking.

Middle adults span from age forty-five to age sixty-four. The main illnesses they encounter include heart disease, malignant neoplasms, and accidents in males and malignant neoplasms, heart disease, and cerebrovascular disease in women. Middle adulthood also is a time for persons to re-evaluate their exercise and nutritional plans, and stress management strategies.

"Providing elderly patients with customized information about their health concerns can improve their satisfaction with community medical practices" (Voelker, 1999, p. 1075). Older adults are considered those individuals aged sixty-five and older. Older adults most often encounter health problems associated with malignant neoplasms, heart disease, chronic obstructive pulmonary disease, and cerebrovascular disorders (Valanis, 1999). Physiologic changes that occur with aging can affect patterns of sleep, elimination, nutrition, and sensory functions.

In the guidebook created for this professional project, printed consumer health information that is age-specific referred to information that looked at all ages and targeted information specific to those illness, wellness behavior, and environmental health topics at each age

level.

Concept c) Primary Care
Provider Specific Information

Conceptual Definition. "Information for providers who develop sustained partnerships with patients and practice within the context of family and community" (Singleton, Sandowski, Green-Hernandez, Horvath, DiGregorio, & Holzemer, 1999, p. 3).

Operational Definition. Information for the primary care provider that is affordable and easily accessible in the course of their daily clinical practice.

Perspectives of Primary Care Provider Specific Information. Wellness, illness, and environmental health information can also be enhanced if it is easy for the health care provider to access and is affordable. Health care professionals are ideally suited to handout health information materials to patients at the time when they are most able to apply it to their lives. However, health care professionals are generally not well educated in selecting patient education specific to their patient's needs. "Recent data from medical schools in the United States show that only 65% offer instruction in patient education" (Redman, 1998, p. 105). Thus, there is little organization

of providing patient education for health care professionals.

"The Primary Care Provider's Guide to Printed Consumer Health Information" does not teach health care professionals how to provide patient specific information. However, the guidebook does provide multiple sources for the primary care provider to access and obtain patient specific materials conveniently.

Concept d) Mediators

Conceptual Definition. "Situations that place limitations on the ability to learn" (Billie, 1981, p. 74).

Operational Definition. Factors that affect patients making informed decisions (factors may be external or internal).

Perspectives on Factors that Mediate Health Decision Making. "The Primary Care Provider's Guide to Printed Consumer Health Information" addressed patient specific information with the intent of increasing the patient's ability to make an informed decision. However, there is evidence that multiple factors mediate components of decision-making. Some mediators are external, stemming from outside sources. Some mediators are internal stemming

from within the individual including differences in individual learning ability (Billie, 1981).

Billie (1981) identified several external mediators of learning, including lack of trust and rapport with health care professionals, meager physical conditions of patients, and insufficient socioeconomic status. Several internal barriers or mediators include unsatisfactory psychosocial adaptation, decreased motivation, and age, which may affect the speed of learning. "Patients learn only what they want or are motivated to learn" (Billie, 1981, p. 79).

Many theories have been developed which address the conditions and context needed to learn. Three of the more widely accepted theories are behavioral learning theory, cognitive theory, and social cognitive theory (Redman, 1997).

Behavioral learning theory is based on the premise that human behavior changes according to immediate consequences. Cognitive learning theory is the development of "insights or understandings that provide a potential guide for behavior" (Redman, 1997, p. 20). Social cognitive theory is based on the assumption that "humans respond primarily to cognitive representations of the

environment rather than to the environment itself" (Redman, 1997, p. 20).

Falvo (1985) noted several principles for the health professional to consider when providing material to patients. First, patients may totally ignore the information given and continue along their current pattern of action or inaction despite the consequences to their health and well-being. In contrast, some patients may totally adopt recommendations without question. Finally, some patients may appear to have decided to follow instructions but actually comply with only selected elements of health recommendations.

While "The Primary Care Provider's Guide to Printed Consumer Health Information" does not intend to control all mediating factors, it is important to acknowledge that these factors may or may not interfere in making informed decisions. The aim of the guidebook developed for this professional project was to enhance patients' opportunities to make informed decisions.

Concept e) Informed Decision Making

Conceptual Definition. "The right to determine what shall be done with ones own body" (Whitman, Graham, Gleit, & Boyd, 1992, p. 28).

Operational Definition. The ability to make choices regarding any issue based on the fact that the person making the choice has received all information pertinent to that choice.

Perspectives on Informed Health Decision Making. In the past, patients were often viewed as passive recipients of health care and were not expected to play an active role in their health care decisions. Some health professionals thought that their role would be diminished by sharing information with patients. Gradually, patients have become more sophisticated in seeking health information. Moreover, health professionals have found many benefits in sharing knowledge with their patients including patient compliance, increased understanding of illnesses and greater overall satisfaction (Falvo, 1985). "The Primary Care Provider's Guide to Printed Consumer Health Information", based on the Fieselmann Model is aimed

towards increasing the ability of patients to make informed decisions based on their individual autonomy.

Objective of the Project

The primary objective of this professional project was to assist health care professionals to access appropriate printed health information for their patients.

CHAPTER 2

REVIEW OF LITERATURE

Several barriers exist in the delivery and integration of health information by patients and their families. Yet, as the health care system changes, there are new options for the delivery of such information. The literature review will foster the identification of several of these issues and aid in the examination of new prospects for patient education. These new options have been integrated into the development of this professional project.

Present Strategies for the Delivery of Patient Education and Health Information

In the 1970s only 25% of Americans were high school graduates. Today, 64% of Americans have a diploma. "Along with increased education comes a desire to be more involved with the decision-making process" (Spencer, 1999, p. 88). Overall, American citizens are seeking more information regarding their health. Patients typically obtain health information from several professional and non-professional sources. Information may come from a health care provider

in the form of pamphlets, verbal instruction, or materials of a practitioner's own creation. The patient may also obtain health information on their own through magazines, non- health care professionals, television, and the Internet.

Information From Health Care Providers

Several issues exist which affect the delivery of health information by health care professionals. These issues include less education for providers regarding strategies for delivery of information, lack of time during clinical visits, and increased costs of patient visits. One critical issue is the challenge of locating, screening, and providing high quality health education materials to patients on an ongoing basis. Between the years 1982 to 1994, there had been a significant increase in the proportion of patients receiving written information about their medications. Unfortunately, only a small amount of this information was furnished through the patient's health care provider. Fifty-nine percent of the patients received handouts from pharmacists and only 15% from their physicians (Buck, 1998).

Health care professionals are "generally not well

educated as informants, and have little insight into the construction of educational materials and pamphlets"

(Selander, Troein, Finnegan, & Rastam, 1997, p. 181).

Redman (1998) noted that only 65% of medical schools offer instruction in patient education. Because health care professionals may not be well informed in providing patient information, patients may not receive optimal materials regarding their health concerns.

Cross, Rodgers, Tanenbaum, and Tilson (1998) noted that, "although the majority of health care professionals are willing to provide patient education, many do not know where to begin" (p. 591). They stated that even though health care professionals have an in-depth knowledge of medicine, they may not have the skills to provide patients with appropriate information about their health care. The authors clearly stated that it is every health provider's responsibility to provide patient education. They stated that there should be educational programs to teach health professionals how to provide information because teaching is a skill and "teachers must be taught to teach" (p. 594).

Lack of time is another issue frequently identified in the delivery of health information. O'Halloran (1997) noted that the length of time clients are in contact with

their health provider is shrinking due to changes in the health care system and insurance industry. As clinical time decreases, educational time also decreases. Tang and Newcomb (1998) noted that "37% (of time), was dedicated to performing patient education" in a primary care clinic (p. 564). A ten-minute visit allows an average of 3.7 minutes for teaching. Bonnel (1996) noted that patients are often not ready to learn during the course of a health care visit. She stated that "the health care provider and patient likely have 10 minutes together whether patients are ready to learn or not" (p. 314).

Patients' readiness to learn is a very important principle delineated within Redman's (1997) principles for effective teaching and learning. Today's delivery of patient information often does not take into account the patient's readiness to learn. "Although physicians spend a significant amount of time performing patient education, understanding and retention of the information has been shown to be modest at best" (Tang & Newcomb, 1998, p. 564). Many patients are not emotionally or cognitively ready to learn during their 15-minute clinic visit. O'Halloran (1997) identified many factors, such as fatigue or anxiety

caused by illness or social background, that affect the patient's learning readiness.

"Each learner is unique and has different learning needs and abilities" (Cross, et al., 1998, p. 591). These authors identified factors that influence the ability of patients to learn. These factors include motivation to learn, level of stress, sensory and motor abilities, and previous learning experiences.

The rising cost of patient education is another frequently recognized issue. O'Halloran (1997) observed that many third-party payers do not provide reimbursement for teaching activities. The author also noted that most institutions do not allocate financial resources for patient education, with expenditures coming from a "common pot". Without clinic funds that are specifically earmarked for teaching activities, providers may be forced to spend less time on patient education.

Mariotto (1999) concurred that increasing time for education will become more costly since doctors will have to block more time for patient visits.

"Balancing the interactions between doctors and patients is a noble and pressing idea. But partnership is not a magic formula. The ground is not quite ready. Massive long term financial and cultural investment is required to realize this opportunity

fully—but on the understanding that all patients have the right to delegate decisions to their doctor when this is the most comfortable solution for them” (p. 783).

Information Gathered by the Patient

Personal patient information searches can lead to opportunities for misunderstanding and reliance of poor quality educational materials. Patients may gather health information from friends or family that offer personal opinions rather than facts. They may also gather information from non-health care magazines or the Internet.

Recently, the Internet has become a ready source of health education materials. There are approximately 87 million regular users of the Internet in North America and approximately 50% of these individuals looked for medical information in the past 12 months. Those accessing medical information found over 15,000 health-related sites. Many health information sources on the Internet are not written at an appropriate literacy level for most patients. In addition, such information may also lack reliability (Graber, Roller, & Kaeble, 1999).

Jadad & Gagliardi (1998) noted a vast increase in the quantity of health information Internet sources. Their manuscript discussed the effects of this increase on

consumers and how it has become their responsibility to filter and judge applicable and credible sources. Because this process may be more difficult for lay persons, they stated that there needs to be instruments available to evaluate health information on the Internet. This manuscript provided a review of the few instruments available at this time to review health information sources. Within the author's review, it was noted that the instruments available are incomplete at this time.

Lipkin, Lima, and Weavers (1999) provided a short summary about health information on the Internet. This source indicated that it is important for consumers of health information on the Internet to realize that there are no governing bodies of information. Bill Rados, from the FDA stated that, "My advice to consumers about information on the Internet is the same as it is for other media: You can't believe everything you see, whether it's in a newspaper, on TV, or on a computer screen" (p. 1:26).

Choosing appropriate health information is only one aspect of misunderstanding that can occur in personal patient searches. Integration of this information is another potential area of misunderstanding. Patients' decisions to find health information and to use the

information are based on their health beliefs. "Health beliefs are a person's attitudes and ideas about health and illness. These convictions can be based on factual information, misleading information, common sense, myth, or unrealistic expectations" (DeAmicis, 1997, p. 14). Many theories have been developed that address the processes by which individuals assimilate information to make decisions. By classifying individuals, the goal is that the health care provider is able to identify and target certain areas needed in order to make a change towards health promotional behavior.

The Health Belief Model is one of the classic theories developed to understand how people assimilate information. This model was developed in the 1950s when the authors observed situations where there was widespread failure to accept public health preventive recommendations. The model was developed to explain the social and psychological context of preventive health behavior. This model stated that individuals start with certain perceived susceptibilities and seriousness of diseases. Based on modifying factors, such as the patient's age, personality, and cues to action (such as media campaigns), the individual has a perceived threat of a disease. Based on

this perceived threat, the person may or may not take a preventive health action (Rosenstock, 1974).

In contrast to the Health Belief Model, which is based on the assumption that health actions occur in response to fear and perceived risk, Milio believed that health actions are based on comfort and familiarity with the health choice. Milio (1976) studied the development of individual and community health-related choices. She stated that "most human beings, professional or nonprofessional, provider or consumer, make the easiest choices available to them most of the time, and not necessarily because of what they know is most healthful" (p. 435). The author pointed out that if knowing what is healthy automatically resulted in doing the healthy behavior, then health care professionals would be nonsmoking, low fat eaters. Milio's framework for prevention is based on a set of propositions predicated on the general idea that health-promoting decisions are made from the options available. Based on the recommendations from this framework, health care professionals should work at increasing the range of health-promotional choices available to persons in their community.

Understanding patients and the choices they make can be difficult. Patients are unique in many ways and are unable to be classified or stereotyped according to their views addressing health education. Thus, this professional project targets the distribution of printed health information allowing the option of making an informed decision, rather than planning to make health behavior changes.

Despite the many recognized problems regarding information distribution and assimilation, at this point in time there are few efforts to improve the manner in which patients receive health materials. Gustafson, Hawkins, Boberg, Pingree, Serlin, Graziano, and Chan (1999) noted that our health care system has not emphasized a critical examination of changes that may "enhance consumer knowledge, skills, or power to become partners in their care" (p. 1). Because the health care system is changing and patients are becoming more assertive in obtaining health information, research efforts should address a variety of approaches to enhancing consumer knowledge.

Outlook for Delivery of Health Education and Information

"We have witnessed an explosion in demands for information about medical treatments and today's patients want more information and greater opportunities to be active in their dealings with medical practitioners" (Frederikson, 1995, p. 237).

Having open channels of health information benefits patients in multiple ways. Shared decision making can lead to increase in empowerment, satisfaction, and compliance with health promotional activities.

Health information can help to provide clients with an expanded knowledge base, which is the first step towards empowerment. Gustafson, et al. (1999), placed great importance in sharing information with patients because it assists in building partnerships between patients and providers, which empowers patients.

" (A patient) with a deeper understanding of the diagnosis, treatment, and recovery and who has support from others, is much better equipped to cope with the illness, by using the health system more effectively and changing their health-related behaviors to influence their course of illness and reduce psychological distress" (Gustafson, et al., 1999, p. 1).

Empowerment is defined as an enabling process affecting initiation and persistence of a task by developing a sense of personal efficacy in an individual. Information can help in this process. Empowerment from increased

information can provide greater competence in decision and health activities (Conger & Robinara, 1988).

Tang, Newcomb, Gordon, and Kreider (1997) noted that changing roles within the health care system have led to an increased emphasis on patient empowerment. The author stated

"changing roles in health care call for patients to share increased responsibility for managing their health. Patients may need additional health-related information to participate more fully in health care decisions" (Tang, et al., 1997, p. 672).

Tang observed that patients are seeking more information today than at any time previously. Through shared decision-making, patients gain knowledge leading to increased compliance with treatment plans. Providing

"printed summary information to patients at the end of a clinic visit improves their understanding of their care, enhances their relationships with providers, improves their satisfaction with care, and motivates them to adhere to treatment plans" (Tang and Newcomb, 1998, p. 563).

As noted by Tang and Newcomb (1998), increasing patient understanding can also lead to greater satisfaction and compliance with a recommended treatment regime.

Frederikson (1995) stated that "specific information-related activities are important in terms of particular outcomes and, as the results showed, these outcomes

contribute significantly to overall satisfaction" (p. 245). Shared decision-making allows the patient to feel included as worthy participants in the consultation process.

Cross, et al. (1998) stated that in order to increase shared decision making, health professionals need to be more cognizant of their patient's self-image when providing instruction. "Patients who are treated with respect and who feel they are partners in the teaching/learning process are more likely to be active, positive participants" (p. 591).

Formulating Outlook Ideas into Action

The relationship between patients and health care providers is constantly changing. It is evolving into an active partnership, with each person contributing equally to decisions about treatment or care. Shared decision-making allows the health care professional to become a true patient advocate in health promotion.

There are multiple factors that make shared decision-making a challenge for all parties involved. As noted, health care professionals have limited backgrounds in teaching and in selecting appropriate information for each

patient. "In the medical setting, health information is generally oral and directed towards individual patients. It can be customized to accommodate the patient's needs and it can be supplemented with printed material selected to fit the occasion" (Selander, et al., 1997, p. 181).

Caban, Johnson, Marseille, and Wylie-Rosett (1999) acknowledged that "clinicians need to take an active role in tailoring programs to meet patient needs and promoting lifestyle changes" (p. 33). Taking into consideration time and budget constraints, the author stated that in order to tailor the patient's needs, providers need to include psychological and physiological variables in their assessment. Some of these variables include the patients' past history, present situation, current available resources, and current health status.

Gustafson and Tang emphasized the importance of customized health information. Gustafson stated that "patient education efforts have been much more successful when patients and families are provided with messages tailored to their own perceptions of threats and barriers" (Gustafson, et al., 1999, p. 2). Tang provided a guide for health care professionals to utilize when choosing

information to share with a patient. The guide is an acronym called P.A.T.I.E.N.T. Information.

'P'- stands for 'personal', patients have the desire for permanent access to specific information about their personal health.

'A'- stands for 'articulate', showing the importance of clarity of the presenting information. With clarity comes believability, which influences patient compliance.

'T'- stands for 'timely', providing access to information when the need arises.

'I'- stands for 'informative', which takes into account literacy level, language barriers, and all factors to make the materials patient-specific.

'E'- stands for 'endorsed', patients prefer information that is endorsed or known to be highly reliable from their physician.

'N'- stands for 'next-step', patients want concise and explicit instructions about their care.

'T'- stands for 'therapeutic', meaning "mechanisms to improve understanding and retention of patient information and instructions increase the change of patients' complying with the instruction" (Tang and Newcomb, 1998, p. 569).

Buck (1998) provided literacy and reading comprehension recommendations for the practitioner who is providing written medication information.

"Three basic factors must be met to provide optimal medication information, regardless of source or format: the materials must be readily available, the content must be useful to the patient or care provider, and the information must be easy to read and understand" (Buck, 1998, p. 962).

Since 20% of adults have basic reading and writing skills, handouts should be written at a less than 6th grade level. Bilingual materials should also be provided (Buck, 1998).

Cross, et al., (1998) aimed their customized learning toward understanding the patient. They stated that it is the responsibility of the health professional to evaluate the patient's motivation, ability, and availability to learning resources during the initial interview. Some of the teaching tips they provided were first to assess the patient's readiness to learn. Second, to assess the patient's needs and categorize them according to real needs, perceived need, potential needs, and felt needs. The third recommendation is to integrate the patient assessment into outcome statements. Outcome statements are learning goals for the patient to be evaluated at each

meeting. This article developed an acronym EDICT for teaching.

'E' - stands for 'Explain', which means that the provider explains the main ideas, paying particular attention to the sequencing issues and the outcomes.

'D' - stands for 'Demonstrate', which means that the provider gives hands-on demonstration of a task.

'I' - stands for 'Involve', which means that the provider involves the learner by providing an exercise that requires him or her to use or apply the ideas or information presented.

'C' - stands for 'Coach', which means that the provider observes the learner in the 'Involved' stage and provides corrective feedback.

'T' - stands for 'Test/Terminate/Transfer', which means the provider tests the learner to see if the outcomes have been accomplished. The provider then "designs a mechanism for checking to see if the learner transfers the new behavior or knowledge to the "real" world, and then terminates the learning activity" (p. 594).

Whitney (1999) delineated four issues that the health care professional should acknowledge in the teaching/learning process. The first issue requires that

the health professional learn to empower patients and families to participate in their health care. Health care professionals are patient advocates, which includes teaching patients how to make informed decisions. The second issue is that learning must include creativity. Each provider should take the responsibility to broaden their horizons and look for new and creative opportunities in learning and teaching strategies. The third issue is to encourage new thinking and have a collective desire to learn together. The desire to think of new ideas and learn new topics will be a positive change in patient care. The last issue presented in this article addresses anticipatory learning for the future. Whitney stated that "visionary leaders can anticipate new ideas and concepts and identify future successes" (p. 5).

Utilizing these theories about providing patients with information specific to their needs has been studied and found to enhance patient satisfaction and wellness behavior. One study showed that providing patient specific information increased the wellness behavior of receiving the pneumococcal vaccination. A low-literacy level educational tool was provided regarding the pneumococcal vaccination to inner-city, low socioeconomic status, low-

literacy, elderly population. Use of the tool improved pneumococcal vaccination rates. "The study suggests that educational materials need not be complex, elaborate, or "high-tech" to affect the foregoing favorable outcomes" (Jacobson, Thomas, Morton, Offutt, Shevlin, & Ray, 1999, p. 646)..

Another clinical study, conducted through Dartmouth Medical School, has provided evidence of increased patient satisfaction through the provision of customized information. "The study analyzed responses from 1651 patients aged 70 years or older who were in the care of 45 physicians in 22 primary care practices in New Hampshire" (Voelker, 1999, p. 1075). The outcomes showed that providing patients with customized information about their health concern improved their satisfaction with community medical practices.

The ideas summarized within this literature review are aimed at increasing access to individualized patient information; this in turn may enhance the process of shared decision-making. Many of these themes have been integrated into "The Primary Care Provider's Guide to Printed Consumer Health Information". Based on the Fieselman Model, it is important to remember that while utilizing theories to

enhance the teaching-learning process, there are always factors/mediators that may impede progress to an informed health decision. However, attempts to utilize this recent literature to help health providers deliver consumer health information specific to their patients has been considered in the development of the guidebook.

CHAPTER 3

METHODOLOGY

The purpose of this professional project was to promote access to printed consumer health information for primary care professionals practicing in Montana and the rural West. While the health information sources in the guidebook are appropriate for providers in other communities, the primary focus is communities in Montana. An informal assessment for the need of compiled health information sources was initiated in Montana, therefore the book is applicable mostly for these health care providers.

The assembled guidebook, "The Primary Health Care Provider's Guide to Printed Consumer Health Information", lists numerous sources of printed information tailored for patient education based on the Fieselmann Model. The guidebook addresses the four dimensions of patient-tailored learning described in the Fieselmann Model: literacy level, cultural status, regional location, and age. This model also divides materials into the topic areas of illness, wellness behavior, and environmental health. The whole

project is predicated on the central assumption that the provision of health information specific to a patient's situation can facilitate the making of good health and lifestyle decisions. This chapter outlines the methods used to develop the guidebook.

Development of the Fieselmann Model

The Fieselmann Model was specifically developed for this professional project to provide an organizing framework addressing and evaluating consumer health information. Once the decision was made to develop a guidebook addressing printed health information sources for health care providers primarily in Montana, a conceptual framework was needed. The conceptual framework acted as a structural guide for the project. Wellness, illness, and environmental health were the first topics under consumer health information to be developed. These consumer health information topics covered most patient health concerns. Consumer health information encompasses all consumers' health concerns and therefore should include illness, wellness, and environmental health concerns.

Development of the patient and provider specific topics were integrated into the framework next. The literature

helped to identify specific needs of each type of patient grouping. Cultural, age, reading, and regional needs were drawn from the literature and utilized as specific needs of patients for this model and guidebook. Specific needs of providers include affordability and easy access to printed health information.

The ultimate goal of the model, to facilitate informed patient decision-making, encompasses an ongoing effort for all health providers. Many theories examined in the literature review for this project promote shared patient and provider partnerships, and development of patients' decisions toward healthy behavior. The outcome scope of this project was determined to be informed decision-making. The goal is that the patient may have the opportunity to make an informed health decision through patient education and health information from their health care provider. Milio (1976) believed that health-promoting patient decisions are made on options available. Thus, by distributing health materials to a greater amount of patients, a greater proportion of patients are able to find options to be informed about health promoting choices.

Once the outcome of informed decision-making was determined, some discussion was needed to remind the reader

that many factors may intervene before a patient can make an informed decision. This discussion primarily focused on the role of mediators, and how they can alter the trajectory of decision-making. The mediators for this model included internal and external factors affecting the patient's ability to make an informed decision. The professional project was initiated in accordance to these specific dimensions and concepts of the Fieselmann Model.

A variety of printed consumer health information sources were obtained through primary and secondary contacts by the author and through a panel of experts. The author collected various sources through networking with professionals, library research, Internet searches, informal interviews, and observation at three health information centers. In addition, the author consulted a panel of experts who suggested additional sources and assisted with evaluation of these sources. This model and work provided the guidebook's foundation.

Assembling the Expert Panel

A panel of content experts was chosen to provide insight regarding specific sources of information based on their background, knowledge, and expertise. The experts

were selected by the author based on information gathered about each expert's specialty area of clinical practice or research. Seven teams made of two individuals were utilized for their expertise in the following topic areas; wellness behavior, illnesses, environmental health, regional issues, literacy levels, cultural issues, and age-related issues. The panel included one medical librarian, one master's prepared health educator, three medical doctors, four doctorally-prepared nurses, one student family nurse practitioner, two practicing family nurse practitioners, and one non-practicing pediatric nurse practitioner (see Appendix B for member listing). These individuals came from Montana, Iowa, and Maryland.

The family and pediatric nurse practitioners as well as the physicians were selected based on their clinical expertise. These primary care providers identified practical sources of health information commonly used in the clinical settings.

The medical librarian had extensive experience in selecting materials for health information centers. These centers are designated for patients interested in learning more about their personal health issues. These centers provide computers with access to Internet sites and CD-ROMS

related to health. They also directly provide pamphlets, brochures, books, and video tapes addressing a variety of health concerns. The medical librarian is currently selecting materials for a future health information center at Bozeman Deaconess Hospital.

The doctorally-prepared academic nurses were chosen for the panel because of comprehensive knowledge in areas of environmental health, cultural appropriateness, and regional issues. Each individual had either extensive research or clinical experience in these fields.

A health educator was chosen based on her competence in working with patients and providing them with printed health information. In addition, she had experience in working in centers that provide health information and education for patients and health care employees.

A cover letter and questionnaire were designed for the panel of experts to share their knowledge regarding printed consumer health information in their related topic areas. The cover letter provided an explanation about the author and the project. It also included a detailed explanation of what was expected from each member. The questionnaire had two identifying questions and two questions developed to obtain printed consumer health information sources from

the expert. The first two questions asked the client's name and area of expertise. The third question asked where the experts obtain most of their printed health materials. The last question gave the experts the opportunity to express their top three choices of printed consumer health information sources and provided room for explanation of each choice. An example of a printed consumer health information source was provided in the questionnaire. The panel of experts received the cover letter, questionnaire, and self-addressed envelope in May and June of 1999 (see Appendix C). All questionnaires were returned to the investigator by September of 1999. The goal of the panel of experts was to increase the breadth and quality of sources of printed consumer health information to be used in the guidebook.

Organization of the Guidebook

After assembling the information gathered by the author and the expert panel, and sorting it according to topic areas, the guidebook was created. The data was sorted and organized by the author into the following three categories; wellness behavior, illness, or environmental health. These categories were chosen based on the

Fieselmann Model and because they encompass most patient needs. Each source was also categorized by the author as a brochure or pamphlet, Internet source, or book with fact sheets. For the scope of this project, only printed sources of health information were chosen within these categories.

Sources within the brochure/pamphlet category were further classified by their topic breadth and specificity. Some organizations provide materials addressing a wide spectrum of health issues, while others such as the American Heart Association, supply brochures about specific health concerns. Identified Internet sources were limited to sites offering information that may be printed and given directly to patients. The identified book sources are limited to books with fact sheets that may be photocopied and distributed.

The guidebook is prefaced with a disclaimer and a letter to readers explaining the organization of the book. There is a reminder of the rating system at the beginning of each chapter. According to these categories, the information sources were organized into chapters 1 (brochures), chapter 2 (Internet sources), or chapter 3 (books with fact sheets). Within each chapter, the sources

were further categorized into wellness, illness, or environmental health. The guidebook is printed in Times New Roman, font 12 for easy reading and has a colorful front cover.

Each source was reviewed by the author, and classified according to information specific to cultural, regional, age, and literacy issues. Chapter 1 further reviewed the high quality dimensions for each of the patient specific issues.

Rating System

A symbol-coded rating system, was used to organize information within the guidebook. Sources were rated with a symbol signifying that they are considered to provide high quality information addressing regional issues, cultural status, literacy level, and age issues (see figure 2). For example, information that received a high quality regional focus included printed consumer health information on topics specific to rural or urban settings. These sources contain information on rural job related injury, illness, wellness, and environmental hazards. Examples of such jobs include lumbering, ranching, fishing, and mining.

In this guidebook, printed consumer health information that addressed rural lifestyle was rated with a tractor symbol.

<u>Legend for Printed Consumer Health Information</u>	
	Literacy Level- Pertains to sources that are at an appropriate reading level.
	Regional Issues- Sources that pertain to rural versus urban living.
	Age-Related Issues- Sources that encompass different age groups including pediatrics, adults, and geriatrics.
	Cultural Issues- Sources that pertain to specific cultures or languages.
	Cost- Includes the price of the brochure, pamphlet or other source.

Figure 2: Legend for Printed Consumer Health Information

A high quality age-related focus included printed consumer health information that focused on the health needs of multiple age groups. The information was organized according to age group or developmental stage. Printed consumer health information that was considered age-specific, was designated with a family symbol.

Information that was rated according to a cultural focus included printed consumer health information that can be obtained in multiple languages and incorporates

culturally appropriate information into health recommendations. Some of the cultural groups addressed include Hispanic ethnicity and migrant farm workers (information in Spanish). Printed consumer health information that took into consideration issues of cultural appropriateness regarding lifestyle, beliefs, and language, was identified with a globe symbol.

A high literacy focus included printed consumer health information that targeted the average reader (a 6th grade level). A high literacy focus may also customize brochures to target each client's specific literacy level. For this guidebook, any printed consumer health information considered literacy-specific was designated with a book symbol.

Since, the cost of printed consumer health information is highly variable, materials that have prices listed were highlighted with a money symbol.

Because the rating system within this guidebook is based primarily on the author's opinion, the sources are rated on the presence or absence of the patient specific categories. This rating system was chosen over an integrated scaled system (e.g., 1 to 5) because of its relative simplicity.

Overview of Timeline

In the fall of 1998, the author volunteered at Bozeman Deaconess Hospital in the development of a health information center for patients. The goal of the center was to help patients obtain health materials regarding their specific health concern. The author examined multiple methods of providing health information including videos, textbooks, journals, brochure organizations, CD-ROMS, and Internet sources. At this time, it was noted that the abundant information had not been classified or organized by topic. There was no guide to obtain or screen printed consumer health information. The idea for the professional project was derived from this experience. Once the idea for the project was developed, the fall semester of 1998 was utilized to obtain articles and books on the topic.

In the spring of 1999, the author met with the committee chair and set up a committee. Together, they further defined the scope of the project, and a first draft covering the purpose and review of literature was written. The framework for the project, the Fieselmann Model, was developed specifically for this professional project during

the spring semester of 1999.

The cover letter and questionnaire were sent out and returned from the panel of experts in the summer of 1999. At this time, the methodology was formed. During the summer of 1999, work was also completed on formation of the guidebook.

In the fall of 1999, the chapters of methodology and project outcomes were completed as well as completion of most of the guidebook. Committee meetings were held on a monthly basis to review each chapter and provide input for revisions.

CHAPTER 4

PROJECT OUTCOMES

Chapter three addressed the process and activities that led to the development of "The Primary Care Provider's Guide to Printed Consumer Health Information". Chapter four provides a summary of the evaluation of the guidebook and includes limitations and recommendations for future studies.

The purpose behind the guidebook was to assist health care providers to access patient specific health information. This purpose was predicated on the principle that informed decision-making regarding personal health can be enhanced through the provision of effective printed health information.

Evaluation

The guidebook can aid in promoting informed decision making by directing health care providers to comprehensive and easily accessible sources of printed consumer health information. It is comprehensive in several ways. The

guidebook provides sources of information addressing wellness behavior, illness, and environmental health. It also categorizes the sources into brochures and pamphlets, internet sources, and textbooks. Each source is further categorized to provide information specific to patient needs in regard to literacy level, culture, age, and region. Each brochure source is expanded into broad or specific topics.

The guidebook is easy to follow with a preface that thoroughly describes the organization of the guidebook. An index follows the preface guiding the reader to pages of interest. There is a legend in the preface and at the beginning of each chapter to help guide the reader to patient specific information. Brochures, pamphlets, Internet materials, and textbooks are covered in separate chapters.

A formal assessment of the guidebook's usefulness and ability to assist the patients with informed decisions was not done for this project. Evaluation for this guidebook will be determined by practical application of the guidebook. The guidebook's success will be measured by the ability of primary health care providers to utilize the information contained in the guidebook.

Limitations of the Project

While there are limitations for any project, four limitations were identified within the context of this project. The first limitation involved the factor that this project only included printed information. Other methods of providing health information include audio and visual aids. These methods are very important for patients that do not read or those who learn best by other methods, such as through discussion, video instruction, or computer assisted educational materials. This guidebook does not specifically address consumer health information for patients that do not read. The printed sources were also limited to brochures, Internet sources, and fact sheets specifically combined in a book for the health care provider. Other sources of printed material include CD-ROMS and books with fact sheets.

The second limitation identified was the difficulty in obtaining all pertinent sources of information addressing a particular topic. While the opinion of the expert panel increased the probability of identifying information in a comprehensive manner, inevitably, some sources were missed. In addition, there are associations, companies, and web

sites that create health information sources constantly. For example, currently there are approximately 12,000 health care web sites and 500 medical associations. Thus, the choice for this guidebook was narrowed. The sources chosen to be included in this guidebook were some of the most commonly used and widely accepted.

The third limitation was the difficulty associated with identifying sources that specifically addressed geographic and regional perspectives of health. Many brochure companies included a paragraph about the literacy level of the brochure they were providing or other languages. They also included brochures specific for children, adults, and geriatrics. However, there was limited information regarding the specificity of information addressing rural communities. Thus, comments about rural living and health care issues are limited. However, as rural issues become identified more prominently in the health care literature, more health information will be created that address those needs.

The fourth limitation was the dynamic element of consumer health information. The health care system, as well as health informatics, changes every day. The sources compiled in 1999 for this guidebook may become out of date

within months to years. Internet web sites frequently come and go. However, one goal beyond the scope of this project would be to keep the guidebook updated with new editions every two to three years.

Implications and Recommendations for Future Study

Implications

"Patients need to feel they are not only recipients of information but also that they play an active part in their own health. Even though patients now receive more information, they still are often not actively engaged in the teaching process. It becomes increasingly obvious that effective patient teaching is a shared responsibility between patient and health professional" (Falvo, 1985, p. 159).

The sharing of health information, makes it possible for the patient to make an informed decision regarding their health. The implications of an informed decision include increased patient understanding, satisfaction, and empowerment.

Increased patient understanding is the main goal of patient education.

"In patient education, information should be directed not only toward the patient's understanding of his or her condition and treatment but also toward adaptation and behavioral changes that will produce positive health outcomes" (Lipkin, et al., 1999, p. 1:1).

Understanding is an important ingredient in promoting positive health outcomes.

Through shared decision-making, patients gain knowledge leading to increased compliance and satisfaction with their health care. Increased patient understanding can also lead to greater satisfaction and compliance. Shared decision-making allows patients to feel included as worthy participants in the consultation process.

Empowerment is an enabling process affecting initiation and persistence of a task by developing a sense of personal efficacy in an individual. Health information can aid in the process of empowering patients to provide the most effective self-care in response to their health problems. Empowerment from increased information can provide greater competence in decision and health activities (Conger & Rabindra, 1988).

Recommendations for Future Study

Recommendations for future study involve continued research regarding patient understanding, satisfaction, and empowerment in relation to consumer health information. It would also be useful to study the relationship between providing information and formulating informed decisions.

Future studies could explore outcomes of patient understanding, satisfaction, and empowerment from providing health information. There could also be studies to identify what methods of providing health information ultimately have the best outcomes.

A second recommendation involves studying the effectiveness of printed consumer health information in comparison with other sources such as audiotapes and videotapes. Many people do not read or tend to learn through other methods. Further studies involving comparisons in information retention between different education methods would be useful in identifying the best learning techniques.

Recommendations Outside the Scope of this Project

Activities that are considered outside the scope of this project include dissemination of the guidebook to health care professionals throughout Gallatin County. Funding will be investigated in order to make several copies of the guidebook at low cost to the author.

Two strategies have been planned to enhance use of the guidebook after dissemination. First, the preface of the guidebook provides a comprehensive explanation of how the

health care provider can utilize the book to obtain health information for their patients. For example, they might identify their scope of patients as pediatrics and find suitable brochures for a child and caretaker.

Overall, the main use of the guidebook is for the health care professional to identify different methods of providing health information for their patients. They can identify which method works best for their clinic and patients. A larger quantity of health information sources can be compiled. Once the health care provider has recognized the method to be used in their clinic and created their system for use of printed consumer health information, the guidebook will have a different use.

After a health care provider has their system developed, the guidebook can be used to add to the system or make changes as needed. A second strategy to assist with encouraging the provider to continue with these uses is based on Rogers' Diffusion Model of Change (see figure 3). Rogers developed a model for change that included five stages. These stages follow a linear path to final adoption or rejection of something new. Since this guidebook will be something new that the health care

provider will decide to adopt or reject, this model is important to review (Tiffany & Lutjens, 1998).

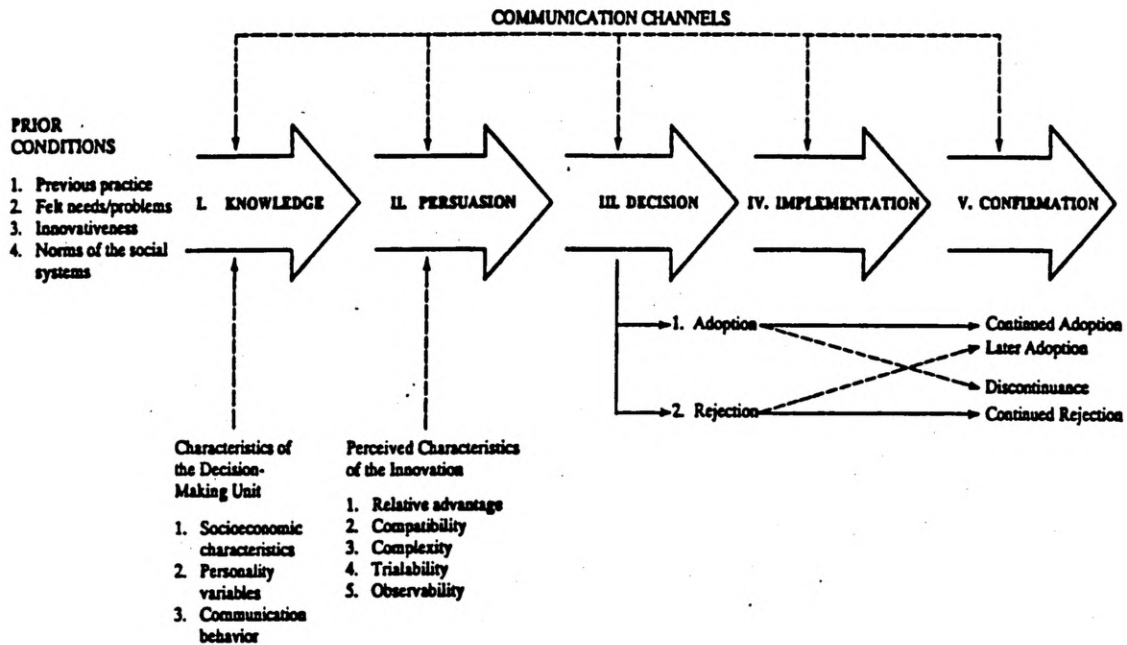


Figure 3: Rogers' Diffusion Model

The last stage in this model is called the confirmation stage. This is the final phase where the health care provider can choose to adopt or reject the guidebook. This stage can be considered an ongoing stage. Adoption or rejection of the guidebook can take place even after the guidebook has been used to plan a system for printed health information. Discontinuation can occur at

any time. Rogers suggests that in order to avoid discontinuation, the implementer should understand implications for planners and implement a plan during the ongoing confirmation stage (Tiffany & Lutjens, 1998).

Ideally a plan to continue with adoption and practical use of the guidebook would encompass a personal visit for each health care provider with the implementer. Rogers identifies this as a stabilizer role, in which "planners solidify adoption and prevent discontinuance... by appearing everywhere to help, guide, give reinforcing messages, and support adopters" (Tiffany & Lutjens, 1998, p. 226).

Unfortunately, there are time and effort constraints that would prevent this strategy for the guidebook. A more practical strategy is based on Rogers ability-developer role. This strategy is based on a role where the planner or implementer sends messages to reinforce adoption decisions (Tiffany & Lutjens, 1998). This approach to adoption could be implemented by an insert in the guidebook of a number to call if they have questions. Another insert could include a self addressed letter to the implementer of the guidebook. The letter could have boxes for the provider to fill out if they have questions or if they would be interested in new editions of the guidebook.

Summary

Printed materials can be an affordable and efficient method for providing health information. There is an abundance of materials available for health care professionals and patients, which makes selection of materials difficult. "The Primary Care Provider's Guide to Printed Consumer Health Information", developed for health care providers, is a tool to easily obtain sources for affordable health information specific to patient needs. Implications for patients receiving these materials include increased awareness, satisfaction, and empowerment. Ultimately, the receipt of information that facilitates patients' understanding of their health needs can assist them in living a longer, healthier life.

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Voelker, R. (1999). Patient satisfaction. The Journal of the American Medical Association, 281(12): 1075.

Whitener, L. (1995). Families and family life in rural areas. The Journal of Rural Health, 11(3): 217-19.

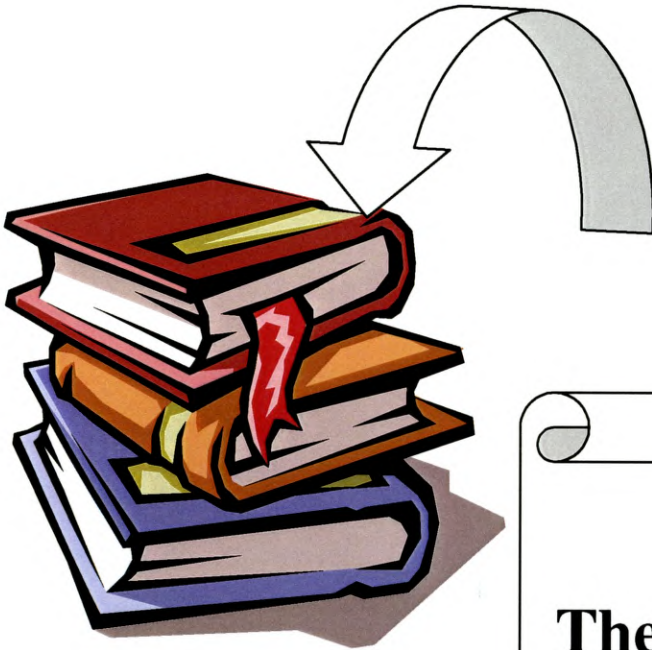
Whitman, N., Graham, B., Gleit, C., Boyd, M. (1992). Teaching in nursing practice: A professional model. East Norwalk, CT: Appleton & Lange.

Whitney, G. (1999). Learn to learn. MedSurg Nursing, 8(1): 5.

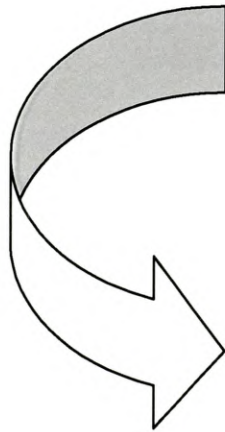
APPENDICES

APPENDIX A

THE PRIMARY CARE PROVIDER'S GUIDE TO PRINTED
CONSUMER HEALTH INFORMATION



The Primary Care Provider's Guide to Printed Consumer Health Information



Emily Fieselmann, RN, BSN

If interested in obtaining a copy of this guidebook, please contact the MSU School of Nursing at (406) 994-3783

Preface



As patients become more sophisticated consumers of health information, health professionals have found increasing benefits in sharing health information with patients. Benefits include greater patient satisfaction and the ability of patients to participate in informed health decisions. The goal of “The Primary Care Provider’s Guide to Printed Consumer Health Information” is to enhance opportunities for the many benefits of appropriate health information. To help achieve this goal, the guidebook identifies information specific to particular target groups including those of diverse cultures, regions, literacy levels, and age groups. Social groups with different backgrounds involve different sets of communication styles, lifestyles, values and health beliefs. For example, patients from rural regions often considered more self-reliant, are more resistant to outside services and advice, and rely more on family and local care-giving than patients from urban regions. These characteristics suggest the need to establish trust and privacy in providing health information to rural patients, and to involve extended family caregivers in the information process.

“The Primary Care Provider’s Guide to Printed Consumer Health Information” also targets individual differences. For example, health information specific to diverse reading abilities helps address the needs of approximately 20% functionally illiterate adults in the United States. The guidebook is based on the premise that information targeted to specific patient background increases the opportunity for patients to learn from printed health information. A discussion of the theoretical background, definitions, and conditions that enhance patient learning is available from the author (see *Construction of a Guidebook for Primary Care Providers to Access Specific Printed Consumer Health Information for Their Patients*, by Emily Fieselmann).

This guidebook is a compilation of Companies, Associations, Textbooks, and Internet Sources that provide printed consumer health information for patients. The sources were researched by the author and through a panel of experts. Titles, addresses,

Internet sites, phone numbers, and ISBN numbers are provided for the primary care provider's use.

It is important to note that the following comments regarding the sources are of the author's opinion. In each category, printed sources of health information are classified in regards to their cost. Informational materials are also classified by age, culture, literacy level, and geographic regional.

The following legend is utilized through this guidebook. The money symbol stands for 'cost' and will be noted before a source that includes their prices. The family symbol stands for 'Age' and will be noted before a source that has information for multiple age groups. The globe symbol stands for 'Culture' and notes a source that has information for specific cultures. The book symbol stands for 'Literacy' and notes a source that has specific printed health information that is considered an appropriate reading level. The tractor symbol stands for 'Regional' and notes a source that has information for specific regions in the country, such as rural communities.

<u>Legend for Printed Consumer Health Information</u>	
	Literacy Level- Pertains to sources that are at an appropriate reading level.
	Regional Issues- Sources that pertain to rural versus urban living.
	Age-Related Issues- Sources that encompass different age groups including pediatrics, adults, and geriatrics.
	Cultural Issues- Sources that pertain to specific cultures or languages.
	Cost- Includes the price of the brochure, pamphlet or other source.

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Chapter 1: Brochures and Pamphlet Sources

Brochures and pamphlets allow patients to take information home regarding their personal health concern. Many companies provide brochures at a reasonable price. Brochures may be displayed in an office or patient room allowing the patient to view the brochure when interested. This chapter provides the addresses and phone numbers to access multiple companies that provide brochures. Generally, catalogs can be obtained by each company that displays prices and topic areas.

This chapter is divided into companies that provide information for wellness behavior, illnesses, and environmental health topics. Companies that produce brochures and pamphlets tend to provide multiple topics or focus on a specific topic. For example, the Channing Bete Company provides brochures on several health and wellness topics. However, the American Heart Association provides brochures that focus on the cardiac system.

The following legend will be utilized for each company:

<u>Legend for Printed Consumer Health Information</u>	
	Literacy Level- Pertains to sources that are at an appropriate reading level.
	Regional Issues- Sources that pertain to rural versus urban living.
	Age-Related Issues- Sources that encompass different age groups including pediatrics, adults, and geriatrics.
	Cultural Issues- Sources that pertain to specific cultures or languages.
	Cost- Includes the price of the brochure, pamphlet or other source.

Wellness Sources (Broad Topic Sources by Alphabetical Order)

The following companies provide brochures and pamphlets about multiple topics of wellness behavior. Such topics may include stress management, exercise, and nutrition.

American Academy of Family Physicians 8880 Ward Parkway Kansas City, MO 64114 (816) 333-9700 www.aafp.org (The Family Doctor http://familydoctor.org/)	
	- 8 th grade reading level
	- Spanish

American Heart Association 7272 Greenville Ave Dallas, TX 75231-4596 www.americanheart.org 1-800-611-6038 Stroke connection- 1-800-553-6321	
	- Spanish
	- Children and adults
	- Brochures for people with limited reading skills
	- 50 brochures for \$5-7

American Institute for Preventive Medicine 30445 Northwestern Hwy Suite 350 Farmington Hills, MI 48334 1-800-345-2476 http://aipm.healthy.net	
	- All ages. Note: may customize your own.
	- Spanish
	- Reading level 3 rd -9 th grade
	- < \$1.00/copy

Channing L. Bete Co, Inc 200 State Road South Deerfield, MA 00137-0200 1-800-628-7733 www.Channing_bete.com	
	- Adults, and includes pediatric handouts with crayons
	- \$.60- 1.60/each

Columbia University Health Service John Jay Hall Columbia University 2960 Broadway New York, New York (212) 854-2284 www.goaskalice.columbia.edu	
	- All ages

FastMark, Inc 125 University Ave. Suite 250 Palo Alto, California 94301 1-650-327-7700 or 1-800-406-2035 Fax 1-650-327-7734 Fastguides@fastmark.com	
	- All ages
	- 4 th -6 th Grade reading level
	- Spanish
	- \$1.35- 2.40/ pamphlet

Great Performance Inc. 14964 NW Greenbrier Parkway Beaverton, Oregon 97006-5776 1-800-433-3803	
	- Spanish
	- Brochures \$0.50/each, Posters \$16

Health Education Resources- Parlay International Parlay International PO Box 8817 Emeryville, CA 94662-0817 1-800-457-2752 Fax: 510-601-1008 www.parlay.com	
	- All Ages
	- \$49- 99- for 22-80 brochures that can be copied in your office

Health Promotions Now 215 Executive Drive Moorestown, NJ 08057-9816 1-800-378-6376	
Note: Very commercialized, provides BSE shower cards, info slides, etc	
	- Adults and children
	- Spanish

International Health Awareness Center, Inc. 350 E. Michigan Avenue, Suite 301 Kalamazoo, MI 49007-3851 (616) 343-0770	
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Journeyworks Publishing PO Box 8466 Santa Cruz, CA 95061-8466 1-800-775-1998 www.journeyworks.com	
	- All ages
	- Spanish
	- \$15 for 50 brochures

Positive Promotions 40-01 168 th street Flushing, NY 11358 1-800-635-2666	
	- All ages
	- Spanish
	- \$0.41- 0.98/each handbook or information card

Springhouse/The Caring Company Springhouse Corporation Health Education Division PO Box 48 Lakewood, NJ 08701-9756 1-877-442-4455	
	- Easy to read with large type
	- Brochure on 'What is a Nurse Practitioner' \$ 0.95/each

StayWell Krames 1100 Grundy Lane San Bruno, CA 94066-3030 1-800-333-3032 www.staywell.com	
	- Spanish
	- States that it is at a lower reading level, does not state what level
	- \$12.50- 17.95/per pack of 50 brochures

Wellness Councils of America

(402) 827-3590

Fax (402) 827- 3594

Whole Person Associates: The Stress & Wellness Specialists

210 West Michigan

Duluth, MN 55802-1908

1-800-247-6789



- All ages



- \$9.95- \$19.95 for Guidebooks

Wellness Sources (targeted for specific groups or topics)

The following companies provide wellness information for specific topics. For example, the first source provides wellness information specific to fitness and exercise.

Aerobics and Fitness Association of America
15250 Ventura Blvd
Suite 200
Sherman Oaks, CA 91403
(818) 905-0040

American College of Sports Medicine
Box 1440
Indianapolis, IN 46206-1440
(317) 637-9200

Food and Nutrition Information Center (FNIC)
National Agricultural Library Bldg.
Room 304
Beltsville, MD 20705
(301) 344-3719

Human Nutrition Information Service
Department of Agriculture
6505 Belcrest Rd.
Hyattsville, MO 20782
(301) 436-8498

Institute for Stress Management

U.S. International University
 10455 Promerado Rd.
 San Diego, CA 92131

Migrant Clinicians Network

PO Box 164285
 Austin, TX 78716



- Provides information for migrant farm worker population



- Spanish



- < 6th grade level reading level

Planned Parenthood

810 Seventh Ave
 NY, NY 10019

www.ppfa.org/ppfa



- Spanish

Tufts University

Center on Nutrition Communication
 School of Nutrition Science and Policy
 132 Curtis Street
 Medford, MA 02155
 (617) 627-3223
www.navigator.tufts.edu



- Adults and children

Western Dairy Council

12450 North Washington
Thornton, CO 80241
1-800-274-6455



- Spanish

Wilderness Medical Society

Box 2463
Indianapolis, IN 46206
(317) 631-1745

Illness Sources (Broad Topic Sources)
Provided in Alphabetical Order

The following sources are companies that provide brochures regarding multiple illness concerns. For example, these companies provide brochures for many illness including heart attacks, diabetes, glaucoma, and asthma.

American Academy of Family Physicians 8880 Ward Parkway Kansas City, MO 64114-2797 1-800-944-0000 Fax 1-816-822-0580 www.aafp.org	
	- 7 th grade reading level
	- \$30/100 brochures

American Academy of Pediatrics 141 Northwest Point Blvd Elk Grove Village, IL 60007-1098 (847) 228-5097 Fax (847) 228-5097 1-800-433-9016 www.aap.org	
	- Children

Bureau of Primary Health Care www.bphc.hrsa.dhhs.gov/ 4350 East-West Highway Room 7-4A1 Bethesda, MD 20814	
	- All Cultures

Center for Health Promotion and Education

Centers for Disease Control
 Building 1 South, Room SSB249
 1600 Clifton Road NE
 Atlanta, GA 30333
 1-404-329-3492

Channing L. Bete Co, Inc

200 State Road
 South Deerfield, MA 00137-0200
 1-800-628-7733
www.Channing-bete.com



- All ages



- Spanish



- \$0.60- 1.60/each brochure

Deaconess Medical Center, Health Information Center (Billings)

1-800-252-1246
 The Deaconess Atrium
 Deaconess Medical Center
 2800 Tenth Avenue North
 Billings, Mt 59101



- All ages

ETR Associates PO Box 1830 Santa Cruz, CA 95061-1830 1-800-321-4407	
	- All ages
	- Spanish

FastMark, Inc 125 University Ave. Suite 250 Palo Alto, California 94301 1-650-327-7700 or 1-800-406-2035 Fax 1-650-327-7734 Fastguides@fastmark.com	
	- All ages
	- 4 th -6 th Grade reading level
	- Spanish
	- \$1.35- 2.40/ pamphlet

Health Gate Data Corp 25 Corporate Dr. Suite 310 Burlington, MA 01803 1-800-434-4283 www.healthgate.com	
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Migrant Clinicians Network PO Box 164285 Austin, TX 78716	
Note: Provides information for migrant farm workers	
	- Spanish information
	- < 6 th grade level reading

National Health Information Center PO Box 1133 Washington, DC 20013-1133 1-800-336-4797 www.nhic nt.health.org	
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National Institutes of Health National Heart, Lung, and Blood Institute PO Box 30105 (301) 592-8563 Fax (301) 592-8573 e-mail at NHLBInfo@rover.nhlbi.nih.gov	
	- Spanish
	- Well-written, easy to read
	- Often free

National Library of Medicine 8600 Rockville Pike Bethesda, MD 20894 1-888-346-3656	
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Parlay International PO Box 8817 Emeryville, CA 94662-0817 (510) 601-1000	
	- All ages
	- Spanish

Prichett & Hull 3440 Oak Cliff Rd NE STE 110 Atlanta, GA 30340-3079 1-800-241-4925 www.p-h.com	
	- Spanish
	- \$10.00 for tear pad of 50 information sheets, \$20.00/ 50 brochures

StayWell Krames 1100 Grundy Lane San Bruno, CA 94066-3030 1-800-333-3032 www.staywell.com	
	- Spanish
	- States that it is at a lower reading level, does not state what level
	- \$12.50- 17.95/per pack of 50 brochures

U.S. Department of Health and Human Services

200 Independence Ave. SW

Washington DC 20201

1-877-696-6775 (Toll Free)

www.os.dhhs.gov

Illness Sources (Specific Associations)
Alphabetical Order By Topic

The following companies provide brochures for specific illnesses. In this section they are categorized by a specific illness topic in alphabetical order.

Cardiology

American Heart Association 7272 Greenville Ave Dallas, TX 75231-4596 www.americanheart.org 1-800-611-6038 or 1-800-242-8721 Stroke connection- 1-800-553-6321	
	- Spanish
	- Adults and children
	- Brochures for people with limited reading skills
	- 50 brochures for \$5-7

High Blood Pressure Information Center NHLBI Information Center PO Box 20824-0105 (301) 251-1222

Cancer

Cancer Information Service
Office of Cancer Communications
National Cancer Institute
Building 31, Room 10A16
9000 Rockville Pike
Bethesda, MD 20892
1-800-4-CANCER

Dermatology

American Academy of Dermatology
930 North Meacham Road
Schaumburg, IL 60173-4014

Diabetes

National Diabetes Information Clearinghouse
1 Information Way
Bethesda, MD 20892-3560
(301) 468-2162

Eating Disorders

The Gurze Eating Disorders Resource Catalogue

PO Box 2238

Carlsbad, CA 92018

1-800-756-7533

www.gurze.com



- All ages

Gastrointestinal

National Digestive Diseases Information Clearinghouse

2 Information Way

Bethesda, MD 20892-3570

(301) 654-3810

HIV

CDC National AIDS Information Clearinghouse

PO Box 6003

Rockville, MD 20849-6003

1-800-458-5231

Neurology

Alzheimer's Association

70 East Lake Street
Chicago, IL 60601
1-800-621-0379

Alzheimer's Disease Education and Referral Center

PO Box 8250
Silver Spring, MD 20907
1-800-438-438

Ophthalmology

American Academy of Ophthalmology

PO Box 45568
San Francisco, CA 94145-0568

Respiratory

Asthma & Allergy Foundation of America

1125 Fifteenth Street, NW, Suite 502
Washington DC 20005

www.aafa.org

1-202-466-7643

Fax 202-466-8940



- Children, teens, and adults



- Spanish

American Lung Association 1-800-586-4872	
	- All ages
	- Spanish

Environmental Health Sources

The following companies provide brochures and pamphlets about environmental health concerns. For example, these companies may provide brochures on topics that include immunizations, pesticide hazards, and child poison control.

American Academy of Pediatrics

141 Northwest Point Blvd
Elk Grove Village, IL 60007-1098
(847) 228-5097
Fax (847) 228-5097
1-800-433-9016
www.aap.org

Note: Information regarding immunizations



- Pediatrics

National Center for Farmworker Health

PO Box 150009
Austin, TX 78715
www.ncfh.org

Note: Go to resources available from NCFH



- Spanish brochures and videos

Note: Topics range from pesticides to TB

US Dept. of Health and Human Services

Public Health Service
National Institutes of Health
National Heart, Lung, and Blood Institute
PO Box 30105
Bethesda, MD 20824-0105
(301)251-1222

U.S. Department of Health & Human Services Centers for Disease Control and Prevention 1-800-232-2522 (English) 1-800-232-0233 (Spanish) www.cdc.gov/nip (for the National Immunization Program)	
	- All ages
	- Multiple regional issues for immunizations, poison control, etc.
	- Spanish

Chapter 2: Internet Sources

There are thousands of health information web sites. The following web sites include patient fact sheets that may be printed from your computer and handed to patients about their health concern. The benefit to this method of providing printed health information for your patients is that it does not take up space in your office. They can be obtained directly from the computer, printed, and handed to your patient.

This chapter is arranged similarly to Chapter 1 into the three topics of wellness behavior, illness, and environmental health. The same legend is utilized for these sites:

<u>Legend for Printed Consumer Health Information</u>	
	Literacy Level- Pertains to sources that are at an appropriate reading level.
	Regional Issues- Sources that pertain to rural versus urban living.
	Age-Related Issues- Sources that encompass different age groups including pediatrics, adults, and geriatrics.
	Cultural Issues- Sources that pertain to specific cultures or languages.
	Cost- Includes the price of the brochure, pamphlet or other source.

Wellness Web Sites

The following Internet sites provide information regarding several wellness topics such as exercise, nutrition, and stress reduction. The sites are arranged in alphabetical order by title of the site.

AMA Health Insight www.ama-assn.org/consumer/specond.htm	
	- All ages

Columbia University: Go Ask Alice www.goaskalice.columbia.edu	
	- Targeted for adolescents

Health Finder www.healthfinder.gov	
	- Spanish Section, minority health
	- All ages

Healthgate www.healthgate.com	
Note: May have to download to get information	

Health World Online
www.healthy.net

Healthy Kids
www.healthykids.org



- For providers, parents, and kids



- Targeted to the specific reader in appropriate language

John Hopkins: InteliHealth
www.intelihealth.com/



- Pediatrics

Mayo Health Oasis Online
www.mayohealth.org/mayo/common/htm/library.htm



- All ages

Tufts University Center on Nutrition Communication
www.navigator.tufts.edu

Note: Useful site that analyzes other nutritional sites



- All ages

Illness Web Sites

The following sites on the Internet provide multiple information sheets to be given to patients regarding illnesses.

American Academy of Family Physicians: the Family Doctor http://familydoctor.org/ or www.aafp.org	
	- 8 th grad reading level
	- Spanish

American Association for Family Practitioners www.aafp.org/patientinfo/	
	- All ages

American Association of Nurse Practitioners www.aanp.org	
	- All ages

American Cancer Society www.cancer.org	
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American Medical Association www.ama-assn.org	
	- All ages

AMA Health Insight www.ama-assn.org/consumer/specond.htm	
	- All ages

American Heart Association www.amhrt.org	
	- Spanish

Consumer Gateway www.consumer.gov	
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Doctors + Designers www.healthed.com	
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Doctor's Page http://DoctorsPage.net/	
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Food and Drug Administration
www.fda.gov

Health A to Z
www.healthatoz.com



- All ages

Health Care Information Resources
www-hsl.mcmaster.ca
 or www-hsl.mcmaster.ca/tomflem/top.htm



- French

Health Finder
www.healthfinder.gov



- Spanish Section, minority health



- All ages

HealthFront
www.healthfront.com



- All ages

Healthtouch	
www.healthtouch.com/level1/hi_toc.htm or www.healthtouch.com/	
	- All ages

Healthwise Toolset	
www.healthwise.org	
Note: Can obtain the healthwise toolset via this email address which is based on evidence-based health information	

InteliHealth: Home to John's Hopkins Health Information	
www.intelihealth.com/	
	- Pediatrics, Adults
Note: Very difficult to read	

Internet Health Resources	
www.ihr.com	
	- Urban sources

MD Consult	
http://www.mdconsult.com/	
	- This is a subscription Web service that costs about \$200/year
Note: Contains over 2500 patient education handouts	

Medicine Net, Smart Med www.medicinenet.com

Medscape Multispecialty www.medscape.com/home/Patient/PatientInfo.html
 - Pediatrics, adults
 - Must become a member (by easy registration to enter)

National Cancer Institute www.nci.nih.gov/

National Institutes of Health: Consumer Health Information www.nih.gov/health/consumer/index.html
 - Spanish

National Institutes of Health: Institutes and Offices www.nih.gov/icd
Note: Has access to many Institutes of specific illnesses

National Library of Medicine http://www.nlm.nih.gov/medlineplus/
 - May be too technical

National Rural Health Resource Center www.ruralcenter.org/nrhrc	
	- Spanish
	- Rural

OnHealth www.onhealth.com/ch1/index.asp	
	- Includes children, aging

Online Pediatrician www.babymd.com	
	- Pediatric population/parents

Patient Education Handouts from MSU Student Health, Dr. Flaherty http://www.montana.edu/wwwwebm/PatientEd.htm	
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PharmInfoNet http://pharminfo.com	
Note: On-line drug information	
Note: Very large site, confusing	

Rx Med: Patient Handouts www.rxmed.com/handouts.html	
	- Easy to read

Medline Plus www.nlm.nih.gov/medlineplus/	
	- All ages
	- Spanish

Spring Net www.springnet.com/np/resources or www.springnet.com	
Note: Excellent source of patient handouts	

U.S. Department of Health and Human Services www.os.dhhs.gov	
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Environmental Health Web Sites

The following Internet sites provide printed information for patients regarding several environmental health topics such as poisonings, immunizations, and other environmental hazards.

Agency for Health Care Policy and Research www.achcp.gov/consumer	
	- Rural information

American Chemical Society www.acs.org	
Note: Great information/not for patient handouts	

American Public Health Association www.apha.org/	
Note: This association does not provide direct patient handouts but links to multiple other sites that can be utilized for patient handouts	

Centers for Disease Control and Prevention www.cdc.gov	
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Department of Health and Human Services www.hhs.gov/	
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Enviro-link Library www.library.envirolink.org/

Environmental Defense Fund (EDF) www.scorecard.org
 - Rural information

Environmental Health Policy Committee http://web.health.gov/environment
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Environmental Protection Agency www.epa.gov
 - All ages
 - Rural farm information
 - Spanish

Health Finder www.healthfinder.gov
 - Spanish Section, minority health
 - All ages

Mayo Clinic Health Oasis www.mayohealth.org/mayo/common/htm/library.htm
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National Institute of Environmental Health www.niehs.nih.gov
 - All ages

National Institute for Occupational Safety www.cdc.gov/niosh
 - All Ages
 - Rural information

New York Online Access to Health www.noah.cuny.edu/qksearch.html
 - Pediatrics, adults

OnHealth www.onhealth.com/ch1/index.asp
Note: Environmental poisoning topics

U.S. Food and Drug Administration
www.fda.gov

World Health Organization
www.who.int/



- International Site

Chapter 3: Fact sheet Book Sources

The following sources that provide printed health information for patients, come from books with multiple information fact sheets. These are beneficial because one can obtain many health topics all in one book which saves space and money.

Since there are only a few of these sources, they are all listed together. The same legend is utilized for these sources:

<u>Legend for Printed Consumer Health Information</u>	
	Literacy Level- Pertains to sources that are at an appropriate reading level.
	Regional Issues- Sources that pertain to rural versus urban living.
	Age-Related Issues- Sources that encompass different age groups including pediatrics, adults, and geriatrics.
	Cultural Issues- Sources that pertain to specific cultures or languages.
	Cost- Includes the price of the brochure, pamphlet or other source.

<u>Dial 800 for Health</u> <u>From the People's Medical Society</u> ISBN 1-882606-30-2	
	- All ages

<u>Ferris Patient Teaching Guide, 1999</u> ISBN 0-8151-8397-6	
	- Available in Spanish

H. Winter Griffith, MD Instructions for Patients WB Saunders Company ISBN 0-7216-7375-9 or 0-7216-7885 (Pediatric), 0-7216-6997-2 (Spanish)	
	- All ages
	- Spanish Version

<u>Mosby's Handbook of Patient Teaching</u> By Mary M. Canobbio ISBN 0-8151-1537-7	
	- All ages

People's Medical Society

462 Walnut Street
 Allentown, PA 18102
 1-610-770-1670

Note: A nonprofit consumer health organization that tries to make unavailable medical information available to consumers so that they can make informed decisions about their own health care

Physicians' Guide to Rare Diseases

Authors: Jess G. Thoene, MD and Nancy P. Coker

Note: Textbook that provides a lot of information on rare disease and some of which could be provided to the consumer

The National Organization for Rare Disorder also puts out an order form for reports and brochures on a large list of diseases. This site can be found at <http://www.NORD-RDB.com/> or mail to: NORD literature, PO Box 8923, New Fairfield, CT 06812-8923

Primary Care Patient Education Material (1999)

By Lipkin, M., Lima, S., & Weavers, S.

Aspen Publishers, Inc.

ISBN 0-8342-0906-3



- All ages



- 6th grade reading level

APPENDIX B
PANEL OF EXPERTS

<u>Degree</u>	<u>Occupation</u>	<u>Location</u>
<u>Illness Information</u>		
Cynthia Harrison, MS	Medical Librarian	Bozeman, Montana
Robert Flaherty, MD	Physician	Bozeman, Montana
<u>Wellness Information</u>		
Cynthia Harrison, MS	Medical Librarian	Bozeman, Montana
Keven Comer, MSN, FNP	Family Nurse Practitioner	Bozeman, Montana
<u>Environmental Health Information</u>		
Patricia Butterfield, PhD	Nursing Professor	Bozeman, Montana
Jane Lipscomb, PhD	Nursing Professor	University of Maryland
<u>Regional Focus</u>		
Clarann Weinert, PhD	Nursing Professor	Bozeman, Montana
Jean Schreffler, PhD	Nursing Professor	Missoula, Montana
<u>Age- Related Focus</u>		
Sandi Burgard, MSN, PNP	Pediatric Nurse Practitioner	Bozeman, Montana
Kathie Lang, MD	Physician	Bozeman, Montana
<u>Literacy Focus</u>		
Joan Truester, MA, CHES	Health Educator	University of Iowa
David Rosenthal, PhD	Marriage/Family Therapist	University of Iowa
<u>Cultural Focus</u>		
Candace Stearns, RN, BSN	Family Nurse Practitioner Student	Billings, Montana
June Persons, RN, MSN	Family Nurse Practitioner	Billings, Montana

APPENDIX C

**EXAMPLE LETTER AND QUESTIONNAIRE
FOR THE PANEL OF EXPERTS**

712 N 22 Ave. Apt. B
Bozeman, MT 59718
Month, Date 1999

Sample Expert
Address

Dear Sample Expert:

I am a Family Nurse Practitioner student working with Dr. Patricia Butterfield, (406) 994-2763, on a professional project for a master's degree in nursing at Montana State University. My project entails the development of a guidebook for primary care providers to access printed consumer health information for their patients. The sources of printed consumer health information for patients in this guidebook will include brochures/pamphlets, Internet sources that can be printed for the patient, and textbooks with printed patient education briefs.

You have been chosen for the panel of experts on printed consumer health information with a wellness behavior (or other expert content area) focus. For example, wellness may include printed information on exercise, nutrition, or how to decrease stress. I have included a questionnaire for you to describe your foremost sources of printed consumer health information on wellness behavior. Please return the questionnaire in one week in the self-addressed envelope.

Thank you for taking the time to provide sources of consumer health information. Please contact me at (406) 586-1299 if you have any questions.

Sincerely,

Emily Fieselmann

Questionnaire for Printed Consumer Health Information

Name:

Field of Expertise:

Where do you most often obtain consumer health information for your patients or clients?

What are your top three (or more) choices of organizations that provide printed consumer health information on wellness behavior and why do you like them (please include phone numbers, addresses, and any comments on the brochures, internet, or textbook options)?

You may also mail copies of any examples.

Example of a Wellness Organization that provides brochures:

American Institute for Preventive Medicine

30445 Northwestern Hwy Suite 350

Farmington Hills, MI 48334

1-800-345-2476

<http://aipm.healthy.net>

This organization provides wellness information on topics such as stress, smoking, weight-control, and self-care. The reading level of the brochures range from 3rd-9th grade levels and you can customize your own if needed. These brochures also target all ages.

What are your top choices?

1.

2.

3.