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Patients as Consumers: The Influence of DTCA and "Becoming Little Doctors."

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To the Graduate Council:

I am submitting herewith a dissertation written by Karen Michele Hood entitled "Patients as Consumers: The Influence of DTCA and "Becoming Little Doctors."." I have examined the final electronic copy of this dissertation for form and content and recommend that it be accepted in partial fulfillment of the requirements for the degree of Doctor of Philosophy, with a major in Business Administration.

David W. Schumann, Major Professor

We have read this dissertation and recommend its acceptance:

Daniel J. Flint, Sarah F. Gardial, Denis G. Arnold

Accepted for the Council:

Dixie L. Thompson

Vice Provost and Dean of the Graduate School

(Original signatures are on file with official student records.)

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Accepted for the Council:

Carolyn R. Hodges

Vice Provost and Dean of the Graduate School

**PATIENTS AS CONSUMERS:
THE INFLUENCE OF DTCA AND “BECOMING LITTLE DOCTORS”**

**A DISSERTATION
PRESENTED FOR THE
DOCTOR OF PHILOSOPHY
DEGREE
THE UNIVERSITY OF TENNESSEE, KNOXVILLE**

**KAREN MICHELE HOOD
AUGUST 2009**

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Abstract

Direct to consumer advertising of prescription drugs (DTCA) accounts for approximately \$5 billion in advertising spending in the US. Critics of this controversial practice cite confusing and misleading information negative effects on the physician-patient relationship as reasons to restrict or even ban DTCA, while proponents claim it empowers patients and facilitates discussions between physicians and patients that may improve overall health.

An ethnography of consumers in the most prominent target market for DTCA initially seeks to understand the meaning of DTCA among middle age adults in the US with chronic conditions. Participants in the study are skeptical about this category of advertising, and describe DTCA as being “good and bad.” They see ads as being helpful reminders about conditions, however, they rarely remember the brand names represented. For them, the downside is that the ads are pervasive and don’t provide enough useful information. Discussion of their interactions with DTCA acts as a keyhole into the life world of patients with chronic conditions as consumers, whose information search efforts amount to “becoming little doctors.” Through emergent design, exploring an expanded set of research questions yields a description of patients as consumers. The process of adjusting to a chronic condition among participants occurs in stages and involves diagnosis, learning and management phases. Information search and social networks play a large part in the adjustment process, as patients consume health care services, information and often, prescription drugs. Implications for marketers, health care professionals and public policy makers are discussed.

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Chapter 1

Introductory Note

The initial purpose of this dissertation was to explore the shared meanings among patients with chronic conditions to direct-to-consumer advertising (DTCA). A number of research questions related to DTCA appear in this chapter and were responded to through the data collection. Early in the data collection, it became apparent that DTCA was like a keyhole into the larger phenomenon of “patient as consumer.” Through emergent design afforded by qualitative methods, the study continued to explore DTCA meanings but also revealed insights into the experiences of patients with chronic conditions which reflect 1) stages and phases of adaptation to the condition, 2) information search, and 3) dynamic social networks which appear to facilitate adaptation and management of the condition. These contribute to a rich description of the participants and their navigation of the world as consumers. Thus in Chapter 4, after presenting the results related to DTCA, a set of extended research questions are offered and interpretation of this broader phenomenon is presented.

Introduction

In 2007, pharmaceutical companies spent more than five billion dollars in the US on print and television direct-to-consumer advertising of prescription drugs (DTCA) (Reuters 2008). Providing information to consumers about health conditions and remedies that, when prescribed by a physician, may treat those conditions successfully and improve quality of life, is seen as one way marketing contributes to society (Wilkie and Moore, 1999, 2004). However, the practice of

DTCA has been the subject of much controversy and debate by critics who believe it increases health care costs, promotes “inappropriate treatment of patients,” and that it negatively affects the relationship between consumers and their physicians (Rosenthal and Donohue 2005). While studies have examined these potential effects, with mixed results, little is known about how DTCA culturally impacts consumers who have one or more chronic conditions. The cumulative effects of exposure to DTCA over the past decade are unclear in the context of an aging population and increasingly burdened health care system.

The very first direct-to-consumer advertisement for prescription pharmaceuticals (DTCA) appeared in the U.S. mass media in 1980 (Critser 2005), but the requirements for this type of advertising imposed by the Food and Drug Administration made it nearly impossible for companies to include the required information in the space and time constraints of either print or broadcast media, and thus was rarely seen until a significant relaxation in federal regulations occurred in 1997. To date, DTCA is only legal in the US and New Zealand. During the past decade in these two countries, consumers have been frequently exposed to marketing messages regarding various prescription drugs through mass media advertising, especially television and print. While other countries, where DTCA is illegal, watch the US and New Zealand experience to inform their own public policy decisions on the issue, scant research has been forthcoming regarding how consumers in DTCA’s primary target audience, those with chronic illnesses, interpret and create meaning from these marketing messages. This dissertation attempts to address this gap in our knowledge.

Controversy Regarding DTCA

DTCA has been controversial since its inception, and this controversy has kept pace with the growth of the practice in recent years. As DTCA has increased significantly in the past decade, so has the debate.

Advocates of DTCA hold that the ads are beneficial to public health in that they promote awareness and may encourage a visit to the doctor among patients who otherwise might have remained undiagnosed (Roth 1996, Findlay 2001, Donohue & Berndt 2004). These advocates suggest that DTCA promotes an understanding of health issues in order to open dialog between physicians and patients (Coney 2002, Auton 2007), empowering patients to take a more active role in their own health care (Holmer, 1999). Some even contend that DTCA, by promoting awareness of available treatments, may reduce the stigma associated with treatment of certain conditions like depression (Smardon 2008).

In contrast, critics argue that DTCA changes the dynamics of the relationship between the physician and the patient, putting pressure on physicians to fill patient requests for prescriptions that may or may not be the best treatment for their condition (Hollon, 1999), and offers marketing messages disguised as educational in content (Wolfe, 2002). Further, the information presented in the ads may be more confusing to patients than educational, often providing technical information that is difficult or impossible for the average consumer to comprehend (Wolfe 2002, Parker & Pettijohn, 2003). Finally, some argue that DTCA drives demand for prescription drugs, therefore encouraging companies to spend more resources on marketing (Findlay 2001), resulting in increased overall costs (Parker & Pettijohn 2003).

The medical literature has been generally critical of the practice, in some cases going as far as saying it should be forever banned (Hasman and Holm 2006). However, the

pharmaceutical industry, free speech advocates, and in many cases consumers, agree that DTCA does provide economic and social benefits (Block 2007). The magnitude of DTCA in the US suggests that it will continue readily for the foreseeable future.

The Prescription Drug Marketplace

In 2006, companies spent nearly \$4 billion to advertise prescription medicines and remedies, a nine percent increase over the previous year (this does not include what was spent on personal selling). Indeed, Advertising Age (2007) reflects nine large pharmaceutical companies among the top 50 domestic advertisers in the US. The average consumer in the US has 12 prescriptions annually. The total cost of these prescriptions to consumers is more than \$180 billion (Critser 2005). Pharmaceutical companies spend a significant amount of money on research and development, and the aging population of the US coupled with new discoveries focused on the management of chronic conditions, has provided fertile ground for a growing market for remedies.

Pharmaceutical companies justify the higher prices they charge for prescription drugs, citing the pressures of the industry. They must incur the high cost of research and development in finding new ways to treat numerous conditions with drug therapy. Limits on patents before generic versions of certain drugs become available leave a short window in which pharmaceutical companies can make a profit on brand name drugs. Also, there is increasing pressure on companies to provide strong scientific evidence addressing the indications for each drug: both for effectiveness in treating the condition and for potential side effects. For this reason, companies work diligently to keep a full product development pipeline.

The History of Prescription Drug Marketing

Historically, prescription drugs and remedies were marketed to physicians, both in person and in medical journals. Doctors have long enjoyed, and have been socialized to perform the role of “learned intermediary,” a term which dates back to the teachings of Hippocrates. The underlying philosophy reflected the belief that the general population would be unable to facilitate, or understand the proper use of some remedies. The physician was the one identified as the person trained in the properties of medicines and their appropriate uses, training that the general public was not privy to. And, due to the public’s compromised judgment in the throes of their own illnesses, or of their family members, prescribing should be left to the physician. For many years in the US, this arrangement was supported by the status of physicians in the community where phrases like, “doctor’s orders,” meant you did what you were told. Under the rule of the learned intermediary, marketing of prescription drugs was limited to advertisements in medical journals coupled with the practice of “detailing,” where pharmaceutical companies would send representatives to market drugs directly to physicians.

Enter the HMO era, an aging population, and new awareness and a growing responsibility of the individual for his or her own health. The healthcare system and communities have shifted so that patients are now encouraged to be partners in their own health care, to work in tandem with their doctors and other health care professionals. An increase in health care personnel and a shift in responsibilities for nurses, nurse practitioners, and physicians’ assistants, brought changes to the health care system that made it possible, if not necessary, for patients to seek out information about their own health, to self-diagnose, and to ask questions of their health care professionals.

In response to increasing health care costs and reduced resources, especially time with a physician, new reference guides and other information became available to patients in the popular press, and with the advent of the Internet, patients now have access to extensive medical information, much of which has been tailored to the general population and made freely available.

For many years, these ads were not legal and governance of the advertisement of prescription drugs fell under the Federal Trade Commission's rules of broadcasting. However, more recently, that responsibility has been transferred to the Food and Drug Administration, whose regulations are based on the requirements for labels that appear on food and drug products.

Why is the Study of DTCA Important?

The study of direct to consumer advertising and other, readily available health information and its meaning, is important for several reasons. First, as noted earlier, advertising of this kind is only presently legal in the US and New Zealand, and pharmaceutical companies are lobbying governments of many other countries globally to move forward with legalization. These countries are looking to the US and NZ for examples of its effects on the general population, the economy, and public health as they consider similar legislation.

The health care culture of the US continues to experience changes as the largest segment of the population reaches the age at which many chronic conditions develop and longevity becomes an issue. At a time when the US government officials are concerned with the ability to provide health care to its citizenry, this shift in the population becomes even more important.

DTCA, as mentioned before, is only one of many marketing tools employed to promote prescription drugs, and it is a small portion of the overall marketing budget for any given drug. Pharmaceutical companies generally choose to use DTCA for high-quality products having the largest *potential* market, not necessarily the largest existing. In this case, that means products that address conditions which are largely under-diagnosed, under-treated and chronic, or requiring treatment for an extended period of time (Iizuka, 2004, 2005). As a result, drugs most often represented in DTCA are treatments for hypertension, high cholesterol, diabetes, allergies and depression. Further, the likelihood of having one or more of these conditions increases with age, and people with one chronic condition are more likely to have a second or third chronic condition as well (Hwang et al.2001). Because consumers who have these conditions, or symptoms of these conditions, are believed to be the target market for DTCA, the ads are presumed to have the greatest potential effect on this audience.

The study of the effects of DTCA is still evolving as research efforts increase. Traditional quantitative methods can provide insight into certain responses, such as attitudes, attention and cognitive processing. However, it is also important to understand how this type of advertising is interpreted as a whole by consumers who may or may not have chronic health conditions that may be treatable with prescription drugs. What meanings do these consumers take away from their exposure to DTCA? What actions may occur as a result of this exposure? Beyond correlation studies of the relationship between spending on advertising and spending on the prescription drugs, it is important to gain insight into how consumers interpret the messages carried via DTCA, messages that are information-rich, and contain emotionally laden and relevant images. By exploring how meaning is constructed by consumers, especially those in the

primary target audience, researchers may provide insights that can inform the debate over this type of advertising and its effects on our society.

The Purpose of this Dissertation

This need for continued inquiry into DTCA and how it fits into the consumer culture has generated a core set of guiding research questions for this dissertation.

- What, specifically, does DTCA mean to consumers?
- How do consumers construct meaning from DTCA?
- How do consumers utilize the information contained in DTCA?
- How is the influence of DTCA apparent in the lives of consumers with chronic conditions?
- What are the apparent influences on treatment choices of consumers with chronic conditions?

This study employs an ethnographic approach to pursue insight into these questions and others that arose as the study evolved. Ethnography allowed this study to more deeply examine how the primary target audience of DTCA uses the messages of direct marketing of prescription pharmaceuticals by studying the shared meaning of these messages among the culture of US consumers with chronic conditions. Chapter Two consists of a review of the literature, including general and health care-specific marketing and advertising, health care/medical, and other social sciences, and the methodological approach that will be used in this inquiry. Chapter Three will include the specifics of sampling and methods used for data collection.

Chapter 2

Introduction

Historically, pharmaceuticals were only marketed to doctors and pharmacists. However, in the early 1980s, this barrier was broken by offering promotional messages directly to patients (Richardson and Luchsinger 2004). To date, it is legal only in the United States and New Zealand to practice direct-to-consumer advertising of prescription pharmaceuticals (DTCA). In 2006, companies spent more than \$4.8 billion on DTCA in the United States, which is twice as much as the entire budget for the FDA (Kallen et al 2007).

Congress passed the 1906 Federal Food and Drug Act with the intent “to protect the people of this country from misbranded and adulterated commodities by prohibiting their introduction into interstate commerce.” In 1912, the Act was amended to include prohibition of false advertising of “the curative or therapeutic effects of medicines... with willful intent to deceive,” (Olsen 1948 p. 56). This amendment required that the claims in advertisements must be factual, and information to consumers must be accurate and inclusive,

“there shall be taken into account not only the representations made or suggested by statement, word, design, device, sound or any combination thereof, but also the extent to which the advertisement fails to reveal facts material in the light of such representations from the use of the commodity to which the advertisement relates under the conditions prescribed in said advertisement, or under such conditions prescribed in said advertisement.”

Further, “no advertisement of a drug shall be deemed to be false if it is disseminated only to members of the medical profession...” (Olsen 1948 p.54). Today, the regulation of advertising of pharmaceuticals in the US is more complex, and is administered by the Food and Drug Administration. The US has seen a monumental increase in the amount of advertising of prescription drugs direct to the consumer (DTC), the environment in which messages about health care remedies, especially prescription drugs, things have changed significantly.

Direct to consumer advertisement of prescription drugs (DTCA) comprises a significant amount of the US national advertising budget among consumer products companies. In 1997, the Food and Drug Administration relaxed requirements for information in DTCA, opening the door for companies to advertise prescription drug products within the parameters of television spots. Prior to this regulation change, DTCA appeared in the media (since 1980), but only in limited amounts. During that time, the requirements of inclusion of information in print and broadcast advertisements were practically impossible to meet within the time and space constraints of the media, rendering these advertisements cost prohibitive. In addition, and to this day, investing in detailing (which will be defined in the next section of this chapter) to physicians is much more lucrative than DTCA.

What is DTCA?

Direct to consumer advertising of pharmaceuticals takes many forms. Ads in the US are found in print, especially magazines, in broadcast, mostly television but also some radio, and on the Web. It is important to note that DTCA includes only part of the total marketing picture for prescription pharmaceuticals. Companies employ highly integrated marketing communication approaches. These campaigns include DTCA in multiple media forms, “detailing,” the

pharmaceutical industry's version of personal selling aimed at doctors, and a large volume of printed information aimed at both professionals and consumers. Marketing efforts beyond DTCA and detailing are often referred to as "OMEs" or Other Marketing Efforts (e.g., in-hospital or in-office promotion, sponsorship of medical seminars and other educational events.)

Factors leading to the growth of DTCA

Aside from changing regulations that have led to the growth of DTCA, there are three environmental factors within the past decade that have increased the demand for health care information in general, and information about drug therapies in particular. First, the increase in the segment of older Americans has driven the demand for more information. In the US, the life expectancy continues to increase, with seniors (62 and older) now typically living into their 80's and 90's. This has also had a pronounced impact on the largest segment of the population often referred to as the Baby Boomers, who are age 44-61 and have significant buying power in the marketplace. The continued maintenance of both seniors (labeled in the demographic literature as "Matures") Baby Boomers will be a function of the increase in life expectancy, affluence and a corresponding expectation of a high quality of life (Richardson and Luchsinger 2004).

Second, and probably the most significant environmental shift, has been the change in the structure of the health care system. The system had existed for many years in a climate of insured consumers who would visit a physician only when necessary, largely in a reactive posture. Physicians were regarded, both by consumers and by the commercial sector, as learned intermediaries. In this role, as it has been for centuries, physicians have had access to privileged information about medical conditions and their treatments. Information of this nature was not available to consumers, and thus they respectfully relied solely on physicians and regarded their

opinions as the final word. With the advent of the Health Maintenance Organization (HMO) and the increased cost of health care services, more health care professionals came in contact with patients. Health care and health information has grown significantly to now become part of a larger social network in which information is shared. Consumers are now encouraged to take more responsibility for their own health, at every stage in their adult lives. Consumers now consult not only physicians but with other health care professionals to include nurse practitioners and physician's assistants, specialists from different areas and pharmacists. Technology has also played a part in fulfilling the increased demand for information by consumers.

Health information is the most often searched subject on the Web in the US, having surpassed pornography searches (the second most searched topic) in 2000 (Jaderberg 2002). A search for the term "health information" on the popular search engine, Google.com (2008), yields a long list of web sites where consumers can find information about symptoms, medical conditions and possible treatments. The content provided on these sites is provided by a variety of sources. WebMD and Healthline are medical databases, supported by a medical panel of experts and written in colloquial language that is relatively easy for the average consumer to understand. The Mayo Clinic and other medical facilities also provide content designed to serve both the medical community and to consumers on their sites. Consumers also have access to medical journals such as the *Journal of the American Medical Association* (JAMA) which contain details of scientific studies written by medical scholars and contain the language of the discipline, which is difficult for the average consumer to understand. Health topics are also popular content included in websites for local and national news, lifestyle magazines and online communities such as Yahoo! and America Online (AOL).

Other websites containing health information are those sponsored by pharmaceutical companies, such as the Merck Manual Medical Library. In recent years, pharmaceutical companies have developed websites devoted to specific diseases or conditions. Two examples are Diabetes.com, a site which is dedicated to the management of type 2 (formerly known as adult onset) diabetes; and asthma.com, which offers information about managing life with asthma. These sites are owned and operated by GlaxoSmithKline, a company which manufactures well-known treatments for these conditions, although no brand names appear on the sites. These are in addition to the websites pharmaceutical companies have established to promote individual prescription drugs. It is important to note that although websites that include prescription drug information contain a disclaimer indicating that it is intended only for US residents, these sites are accessible by anyone in the world. As the shift to a social network of health care has evolved, one consequence has been a corresponding shift in responsibility from doctor to patient. Patients, due to the changing conditions of health care in the US and possibly the world, along with the availability of health information, have placed themselves in more of a partnership role with health care professionals. (Parker and Pettijohn 2003)

Finally, the increased pressure on pharmaceutical companies to be profitable early in the lifecycle of a prescription drug product given patent regulations (i.e., life of a patent), also appears to have had an impact on the decision to advertise directly to consumers. Companies work to market these products effectively when they are new and under patent partly to recoup the costs of research and development. While other marketing activities, such as detailing to physicians, have been shown to be more directly effective, it is the cumulative effect of DTCA and these other marketing efforts that enhance brand loyalty among consumers and physicians

alike, providing some protection against loss of market share when the drug's patent runs out. DTCA appears to be an important marketing facet of the overall marketing campaign for new drugs. For example, for one drug, Vioxx, a treatment for arthritis pain and inflammation, Merck spent \$161 million on marketing, including DTCA in 2000. The same year, sales of that drug quadrupled to \$1.5 billion, and the sales of two other drugs in the same category increased as much as 39 percent. More recently, Vytorin, a drug that addresses several risk factors for heart disease, was the subject of a \$200 million advertising campaign, and has realized estimated sales of \$5 billion in the US (CNN 2008).

The Debate over DTCA

The advertising of health remedies to consumers has been controversial since the early 1900s when it was common to see advertisements for potions and elixirs that claimed to cure everything from digestive issues to heart problems. The new, more lenient, regulations in the US and New Zealand, combined with consideration of legalizing pharmaceutical DTCA in more countries around the world, have fueled the most recent debate (for a more complete review, see Roynes and Myers, 2008). In addition, many feel that the system is flawed when it comes to mass marketing of new drugs and the warnings of possible side effects. In the example above, the drug, Vioxx, was removed from the market in 2004 after reports surfaced that a disproportionate number of the drug's users had suffered heart attacks. Similarly, clinical trials for Vytorin reported early results that the drug may not be effective, and medical researchers launched a call for physicians to return to more traditional treatments for heart disease.

First, critics claim that by advertising directly to consumers, pharmaceutical companies are negating the physician's role as a learned intermediary. In fact, it has been said that

“Doctors are being disintermediated as the primary gatekeepers of health related information, often by other healthcare providers,” to which some physician educators have replied, doctors are not being “displaced as the primary authority on individual patients’ actual care,” (White et al 2004). Those in favor of DTCA argue that it actually empowers patients and improves the patient-physician relationship by inviting consumers to participate in the conversations about their care (Jaderberg 2002, Auton 2007, Choi and Lee 2007). Patients who had a chronic condition and had seen DTCA were more likely to talk with their physician about their condition (Sumpradit, Fors and McCormick 2002). It has also been said that any disintermediation of physicians has been facilitated by the changes in the health care system, availability of information in general, and the existence of online pharmacies, through which consumers may obtain prescriptions with little effort (Myers and Royne 2007). The legal literature has weighed in on the Learned Intermediary doctrine as well, stating that pharmaceutical companies can now be held liable for advertising claims by consumers when DTCA is in place. Advertising directly to consumers negates the learned intermediary doctrine, as does “overpromotion,” or promoting a drug to a point that consumers can’t help but be exposed to the messages about a drug (Matter 2002).

Second, opponents claim that DTCA makes it appear that certain conditions require treatment with prescription drugs when it might not be necessary, and that it makes the prescription drug appear to be the best treatment. With longer life and an expectancy of a high quality of life, demand for treatment of chronic conditions and “lifestyle” conditions has risen as well (Richardson and Luchsinger 2004). The growth of the population in the US over the age of

60, combined with general value of youthfulness has made what might be considered normal conditions of life into medical problems that require treatment (Mintzes 2002).

Third, some have argued that DTCA increases demand for prescription drugs, driving up the cost of the drugs and, consequently, overall health care. While spending on DTCA by pharmaceutical companies can be correlated with sales and profits of those companies, a causal relationship has not been identified, as the expenditures on other marketing efforts such as detailing can also be correlated in the same way. While a correlation exists between these numbers, studies suggest that spending on physician detailing is much more profitable, dollar for dollar, than DTCA (Findlay 2001).

Fourth, in the medical community, physicians have reported that DTCA may generate expectations among consumers that they will receive a specific prescription for their condition if they ask for it, negatively affecting the physician-patient relationship. Some commentaries have expressed fear that if a patient's request was not filled, that patient might seek the treatment from another doctor (Hollon et al 2001, Auton 1999). However, a study by Shah, Bentley and McCaffrey (2005) did not show a significantly more negative evaluation of a physician who did not honor a request for a drug; however, the study also revealed that this finding was moderated by a physician's communication style. (Shah, Bentley and McCaffrey 2005). One study's findings reflected that half of the consumers surveyed would be disappointed, but only 15% said they might switch to a different doctor if they didn't receive a prescription they requested. (Bell, Wilkes and Kravitz 1999.) Doctors surveyed reported that more than half of the patients who mentioned DTCA had expectations of receiving a specific treatment or action, and of those, about half were deemed by the physician not to be the best course of action (Murray et al 2003).

DTCA Content and Comprehension Findings

Because of the limits of DTCA, in time and space for broadcast and print respectively, the amount and depth of information presented is restricted. Risk and side effect information is often presented in a much different form than the promotional message, usually in chart form or small print on the back page of a print advertisement, or in a rapid announcer voice and/or graphically on a broadcast advertisement. Regarding DTC websites, one study found that in 70% of the web sites studied, the risk and side effect information was “significantly subordinate” to the promotional messages (Sheehan, 2007).

Critics of the quality of information, especially pharmacists, are concerned that this information is not attended, and if it is, it is not complete, or perhaps is presented in a way that is not easily understood by patients. In broadcast DTCA, adults with low levels of literacy were able to answer 59% of comprehension questions effectively, but while the type of information and the vehicle used (text vs. audio) were predictive of comprehension, questions about risks were more often answered incorrectly than questions about benefits. Similarly, information appearing in text was not recalled as often as information given only in audio (Kaphingst et al. 2005).

Comprehension of DTCA also may be compromised through the use of words like “might, may, can, and could,” and consumers may infer an implied meaning that is much different from the actual meaning of the text in an advertisement (Handlin, et al. 2003). These inferences are what may lead to a perceived increase in the number of requests for treatments that doctors saw as “inappropriate.” However, trying to include the most complete and explanatory information in the context of DTCA may result in information overload and a reduced comprehension of that information by consumers (Hoek, Gendall and Feetham 2002).

In a study of DTC television advertisements in the US, Frosch et al. (2007) found that although most commercials contained rational arguments, almost all (95%) contained emotional appeals. They found that the television ads were lacking in information about the conditions and their causes, and none mentioned lifestyle changes or other alternative treatments for the conditions. The appeals in most of the ads studied (85%) portrayed the drugs as a way of gaining control and emphasized social benefits of taking the drugs. In 58% of the ads, the medication was “portrayed as a medical breakthrough,” (Frosch et al 2007).

DTC ads have been shown to contain little educational information, while fulfillment materials, requested by consumers by calling a toll free number or visiting a website, were found to contain slightly more. One content analysis claims that these materials still require a high level of literacy. (Chao 2005). While the requirements for inclusion of a “brief summary” outlining potential risks and side effects remain for both broadcast and print advertisements, studies suggest that consumers pay far less attention, if any, to the portions of the ads containing this information (Prevention 1999). DTCA often contains both positive and negative emotional appeals (Main, Argo and Huhmann 2004) in addition to rational appeals. In a 2002 study, researchers found that in print advertising, most ads did not mention how likely the treatment was to be successful and many did not mention any alternative treatments for the condition described in the ad (Mintzes 2002). Other studies have found that the literacy demands of the information in DTC to be well above the average consumer’s literacy level. (Kaphingst et al. 2005; Kaphingst and DeJong 2004)

The concerns about information are significant not only due to a drug’s popularity and the size of its consumer base, but also because some drugs address more serious, often life

threatening conditions such as HIV. One content analysis indicated that while ads have been modified more recently in response to concerns about their content and implied meaning, the print ads still lack specific information about how effective these medications are, how they might fit into an existing treatment regimen and possible serious side effects (Kallen et al 2007).

The New Zealand Experience

The only country outside the US that allows DTCA is New Zealand, where the DTCA experience has been highly criticized. Companies who took advantage of the relaxed self-regulation system in NZ and purchased outdoor, broadcast and print advertising by and large represented drugs for weight loss, baldness, depression: conditions some say are natural and associated with the normal human condition, especially with aging. Thus, much of DTCA in New Zealand was criticized for contributing to the medicalization of conditions that are deemed to be normal progressions of life. These ads were seen as promoting simple pharmaceutical solutions to what amount to social or value oriented problems (Coney 2002). The style of advertising used in New Zealand employed edgy humor, nudity and dramatic appeals, and the country's widespread use of outdoor and convenience placement of advertisements made them nearly impossible for consumers to avoid. This led to much criticism about the presentation of information and the quality of the information as it relates to a consumer's ability to make an informed decision – about the condition or its treatment (Coney 2002, Hoek and Gendall 2002). However, in the self-regulatory environment, pharmaceutical companies appear to have been responsive to concerns raised in the public policy arena (Cohen 2002). An added concern about the influence of DTCA in New Zealand is that health care, including prescriptions, is subsidized by the government. Therefore, the government is even more concerned by any increase in

demand for more costly prescription medications, especially when lower cost alternatives may be available. While a comprehensive review in 2001 showed inadequate evidence that DTCA had a negative impact, government agencies continue to monitor its effects (Hoek and Gendall 2002). While this dissertation study will focus on consumers in the US, it is important to note that the experience with DTCA in New Zealand is a significant consideration for those countries that are considering changes in policy abroad to allow DTCA.

Effects on Consumers

Consumer attitudes toward DTCA have been measured as a factor of their exposure to these types of ads and their level of consumer knowledge. Those with low consumer knowledge regarding the regulation of prescription drugs and their promotion had more critical and less positive attitudes toward DTCA. However, those who had previously been exposed to the ads had more positive attitudes toward DTCA (Vatjanapukka and Waryszak 2004). Women have been found to be more likely in favor of DTCA (Robinson, et al 2004) and older Americans had more favorable attitudes toward DTCA as well, and were more likely to consult a physician after seeing an ad (Williams and Hensel 1995).

Studies have reported mixed results regarding the valence of consumer attitudes toward DTCA. In early studies, some before the regulation changes of 1997, consumer attitudes were generally positive toward DTCA, and positive attitudes among consumers were related to prior exposure to this type of ads. However, more recent surveys indicate that the attitudes among consumers are less positive (Robinson, et al 2004), This suggests that consumers may be experiencing a “wearout factor” that is, now that they have been exposed to the advertising liberally for more than a decade, they see it as less positive (Pechmann and Stewart 1988). It is

interesting to note that among Australians, attitudes towards DTCA were more positive among consumers who had reported having seen DTCA (but in whose country DTCA is illegal) compared to those who had not been exposed to the ads.

Attention to ads, and resulting behavior

"The ads are very appealing and I would like to take that drug. I can't tell what it's for, but the result of taking it seems to be improved gardening skills, well-behaved grandchildren and being able to bicycle into the sunset."

--Consumer comment in Endresen and Wintz, 2002.

Regardless of attitudes toward the ads, consumer studies have revealed a relatively low rate of recall for information included in DTCA. In a 1999 survey of consumers by Prevention Magazine, while many consumers could recall several drug brand names and their advertisements, few could recall the diseases they were intended to treat or the symptoms. Forty percent of those consumers surveyed were not aware of the "brief summary" section of the advertisements, where important indications such as potential side effects of the advertised drug are listed as required by FDA regulations. Of those who were aware, 10 percent ignored it (Prevention 1999).

Among older consumers, there appears to be a third-person effect of DTCA. That is, older consumers don't believe they are affected by DTCA, but they do believe that others are significantly affected. The third person effect theorizes that one's behavior is influenced by the perceived effects of a stimulus on others (DeLorne, Huh and Reid 2006). Those with symptoms or a condition described in a DTC ad, or those who take prescription drugs in general are more likely to read most or all of a print advertisement, suggesting that involvement is a major factor in a consumer's attention to an advertisement. Age and use of prescription drugs are factors in

the amount of attention readers pay to the ads, as well as their response to ads in this category (Robinson et al. 2004).

While consumers are the end users of prescription drugs, the system makes them only one influence in the process of treatment choice (Mehta and Purvis 2003). The process of obtaining a prescription drug is different from most other consumer buying decisions in that the process includes visiting a physician, having that physician write the prescription and then filling that prescription at a pharmacy. So to result in a sale, DTCA, unlike advertising for other products, must motivate the consumer to initiate these additional steps.

DTCA does encourage patients to ask their doctors about both a condition and a potential drug treatment, and as a result, patients may insist on a prescription for the treatment mentioned in an advertisement (Mehta and Purvis, 2003). For certain drug categories, DTCA appears to increase sales within a drug category, but not for specific brands. DTCA for osteoarthritis drugs, for example, was found to increase the number of prescriptions within a category, but not necessarily for the specific brand being advertised (Bradford, et al, 2006; Datti and Carter 2006, Parker and Pettijohn 2003). Television advertising has been shown to increase the number of physician visits for a condition that was mentioned in the advertising messages. (Bradford et al 2006). Wosinska (2005) found that DTCA exposure is also related to an increase in a patient's compliance with a prescribed therapy for cholesterol drugs, that is, patients who see DTCA may be more likely to take medication already prescribed for them for this condition, but this effect isn't necessarily significant for the specific brand advertised. In a study of older American adults who had been exposed to DTCA, 31 percent had requested a prescription drug from their physicians, of which 69 percent received the requested drug. Adults over the age of 75 were less

likely to request a drug from a physician, however, this may be a reflection of generational norms. Future generations may be more likely to request drugs from their physicians (Datti and Carter 2006).

Some recent research also points to a potential placebo effect for heavily promoted prescription drugs. The placebo effect has been identified in the medical literature as “a substance or procedure that has no inherent power to produce an effect that is sought or expected” (Stewart-Williams and Podd 2004). Waber et al. (2008) found that, among study participants who were given placebo pills for chronic pain, those subjects who were told their pill was a new, branded, more expensive drug reported greater effectiveness than those who were told they had received a less expensive, generic pill. The placebo effect has appeared in the marketing literature as a function of a consumer’s expectation that a product will have a particular effect. In a study of energy drinks, for example, consumers who chose a higher priced, branded drink over a generic less-expensive drink, both of which had identical ingredients, reported experiencing a greater physical effect (Irmak, Block and Fitzsimons, 2005). The premise of the placebo effect can be used to explain this effect for many products, and DTCA may be no exception. Consumers’ exposure to pleasant images and strong brand presence through advertising may create expectations that the advertised remedies are actually better than less expensive, more conventional therapies, even though they may work equally well or the latter even better in some cases.

Effects of DTCA on physicians

Overall, most studies report that physicians generally have negative attitudes toward DTCA (Robinson et al 2004, Lipsky and Taylor, 1997, Gonul, Carter and Wind 2000, Hoffman and Wilkes 1999). These are based on beliefs that the advertisements don't provide adequate nor accurate information and that they influence patients to request specific treatments (drugs) and form patient expectations that may be unrealistic or inappropriate, specifically expectations that physicians will prescribe the drug. These expectations may lead to inappropriate prescribing practices (Robinson, et al 2004.) Also, DTCA discussions with physicians increase the amount of time necessary to cover all of a patient's concerns, which was the primary reason physicians gave in a 1997 study where 80 percent or more of the respondents stated they thought DTCA was not a good idea.

Of those physicians who reported having positive attitudes toward DTCA, "better informed patients" and "promoting physician-patient communication," were the most common benefits they noted (Lipsky and Taylor 1997). Murray et al. (2003) found that 39 percent of physicians surveyed said they thought that discussing DTCA enhanced the patient relationship, but that discussion also made time with the patient less efficient.

The medical literature has called upon physicians, in the face of DTCA, to maintain their role as counselor and gatekeeper for prescription drugs. Doctors are still the highest valued source of healthcare information, ahead of friends and relatives, pharmacists, other health care professionals, and advertisements seen in a physician's office (Kaiser Family Foundation 2001).

When approached with a request for a prescription drug resulting from exposure to DTCA,

“doctors have the added responsibility of directing any conversations to a patient's symptoms and physical complaints to determine the appropriate treatment by asking questions about what the patient may have seen or heard in an advertisement in order to

manage their expectations and move the conversation in a direction that makes the appropriate treatment acceptable to the patient without discounting their original expectations (a prescription)” (Kravitz, 2000).

DTCA as a Contribution to Society

DTCA has been given credit for bringing awareness and acceptance among consumers who have health conditions that were previously stigmatized by society, such as depression, erectile dysfunction and incontinence (Donohue, 2005). For example, in a study of the costs and benefits of DTCA for depression drugs, researchers found that 94% of patients who received a new prescription for antidepressants as a result of DTCA did not actually suffer from depression. These results, analyzed in a purely economic framework, were significantly outweighed by the effective benefit of treating the remaining 6% who did suffer from the disorder, in terms of a “positive social welfare effect,” (Block 2007).

DTCA’s contribution to society appears to be that it provides information about possible treatment choices and about conditions that may be undiagnosed. This, in turn, may provide information about and encouragement to stick with a treatment, thus increasing compliance to needed treatment programs.

Many pharmaceutical research studies have been criticized for small or otherwise limited samples, and that many studies have been subsidized by the pharmaceutical companies as a means to promote the benefits of DTCA (e.g. Bodenheimer 2004). While there is much in the literature that is critical of the commercialization of pharmaceuticals, there is also significant evidence that positively endorses the practice. Thus, there appears to be room for error on both sides of the debate. What, then, is left to learn about DTCA and its impact on consumers? The debate over how it’s best to measure the effects of advertising continues, although there are several ways to quantify the effects as reflected in the studies cited above: number of physician

visits, attitudes toward the advertisements, dollars spent on the product, number of prescriptions, awareness of medical conditions and their treatments, and confidence in treatments for a condition.

DTCA and Chronic Health Conditions

What has not been examined, however, is that of a gestalt effect on the consumer who sees and attends to these advertising messages. For example, what is the meaning derived from these messages communicated to consumers by pharmaceutical companies about prescription drugs? What role does DTCA play in the lives of those with chronic conditions? How do consumers with chronic conditions view themselves in the context of these advertisements? To explore these questions calls for more in-depth qualitative examination of the experiences of consumers. One place to start is with those consumers who are presumably most affected by the messages and the treatments they represent: consumers with chronic health conditions.

A chronic condition is one that exists over a period of time, usually longer than three months, and is not self-limiting (VanKorff et al. 1997). In DTCA, the categories of drugs on which the most money was spent in 2002 were antidepressants, antihistamines and nasal sprays, anti-hyperlipidemics, and proton pump inhibitors. These drugs address depression, allergies, high cholesterol, and acid reflux disease, respectively, all of which are considered chronic conditions (Berndt 2005). More recently, Merck began using DTCA to promote its new drug addressing type 2, also known as adult-onset, diabetes (Merck 2007). As mentioned in chapter one, this is presumably due to the market potential in these categories, as many of these conditions have somewhat ambiguous symptoms, and are largely under diagnosed and undertreated (Iizuka 2004).

The most common chronic conditions, according to the National Academy on an Aging Society (2000) for all ages are sinusitis, arthritis, orthopedic impairments, hypertension and hay fever (allergies). For those over 75 years of age, the most common include arthritis, hypertension, hearing impairments, heart disease and cataracts. Of those, the most common conditions represented in DTCA are allergies (sinusitis and hay fever), arthritis, hypertension and heart disease. More than 50 million Americans are estimated to suffer from some kind of allergies responsive to a skin test. More than 46 million adults in the US have been diagnosed with some form of arthritis. Heart disease, in the form of hypertension, afflicts 73 million people in the US. In 2005, more than 100 million people were estimated to have high cholesterol, which also contributes to heart disease, and 37.2 percent of US adults had levels considered to put them at high risk for a coronary event such as heart attack or stroke (American Heart Association 2005).

There are other chronic conditions that are relatively widespread and are often represented in DTCA, although not in the top five most prevalent conditions. Diabetes can be a contributing factor to hypertension and heart disease. It afflicts more than 20 million Americans over the age of 20, with about half of those being over the age of 60, or 20 percent of older Americans. An estimated 6.2 million of people with diabetes are undiagnosed, and 54 million more in the US are considered to be pre-diabetic (American Diabetes Association 2007). Also, approximately one fourth of the US population experience sleep disorders at some point, and about half of those cases are considered chronic. (National Institutes of Health 2005).

DTCA has well-defined target markets, and the trend toward targeting is increasing (Berndt 2007). Consistently, the majority of expenditures on DTCA have been for drugs which

address chronic conditions, and are primarily aimed at middle-aged and older Americans (Ad Age 2007). It is important to study chronic conditions, not only because of their prevalence among the US population and their appearance in DTCA, but because these conditions are considered to be most costly to individuals and the health care system in general. By the year 2040, an estimated 160 million people in the US will have chronic conditions at a cost of more than \$800 billion (National Academy on an Aging Society 2000). An estimated one quarter of all Americans had at least one of the following chronic conditions: mood disorders, diabetes, heart disease, asthma, and hypertension. Half of their health care spending was for the primary condition, and the other half was on additional conditions (Druss et al. 2001). An MIT study found that for hypertension, heart disease and diabetes, when patients did not receive benefits to cover adequate treatment for these, they became a higher cost burden upon reaching the age to qualify for public health benefits in the US (Medicare) (Berndt 2005).

Chapter three will cover more details of the study, including sampling procedures and data collection and analysis frameworks.

Chapter 3

Methodology

The methodology employed in this study follows an ethnographic approach. While quantitative studies have attempted to observe consumer behavior in the context of DTCA, ethnography seeks to understand a phenomenon from the “native’s point of view” (Creswell, 2007 p. 217). Ethnography is the study of culture, as defined as “shared knowledge” (Wolcott 1999). Culture, in turn, is the collection of beliefs and behaviors shared within a group which affect an individual’s behavior and perception of oneself and the world (Galanti 1991). This methodology “focuses on an entire cultural group,” which may be small or large, with the understanding that those in the group have shared experiences that cause them to develop a “shared patterns of behavior, beliefs and language” regarding these shared experiences. Creswell (2007) extends this notion suggesting that ethnography is a description and interpretation, through the lens of the researcher, of “shared and learned patterns of values, behaviors, beliefs and language” and their meaning (Creswell 2007). Because ethnography is “both a process and an outcome of research” (Agar, 1980), this methodology has the potential to yield both rich description of the meaning created by DTCA, and a portrait from which implications for consumers, researchers and practitioners may be drawn. With roots in anthropology, ethnography consists of an extended period of observation of the participants in a group, in which the researcher may actually participate in the activities of the group. For the purpose of this study, the group consists of consumers who believe they have a chronic condition, one of those for which prescription drug treatments are frequently marketed direct to consumers, and

the social network to which they belong. Those with chronic conditions are more often the target audience for DTCA, and, in fact, the companies spending the greatest amount on DTCA are manufacturers of remedies for chronic conditions. Further, it is believed that due to a high level of involvement with their health and symptoms, those with chronic conditions are more likely to pay attention to and follow directions to seek further information about drugs featured in DTCA.

Approaching the research objectives qualitatively allows the collection of rich data that may assist in understanding how meaning of DTCA is constructed by consumers in the context of the culture created around a chronic health condition. Qualitative methods provide the flexibility to ask elaborative questions of the participants and therefore examine the “how and why” of this culture.

Population of Study

Past qualitative studies of different aspects of chronic illness have included inquiry into the individual’s lived experience, treating the chronic illness as a phenomenon (Gullickson 1998, Thorne et al. 2002). This study took a different perspective, identifying those living with a chronic CONDITION in the US who generally subscribe to the US Biomedical model as a culture. We use the term “condition” rather than “illness” in this study, to reflect the nature of some afflictions as non-life-threatening and not necessarily debilitating, but rather manageable imperfections that affect quality of life, and those that may be corrected by changes in lifestyle and habits. Some examples include insomnia, incontinence, erectile dysfunction, mild depression, and anxiety. Further, in the instance of chronic conditions, individuals are confronted with not only the medical element of their illness, but also the social and psychological aspects of coping with their issues (May et al. 1989). The US Biomedical model

speaks to an overriding philosophy of health care among physicians and patients which is described as “a set of values or tenets... such as dichotomization of mind and body, the belief that individuals can control their environment, and the value of taking responsibility for one’s health,” (Reiser 1985). It is important to note that this model is assumed to represent “mainstream” values and attitudes and may not apply to consumers in ethnic or other cultural minorities (Becker et al. 1998).

This dissertation focused on individuals who have a subset of similar, non-life-threatening chronic conditions which are most often the subject of DTCA. These included hypertension, high cholesterol, allergies, insomnia, migraine headaches and mild depression. Some participants had two or more chronic conditions, some of which may be related to one another. For example, several had hypertension and high cholesterol. Other chronic conditions that are often found in addition to these are those which may be construed as “lifestyle” conditions, that is, those that are not life threatening but significantly affect the quality of life, include erectile dysfunction, depression and insomnia. By choosing participants with similar characteristics such as age group and cultural background, this study sought to focus on and understand commonalities among people experiencing chronic conditions and how they interpret and create meaning from the marketing messages of pharmaceutical companies, which are often directly targeted to this group. Previous studies have shown that there are differences, especially among older ethnic adults, in how chronic illness is viewed and treated by the individual (Becker et al 1998). For this reason, a homogeneous sample of adults who subscribe to the mainstream biomedical model of the US were selected to participate. In summary, the sample consists of mainstream Americans, representing adults between the ages of 40 and 65, with chronic

conditions most often represented in DTCA, who subscribe to the US biomedical model of healthcare and are exposed to primary media on a regular basis where DTCA appears. That is, this study examines the group which most often comprises the target audience of DTCA.

The Process

Potential participants were identified by issuing a public call, using one or more of the following: posting paper flyers on bulletin boards at hospitals and other health care facilities, placing an advertisement in a community newspaper or through an online community such as Craigslist, and making the information available to healthcare professionals who may forward it to their patients who may qualify. The request for participants was for adults over the age of 40 who 1) have been diagnosed with, or believed they had a chronic condition and 2) had been exposed to Direct-to-Consumer advertising and marketing efforts directly from pharmaceutical companies. Interested individuals were instructed to contact the research team via email or by phone, to ensure inclusion of those with and without technology expertise or access. Those who responded received more information about the study and were asked to complete a short informational survey, which included demographic questions and inquiry about their condition, diagnosis, and media exposure. This survey was administered on the telephone or in person. From the completed surveys, a smaller sample was selected, based on the answers to the survey including duration of the condition, severity, and amount of media exposure. This subset was asked to participate as participants of the ethnographic study for a period of three months, during which time they may be asked to collect artifacts reflective of their condition and how it affects their lives and to participate in recorded, open-ended interviews. Each participant who completed the process received an incentive in the form of a \$50 gift card.

After a group of initial interviews was conducted, written transcripts of the interviews were analyzed by the primary investigator and an interpretive group of at least two other researchers to establish categories and emergent themes. Theoretical sampling determined the direction of a second group of follow-up interviews, including characteristics of future participants such as age group and nature of the chronic condition. This process was repeated until the analysis reflected a saturation of categories and a core set of themes in the context of DTCA. In ethnography, “crystallization” occurs when analysis reveals commonalities among participants and significant themes across the data (Fetterman 1998). Theoretical saturation is reached at a point when new data confirm and support crystallized categories and themes, no longer reflect new information, but rather, confirm what has been revealed in previous data. At this point, the study may conclude (Strauss and Corbin 1990).

Prior to beginning the study, a researcher skilled in qualitative methods conducted a bracketing interview in order to identify the predispositions of the dissertation researcher. Because the researcher is the instrument in this methodology, it was important to understand any prejudices or preexisting frameworks that may bias the research process. Once this interview was conducted and analyzed by a third party, the researcher reviewed the results and was careful to “bracket out” any findings that might, in the process of conducting the research, influence participant responses or behavior during the observation period.

The data collected in ethnographic study consisted of, but was not limited to, transcripts of audio and/or video of in-depth interviews, photographs or other visual representations of artifacts collected by the participants to represent their condition and treatments. Some participants received a container, either a box or a bag, in which they were to collect artifacts that

pertain to their lives as consumers with a chronic condition. These included, but were not limited to, drugs or devices used for treatment, medical printed information they have received in the mail or from their physicians, advertisements for drugs they take as treatment for their condition, photographs, and journals. These items were returned to the participants following analysis as desired by the participants, in order to encourage participants to include items regardless of their intrinsic or extrinsic value.

As mentioned earlier, ethnography is both a methodology and a finished product of research. Using these methods, this study attempted to provide rich insight into the effects of direct to consumer marketing of prescription drugs to consumers with chronic conditions.

Analysis and Trustworthiness of Data

In this study, several methods were employed to ensure trustworthiness of the data and to meet the criteria outlined in previous qualitative marketing research (Flint, Woodruff and Gardial 2002). Because ethnographic methods were employed, criteria for quality ethnography were also included.

The first set criteria for trustworthiness include credibility, transferability, dependability, integrity and understanding (Lincoln and Guba 1985). Credibility is how closely the results in the study appear to represent the data. The interviews in this study were conducted over a six month period, and data were analyzed by an interpretive group during that time. Transferability speaks to how closely findings in the same study apply across contexts. In this study, theoretical sampling was used to compare findings for participants with one chronic condition to those with different chronic conditions and participants with different routes to diagnosis. The concepts were found to be universally represented in the data across cases. Dependability refers to

“stability or consistency of explanations” over time by participants. In the interviews, participants described current experiences, but also reflected on events from the past. Confirmability is the “extent to which interpretations are the result of the participants and the phenomenon as opposed to researcher biases.” The primary investigator took part in a bracketing interview prior to beginning the study, during which potential biases and beliefs were identified. A co-researcher analyzed the initial transcripts of interviews in the study to verify that those biases had not materially influenced the data collection. Additionally, an interpretive group initially reviewed the preliminary data analysis and subsequently the final data analysis, comparing concepts to actual excerpts from the interviews and identifying additional themes and categories for further study. Integrity in the assessment of trustworthiness refers to the openness of participants, or the extent to which they give honest, straightforward accounts of their experiences. To ensure integrity in this study, the confidential interviews were conducted in a professional manner in a comfortable setting. Questions and directions given to participants were delivered in a manner that allowed them to express their true thoughts and feelings about their experiences. This was also verified by members of the interpretive group. Understanding has to do with the extent to which participants agree that the analysis is representative of their expression. Select participants reviewed summaries of the study results and were given the opportunity to verify the findings as a representation of their experiences, and a group of colleagues reviewed the preliminary analysis for their feedback, and there was agreement that both were accurate interpretations of the text.

The criteria for quality ethnography include recording 1) data in context, 2) developing and exploring hypotheses as they emerged, 3) recording observations over time, 4) using

systematic methods to gather information, 5) and maintaining an objective research perspective (Spindler and Spindler 1987). The following is a description of these methods and checks.

Observations were collected via audio recording and field notes. The digital audio recordings were made of depth interviews at a place convenient for the participant and then transcribed by a professional service. Transcripts were then read by the principal investigator, and the recordings were revisited where necessary to clarify parts of the interviews. Several participants were contacted a second time to verify the meanings of passages in the transcripts or to discuss some other aspect of the study. These methods were employed to ensure that data was collected in context.

Two participants were interviewed a second time in a semi-structured format. During these interviews, participants were given a book of magazine clippings containing mostly full-page print DTCA and other full color advertisements as a prompt for the discussion. This method was employed when early interviews yielded minimal information about DTCA and was an attempt to prompt additional conversation specifically about advertising, and helps fulfill the criteria for collecting data over time. The second interviews were conducted approximately six months after the initial interviews. Use of the magazine ads and the semi structured format were efforts to fulfill ethnographic criteria 3-5 above. To develop and explore emerging hypotheses, the interviews were coded one at a time and themes were synthesized after every two or three interviews for the purpose of theoretical sampling in subsequent interviews.

Chapter 4

Introduction

This study began as an investigation into the experience of direct-to-consumer advertising (DTCA) among middle aged American consumers with chronic conditions. Its original intent was to discover how consumers interpret, use, and feel about DTCA in their experience with chronic conditions such as allergies, asthma, hypertension and mild depression, among others. The plan was to explore these phenomena in the culture of middle class American consumers by asking questions focused upon how they live with their chronic conditions and asking indirect questions about how they learn about possible treatments, assuming that DTCA would emerge in the course of the conversation because of its pervasiveness.

While a significant amount of valuable data was collected pertaining specifically to DTCA, analysis of the first few interviews led to the discovery that DTCA is one piece of a much larger picture of the life world of a person diagnosed with a chronic condition. Through these interviews, participants revealed a much broader experience, that of *patient as consumer*. In fact, DTCA appears to be viewed by this group of consumers, who are considered to be the primary target audience of most DTCA installments in broadcast and print, as one of a number of information sources that assist them in their quest to manage their chronic condition. As a result, examining DTCA in this life world became something like looking through a keyhole into this world of managing a chronic condition. These participants had arrived at a stage of life, a certain age, when chronic conditions were more likely to develop. In fact, after age 60, most Americans have at least one chronic condition which requires daily or frequent treatment to be considered

“managed” and thus no longer potentially capable of causing more serious, permanent, health problems.

Therefore, in this chapter, the analysis of data collected in this study will be described in the following manner. The first part will include a description of the data and subsequent interpretation as it pertains to the original DTCA related research questions. The second part will discuss the analysis and interpretation pertaining to a set of new, broader research questions addressing the patient as consumer’s management of chronic illness. Theories will be considered that pertain to the interpretation of the findings. In chapter five, implications of these findings to practitioners, public policy makers and consumers will be discussed along with future directions for research.

Sample

Participants were selected from a group of individuals responding to 1) recruitment announcements posted on bulletin boards at a local church, 2) emails sent out to general lists by two local market research companies, and 3) the primary investigator’s social networking web site, Facebook. A brief questionnaire was administered to the respondents by telephone to collect demographics, information on media use, chronic conditions and current state of general health. Thirteen participants (see Table 1) successfully completed depth interview sessions, and semi-structured follow-up interviews were conducted with two of those, for a total of 15 interviews. The final sample was comprised of five men and eight women, ages 45-60, with a median age of 52. All but one was employed in professional careers full time. Interviews were held primarily at the participants’ workplaces, although some were in public locations such as the county library and a coffee shop, and two were held at the participants’ homes.

Table 1: Participants

Pseudonym	Gender	Age	Condition	Education	Interviews
Bob	M	54	GERD, blood clotting disorder	Ph.D.	1
Bonnie	F	58	Allergies	Masters	2
Carl	M	55	Hypertension, sleep apnea	Bachelor's degree	1
Carrie	F	49	Allergies, depression, hypertension, high cholesterol, arthritis, GERD	Masters	2
Everett	M	60	Hypertension	Bachelor's degree	1
James	M	55	High cholesterol	Some graduate	1
Joel	M	60	Hypertension	Ph.D.	1
Judy	F	56	Allergies, mild depression, high cholesterol	Some graduate	1
Linda	F	40	Allergies, asthma, high cholesterol	Ed.S.	1
Melissa	F	45	Allergies, mild depression, hypertension	Bachelor's degree	1
Sharon	F	54	High cholesterol	Bachelor's degree	1
Susan	F	48	Migraine headaches, insomnia	Bachelor's degree	1
Marilyn	F	47	Hypertension	Bachelor's degree	1
		52	Median Age		15
					Total Interviews
Total:			13 participants 5 male, 8 female		

Exploring DTCA

This study initially addressed the following research questions:

- What does DTCA mean to its primary target audience?
- What are the shared meanings of DTCA and its messages among middle aged Americans who have chronic conditions?
- How do participants use the meanings they construct from DTCA in their daily lives?

This study did provide insight into these questions. Broadcast television advertisements in the evening hours were those most often mentioned, followed by print advertisements in popular magazines such as *Guideposts*, *Better Homes and Gardens*, *Southern Living* and *Good Housekeeping*. The primary categories of drugs in the advertisements mentioned in these interviews include those that treat allergies, asthma, hypertension, high cholesterol, depression, osteoporosis, adult bladder conditions and erectile dysfunction.

Ads are both “Good and Bad”

Many participants expressed a belief that DTCA is “not all bad” and acknowledged that there are benefits to broadcasting information to “some other people” who could potentially benefit from hearing about a condition and/or a drug, especially if they did not have access to other, more reliable information.

“ I think doctors may not appreciate the fact that we’re all becoming little doctors, you know, we’re really a lot of us trying to be more knowledgeable and I know some people don’t have access to the internet, that’s just a fact, but those of us who are, if there’s any health issue that comes up we immediately go to the online MD’s and all of that kind of stuff to become knowledgeable and I think the TV ads are just a part of that, you know they’re providing the information in a different format. Maybe people who can’t get the internet are watching it on TV so as long as it’s truthful I think it’s a really good thing.” -- Bonnie

Among the positive effects the participants believe DTCA has are educating the public about common conditions, reinforcing treatment choice for people who have already been prescribed a medication, and facilitating conversations between doctors and patients that might not otherwise take place.

“What those ads will do though is it will I think inspire you to think not so much about the name of the pill but think about a condition. Because then if they describe the symptoms you think oh that you, again the Alzheimer’s thing, if you think dad’s forgetting or something you perk up because you relate to it and you’re like wow that’s what I’m going through or that’s what my family is going through, so I think it might get you to go in, for me at least, not so much to ask my doctor about that particular pill but to ask him about that condition.” -- Marilyn

However, despite some acknowledgement of positive effects, the participants expressed strong potential negative effects, as well as negative attitudes toward prescription drug ads in general and specific qualities of the ads in particular.

Inundated with ads

What consumers reported, when DTCA became the topic of conversation in their interviews, their initial responses were observations of the pervasiveness of advertisements in programming they watched on television.

“Those things, they’re almost ubiquitous you don’t have to say what they do anymore because everybody knows what they do if you’re above a certain age. Is that gonna convince you to use that product over another? I don’t know.” -- Bob

“I mean we are so inundated with that crap it’s just crazy...Oh, I get a health magazine, so there are a lot of them in there, but mainly it’s just things like you’re just inundated on TV, 6 to 7 (pm) is just miserable.” – Melissa

They found these advertisements to be irritating and often ignored, or tried to ignore the ads when they appeared on television or pass over them when they appeared in print.

“I don’t listen to it. I tune them out or I turn them off, or I mute it if I’m seeing it on the TV or on the radio, I’ll flip channels.” – Carl

“Let me preface it by saying I’ve spent a good part of my adult life not paying attention to ads and so I’m pretty good at it so I’m not, you know, what’s the last one I saw that I can recall? Probably something for depression and I can’t recall what was being advertised. The reason I pay any attention at all is that I don’t like those ads; I don’t think they’re honest.” – Joel

Overall, frustration among the participants spurred discussion of how they ignore or “block out” advertisements when they recognize them as being DTCA.

“I’m getting pretty good at it.” -- Joel.

“I see (DTCA) more often than hamburger ads. Now, I don’t eat hamburgers very often anymore, but I’ll watch a hamburger ad. But a drug ad? no.” -- Everett.

When the ads cannot be or are not ignored, consumers may treat them as the target of jokes, especially for conditions like erectile dysfunction and poor bladder control.

“I had a discussion recently with a bunch of folks - just the names of the products and how odd they can be and commercials are messages that I remember seeing...we were giggling about that.” – Carl

“The Flomax ad shows a group of older men who, which is typically who have enlarged prostates, and they’re all doing manly, guy stuff, you know they’re riding their bicycles or deep sea fishing or whatever they’re doing ... All these manly men doing all this stuff and I think it’s funny because we’re all doing all these manly things and they’re stopping every 5 minutes to go to the bathroom. Then they take this medication, now they’re deep sea fishing, and they’re riding their bicycles 20 miles and stuff like that. And I just thought you know it’s really funny to see those kind of ads and it probably works but it just seems like they’re all enjoying life now because they don’t have to go pee every 10 minutes.” -- Bob

Many participants considered some drug ads to be targeting people who had, not medical, but lifestyle conditions.

“I see ads at two different levels. Some ads say, ‘life is better with this drug,’ instead of ‘you need this to keep yourself alive or healthy.’” -- Joel

“Viagra, you can live without.” - Bob

“There’s a new one out for, oh fibromyalgia there’s a couple ads out for fibromyalgia and ... I always think about that, fibromyalgia: has it really been deemed a disease?” – Melissa

What participants recalled from DTCA varied, but a few points of commonality emerged.

Most often, brand names were not recalled, and sometimes even the condition was not recalled.

What they did recall was pleasant or exciting imagery, usually with an element of familiarity.

“She’s on holiday with her husband I think, as long as they’re in New Orleans. That’s another reason, I always stop to look and say oh I think she’s, you know I’ve been there so many times you stop and look at where she is.” – Melissa

“They show this woman and she’s walking along the beach and you see the ocean in the background and she’s going across the sandy dunes, they’re not very large dunes. She stops at this house and she puts her arms around this man.” -- Carrie

Moreover, very specific points of familiarity were often recalled. For example, many participants mentioned ads for Boniva, a drug which treats osteoporosis in women and features actress Sally Field as spokesperson for the drug.

“Well, she is sitting out in the yard and it’s very homey and, of course, Sally Fields is one of our special movie stars. I mean, she automatically makes you look at her, and then her voice is so pleasant and what she’s saying is so helpful. It’s almost like two women sitting... it’s almost like me sitting across from her listening to what she’s saying. I think she’s playing with her dog, maybe, and it’s outside. The one I’m remembering, I think she is just dressed very casually, but it’s like she’s everybody’s friend, everybody’s girlfriend, so I think she’s very effective with it.” -- Bonnie

Others commented on perceived similarities between themselves and specific actors in advertisements, and were able to recall details about the imagery of those ads that portrayed situations or actors with familiar qualities or with which they could identify.

Similarly, participants recalled advertisements that mentioned symptoms they had experienced, conditions for which they had been diagnosed and drugs they had taken in the past

or were currently taking. And, there appeared to be a high level of recall for ads pertaining to conditions their friends or relatives had.

“I watch out for the stuff my dad takes, he has trouble breathing so he takes Singulair and some of those and I watch those commercials or if I see them I’m more alert to them anyway.” -- Sharon

“My daughter did have asthma so I probably pay attention to those a little bit more because of that.” -- Susan

“I don’t know (why I remember it,) I guess because my sister is bipolar.” - Carrie

High levels of recall were also apparent for advertisements that were considered repulsive or shocking to consumers. In one instance, the participant reported seeing a commercial for a migraine medication which featured a special effect which made the actor appear to displace their own heads and hold them in their hands out in front of their bodies. “When I get a migraine, I just want to take my head off,” the actress proclaims in the ad as she holds her head on her hip a la the headless horseman.

“There’s some... ads that I just hate to watch. There’s one I don’t know if it’s over-the-counter or not but it’s where they rip their head off. I’m like eww no, I live with this I don’t want to think of it with that visual in my head.” – Susan

Another ad, one that did not have content relevant to the participant but that she remembered because it “grossed me out,” was one for the prescription treatment of toenail fungus. The advertisement featured a cartoon character portraying the actual fungus.

“Oh, you know the one that’s coming to mind, the one that deals with the fungus under their toenails that was so nasty it was an awful ad. I don’t remember the brand and I closed my eyes every time it came on but I remember it.” -- Susan

“It’s awful, it’s nasty. If you’d seen it you would remember it because it’s hilarious because it’s just so awful, my whole family just goes, turn it down!” -- Susan

Finally, the most commonly recalled imagery from DTCA in print and broadcast was from one campaign that was mentioned by every participant in this study. The ad features a man and a woman, each in a separate bath tub but very close to each other, looking out at a sunset at the top of a cliff overlooking a beach. Interestingly, although these scenes were easily recalled by almost every participant, only one was able to accurately name the drug advertised (Cialis.) All recognized it as an ad for an erectile dysfunction drug, however, most of those who mentioned a brand name recalled another brand name.

“It’s just something about the scene, who would be in the middle, on a hillside in bath tubs; it just is, looking out over the sunset? I mean you know what they’re portraying and looking out into the sunset and you’re prepared for the absolute right moment, I don’t know what the tubs have to do with it but it just is, I can’t tell you anything more than that I just find it amusing.” – Carl

“They have a husband, well a man and a woman and they are in separate bath tubs and they are either overlooking the mountains or the beach. Why are they in bath tubs, it makes no sense.” – Melissa

“(I remember) the one for erectile dysfunction has the couple in the bath tub outside.” –Judy

“And then I’m sure because when I’m watching these things about erectile dysfunction they’re in the bathtub you know in the sunset and the surf in their own little bathtubs a man and a woman and I think why don’t they put them together in one big tub in a hot tub or something, I mean how could that work?” – Carrie

The reactions to this category of ads ranged from male participants indicating they were glad the drugs are there for those who need them, to a level of embarrassment so intense that it left one participant in a fit of giggles that made it difficult for her to speak. The acknowledgement by some participants of a possible need for the drug for “some people” suggests that there is a level of acceptance of this condition that may not have existed prior to DTCA. However, several participants brought up the ad in their discussion and expressed that

they were embarrassed by the ads, especially when they aired when mixed company was present. For some, their embarrassment stemmed from fielding questions from children about the drugs.

“I wish they weren’t on TV. Because I have my grandkids over here and here comes these commercials whats that grandma and I just don’t wanna go there.” -- Sharon

Skepticism about ads

A recurring theme that emerged in this study was the irritating quality of DTCA. Remarks about DTCA focused on the inability to avoid these advertisements. The large volume of advertisements seen by participants in the study suggests that the commercials are placed in programming that is demographically appropriate for reaching this target audience. However, attitudes toward the ads were relatively negative, especially as they pertain to the frequency and repetition with which they were seen.

Also mentioned were the lists of disclaimers about the drugs being advertised and the common side effects. Participants deemed these to be required by the government in the same way that auto dealers who offer financing must include “fine print” in radio commercials. This information was considered to be presented in a dry, uninteresting way, and often in a way that was difficult for the consumer to understand.

“They’re not communicating, for me it’s not communicating anything; I don’t care about the disclaimer. My doctor will tell me the disclaimer or when the pharmacist dispenses the medication to me he always tells me anything I need to know about the product to make sure I understand anything about it. So, for an advertising message to have to divulge all that information in 30 seconds and it seems like 20 seconds is devoted to a disclaimer, it’s like car commercials that put all that little fine print at the bottom and you have no idea what it says but they have to put it there because you know the government said to put it there. That stuff doesn’t give me any information about what the product does or why I should consider the product so I find it irritating, it’s wasting my time.” -- Carl

“They generally give those in the last 10 seconds and it’s @!!*@!” -- Sharon*

“That’s why I thought they were on there ... I mean to try to prevent law suits to the drug companies, you know C.Y.A. (cover your ass) work.” – Sharon

What consumers say they want from DTCA

When asked what they would rather see in commercials about prescription drugs, participants most often mentioned information as number one on their wish lists.

“I wanna see the ad tell me, this is what it does and it’s gonna work because that will make me think about this drug is better than that drug. Maybe that’s because of my background but I think most people would like to see something that says, you know this is why I should buy you, this is why I should take this drug. Why is this better than that? That’s what I wanna see in commercials.” -- Bob

Something more seems to be happening

There seems to be something more going on than was noted above. Participants remembered the imagery and the scenery, or perhaps the visual mechanism in the advertisements, especially when they were relevant to their condition. Is it possible that these consumers see the advertisements as additional sources of information and attend to them when they recognize them as being relevant, but then at some point disengage once they become frustrated when complete information isn’t forthcoming?

This suggests that perhaps there is a level of attention and an expectation that information will be presented. However, when relevant information does not appear early in a 30 or 60 second spot, the consumer disengages, and fails to attend to the end of the ad where the brand name is usually mentioned. What may result, therefore, is an inability to access brand names from memory. Moreover, the more this occurs, the more consumers are disenchanted by ads that don’t seem to deliver needed information, and thus the more regularly they filter ads out to

avoid either what is perceived to be repetitive scripting, or continued disappointment or discouragement.

“Give me information, I don’t care whether they give it to me in an entertaining, I don’t care how they give it to me but I want to know about the product and so I can form, at least an image of the product with current pharmaceutical advertising, I don’t form any image of the product other than it’s a drug. It takes on no personality, there’s no brand personality and I like, you know from a communications stand point, help me form an opinion about the product based on what you can tell me.” -- Carl

Ask Your Doctor

Participants recognized and noted the specific message strategy in ads to “ask your doctor.” While some were puzzled by why companies were encouraging patients to seek additional information, others were critical of this practice.

“Why would anyone ask their doctor? I would worry my doctor would think I was just after a drug.” -- Susan

“I’ve never gone to my doctor and said, ‘tell me about this medication, tell me about this pill. I’ve never done that, well I’ve never taken that many pills; this is the first one I’ve been on as a regular medication and at this point I can’t imagine doing that because just hearing a name isn’t enough to say, doc tell me about this pill?” – Carl

“I think there are people, particularly as the, as folks in our society become, they are not as trusting of their physicians as I may be at this point, so they question everything. And if they hear something, because they want an instant fix to their health condition. If they hear something, if they know a certain pill does a certain thing I think they’ll be, they are open to asking a physician about it.” – Carl

“I mean, is it a realistic situation where the patient goes to the doctor and says doctor I’d like to take Lipitor, I think I have xyz. Or doctor I wanna try this new Nasonex or this something where heretofore people did not realize a remedy was available?” – James

“(The ad is) generally like a man or a woman dancing around and this is gonna make your life so much better and people having a good time and this drug is

making their life, improving the quality of their life but you don't know what it's curing or fixing or. And they generally say go ask your doctor for these drugs. I'm like how could I ask my doctor? I don't even know what's wrong with you!" – Sharon

"They really simplify a condition. They tell you that if you have the condition, you can take the pill and everything will be alright. The situation is a lot more complex, there's a lot more going on and these commercials ignore the other stuff that goes with (a chronic condition)." -- Joel.

This message strategy of providing a small amount of information and then directing viewers to visit a web site or other source that will provide additional information, may work for some in that it directs their search. But for others, it seems to produce frustration at a higher level and produce a reactance that makes the consumer resist seeking additional information. Or, viewers perceive that the website to which they're being directed won't satisfy their information needs. They may perceive it to be a "sales" site and therefore have reduced credibility in their eyes.

Participants also expressed an acute awareness of the persuasive intent of the ads.

"Because if you've got a medical problem in a sense you are trapped. A certain amount of the advertisement can be looked on as public service of making somebody aware, but the greater part I think is the element to be persuaded to buy that product and it seems like a little trap there compared to a completely free decision." -- James

"It made me feel, what did I say? Just uncomfortable, just pressured. Pressured." Susan

"I'm trying to think between print and television. No, for all drug ads even the ones that I don't take I just have this image of just a brightly colored you know, I'm trying to think, kind of probably what you'd sell MacDonald's hamburgers with or something you know. Yellows and oranges or reds and you know. They may show someone sneezing if it's a, you know ... they're going ahead, because of this drug they were able to have a healthy lifestyle." --Linda

DTCA and the patient/physician relationship

Participants acknowledge that doctors are also hearing about prescription drugs from pharmaceutical reps on a regular basis. Several mentioned the extensive detailing that pharmaceutical companies engage in and the influence they predict happens as a result. One noted that doctors must handle information provided to them in this manner in a professional way.

“You know, they get a sample of this, a sample of that, and the stuff is all over the office.” Carl

“I know the drug companies give a whole lot of samples to doctors and then it’s really nice that they pass it onto you but on the other hand I think they are inundated too and sometimes the one that are advertised the most and given the most samples out too tend to get naturally pushed where maybe they shouldn’t.” - Judy

“...(doctors are) hammered all the time with pharmaceutical reps saying would you please, here’s this great drug and here’s what it does, please prescribe it and it would be good for you to do that. It just shows that the pharmaceutical company may be behind the product so there may be some longevity there in that if they prescribe a brand medication, non-generic to the patient, that the patient is very likely to say okay, I’ve heard of that and it’s probably okay.” – Carl

“So, the drug companies... I know their sales people are coming in and giving free samples and all this stuff and ‘try this,’ and ‘if you have a patient...’” – Linda

Possible reasons for negative attitudes toward DTCA

Participants’ reactions to DTCA overall strongly support the wearout factor. This theory, (Pechmann and Stewart, 1988) proposes that attitudes toward advertising become more negative after exposure reaches a certain point (Schumann, Petty and Cacioppo 1991). That is to say, when advertisements are seen by viewers repetitively over time, they are regarded more negatively the more they are seen. Comments from the participants in this study suggest that negative attitudes apply to the advertising category of DTCA, as well as to certain ads.

Reactions appear to range from the mere observation of the number of ads to disgust at how pervasive they are. In a presentation to researchers during the analysis of this study, one academic shared anecdotally that he routinely watched the news with his 8-year-old son. After watching a 30 minute program with an untold number of DTCA ads, his son asked him, “Daddy, do only sick people watch the news?”

“I wish they weren’t on. Because I have my grandkids over here and here comes these commercials what’s that grandma? and I just don’t wanna go there.” – Sharon

“The Levitra and Cialis ads you can’t miss them, I’m offended by them, I’m not at all a prudish person but I’m offended by them because of the context of them, being on the news.” -- James

While one participant originally thought that the purpose of DTCA was to reinforce the doctor’s choice of treatment with consumers (Everett), it was not apparent in this study that DTCA promoted awareness and acceptance for stigmatized health conditions (Donohue 2005). Participants recalled and expressed involvement with advertisements about treatments for conditions they or a family member experienced.

One condition mentioned in Donohue’s (2005) study is erectile dysfunction, and while DTCA appears to have raised awareness about the condition and its treatment, participants expressed the most negative attitudes toward these ads, citing reasons primarily related to content they deemed inappropriate for mixed audiences, and especially children. Participants did report that they had been unaware of drug treatment choices prior to their own diagnosis.

DTCA as the Keyhole view into the Life World of Consumers with Chronic Conditions

Once again, this study focused on individuals who experience chronic, but not critical, health conditions. While the original goal of this study was to better understand how DTCA

affects how one manages a chronic condition, as the study evolved, an entire life world took shape, a world in which DTCA was only a partial contributor. Looking at DTCA became somewhat like looking through the keyhole into the complex world where patients experience different emotions, act on different motivations, and navigate information from a number of sources through a series of stages. This life world of patients as consumers in what is an increasingly information-rich environment then became the evolved focus of the study, as it offered significant insights for marketers, pharmaceutical companies, consumers and public policy makers.

As consumers, patients have taken on the role of information filter, discovering what is useful or not, consulting a variety of sources, and then seeking to clarify and verify the information. In some ways, although most continue to see the doctor as the final authority on treatments, patients as consumers are motivated to be their own “learned intermediaries” or “little doctors” as was noted above.

New Broader Research Questions

As the study evolved, more research questions were explored through additional interviews with the original participants in addition to an altered discussion direction with new participants. These new, broader research questions explore the life world of consumers with chronic conditions.

- What is the experience of middle aged adult Americans with a diagnosed chronic condition? What are the experiences of a patient as a consumer?
- What services do consumers employ to help manage their chronic condition?

- What consumption processes do consumers with chronic conditions employ to manage their condition?
- What information providers are critical for a consumer to manage a chronic condition?

In exploring the answers to these questions, it quickly became evident that individuals with chronic conditions were involved a process with multiple stages. We will examine this process from existing beliefs and history about the chronic condition through to diagnosis and subsequent stages related to managing the condition. Next we will consider the tensions, motivations and emotions that go along with each of the stages. Finally, we will identify how members of a social network are included, what participants do in their experience of social networking, the information available to them, and the environments in which they function.

The evolution of the study of Chronic Illness since the 1980s

In the past, patients with chronic conditions and their experiences were studied in ways that considered the illness as a loss, as suffering that interrupts the life of the patient, and patients as playing a “sick role” (Stewart & Sullivan 1982). This study follows in the order of newer research on chronic conditions, which has shifted from the perspective of the care giver to the perspective of the “insider” or patient and from the treating of a disease to preventing disease and promoting wellness. A review of studies of chronic illness reveals that more recently the focus has shifted away from the patient as a victim of the chronic disease needing to be “saved” through health care services. Today the patient and health care provider approach the condition by focusing on the health and well being of the patient. The patient proactively co-manages of the condition in partnership with the health care professional (Thorne and Paterson 1998).

Chronic Conditions are experienced in stages

The literature contains many health care theories about chronic conditions that purport a movement that takes place through a series of stages toward a temporary or final state of adjustment. As in previous literature, the results of this study reflected various progressive stages. In the following section, we group stages found in this study within three broader phases: onset, learning, and management. The stages that emerged from this data are then compared with those stages from previous health care literature. Table 2 represents phases identified in a review by Livneh and Antonak. There are similarities and a few differences, but the data support previous theory about stages of chronic illness. It is also important to note that the stage theories, also called phase models in the health care literature, utilize a broad definition of chronic illness, ranging from minor allergies or hypertension to terminal, life threatening conditions such as cancer or heart disease to severely functionally limiting events such as loss of a limb through amputation. However, regardless of the perceived severity, chronic conditions appear to share a process of adaptation that occurs in stages over time.

It is important to note when reading this analyses that these stages not only include a function of time, but occur in a temporal order. Depending on situational and individual differences, some stages may last longer and some may be skipped altogether. Some stages may

Table 2: Stages and Phases of Chronic Illness

		Stages from Analysis
Onset	Stage A	Symptoms or a Critical Event
	Stage B	Diagnosis
Learning	Stage C	Confusion, need to know, fear
	Stage D	Trial and Error
	Stage E	Understanding
	Stage F	Acceptance
Management	Stage G	Routine
	Stage H	Equilibrium

be experienced more intensely by some individuals and some stages may be revisited as a result of regression in the process.

Some other assumptions shared by stage models of chronic illness include disruption of psychological equilibrium when symptoms occur (or at diagnosis, as we will discuss below, in asymptomatic conditions), and effects on both progression and sequencing of the stages by internal and external factors. Examples of internal factors include changes in the way a patient thinks about the condition and about self in the context of the condition. Examples of external factors include seeking information and engaging in other behaviors as a result of the condition and its consequences.

Phase One: Onset

Phase one contains two stages that emerged from the data and represent what happens up to the point of the initial diagnosis of a chronic condition.

Stage A – Pre-Diagnosis

During this stage, prior to diagnosis, participants exist in the context of their beliefs and attitudes about health in general and toward certain health conditions. For those with asymptomatic conditions, this stage includes only these general beliefs and attitudes and continues through the occurrence of a critical event. For example, some participants who have hypertension originally had no noticeable symptoms and were only diagnosed after they experienced serious “attacks” that either were or appeared to be life threatening and required hospitalization. For those participants whose conditions included more obvious symptoms over a period of time, this stage includes the escalation of those symptoms which intensify until they become unbearable for the patient and he or she seeks medical treatment for the symptoms.

The Health Belief Model (HBM)

The HBM proposes that how a patient approaches health care is based on their beliefs about themselves and the condition with which they are faced (Becker 1974). It includes a positive or negative motivation toward health in general, perception of the level of threat a disease or condition presents, and perception of how their behavior might alleviate or eliminate the disease. A patient’s beliefs about these three areas precipitate their actions toward their health. A disease or condition is looked upon as having some level of threat and actions are perceived to have a certain level of threat reduction potential. Being able to reduce the threat is

how likely the person perceives a certain behavior will put them in their desired state, with consideration to what it will cost them to perform that behavior (Becker 1974).

The HBM is derived from social psychology and was first conceived in the context of public health. The basic premise of this model, how an individual behaves with regard to health, depends first on their desire to be well and the perceived likelihood that a certain behavior will either prevent illness in a well person or restore health to an ill person (Maiman and Becker 1974). The dimensions of the HBM are as follows:

- Perceived susceptibility – how vulnerable one feels to a condition in particular or illness in general
- Perceived severity – one’s evaluation of how serious it is/would be to contract an illness or condition
- Perceived benefits -- one’s perception of the efficacy of a certain behavior or set of behaviors to maintain an acceptable level of health
- Perceived barriers – possible negative effects or perceived costs involved in performing the behavior.

In addition to these variables, a “cue to action” is the final force in response to which the patient chooses to act or not. This cue may be the symptoms or some other internally generated force, or it may be some form of communication from an external source.

This model is introduced here because it emphasizes the role that existing beliefs and values play in the management of health. In this section, we will primarily address perceived susceptibility and perceived benefits of preventive action. In later sections, other variables in this model will be revisited as they pertain to each stage as it is identified.

Perceived Susceptibility

In this study, participants described how chronic conditions are often first experienced second hand through a parent or other close relative. For example, several participants who were later diagnosed with hypertension and high cholesterol had already experienced the effects of heart disease by seeing a parent or other older relative suffer with or even die from the same conditions at a young age.

“... my mother had died of her third heart attack when she was only 52. She had her first heart attack when she was 36 and I didn't want to repeat her habits. -- Sharon

“My mother actually had visible cholesterol deposits in her eyes and skin and stuff like that and she died in 1968 when she was 57.” -- James

For these participants, the memory of their loss or of a relative suffering stirred deep emotions and motivation to address their own health care issues as they came up so they would live longer and with a better quality of life. Often, those who lost relatives or saw them suffer in ways they deemed unnecessary expressed an understanding that in today's society that better knowledge, medical treatment and lifestyle habits would allow them to completely avoid or lessen or delay the effects of some conditions. Some expressed blame for their relatives who experienced serious problems due to inattention to a chronic condition, therefore framing the belief that inaction to prevent the condition is unacceptable. There is support that the awareness of past cases influences how the participants intend to address their own health.

“Both my parents died of heart disease and both at 74 but my dad really had his first heart attack at 55 and so that was kind of looming out there and when I started it, so and both my grandfathers died of heart attacks so there was a high risk there. So my awareness was heightened and yeah, I think I would fear that something would happen if I didn't treat it in some fashion or have it under control. -- (Carl)

“It’s a wake-up call I mean it’s, I’m having a hard time coming up with words. It’s a warning to us that we need to take better care of ourselves along these lines. We know we’ve got these issues and mom was the first one to have those issues that we know of and she didn’t have any warning, I’ve been warned. If I don’t take care of it silly for me.” -- Sharon

These experiences portray perceived susceptibility and attribution of negative outcomes for their relatives to poor behavioral choices.

Most participants reported making an effort to develop health lifestyle habits such as maintaining weight goals, eating healthy foods and exercising on a regular basis. Overall, they reported making efforts in their daily lives to maintain a healthy quality of life, for themselves and “to be around for (their) children,” or significant others.

For some conditions, this stage occurs when symptoms are present or when the participants experienced a critical event, a serious “attack” in some cases requiring hospitalization. Other conditions are asymptomatic, in which case this stage consists of existing attitudes or beliefs about general health, and about particular conditions. For those who experience symptoms, this stage indicates an escalation of symptoms to a point where the participant seeks help from a health care professional.

Stage B - Diagnosis

A diagnosis appears to emanate from three different events. The event reflects the condition, its symptoms (if any), and its severity. First, and very common for people with hypertension or high cholesterol, diagnosis occurs in the course of a regular checkup. One participant was diagnosed with hypertension during a routine gynecological exam. Others were diagnosed as a result of their yearly physical examination for insurance purposes. Second, some participants were diagnosed by medical professionals when symptoms of the condition, such as

allergies, became unbearable for the patient or when symptoms interfered with daily activities. Finally, a diagnosis may result from a critical medical event, where the patient has become incapacitated in some way and/or been hospitalized as a result of severe, possibly life threatening symptoms.

Two participants were diagnosed after experiencing a critical event, and the emotions they described were shock, extreme anxiety and self-blame.

“I thought, I’m gonna die right here, you know?...And so I went to the doctor and I don’t have the headache at this moment and I’m describing it to him and just me describing it to him made it come on and he’s sitting there looking at me kind of freaking out, you know what’s happening.” – Marilyn

“My first question to the doctor, after I came out of it, was ‘what did I do?’ and by that I meant, what did I do to contribute to this? What should I have been doing?” – Everett.

For those diagnosed after experiencing escalating symptoms, for example, allergies and depression, the diagnosis brought feelings of relief. Being diagnosed with a particular allergy enabled Bonnie to pinpoint the possible triggers of an attack. For Carrie, receiving a confirmation from her doctor that she was clinically depressed and in the same meeting, learning that there were treatments available to help her, brought validation and put a name to the condition she had attributed to her own shortfall.

“The other side of the coin is that there is still stigma attached if you’re suffering from depression or bipolar or any kind of mental illness or whatever but it is treatable, you know, and since then I’ve come to understand that more people than not are probably taking something to help them cope, so I’m not alone and I feel like, you know I’ll do whatever it takes.” – Carrie

Phase Two: Learning

The second phase in the progression of a patient with a chronic condition is characterized by a learning process. Once the diagnosis has been delivered, patients begin to sort through their beliefs about health and what they already know about their condition from their pre-diagnosis lives. They formulate questions they will need to answer in order to inform subsequent decisions on what course of action will be necessary to manage their condition and move them to an acceptable level of health. In this phase, patients go from a state of not knowing just what questions to ask, to searching for and finding information to answering those questions, thus developing their own “story” of what needs to happen. This learning phase appears to take place in three stages.

Stage C – Confusion and the Need to Know

During this stage, patients are confused about why the condition has occurred and feel the frustration of not knowing that in addition to how it will be resolved. Emotions of fear, depression, hope and self-doubt continue in this stage. Some participants expressed anxiety about future effects of their condition, especially about having another attack in the case of those who experienced critical events. Uncertainty of the situation at this point appears to be the source of fears about dying from the condition, fears about the severity of the condition and fears about how if and how the condition can be controlled. This stage is characterized by the desire to learn about and to control the condition.

“I don’t want to be one of those people who thinks they have all these (conditions), I want to be normal.” -- Marilyn

“I don’t want to be ignorant about what can happen.” -- Carl

For those whose symptoms developed over time, such as Carrie with her depression and Linda regarding allergies that spurred chronic sinus infections, there was a sense of despair.

“I’ve forgotten how it feels to feel well.” – Linda

“I just felt so bad for so long, I started to wonder, ‘was I ever going to feel better again?’” – Carrie

“I did everything right –ate well, exercised, took care of myself, took vitamins and I still have this!” – Melissa

“I asked the doctor when I could get off the pills, and he said, never.” -- Joel

While a health care professional is involved in the diagnosis and presents some preliminary information and perhaps treatment options, participants in the study defined this stage by an increased search for information through traditional non human sources, such as the Internet, in addition to a search for information and support from their social network. This is the first step toward sense making, or a resolution of dissonance between how things were and what they have become now that a diagnosis has been issued, now that there is a name put to the condition.

One of the primary motivations to undertake this search for information and support appears to be fear of the unknown and uncertainty of the outcome. In addition, this stage is where a patient’s sense of responsibility for their own health is apparent and the information search comes across as an attempt to resolve a breach in their integrity as steward of their own health, to restore their credibility in some way. At this stage, a health deficiency has been identified but it is not yet clear how or if that deficiency will be remedied.

Uncertainty in Illness Theory

While there is uncertainty for some participants prior to this stage, it is at this stage that all participants experienced uncertainty with relation to their condition. A health care theory that supports the data related to uncertainty is the uncertainty in illness theory (Mishel 1988). Originally conceptualized to explain patient psychology surrounding severe or terminal illnesses, the theory was revisited more recently and adjusted to be applied to non-life-threatening conditions (Mishel 1990). Uncertainty of the condition itself is present in Stage C, and that uncertainty is focused on treatment and management methods in the next stage.

“In qualitative investigations of uncertainty, it was found the longer chronically ill subjects lived with continual uncertainty, the more positively they evaluated the uncertainty. Therefore, the appraisal of uncertainty evolves over time.” -- King and Mishel, 1986

This theory employs chaos theory and applies it to chronic conditions. In chaos theory, confusion and disrupted systems move toward a point of equilibrium. They move toward this point to the extent that they're allowed to exist in chaos and the complexity is respected. In studies of patients with chronic illness, it was found that patients developed more positive evaluation of their condition the longer they had the condition (King and Mishel 1986). More recently, this theory of uncertainty was expanded to incorporate:

- a. change over time
- b. evolution in the appraisal of uncertainty
- c. the emphasis on the person as an open system, interchanging energy with the environment
- d. an orientation toward increased complexity.
- e. an orientation toward increased complexity rather than an equilibrium ideal.”

Over time, the patient begins to accept the uncertainty of his or her own condition, which becomes apparent in subsequent stages. This acceptance is noted by Mishel to be reinforced by the surrounding social network. That is, when health care professionals and close members of the social network acknowledge the uncertainty of the situation with positive reinforcement, the patient is encouraged to accept that things will not be as they were prior to the diagnosis, and will possibly not be resolved in a way that resembles the previous condition. This acceptance of uncertainty allows them to work within the uncertainty (the fact that they don't feel a certain way or aren't perfect in health) and move toward a point of equilibrium. In our analysis, that equilibrium is characterized by Stage H. So, by experiencing the emotions and tension throughout the process, and eventually accepting a level of uncertainty and accepting that they will always have to take drug therapy or always have to do something to maintain their health with the resources they have (their imperfect bodies, assorted information, limitations of health care, other things surrounding their condition that aren't perfect,) they can then move toward a place where the condition stabilizes in their eyes, a place where they are no longer in imminent danger and therefore no longer need to actively seek help. (Mishel, 1990)

Stage D – Trial and Error

Following diagnosis, there is a stage during which both doctor and patient search for solutions and treatments for the condition. It is during this stage that patients engage in the most intense information search. It is at this point that patients seem to be searching for a resolution to the condition. As a result, while they are attempting to reach that point, they express frustration with their condition, their treatments and the uncertainty that comes with trying different approaches to the management of the condition.

“This is where I got kind of, I’m gonna be honest, you know, you go to the doctor and you take what they give you, and we were trying so many different things at that time and I just was sick and it wasn’t getting better. And I guess my frustration, I don’t feel like I was not getting lack of care from my doctor but I just had to say there had to be something else out there that had to work, maybe I was looking for the magic bullet I don’t know ... I’d get well for a little bit you know so I could do some things, and then it would be back, back on you know 2 weeks of antibiotics then it would clear it up for awhile and then something else would happen and so I just got frustrated, couldn’t do things.” – Linda

This stage can be lengthy, and a patient may, over time, return to this stage after a period of time. During this stage, doctors often prescribe treatments and “wait and see” how the patient and the condition will respond to the treatment. If the condition is brought under control, the patient moves on to the next stage. If the condition is not brought under control with the prescribed treatment, which may include lifestyle changes, prescription and/or over-the-counter medications, or if the patient develops side effects of the treatment, this stage can last over an extended period of time.

“It was odd because I had taken...it would have been at least 7 or 8 years after I had first started ... and I couldn’t stop coughing, I just had this chronic cough and then I remembered that when I started this the doctor had said one of the side effects was a tendency to cough with whatever it was that I was taking at the time and so but I didn’t connect them up for a while and so finally I went him and he said it’s that and so we changed to something else.” – Joel

“I mean (I felt) nauseated just like I wanted to throw up... Well it started about 3 to 4 weeks after I took (cholesterol medication) and so I went off of it and so I called the nurse back and that’s when they gave me the Zetia and so I’ve been taking that now for about almost 2 years.”-- Linda

“I realized I was physically unable to do (a routine chore) and I said something is wrong with me and I said I wonder if it could possibly be a side effect of the medication...At any rate I quit taking the medication and made an appointment with my doctor because I was gonna obviously see whether I felt better, really right away, absolutely, positively, instantly, I felt 10 years younger. I had been attributing all those effects to aging..., I’m not taking the medication, I’ve only had one cholesterol check between then and I think it was up to 218 so I still have a problem, I still have to do something about it but I’m undecided as to what to do

about it now... but there is scarcely a system in my body that has not improved since that point.” -- James

In some cases, this can last several months or even years.

“It was like, this works, this works and this I can take it every day and I’m gonna feel level and like I said it was the combination of those two drugs together. But she had to work with me and I had to work with her, but it took years before we found the right combination.” -- Carrie

During this time, patients often try lifestyle adjustments first.

“I lost about 35 pounds over a period of 12 months I didn’t try to do it in short order, but the main thing that I accomplished during that period of time was a change of lifestyle.” -- Everett

“My cholesterol came down probably 25 points in one year just from being active, because I had to change my diet.” - Melissa

Allergy and migraine sufferers take steps to avoid potential triggers of their symptoms.

Others adjust their eating and exercise habits and take steps to manage stress in their lives. For some, routine medication is prescribed at the beginning of this stage, for others, only lifestyle changes are prescribed to start with, but if those don’t work on their own, medication is usually the next step.

“The doctor just watched it for probably a year. You know and at first we tried the diet, and I tried a little bit, but I really just wasn’t. You know what I think you just don’t get convinced about it when you don’t know a whole lot about it and, so then when it never did come down on its own, that’s when she went ahead and put me on Lisinopril.” – Melissa

“(The doctor) kind of watched it for a year and then she was just like, we need to get you on medication.” – Sharon

“To manage it, to keep (migraines) away well anything like Pilates and exercise, anything like that helps that in general it is connected to stress and we all know exercise has a positive effect on stress.” -- Susan

Patients may try homeopathic or OTC remedies, for example, for allergies either to supplement or replace other treatments when they either stop working or don't work in the first place (e.g. allergies).

“I've read things, especially on the internet about the time of day to avoid being outside because the pollen is heavier I think in the morning. And let's see what else, there are recommendations about removing carpet and putting hardwood down, of course I can't do that, I mean I understand the recommendation.” – Bonnie

“I tried to look at some holistic things for example I still use my (prescription) nose spray, and I have to see what it is, but saline, a solution of saline... Oh another one, if I'm really, really sneezy, itchy, I'll take like a third of the old fashioned Benadryl... and this is just your old fashioned Benadryl and it works.” -- Linda

Also during this stage, both patients and doctors monitor the condition on a regular basis. For some, this means periodic doctor visits, and for others this means self-monitoring in the form of home monitoring equipment such as a blood pressure machine.

“Well obviously since I was diagnosed with (hypertension) the doctor had me in routinely checking the status on it...But he could detect it by monitoring me and once we would get it settled out then I would go for longer intervals between his checking it. And over a period of time I purchased a number of different blood pressure monitoring devices and still have some pretty competent equipment in my home and I check it periodically just to see...” -- Everett

In addition to monitoring and trying different treatments during this stage, patients engage in an extensive information search. This search takes a different turn for each of the three routes to diagnosis. For those whose symptoms increased over time, they may have engaged in a low level information search prior to diagnosis in an effort to understand their symptoms or to research conditions that are in their family history. For those whose conditions are diagnosed in a routine exam, they tend to engage in a mid level search during this stage, and utilize their social networks in addition to other medical information sources to clarify and verify

information they receive from their doctor and in an attempt to understand the treatment the doctor has prescribed. For patients who experienced a critical event, the information search starts while they are recovering from that event right after diagnosis. The event has a “wake up call” effect on them, and they are highly motivated to aggressively make whatever efforts are necessary to avoid another critical event in the future, which includes an information search.

Some patients may move forward to the next stage, and then return to this phase in the event of a side effect or when a treatment stops working. Regardless, this stage can prove exasperating, as shown in Linda’s comments about her battle with allergies. It is important to note here that her pace quickened throughout her comments and there was a nervousness to her voice as she spoke about her trial and error period with allergies:

“Oh I’ve had that all my life; I’ve tried the shots, a couple of years of injections, of shots. It has been put on Claritin - just name any kind of drug that you would hear for allergies I have tried it, I mean truly. Then when it got worse, at first it was seasonal and think you can tell I’m all clogged up now, but now it pretty much stays constant and so about 5 years ago I got really, really sick. Antibiotics, they put me on a lot of antibiotics, you know it would go to sinus infections and then. But about 5 years ago I just couldn’t shake it so that’s when they started using Advair for just the daily asthma and then what was the one that they use for emergency? Albuterol I think for if I just got really, really like the elephant sitting on your chest kind of stuff. And so they said that the asthma and the allergies kind of go hand in hand that they somehow, I keep saying they but I guess my physician, you know, again we went back and did the testing and I am basically allergic to life if you really wanted to know. I have a choice either I live in a bubble, or I try to manage it. So I just try to manage it with drugs and you know, just whatever I can. And not food though, its dogs, cats, smoke is really, really bad for me and so I guess I just. I mean I’ve had such bad sinus infections where my eyes were swollen up and it’s just been disgusting, I just, that’s pretty honest.”
-- Linda

The Self Care Deficit Theory of Nursing

A popular nursing theorist, Dorothea E. Orem’s Self-care deficit theory, in brief, proposes that an individual does certain things to maintain his or her health and well being.

Beyond that, people have a need to perform certain actions to care for themselves and manage their own quality of life and health and to recover from illness when necessary (Berbiglia 1997).

Further, an individual has a set of self-care requisites, which are a set of factors the individual knows need attention in order to function according to norms learned, presumably, through socialization. These include basic needs such as air, water, and food; elimination, balance of activity and rest; balance between solitude and social interaction; “prevention of hazards to human life; promotion of human functioning and development within social groups in accordance with human potential, human limitations and the human desire to be normal.

Normalcy is defined as that which is essentially human and that which is in accordance with the genetic and constitutional characteristics and talents of individuals.” (Orem 1995)

In addition, it is understood that an individual has “self-care agency,” or power to act to satisfy these requisites. A health care professional is needed when there is a deficit in self care, that is, a need for additional actions beyond the individual’s ability or scope of knowledge due to an illness or injury or “health deviation.” This theory notes that health deviations can affect how an individual functions: physically, psychologically and as an integrated person, consequently diminishing their powers of agency.

In the analysis of this study, to the extent which an individual is unable to act as his or her own agent, he or she transfers some of their agency to health care providers and in many cases, other members of their social networks. Information, in both human and non-human forms appear to guide decisions that will either regain their own agency, or inform or reinforce a decision to transfer their agency to someone else. By gathering information, researching their condition and learning new ways to manage their chronic conditions, these patients are able to

regain some of their own agency, and in doing so, their independence and self-esteem. As our social network descriptions show, these activities can be a result of interaction with both human (health care providers, friends and family members) and non-human (magazines, medical journals and web sites) information sources.

As mentioned in the last section, this stage is laden with frustration on the part of the participants, and that frustration may be explained by the self care deficit model (Orem 1995). It is at this stage that the patient grapples with his or her own self care agency. “Agency” is a word commonly used in the health care literature to mean the individual or product that is taking or assuming assignment of care for the patient’s condition. This could be the patient or another person or a combination of people, or a pharmaceutical product (e.g., family member, patient working with a member of the medical community). The self-care deficit model suggests that because the condition has created a deficit which requires the intervention of a health care professional, the patient often assigns a large part of his or her agency of care to the health care professional. However, there also seems to be a desire to regain that agency, to be able to manage the condition to a point where the level of intervention is no longer necessary. The information search, making efforts to manage the condition with lifestyle changes that are presumably the primary efforts of the patient, and the process of self monitoring are all examples of attempts to maintain agency or control of one’s own health. Assigning that agency to a doctor or to a medication appears to be uncomfortable for these participants and their efforts appear to reflect their attempts to resolve that discomfort. Further, when a treatment has been prescribed and it ceases to work or when side effects develop and a new treatment must be sought, the feelings of frustration intensify and those efforts to self-manage increase. This is evident when

James ceases to take his medications and tries to manage without them after developing side effects, and when Linda resorts to taking “old fashioned” over the counter remedies in addition to her prescription nasal spray and inhaler. These attempts continue until the point characterized in the next stage, which is when some level of balance is struck between patient and doctor agency, and just the right treatment is discovered.

Stage E - Understanding

In this stage, patients develop a clearer picture of what it takes to manage their condition. During this stage, they synthesize the information they’ve gathered via information search, social sources, the health care team, and internally from their experience of the condition over time. The understanding is that of the condition, possible origins, triggers, treatments and possible consequences of not following therapy. It is at this stage that patients begin the process of developing habits and routines, “wrap their heads around” the condition and its consequences. They develop an understanding, a synthesis of the meaning of their condition.

“So that was basically it and then I realized it was a chronic condition, so. And I said can I ever, you know is there any possibility I could ever stop? And (the doctor) said well, you could take a holiday from the medicines and you could see but I’ve never (stopped taking pills)...to see if I could you know, just that would be one less thing I would have to do but yeah I mean I think as I understand the condition it’s not going to go away, so.” – Joel

This stage signifies a shift in thinking about how things were prior to diagnosis, integrating an understanding of how things are now with regard to the condition. The cognitive dissonance experienced during the trial and error stage is resolved internally at this stage. While health care professionals are still involved, agency appears to be reclaimed by the patient to an acceptable level.

“So it was just, I was like, oh, okay a lot of it has to come from me. You know the pills are gonna help what I can’t control but there’s a lot I can do in about this, just about my attitude and how I react to things, so.” – Marilyn

Phase Three: Managing

The final phase contains three stages. The participants, now having synthesized the information gathered in previous stages, and, having experienced a mental shift internally, experience the final three stages leading to adjustment. Internally, the realization of the chronic nature of the condition becomes more salient and with it, the realization that, while it is something that will require attention, it is manageable.

The Health Promotion Model

The health promotion model (HPM), originally conceived by Nola Pender in 1975, focuses on what factors influence decisions individuals make and actions they take to prevent disease (Sakraida 2001). This model is helpful in describing the managing phase, because it focuses on not only the condition, but what patients do in order to promote an overall healthy lifestyle.

This model has been updated several times, and of special interest in this study is its 1996 version. This theory has roots in Social Learning Theory from cognitive psychology, Expectancy-value theory (Feather, year) and goes a step beyond the Health Belief model introduced earlier, to include behaviors that are wellness-related in addition to those that are undertaken to prevent and remedy disease.

Like the HBM, the HPM consists first of existing individual characteristics and experiences, which includes an individual’s prior related behavior and personal factors such as biological, psychological and sociocultural background. These combine with a set of behavior-

specific cognitions and affect. Perceived benefits of action and perceived barriers to action are a direct result of perceived activity-related affect, and perceived self-efficacy, or one's perceived ability to successfully perform a specific health-related behavior. These combine with both situational and interpersonal influences. Situational influences are an individual's perceived options, demand characteristics and aesthetics in the environment that may directly or indirectly lead to certain health behaviors. Interpersonal influences, of course, include family, peers, health care providers included in our model of the social network and the norms they generate. The combination of these internal and external factors contributes to a group of behavioral outcomes. Commitment to a plan of action is moderated by competing demands in low control situations and preferences in high control situations leading directly to the health-promoting behavior. A previous iteration of the model included the importance of health and perceived control of health, which appear in our analysis to also play a significant role in the behaviors of consumers as patients. The most recent model includes perceived health efficacy (one's capability of organizing and performing a health-promoting behavior), definition of health, perceived health status, perceived health benefits of health-promoting behaviors, and perceived barriers to health-promoting behaviors. In the model, these factors are subject to any of a set of modifying factors, which include demographics, biological characteristics, interpersonal influences, situational factors, and behavioral factors. These combine to produce participation in health-promoting behavior, which consists of cues to action and likelihood of engaging in health-promoting behaviors.

This model is introduced here because its roots in social learning theory are reflected in the participants' focus on outcomes. The data in this study suggest that the participants engaged

in gathering of information in previous stages from both human and non human sources, and their synthesis and organization of this information over time leads them to the subsequent stages outlined here.

Stage F - Stage of Acceptance

This stage is one where patients accept their treatment, accept that the chronic nature of the condition means that it isn't going away, that it's part of their lives.

Downward social comparisons are common at this stage. A downward social comparison is individuals comparing themselves to others who have worse conditions in order to feel better about their own condition. This includes comparing the consequences of their condition and its treatment to the health situations of those around them, and deciding that their situation is much less taxing and threatening than what some others face. This downward social comparison reinforces the patient's self esteem and helps them adjust to a new self-view, moving from victimized to proactive. At this stage, the condition is often minimized in comparison to what others may face.

“(I feel)normal, it's a situation that I have that I can fortunately correct with better lifestyle and medication and the next person next door to me... has cancer ... and they're having to deal with that as best they can...all I'm really saying is I could be dead from hypertension, they could be dead from cancer, you just analyze where you are. I'm not trying to make those equal by any stretch but that's why I say I feel normal because everybody out there has something that they deal with.” – Everett

“I've always done the right things I work out, I eat right I don't drink or smoke, you know, I said damn you did everything right and you've still got to take these pills each day. But then I see other people and the things people have to deal with and I think wow is all I have to do is keep being who I was and add these 4 ½ pills I can live my life. And not taking these pills or any of the conditions I have holds me back from doing anything. I guess there are rides in Disney World where it says if you have high blood pressure you shouldn't ride. (laughs)” -- Marilyn

Stage G – Becoming the Routine

During this stage, the habits of managing the condition become routine. Monitoring and treating the condition on a regular basis, usually daily, has become a habit at this stage and is incorporated into the patient's lifestyle. Developing these habits and these routines enables patients to feel in control of their condition and their overall health. Almost all of the participants reported seeing a doctor on a routine basis to help manage their condition, and three reported using equipment or testing supplies at home to monitor their condition between doctor visits. For most, though, self-monitoring is part of a carefully developed routine designed to manage the condition.

“I think I pay more attention to myself. In the long run it's paid off because I am very rigorous about taking my medications, I also can figure out, I wanna know the why I feel certain ways and I can figure out, oh that's what's causing it, and so it's not such a big deal.” -- Bob

“I have a sense of my blood pressure changing, I know my body enough, like when I'm under stress or worried about things, then my body just let's me know what's going on.” -- Carl

“Every morning no matter what, first thing I do drink a glass of water and take that pill in the morning. I'm very good.” -- Melissa

Stage H – It's just Normal

For many patients, this leads to what most participants indicated they were striving for, and that is to arrive at a final stage, one of equilibrium, where the condition is managed and perceived to be under control. The routines they developed in the previous stage are established and require little thought.

“I don't think about it at all anymore because it's under control.” - Carl

“It's not one of those things that I consider to be onerous at all. I guess if I were to choose between chronic conditions, you know hypertension would be the one to choose for me at least because I've never, except for that one time that I've

described I've never. First of all it has no symptoms as far as I know and then taking the medicine is pretty benign too; it has no symptoms either, so you know I certainly don't think about it much." -- Joel

At this stage, patients appear to have reached a point of satisfaction with the state of their health. The recurring theme is that at Stage H, they feel “normal,” and no longer actively seek additional alternatives to their current treatment.

Stage H represents feelings of accomplishment, of pride in their accomplishment, and of balance, based on attributions to the efforts they and their health care professionals employed in the earlier stages.

Psychosocial Adaptation to Chronic Illness – Phase theory from extant literature

Livneh and Antonak's (1997) account of the social psychology of chronic illness includes a literature review of the different phase theories of chronic illness (phase and stage are used interchangeably here). The stages most commonly identified in the review are: shock, anxiety, denial, depression, internalized anger, externalized hostility, acknowledgment and adjustment (see Table 3). Recall that the participants in this study have non-critical chronic conditions, that is, conditions that are not immediately life threatening and do not represent significant life changes when compared to amputation, for example. The participants in this study have not had a critical episode related to their condition within the last year and most described themselves as being at Stage H. The phases from the psychosocial literature are described next and focus on the emotional changes patients encounter, while the analysis in this study focus primarily on behaviors. As a result, the intense emotions characterized by the psychosocial literature's phases are not as apparent as they might be with another sample of patients who experience more

serious conditions or are at varying behavioral stages. In addition, there is still some controversy in the psychosocial literature regarding the temporal order of the stages.

Phases from the Psychosocial Literature

The first stage, shock, refers to an initial reaction to the onset of symptoms or the critical event we described in the data analysis. This is the primary impact of the experience, which can be overwhelming and the resulting effects in this stage include “psychic numbness, depersonalization, and cognitive disorganization.” This study’s analysis, as we described earlier, supports shock as a phase for those whose diagnosis came as the result of a critical event. For others, the emotion was much less intense.

The second stage is anxiety, or the “panic-stricken reaction upon the initial sensing of the magnitude of” the condition. Anxiety was present in many forms in the current study across several of the stages. The anxiety we found was centered on feelings of lack of control and fear of mortality, especially in cases where participants knew others who had been seriously ill or died as a result of their condition. Feelings of lack of control were evident in participants’ experiences in the confusion and trial and error stages. The behaviors they engaged in during subsequent stages were attributed to a need to resolve those feelings.

The third stage, denial, occurs when the patient tries to minimize the condition and/ or wishes it away, having “unrealistic expectancy of recovery.” Two participants in the current study gave accounts of situations in which they tried to perform normal activities when they were experiencing symptoms of their conditions. These accounts suggest they might have been in denial of the severity of their conditions.

“I was starting to get a migraine, I could feel it coming on, and I drove home, which was kind of stupid. Yeah, I got home and got yelled at for that one.” – Susan

“I had been putting down a wood floor in my spare time, prior to that I had driven from here to Northern Virginia and back, like a guy, non stop and the next thing I knew I was in the hospital for 4 days with these clots.” -- Bob

It was not clear in the data whether any of the other participants experienced denial. If they experienced denial, it may have been short-lived or have gone unnoticed.

Next is depression, during which patients experience the pain of loss. In this sample, it is a loss of freedom that results from the routines and monitoring behaviors undertaken to manage their conditions. Depression also includes “feelings of helplessness, hopelessness, despair, isolation, self-depreciation and distress.” Again, data in this study supports depression as an experienced emotion, but it was experienced by participants at several different stages rather than being a stage in itself.

“I just got frustrated, couldn’t do things... some work of course, but let’s just say somebody wanted me to go out to dinner, I would refuse, more social. And I think that leads to depression, I’m pretty sure I was probably a little bit depressed in there, so maybe frustration, depression all that kind of just worked in...” -- Linda

Internalized anger refers to one’s resentment and feelings of guilt, that there must have been something the patient did or didn’t do in order to have arrived at the point of diagnosis; that the condition was somehow avoidable, but happened anyway due to the patient’s action or inaction. The early stages in our analysis support these emotions.

“Well, for a 31 or 32 year old person at the time, I guess it’s best explained by what I asked my doctor, ... and my question to him was “what have I done wrong?” What have I done wrong, what am I doing wrong and his response was you haven’t done anything wrong, you’re not doing anything wrong, you’ve just got a genetic tendency.” -- Everett

Externalized hostility refers to anger toward others or the environment. In this study, the environment is probably more often the target. It is at this stage that a patient is likely to blame others and have critical attitudes that might interfere with their treatment. There were no specific examples given by participants in this study, however, the frustration with doctors and treatments during the trial and error stage might be interpreted to represent conflict with one's environment. It is possible that frustration while experimenting with treatments has the potential to trigger angry reactions.

The next stage, acknowledgment, is similar to the stage identified in the analysis as acceptance. This is where the patient reorganizes cognitive structures surrounding the self and the environment. This is the stage at which the patient begins to include the limitations of the chronic condition and the practices involved in treatment and management into the routine, as being part of who she is and what she does. The product of this stage is a new sense of self and acceptance of that self concept with its new meaning.

Finally, "adjustment" is the final identified phase, and closely resembles what we referred to in this analysis as Stage H. This is the point of equilibrium that the participants in this study appear to be motivated to reach. This point is when the patient has achieved "affective internalization and socio-behavioral reintegration into newly perceive life situation." It is in this phase that the patient has completely embraced the "functional limitations" of the condition, whatever they may be and once again is moving forward with life goals. Stage H's examples of participants who no longer have to think about their treatment, and who report finally "feeling normal" are consistent with the literature's description of this phase.

Significance of Phases in Chronic Conditions

As stated earlier, a review of the psychosocial literature suggests that there is still controversy over the temporal order of the phases (Livneh & Antonak). However, there seems to be agreement among those studies and in this study as well, that adaptation to life with a chronic condition is a process, and patients go through phases as they adjust to their diagnosis.

Situational and individual differences likely play a large part in the length, intensity and resolution of each phase. The analysis presented here suggests that each phase represents a progression of emotions and behaviors that lead to a goal, which is to be “normal” again after diagnosis.

Social Network Surrounding Chronic Conditions: Human Sources of Information and Support

Network Members

Participants in this study often mentioned information and support they received from members of their social network. Those mentioned included physicians, family members, co-workers, other health care professionals such as pharmacists and nurse practitioners, classmates and even near strangers such as the friend of a hairdresser. As he progressed through the stages of their chronic condition, Everett called the process of collecting information and preparing to address the condition, “Assembling the army.” While the network is dynamic throughout the process, several members were common among the networks our participants called upon.

Physicians

In chapter 2, the concept of the doctor as “learned intermediary,” or one having the final say on diagnosis and treatment choice, was discussed. The findings of this study revealed that,

for the most part, the doctor is still considered the final authority on health care; however, he or she is now part of a much wider social network. Further, patients in our sample appear to accept some level of responsibility for being prepared and informed ahead of their discussions with doctors. As pointed out earlier, the changes in the health care system in the U.S. have greatly reduced the amount of time physicians have available to meet with each patient (CITE FROM (Kravitz and Halpern 2006). At the health care system level, patients are often exposed to a number of other health care professionals in addition to the primary physician. Participants in this study acknowledged the limitations to the physician's position when explaining why they would seek out information prior to seeing their doctor.

“And that’s a good question, I don’t know if they have time. Do they, I don’t know and that’s something I need to talk to her about is to say you know I have some concerns, I’ve been on this for this many years and I’ve been on this for a year so this is what I understand about this, is this true. To go in with a list of questions to your doctor as you sit down and go through them.” – Linda

“(the doctor) really didn’t take any (time), he never has, he rarely asked questions and when you asked any questions there were short answers, he just didn’t take any time, they were always quick. It was well I think this is what’s going on here I’m gonna write this prescription, this prescription then invariably we’d have to go back because that wasn’t working or wasn’t right, so there’d be another visit, time taken away from work or school and he just wasn’t, he wasn’t really diagnosing what the problem was he was looking for what was on the surface.” -- Carl

The availability of medical information to this sample also seems to be playing a part. All participants reported searching for additional health information, for themselves or for a family member, online and in print sources. Some reported reading magazines, books and even medical journals. These searches, once again, were not as a result of a mistrust of the doctor's ability, rather, they are the result of information availability and recognition of the limitations under which doctors perform and a need to be informed, to know what to expect, and appear credible

as a patient in the eyes of their doctor. By accepting their responsibility as a patient and “doing their part,” patients regarded their relationship with the doctor as more of a partnership than in past generations.

“And I think (my doctor) is a wonderful person, I don’t really fault her in a way because maybe you know because I should be able to carry on, hey she doesn’t know that this bothers me, she doesn’t know that I have questions.” -- Linda

It is important to point out that this sample of participants are from an upper middle class socioeconomic segment, all have health care insurance and all have relationships with their primary care physicians that are relatively long term. That is, they know their doctors, and in some cases, interact with them socially.

“Yes as a matter of fact I actually said something to my doctor one time just because of the relationship, we get past the offices and then we socialize for a while because I’m usually his last patient of the day just for that reason.” – Everett

“He knows me; he’s the kind of doctor...I went in to the emergency room (for something), and he shows up just to check on me, like I didn’t call him you know he was just making his rounds, saw that I was there, recognized the name and came to check on me, I thought that was kinda cool...He’s a good doctor, good doctor. For one, I think he trusts me.” – Susan

“...he talked and he didn’t prescribe anything at that point, he was just said these are personal things you just have to do and it was like huh. The other doctor would have written a script and said here take this you’ll be better in the morning. Whereas this guy just talked through and helped to understand life issues, how you live your life and tried to get at everything in relation to your life. So to me, you know, the rapport established was phenomenal. I can talk to him, I feel like I can talk to him about anything.” -- Carl

Participants reported knowing their doctors well enough that they may contact them after hours and on their private cell phone lines. Perhaps it is the socioeconomic status that enables this type of relationship for this group, however, there seems to be a sense of equality between the physicians and their patients in this situation, evidenced by statements made by participants

regarding their need to be prepared to see their doctor, and their efforts to not appear as having over-studied. Additionally, they expressed a desire to help the physician perform the duties of diagnosing and making decision on treatment for their conditions.

“The General is the doctor as I have told him many times you’re the bus driver and if you need me to read the map a little bit I’ll do that but you’re the driver, you make the decision whether we go forward, backwards or sit still.” – Everett

“I depend on my doctor to help me make sense of it all.” -- Susan

“I think you have to communicate that way and do it in a very systematic way to your Physician because they tend to hear excitement from clients rather than some sort of factual interpretation of what the symptoms are and I think that makes it harder for them to evaluate what’s going on.” -- Everett

Together, these dialogues suggest that patients work hard to maintain a mutual respect between the doctor and themselves, and part of that appears to come from equality established by obtaining information, by doing their homework. This homework goes far beyond DTCA. Participants noted that they did research ahead of time so that they would know what they might hear in the form of a diagnosis or a treatment, but then when they saw the doctor, they would hold back that information and wait for the doctor’s diagnosis.

Carrie described a situation in which she researched a foot problem she was having and brought the results of her search, which included two possible diagnoses, to her next doctor’s appointment. It was important to her that the doctor give her the final diagnosis, and she hid the information from him until he gave her his diagnosis, which turned out to be one of the possibilities she had found on her own. When asked what she might have done if the doctor’s diagnosis was different from either of the possible conclusions she had drawn, she stated that she wouldn’t have told him of her research. Additionally, her tone was triumphant when she described how the doctor’s conclusion had matched her own.

Relationships between this culture of patients and their physicians are intricate. However, an overlying theme in these relationships seems to be mutual trust. This is evidenced in the wanting to be prepared for the doctor's visit, wanting the doctor to issue the final diagnosis, and combining those two elements in order to work together toward a resolution of the problem.

The Significant Medical Other

An important element of the social network surrounding a patient with a chronic condition is a person we will call the Significant Medical Other (SMO). This is a relative, close friend or acquaintance that has some medical training or knowledge and serves as a source of information or verification of other information sources. The patient turns to this person to prepare for doctor visits and to clarify information they've found from a questionable source, or solicit anecdotal information about other cases or condition. Almost every participant indicated that some member of their social network played this role in the management of their chronic condition. They often asked questions of this person and took seriously any information they offered.

“Well there again there is two sides to that story and I ask that very question of (my husband), you know my “ask a nurse” person” – Carrie

“My wife is a veterinary technician and our cats were having their physicals right before I quit taking the Lipitor and we were talking about cholesterol issues and they have some cholesterol issues in the doctor's family and she knows a lot of cardiologists and she was saying these cardiologists that she knew were putting themselves on this Lipitor whether they had cholesterol problems or not to take advantage of some of the other benefits of the medication. And so I was thinking you know maybe I ought to talk to my doctor about putting me back on Lipitor.” – James

Pharmacists, nurses, educators and technicians can all serve as SMOs for a patient with a chronic condition. Often, the amount of education or type of medical qualification of the SMO is irrelevant. The single prerequisite to be considered an SMO is some type of education or experience related to health care.

Family Members

Family members also provide social support to patients with chronic conditions. One participant referred to his wife, who had made great efforts to improve the couple's lifestyle habits, as "The Force."

"close friends and associates that respect what you need to do have a big impact on you as an example my wife. She understands my limitations and not only doesn't ask me to go beyond that but insists on me not, you know what I mean?"

"my wife, it became a high priority for me, interesting way of approaching life so I think we all tend to react to external forces and that was an external force that put me and herself on a diet... Well the force, it's a mutual deal the force wants me to stay healthy but at the same time I want her to benefit from it so we are mutually complimentary and I don't deviate from it because she doesn't need to deviate from it" -- Everett

Family members often reinforce treatment routines and healthy lifestyle habits and remind patients about medications and other management issues. This includes initiating discussions about the condition, monitoring the condition, perhaps cooking healthy meals and acting as an exercise partner. In addition, immediate family members often are most in tune with the symptoms and triggers of the chronic condition and may act as buffers for the patient to help him or her avoid situations and triggers that may interfere with management or worsen symptoms.

"Well I guess my immediate family my husband and my kids know they were there I mean they saw the headaches and they got very scared when they saw me in the CCU and so when there is a stressful situation, which my mother lives 1,000 miles

away but my mother, that's a stressful situation so the few times when she does come to visit or I go to visit her they do act as buffers you know particularly my daughters." -- Marilyn

"my brother-in-law... he has cluster headaches they're terrible so he's always saying yeah you should use it (another remedy for migraines)." Susan

With family members, participants described how they discuss their own conditions and treatments with their family members, but also gave examples of how they, in the process of their own self management, felt responsibility for their family members and their health. Several told stories of how they provide support for their siblings, children and parents in the course of their information searches and what they synthesized in that process.

"my brothers both like I said they're on high blood pressure pills but they also have that cholesterol part which I have very low cholesterol, but we, they talk about it...we sound like old people, going 'what are you on?'" - Marilyn

In many cases, this responsibility seems to stem from the probability that they might have similar experiences due to their genetics. In the case of caring for parents, they discussed how they anticipated having the same conditions their parents were experiencing as they age.

Social Network: A dynamic system

Throughout the stages of the chronic condition, the social network appears to change. Again, individual differences and the route to diagnosis play a part in how the changes take place. Patients may or may not continue to consult others for information, but more for support once the doctor has made a decision about treatment and/or once the condition reaches the acceptance stage or later.

Information search among non-human sources

Figure 1 portrays information search over time by patients based on the three different routes to diagnosis. The length of time may vary for each patient, but the temporal order of spikes and valleys in information search is the same. The amount and intensity of the information search is on the Y axis and time is represented by the X axis.

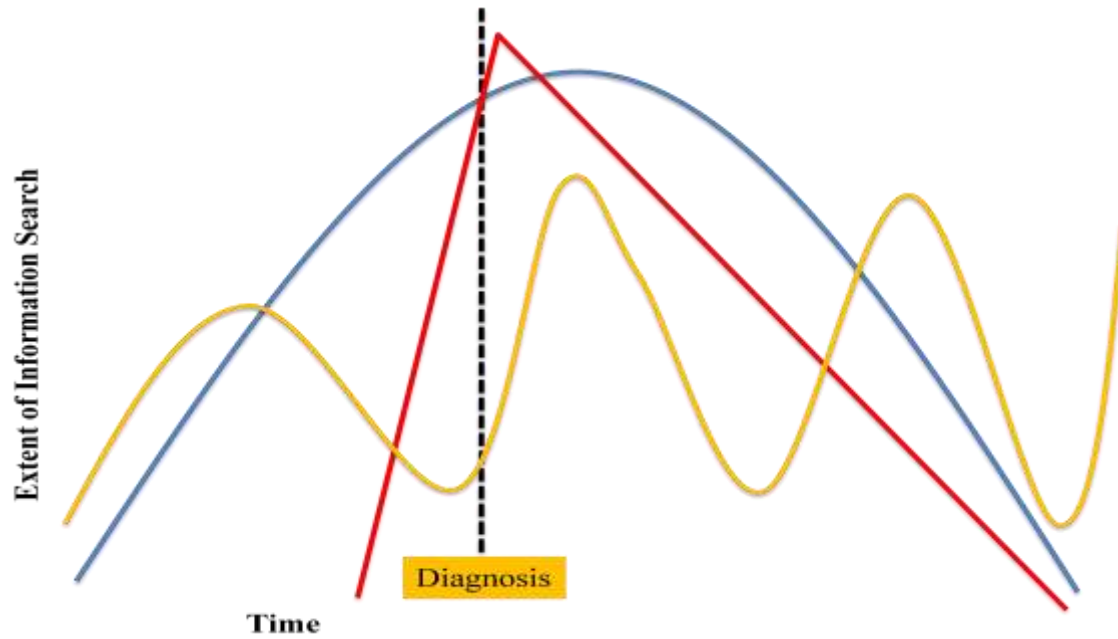


Figure 1: Information Search

The information search undertaken by participants with chronic conditions depends on several variables. Most notably, the intensity and the amount of information consulted seems to vary according to the route to diagnosis. For patients who were diagnosed as a result of ongoing symptoms, such as allergies, there is an increased amount of information sought at many different stages. In some cases, there is an ongoing information search, with spikes in the search before visiting the doctor, after diagnosis and, for the participants of this study, it doesn't seem to have an end point. Participants in this category appear to continue to search for the next advance in medicine, the next pill that lasts just a little bit longer or that works just a little bit better to alleviate symptoms.

Diagnosis as the result of a critical event, such as being hospitalized for symptoms of hypertension appears to precipitate a steep information search curve, with the amount and intensity of search spiking just after the critical event, at the time of diagnosis, followed by a rapid decline after the critical event has passed. The critical event appears to act as a catalyst and motivation for the patient to strive for control and pursue Stage H.

Diagnosis as a result of regular checkups appears to result in a normal information search curve that is flatter, but not necessarily any longer than that of the critical event patients. In the cases here, there was a pre-existing family history of the condition, so patients had some information, although they gathered it in a more passive way. Following diagnosis, the information search increased and then tapered-off, stopping active search once the condition reached a point of equilibrium.

Types of Non Human Information Sources

The participants utilized a number of different information sources in their search to find details about their own chronic conditions. Each participant in this study relies heavily on the Internet for their health information in general. On the web, credibility is the most important factor in determining whether one will continue to utilize information. Most reported visiting sites associated with a well-known hospital or medical school to obtain the most credible information. WebMD was often mentioned, as well as its affiliation with a large teaching hospital. Others used government health websites such as the FDA. Most indicated that, when they encountered a new website, they investigated the source of the information contained on the site. If they determined the site to be sponsored by a company whose intent was to market or to sell a product, they either abandoned the site or incorporated that information into their consideration of the validity of the information. Almost all of the participants mentioned having done an Internet search using popular search engines such as Google, and all reported they were more likely to visit a website that had no indication of affiliation with a marketing effort. They looked for what they considered to be unbiased, medically credible information. Television shows, news websites and magazines were also popular sources of health information. More than one participant mentioned CNN's Dr. Sanjay Gupta and the Oprah Winfrey Show's Dr. Mehmet Oz (also a well-known author of health promotion popular press books) as credible sources of information.

“Well, if there were an article on CNN you know or Dr. Gupta you know somebody like that would be somebody I would trust in what he said.” -- Bonnie

Applying theories from the medical literature

Classic medical theory looks at treatment of an individual with the goal of finding which system or organ is diseased and then treating that diseased part or removing the disease in some way. This is what physicians are taught in their training, to diagnostically treat what is wrong in the body's systems. In the purest form of this theory, the systems are examined independent of one another in order to identify where the problem is. Nursing theory, on the other hand, is dedicated to the overall management of the individual and how the systems work together. There is a broader focus in the nursing discipline, which expands to include psychosocial aspects of medical problems and their management. Because nursing theory offers this broader focus and provided greater insight into these results, several were employed in this analysis and interpretation.

“Good” and “Bad” Patient Behaviors

Throughout the study, participants made reference to behaviors that they deem acceptable, if not necessary on the part of a patient in a doctor-patient relationship and those behaviors they believe are unacceptable, or at least undesirable. Many times in the context of the discussion about DTCA, participants expressed thoughts about a possible third person effect of DTCA and in so doing, what they thought were appropriate ways to interpret advertising messages and interpret other medical information. The third person effect and access and utilization of persuasion knowledge, that is awareness of marketing strategy (Freistad and Wright, 2007), are apparent in these passages, but the product of these conversations is a set of distinct descriptions of what it means to be a “good” patient or a “bad” patient. While most participants considered themselves to fall into the “good” category, one participant, Judy,

described her philosophy on her own health care, use of prescription drugs and information, as precisely what other participants had described as being less than desirable behavior on the part of a responsible patient.

The view of a positive, proactive patient was indicated by a set of behaviors and assessment of the environment of a doctor's office. For these participants, it is desirable to understand the state of the medical field and limitations physicians face in light of increased patient loads, limited time and insurance provisions for certain kinds of care. With this realization, participants indicated that if they have a responsibility to not add to the chaos of caring for a great number of patients, all who may have their own ideas about how they should handle their conditions and ailments. These patients see themselves as enlightened and cooperative and acknowledge that the doctor often sees patients who are not so. The patient should recognize that medicine is an industry, and the doctor is presented with many challenges when diagnosing and prescribing treatment in the short time available during most doctor visits. This industry requires cooperation from its clients, and a patient must simply "read the map" for the doctor. That is to say, to eliminate confusing emotions or other potential superfluous information that may confuse the issue. Reading the map entails listing the physical aspects of one's condition, systematically and factually.

A "good" patient knows that prescription drugs are not "one size fits all." When encountering medical information, and especially when viewing DTCA, it is important to understand the nature of the information and accept the fact that the information is general and there may be intricacies to its effectiveness that only the physician or other health care professional can interpret.

A good patient takes what the doctor gives them. While it is acceptable to ask questions, a good patient is accepting of the doctor's recommendations and follows them as directed in order to address a condition. Not trying leaves room for fault on the part of the patient, so it is important for the patient to "do his part" in the management of the condition.

Similarly, a good patient allows the doctor to make decisions about the course of treatment without influence from the patient. The patient may give input in the form of answers to the questions, but it is desirable for a patient to listen to the doctor's recommendations without judging whether he thinks they are right or wrong. In other words, the patient should not impose his or her preliminary beliefs about how the doctor should or should not treat the condition based on information he has gathered prior to the doctor visit. This is especially true when the patient has heard about a specific treatment. Most participants brought up the common DTCA theme, "Ask your doctor about..." and indicated that asking the doctor for a specific drug was not acceptable. It is good to know what's available, but to come in with that knowledge as background information, not as an absolute.

Finally, a good patient has a good relationship with the doctor, one based on respect and trust. As mentioned earlier, because of the socioeconomic background of the participants in this study, the relationship is more likely to be a social one outside of the office, but participants who said they had social relationships with their doctors indicated a separation between those interactions inside and outside the doctor's office.

The "bad" patient

Behaviors that participants characterized as being undesirable are those performed by less informed, easily swayed patients who might question the authority of their health care

professionals. Some patients are seen to be “All set to order (a prescription),” having digested only information they acquired passively through DTCA or media reports with questionable credibility. These patients are not as trusting of their physicians, and perhaps don’t enjoy the relationship of mutual respect enjoyed by the participants. As a result, they have a tendency to “play doctor” for themselves. These participants believe that some patients don’t take very good care of themselves, believe they have every ailment they see on television or hear about some other way. In addition, they believe that they require every remedy that they see advertised on television. Patients like these want an instant fix to any condition they are facing, and perhaps they don’t understand the implications of the condition they have, that is, the long term effects of the condition itself, if left untreated. They also may not understand the value of combining prescription pill therapy with lifestyle changes.

In sum, participants in this study appear to judge others based on the amount of responsibility they assume for their own health and the amount of initiative they put into learning how to address their own self care. Patients who take responsibility and search for information and seek the advice of a professional are perceived as being better able to synthesize the information they collect and make better decisions about their own health care. It is these behaviors that then tax the health care system with phone calls and unnecessary doctor visits

Judy

One participant expressed beliefs and told about behaviors that are consistent with what the other participants described as being undesirable or unacceptable for a patient. Judy described having thoughts about and even doing these behaviors, and in some cases she indicated she had doubts about these being acceptable.

“I’m terrible about if there is a pill for it I wanna take it...Because I think I, like a bunch of lazy people wanna take the easy way out if there is a pill that will fix something.” -- Judy

In her interview, she describes how she might go about trying to obtain a prescription she believes might shorten a bout with the flu.

“You have to call and say, aw c’mon Dr. (P.) what’s it gonna hurt?”

“I’m sure I told him how miserable I was, you know it’s been so long ago I don’t remember exactly how it came about. I’m a big complainer so I would have, can you fix this, can you fix that?” -- Judy

Judy further describes her doctor as being “old fashioned” and describes her attempts at persuading him to prescribe certain treatments as almost enjoyable.

“Well on one hand I like that, he’s not nearly as quick to give drugs, he’s not nearly as quick to give a test for everything.”

“I know he won’t give me something without having thought it out for a long time, I have to fight for medicine from him, I never have to worry about being over prescribed or, that’s what I mean by old fashioned, in a way I’d rather fight for my drugs.” -- Judy

And, for chronic headaches, she describes preparation for her discussion with the doctor about her symptoms in order to receive the treatment she would like to have.

“Beg, ‘I’m dying’, between you and me I have to give the worst case scenario I have to not tell jokes, I have to be extremely serious, I have to look like I’m dying, which at home I am, but I like people a lot so I tend when I’m around them to want to get happier. Boy did I ever learn about 20 or 30 years ago to tamp my personality down, be a different person when I go in and meet a doctor for the first time, otherwise they think I’m crazy. Because I’m a joker and yes I guess you just have to do that everywhere but it was something that doesn’t come easily to me. I don’t fib well, I don’t fib at all and I like to play and I like to be a goofball but like my daughter would say, just behave yourself.”

“I’ve been in pain most of my life and it doesn’t show. There is always this, ‘well maybe you don’t need that much,’ and truthfully, I usually start off breaking a pill in half and trying to take the least amount I can, because they’re not that easy to come by. That’s what I mean fight for them, I have to be the serious person, I can’t tell any jokes and I have to act the way I am at home by myself.”

“If I’m my silly self it’s like well you wouldn’t be joking if you felt bad, but I’m a very, I’m energized when I’m around people.” – Judy (all)

While Judy’s descriptions of her own behavior match what other participants mentioned were unacceptable, Linda summed up what may be a reason that patients in general self-monitor during their encounters with their physicians.

“I guess we’re all looking for the silver bullet that’s going to take this away.” – Linda

While several of the participants indicated that they wanted to make managing their conditions as simple as possible, it was often with a sense of shame that that was what they wanted. In their statements, it was almost as though they wanted a simple solution to the problem of their condition, but viewed that as somewhat of a cop-out. They made judgments about those who sought pills as an “easy fix” as somehow being less responsible, less willing to put in effort to manage the condition. Joel mentions that he sees it as some people wanting to take a pill for the symptoms, while not actually getting to the root of the problem, or other potential causes of the condition.

“Well (the ads) are very formulaic I mean they had a condition, take the pill and it’s over, or it’s done, or cured or managed or people are a lot better and I don’t think that’s, to me it simplifies what is often a very complex thing because if you look at it realistically people who have depression or whatever it is have a lot more going on in their life than just depression. So to all of a sudden go symptom, condition, medication, and cure or felt better I think that’s too simplistic.

“I mean that’s it, that’s the formula and at the end you think oh gee all of us would like to be that person, you know well I don’t think it’s quite like that.” -- Joel

Patients as Consumers

Through the experience of chronic health conditions, participants in this study described how they act as consumers of information, health care services and prescription drugs. These

three elements construct a world of managing one's health as a partnership with health care professionals. Each of these three elements in their consumption process requires information and decisions on the part of the consumer. The social network surrounding consumers, along with other sources including DTCA provide information which the consumers filter, synthesize and utilize in order to work within that partnership for the purpose of gaining control of the chronic condition at an acceptable point of equilibrium.

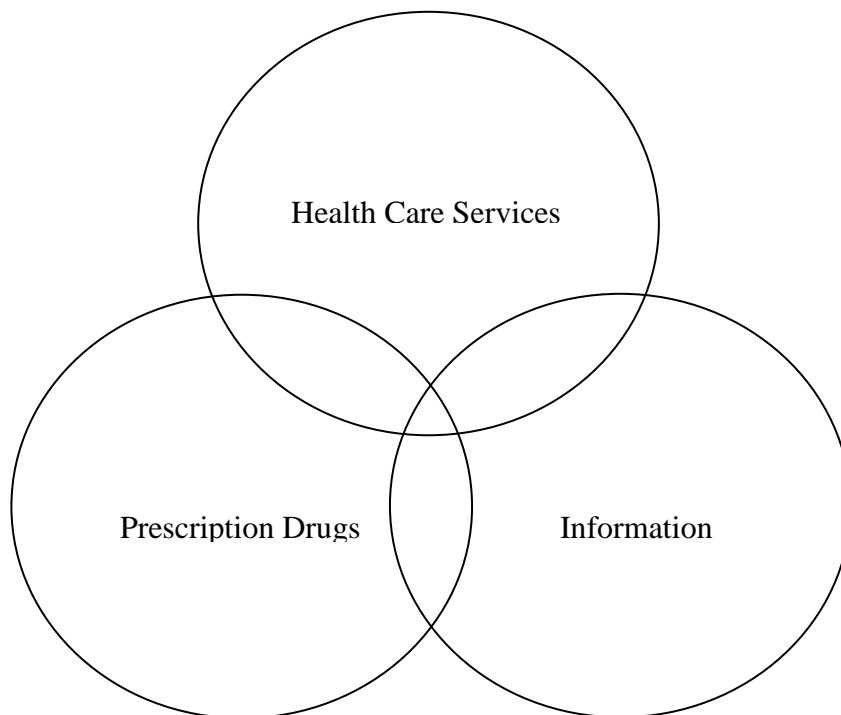


Figure 2: Consumption Categories of Patients with Chronic Conditions

Conclusion

In sum, this study found that DTCA, while it appears to be playing a role in the life world of consumers with chronic conditions, is only one of many elements and sources of information in this world. In addition, the role it plays appears to be an agent of confusion and frustration. In looking at the broader picture of this world, we discovered that consumers go through different stages in their chronic conditions. During different stages, they utilize both human and non-human sources of information, evaluating their credibility as they go and synthesizing and filtering the information available to them in order to become an informed patient, or “little doctor.” Social networks play the role of information source and “buffer” for consumers with chronic conditions. Doctors are still regarded as having the final say for this group on the treatment for the chronic condition, but consumers demonstrate an increased level of responsibility for the management of their own health.

Chapter 5

Findings

This study attempted to describe the experiences of consumers who are the primary targets of DTCA. In the process, their experiences with advertising of prescription drugs revealed a complex world of managing chronic conditions at a stage of the life cycle when chronic conditions become more common. With the availability and accessibility of large amounts of information to consumers, the life world of patients as consumers is becoming more and more complex. The purpose of this study was to more closely observe consumer behavior and emotions through the process of managing chronic conditions. Following is a summary of findings based on the original and extended research questions.

The first research questions concerned meaning of DTCA among consumers. The data suggest that DTCA is simply an additional source of information for consumers with chronic condition. Consumers are looking for information when they pay attention to DTCA, sometimes processing story lines and images in the advertisements rather deeply, identifying with celebrity endorsers and other characters portrayed in the advertisements. Often, the constraints of time and regulations that require advertisers to include a great deal of technical medical information don't allow for a significant amount of information to be shared in an advertisement. This proves frustrating to consumers, who are making efforts to gather credible information from sources such as the Internet, magazines, news media and even medical journals. DTCA is perceived to simplify complex situations surrounding chronic conditions and therefore can create confusion that requires patients to engage in further information search. Participants' accounts

of their experiences suggest that they attempt to utilize that information to make decisions about their own care and the care of others close to them. However, they find DTCA to be irritating and frustrating, as they perceive it to contain only partial information and recognize its persuasive intent. Therefore, messages in DTCA are often interpreted through a lens of skepticism. None of the participants indicated that DTCA provided them with significant information that might help them make a decision about their treatment.

The second set of research questions that were addressed as a result of emerging themes focused on the experiences of patients as consumers. It was discovered that a patient as consumer with a chronic condition experiences their illness in stages, beginning with their existing beliefs and observation of others with the same chronic condition. Diagnosis of the chronic condition may be through one of three avenues: in a routine medical exam, as the result of escalating symptoms, or after a critical event that requires hospitalization. An information search is undertaken by the patient and, depending on how a patient is diagnosed, information is consumed in different patterns. The diagnosis is often a source of confusion and patients spend time formulating questions about the condition itself, how and why it came about, and how it might be treated going forward. Following diagnosis, patients and their health care professionals go through a period of trial and error where different treatment options are used to attempt to control the condition. These may include lifestyle changes or simply a “wait and see” approach. If the condition persists, doctors may prescribe medication. If the medication, combined with other lifestyle management efforts on the part of the patient, are enough to keep the condition under control, the patient moves into stages of understanding and acceptance. However, in some cases, medications may carry side effects that are unacceptable or they may stop working at

some point, requiring the doctor and patient to continue in the stage of trial and error until an effective treatment is found. The stages continue and move toward a state of equilibrium when the condition is integrated into the patient's life. At that point, the patient understands the condition and its chronic nature and is able to integrate what she has learned about the condition and develop a management routine that becomes part of everyday life. During this process, patients are consumers of information, health care services and often, prescription drugs. Throughout this experience, patients interpret and filter information from both human and non human sources, interact with people in their social networks and work as a partner with their health care professionals in order to arrive at the desired state of health.

The remainder of this chapter discusses the limitations of the study and implications of the results for marketers, health care professionals and public policy makers.

Limitations

While there are several different facets of discovery in the analysis in this study, there are also several limitations to this study. Specifically, these include the qualitative approach, interviewer as instrument, and sampling techniques.

Some limitations are inherent in qualitative research and this study employed methods to attenuate the effects of these limitations, as described in Chapter 4. The principal investigator, when interviews are the primary means of data collection, is the instrument in this study. Data is collected through the lens of that investigator's interpretation. Use of a bracketing interview prior to the study and an interpretive group during the analysis stage attenuated biases, however, it is impossible to eliminate the possibility that data or interpretations are influenced by the investigator's existing beliefs.

Participant recall and self monitoring are also potential limitations when using depth interviews as a tool for data gathering. The participants have had vast life experience, and for many, the onset of their chronic condition is long in the past. For this reason, many emotions and the intensity of those emotions that the participants encountered in the early stages of their chronic condition may not have been captured in the face to face interview. Certainly, in retrospect, especially when dealing with a process of resolving issues such as a chronic condition, the distance from that time may diminish the intensity of emotions and memory of events. Individuals at different stages will likely have a different view of their conditions. Recall that most of the interviews in this study were recorded in public (coffee shops and the library) or semi-public (offices) places. It is likely that self monitoring was higher in these locations than it might have been in more private surroundings. While this was minimized as much as possible through the process of building rapport, maintaining anonymity, the risk remains that the environmental factors may have had an effect on the responses.

Other limitations are related to context. The participants live within a 25 mile radius of Knoxville, Tennessee. While some have lived for extended periods in other regions of the country, those who are native to the Southeast are likely to be heavily influenced by norms of southern culture which tend to include overt politeness and more traditional conservative values and beliefs than might be found in other parts of the US and the world. In addition, their level of education and socioeconomic status are high. This means that financial and informational resources are readily available to them, and that is not the case for much of the US population. Further research is necessary to explore the experiences of consumers with chronic conditions in different regions of the country and of the world.

This study does not address the experiences of consumers whose resources are limited, or consumers who perceive their resources to be limited. Uninsured, less educated people from lower socioeconomic strata are likely to experience chronic conditions, health care in general and therefore DTCA, in entirely different ways. More research is suggested to understand the experiences of those in these presumably more vulnerable groups.

Finally, sampling techniques might also present a limitation. After the first few interviews were conducted, purposive theoretical sampling was used to determine the characteristics of subsequent participants as well as the direction of subsequent interview discussions. As concepts emerged from analysis of a group of interviews, participants were chosen and interview guides were modified to focus on exploring those concepts.

Implications

Marketers/Pharmaceutical Companies

People do look at DTCA. They see it. They understand the stories in the television commercials. They inject themselves into the stories and the imagery of the ads. They remember ads, even the ones they don't quite understand. Ads are ubiquitous.

Consumers may not like DTCA. They make jokes about it. They object to it. They are offended that they must explain e.d. to their five year old grandchildren. They feel inundated by it. This doesn't mean that DTCA is not effective; it's not clear what constitutes effectiveness.

One must question how the wearout effect will influence the success of DTCA now that the U.S. has seen widespread use of this type of advertising for nearly 12 years. Attitudes toward an ad have been shown to have an effect on attitude toward the brand which in turn has the potential to affect attitude toward the product and purchase intention (Lutz, McKenzie and Belch

1983). However, our study supports earlier data (Wozinska 2005) reflecting that consumers don't always remember the brands in DTCA, but they do tend to remember the category of drugs represented in the ads. Future research is warranted to test the relationship between negative attitude formation toward the category of DTCA and its effects on attitudes toward the products in a given category and therefore purchase intention. Future studies in this context might need to consider inclusion of more behavioral dependent variables like purchase intention within the scenario of prescribed products, where the doctor, insurance company and pharmacist all have potential influence over the final drug purchase.

There appears to be a great deal of skepticism among consumers regarding DTCA and drug companies in general. Advertisers must be cautious about the level of trust they are able to create and maintain with consumers. Future research may further explore the nature of trust for large pharmaceutical companies. For some consumers, the amount of conspicuous promotional dollars spent to market a drug may negatively influence their level of trust of a drug company. Similarly, if consumers see evidence that a doctor has been influenced, through gifts or other items, their trust for both the company and the doctor may be diminished. DTCA is only part of a much more complex integrated marketing communications program. Further research is needed to determine which messages and which channels of communication carry the greatest influence on trust. Which channels and what kinds of promotion have the potential to increase trust?

Finally, the skepticism extends to the messages themselves. Some participants' skepticism went as far as labeling DTCA as "untruthful." While it is advertising's function to aid in influencing purchase behavior among consumers, advertisers must consider whether the

messages they are conveying in their advertisements facilitate symmetry of information.

Certainly, that is one goal of the FDA guidelines, but if consumers continue to question the truthfulness of the advertisements, then their effectiveness may need to be questioned. Again, recall that attitudes tend to apply to a category of products in this case, not just to one brand.

This study suggests that one area of effectiveness is the target market. The study of the economic impact of DTCA (Iizuka 2003) suggests that the primary target market on which the highest amount of money is spent is consumers who have demographics similar to our participants, and these participants report that they are liberally exposed to DTCA. Marketers may benefit by learning more about the experiences of these consumers and what they are really looking for. Our analysis suggests that they are intelligent and willing to search for information, and they don't want to appear or be treated as though they are ignorant. They are looking for information and when they are unable to get the whole story from a source, they are frustrated. Advertisers might consider ways they can better serve the need for information about chronic conditions and about different treatment options.

Advertisers will also benefit from acknowledging the social network utilized by consumers to help synthesize health information. A patient's social network is made up of many different kinds of people. Family members make up a significant portion of the social network, however, the network can extend from close relatives to simply anyone who will listen. The Significant Medical Other may have any level of health education, but is often consulted for medical advice. Information given to them needs to be consistent with the information that consumers receive to avoid the "what they didn't tell you is..." conversation that might reduce trust and undermine marketing efforts. Further, advertisers might benefit from knowledge of the

stages of chronic conditions. They may be able to provide time sensitive information by appealing to patients who are in particular stages of their condition. It is apparent that some companies may already be doing this for the earliest stages through messages that encourage patients to see a doctor if they encounter certain symptoms.

Consumers either don't admit or don't want to admit that they ask their doctors about a specific drug after viewing an advertisement suggesting they do so. They consider doing so to be unrealistic on the part of a responsible patient. However, they are likely discussing it in their social network. This implies a need for quality information that is deemed credible and reliable by consumers. The information must be documented as coming from a reliable source and statements made about medications should reveal a complete picture of the options for treatment of chronic conditions.

Physicians

This study suggests that for some consumers, the doctor is still the final authority on treatment options, especially prescription drugs. However, patients want to do their part to address chronic conditions, but may be secretly wishing for the silver bullet to solve their issue. This result suggests that DTCA as a threat to the physician-patient relationship may be a myth. While participants in this study indicated they are aware of the messages DTCA conveys, they see it as unacceptable to ask a doctor for a specific drug. While they gather information related to their symptoms and conditions from various sources, they still defer to the physician for the final decision on diagnosis and treatment. Their efforts to educate themselves appear to be motivated by a desire to be competent enough to work in partnership with their doctors, not to undermine or replace the expertise their health care professionals. Further, these efforts utilize a

number of different sources of information, and DTCA was one source that they considered lightly compared to other sources due to their knowledge of its persuasive intent. As Bonnie indicated, “becoming little doctors” is the result of the availability of health care information and consumption of that information in an effort to make up for constraints of the current health care system. However, none of the participants in this study suggested that this diminished their respect, trust or other aspects of their relationships with health care professionals. This suggests that health care professionals have no basis upon which to feel threatened by DTCA messages.

The results of this study revealed numerous motivational states. Patients as consumers are willing to take action as long as that action is perceived as one that will get them to an end point, to a point where their state of health is acceptable and they feel “normal.” They want to feel intelligent, be able to take care of themselves, and consumer information, services, and products that will facilitate this. They want to live longer and better than their parents did. They don’t want to have to think too much about what they do as a routine to address the chronic conditions they have, that is, they want a management regimen that becomes automatic. They don’t want to appear to themselves or to others around them as being infirm in any way. They want to look and feel young and energetic and able to do all the things in life they want to do. They want to look competent and healthy to their peers at work and to their families so that others won’t worry about them. They want to be healthy in order to take care of their families.

Physicians are not the only Learned Intermediary anymore, but that doesn’t necessarily diminish their importance in the social network of patients with chronic conditions. Managing information and expectations is more important than ever. Patients have been looking on their own to compile a sense of what might happen or what they might have. This isn’t because they

don't respect the physician's opinion, rather, it's because they want to appear credible and responsible in the eyes of the health care professionals. Consumers appear to want to be trusted by, as much as they want to trust, their physicians. For this reason, physicians and other health care professionals need to understand that many patients as consumers are taking on more responsibility for their own health care out of their realization of constraints on the health care system.

Additionally, patients as consumers are aware that physicians are visited and potentially incentivized to prescribe certain medications. Therefore, they watch prescribing behavior and may compare with other patients and discuss with others the prescribing habits of physicians.

Other Medical Professionals

A significant contribution to the nursing literature is the definition of the stages of chronic conditions as defined by emotions and behaviors. Previously, phase theory primarily relied on definition of stages in chronic illness or traumatic health events based on emotional responses (Livneh and Antonak 1997). Many chronic conditions exist that are not perceived to be immediately life threatening, but with new awareness of their potential long term effects, consumers do appear to embark on a process of coping, learning and adapting to life with these chronic conditions in order to avoid those long term effects. Understanding this process as one of gathering information, learning and behaving may help medical professionals provide more comprehensive support for patients with chronic conditions. Certain interventions may be more effective for patients in one stage or another in the process, so further research may address assessment of patients to determine their position along the continuum. Once assessment is available, protocols for intervention at each stage may be implemented in order to assist patients

in their progress toward the state of equilibrium, or adjustment. For example, if physicians are able to recognize that a patient is at the confusion stage, they can then develop procedures to provide education in a directed environment that will help the patient move to the next stage. Alternately, if a patient is in the trial and error stage, health care professionals might monitor the patient more carefully and frequently to discover if a treatment is working and if not, what the patient might be doing to self-manage.

Public policy Makers

Public policy makers face many questions about DTCA and the regulations that govern its use. While providing information about products that may potentially improve the quality of life, this type of advertising has specific responsibilities in the eyes of consumers that go beyond what advertisers of traditional products bear. The buying process is different for prescription drugs and, therefore, regulations are necessary.

One of the criticisms of DTCA is that it produces an asymmetry of information among consumers because of its literacy demands, both from the advertising itself and from the supporting materials consumers are referred to such as web sites. Among these participants, it is clear that some ads generate confusion and are therefore a source of frustration. If that is the case for this group, who presumably has high literacy levels, it is possible that DTCA is even more confusing among groups with lower literacy. Those with high literacy are more likely to utilize a variety of other reliable information sources to further investigate health information they see via advertising, where lower literacy individuals may rely more heavily on what they see on television (Lee, Salmon and Paek 2007), making DTCA a much more significant piece of the information puzzle. Literacy levels are highly correlated to education, so more research is

necessary to better understand the lower literacy population and how they utilize health information. With the constraints of time and regulations, the current study supports that DTCA is unable to present a complete account of a condition and its treatment options. It would follow that lower literacy individuals who depend on mass media for their health information are at a significant disadvantage when it comes to learning how to prevent or treat chronic conditions. This information asymmetry among consumers calls for significant education efforts aimed at this vulnerable population.

A primary argument for the continuation of DTCA in the US has been that DTCA increases awareness among consumers about chronic conditions and their treatment, reducing social stigma attached to some more sensitive conditions. Pharmaceutical companies propose that DTCA does contain information regarding symptoms of certain conditions that many encourage consumers to visit a doctor for diagnosis and treatment, and this amounts to education for consumers. The data presented here show that, while consumers also believe that DTCA contains some information, the information is insufficient to support health care decision making. Several participants expressed concerns that, while they have access to further information that elaborates on claims made in DTCA, other consumers are likely to be misled by DTCA's limited capacity. These two points suggest that DTCA does not carry educational value.

The data also concur with earlier studies' conclusions that there is little recall of brand names from DTCA. While consumers tend to recall imagery and the drug category represented in DTCA, they often do not recall the brand names of drugs. Arnold (2009) proposed that DTCA be limited to non-branded announcements describing conditions and their symptoms, stating that treatments are available from health care professionals. This study suggests that this

proposal may be a cost-effective way to present information in a way that consumers of all literacy levels can understand without the distraction of disclaimers. It is possible that eliminating the branding messages may provide a more complete picture for consumers to make better informed decisions as they explore their diagnosis and treatment options. Providing unbranded, condition-specific advertising informative public service announcements is one solution to the need to share information, communicate about conditions and possible treatments, inform consumers about symptoms and treatments without branding, without “selling” and therefore triggering persuasion knowledge defenses. By taking on a cooperative initiative to provide these unbiased messages, which is what this group of consumers is saying it wants, pharmaceutical companies may not only build credibility with consumers but also may improve self regulation, therefore reducing the burden of remedial regulation on the part of the FDA.

Future Research

Advertising effectiveness is an evasive concept, and as marketers, it is important to consider the effects of this category of advertising over time. Advertising effectiveness has been measured in a number of ways, most often in terms of increased sales of a product, recall of the advertising content, or purchase intention. Traditionally, these effects are conceived in terms of thinking and feeling, which influence behavior (Vakratsas and Ambler 1999). Whether an advertisement is effective or not, then, depends on its intent. If, as mentioned before, the intent of DTCA is to educate, this data suggests it falls short. If the intent is to reinforce brand identity, this study suggests it may not, at least not cognitively. A number of contemporary researchers are convinced that marketing stimuli may also be processed through an individual’s unconscious state (e.g., Zaltman, 2003); moreover, some believe that physical response measures will

eventually lead us to greater understanding of effectiveness (Lee, Broderick and Chamberlain 2007). It is impossible from this study to rule out such a potential for DTCA.

The present study is an attempt to identify ways that DTCA does affect consumers in its primary target market. More research is necessary to quantify the attitude change toward the category over time, and for consumers in different demographic segments. As mentioned earlier, the participants in this study are of the age and life cycle stage where they remember a time without DTCA, and therefore may have different attitudes toward advertising than, for example, younger consumers who have never known a culture without DTCA. Longitudinal research over time is always desirable in observing how attitudes change at different stages in the life cycle, defining attitudes among consumers in different demographic groups in order to better understand their point of view. Additionally, future studies must take into account the attitudes of consumers at different stages of their chronic condition. Longitudinal studies may uncover trends in attitude formation and attitude change through the different stages of the condition.

More research is needed on the information search of those with chronic conditions. At what point does active information search begin and end? What individual and situational differences motivate consumers to engage in active information search?

Further research is necessary to address cultural differences in countries where DTCA is not yet utilized. In European countries, DTCA's illegality is due to laws that uphold the learned intermediary maxim – that a doctor should be the primary source of information about treatments and be the sole decision maker about what treatments are necessary. Cultural beliefs about health and self care may differ from country to country, and appear to play a significant part in the diagnosis and management of chronic conditions. Existing beliefs about self care, severity of

chronic conditions, available resources and utilization of health care services all play a part in consumer behavior related to pharmaceuticals, so further investigation is necessary in order to inform the debate over the value of DTCA in those countries.

It is this researcher's intention to continue with a program of research to address the issues here. Quantitative research can be used to further investigate the correlations between socioeconomic and educational influences and how they affect patients as consumers. More is needed to examine how these and other factors change the way consumers approach information search, how they interact in their social networks, how they lend credibility to different messages about health, and how they self-manage chronic conditions and other health issues. We must continue to examine the effects of DTCA and other commercially-funded health messages, especially across different types of conditions and across stages in the consumer lifecycle. It would be interesting to compare the impressions of DTCA across generations, for example, the age group represented in this study compared to consumers who are in their 20s, who likely don't remember a time when DTCA was not prominent. Understanding how patients make consumption decisions is increasingly important as we face public policy issues and the increased aging population.

Conclusion

The original purpose of this study was to provide insight into questions about DTCA. In the process of exploring the meanings consumers construct from this type of advertising, the world of patients with chronic conditions as consumers emerged. The results presented here describe the experiences of managing a chronic condition and integrating that management into daily life. The process of managing one's health as a consumer is a complex one, and this

requires consumer effort to work with health care professionals, learn about the condition and take an active role in treatment and management behaviors. Health care is one of the largest expenditure categories for consumers in the US. The description of these experiences and processes are a framework on which future research can build, toward a better understanding of patients as consumers.

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Vita

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