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INFORMATION NEEDS, USES
AND INFORMATION TECHNOLOGIES
IN THE LIVING CONTEXT OF CHRONIC ILLNESS:
A PARTICIPANT OBSERVATION STUDY

DISSERTATION

Presented in Partial Fulfillment of the Requirements for
The Degree Doctor of Philosophy in the Graduate
School of The Ohio State University

By

Martie L. Parsley, M.A.

The Ohio State University
1998

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ABSTRACT

As information technologies become more pronounced in everyday living, they are recognized as not only influencing the way things are done, but are transforming the way that things are. This dissertation focuses on the ways information technologies transformed, not simply influenced, the living context of the author's life as a chronically ill, oncological patient. In addition to using personal journals from 1985 – 1996, data also included personal narratives and in-depth interviews of family members and physicians, observations from and participation in virtual health communities, on-line health resources, and medical and psychological therapy records. The author, through participant observation, chronicles information needs and uses and the usage of information technologies during the decade from her first brain surgery in 1985 through March, 1996 which was marked by a second brain surgery and Gamma Knife radiation treatment.

These data were examined for themes that led to the development of an emergent three-pronged, six-stage model describing the information uses and needs for chronically ill patients. Three “uses” categories; Internal Assessment, Cognitive Assessment, and External Assessment emerged. The “uses” categories represent options that a patient has to apply or adopt information that he/she has evaluated as relevant to his/her psychological and physical states.
Internal assessment is characterized by the internalization of the information and personal adjustments to accommodate the information. Choosing to cognitively assess the information, the patient may compare and contrast the current information with previously obtained information. When engaged in external assessment, the patient discusses the information with significant others, who can include health care professionals, physicians, family, or other patients.

Six stages of information needs emerged from the data that represent information needs for the patient, from the initial diagnosis of the chronic illness, which is characterized as chaotic, to an accommodating, advancing stage, which promotes personal growth. These six stages are Orienting, Opting, Inquiring, Ensembling, Integrating, and Advancing. Each stage is validated by data, and the influence of information technologies on each is offered.

Conversational data is also analyzed in terms of information processing constructs and communication constructs.
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PREFACE

In 1985, I had to have emergency brain surgery. Even thought the words I heard the doctor saying were implausible, they changed the course of my life. I had no idea what I had in store, how difficult it would be for my family, as well as for me. There was no way for me to imagine not being able to talk, swallow, walk, and even sleep for the next year. I remember thinking “What now?” not in the sense of the present, but in questioning my future. I had no role model for “being” a hospital patient, a home care patient, and as it turned out, a chronically ill patient.

I had made an art out of side-stepping disturbing issues, but it was impossible to side step this, impossible to ignore what I was told. I couldn’t talk myself out of this. There was no one to charm, to convince that I really didn’t need to “do” this. Truly, it was my own body that deceived me. Brain surgery only happened in the movies or the soap operas when the end was near. And it was going to happen to me in three days, and continued “happening to me” for the next ten years. Information became central to my existence, information about the illness, information for emotional support, and information on how to live, or at least coexist with “my problem.”

Fast-forward two years. “We really need to talk,” I said to my parents when I found myself alone with them during a “surprise” visit home in February 1987. I was ready to take the mystery out of why I impulsively traveled 3,000 miles. Steadying myself against the table, as if to muster all my might, I asked the question that had haunted me for so long. As soon as I heard myself asking the question, I knew I really did not need an answer. But once uttered, that question infused the three of us into a new beginning, a new founding, and changed a relationship that seemed to have been constantly rewritten since January 1985. Those words entrusted us, collectively, to travel the figurative journey that was much longer and more profound than the literal one that brought me to this space, at this time.
For more than ten years my parents, family, and health care professionals journeyed together, sharing the burden of chronic illness. Unfortunately, we seemed to be traveling in circles, most obvious when I would relapse. However, once the pain, the memory loss, the swelling, or the grating whispers subsided, we were back on tract, making progress, taking two steps forward. The next bout would take us one pace back, confirming we were never more than one step ahead of "my problem." So, we lived our lives in uncertainty, never ready to admit defeat, and incessantly dismissing the importance of the backsliding. The uncertainty and not knowing were eventually more unhealthy than the physical ailment; knowing was not the enemy.

In 1996, the backsliding could no longer be dismissed when it was certain that I would again have to have brain surgery. Armed with confidence and a false sense of security culled from previous experience, I convinced others and myself that this was nothing. In fact, it was perfect timing. I needed a dissertation and this surgery offered me a unique opportunity for a participant observation study. I fooled myself longer than I fooled others. But their fear was contagious. I realized this was not just a repeat of 1985 and my map of "being ill" was outdated.

Over the years, I had come to realize that I was accountable for my own health states, and in order to be well, I needed to participate in getting well. I had developed almost a remarkable capability to ferret out what was going on, who to trust, and how to "get to the point" with health care professionals who at first seemed reluctant to keep me informed. My self-designated "success" as a chronically ill patient was based on the ratio of how much information there was to know and how much of it I did know. This self-care perspective served me well, and coupled with the "consumerism" perspective adapted to health care in the 1980s, increased my participation in my health care.

By 1996 when my brain tumors once again sabotaged my freedom, information technologies had been firmly ensconced in the way I lived my life. Through my graduate work at Ohio State University, I had academically studied the "information age," and my personal use of information technologies was framed by educational objectives.

Given my information-based understanding of illness and to me what was a clear implication of information for wellness, the use of information technologies in my health
world seemed a natural extension. However, as I began to use information technologies in the context of health, I was constantly frustrated and overwhelmed by the amount of available information. The sheer magnitude of information that was accessible seemed only to point to all that I did not know. There was a perpetual smorgasbord of information to choose from and I obviously needed a strategy to guide my choices.

I easily slid into the routine of travelling to web sites and home pages found through browsing. However, I was surprised at how reluctant and hesitant I was to do more by accessing the thousands of patients who shared a similar fate as I. Information technologies afforded me opportunities never before available, yet down deep, as a chronically ill patient, I felt and feared an inherent responsibility to others once these connections were made. Information gathering was safe; information giving was fraught with accountability.

It occurred to me that when you start a new journey, with no map as a guide, you can never gage how close you are to your destination. This dissertation is an attempt to contribute to such a map. It charters the course of the living context of chronic illness, the influence of communication technologies in this living context, the lessons learned, and the myths debunked in a personal context of a patient of chronic illness.

How to Read

For qualitative mapping, it is critical to detail the inquiry process by thoroughly documenting the steps taken in the research. The following elements of the research process, in order of appearance, are included in this dissertation: a) generating and collecting data; b) the formation of the research question(s); 3) processing and analyzing the data; and 4) conclusions and contributions of the study.

Though the elements are not mutually exclusive, there are multiple procedures used in the inquiry process. The order for presentation of this dissertation material was chosen to account for sequence of steps I used in the inquiry process. Procedures included reflexivity of self, a review of relevant literature, a methods section which addressed ethical concerns encountered in this research, and the discussion section which examined the contribution of this research and suggestions for future research. I have made a concerted effort to provide research literature to explain, validate, and support
themes that emerged from the personal narrative. Ideally, but not viable at this time, all material in this dissertation would be hyperlinked, allowing the reader to move easily from the narrative to the literature review, highlighting areas of interest and concern for the reader. These hyperlinks would link the reader to sections in this dissertation or to web sites, discussion groups, chatrooms, or home pages relevant to the area.

Though the presentation of material reflects the sequencing I used in this work, due to the special considerations that were encountered throughout this study, the reader is encouraged to reorder the material to his or her preference. For instance, the reader may choose to begin with reading Chapter Two, the review of literature and then read the personal narrative, Chapter One. There may be an advantage for some to first read Chapter Three, which lays the foundation for the methods employed in this study, as well as descriptions of field notes, ethical choices, and analysis procedures.

“We need to talk” has, for me, a deeper, more recondite meaning since beginning this research. “We” now envelops those virtual communities in which I now hold citizenship. I hope that I have done the dreams and the defeats justice, the optimism and despair of fellow citizens laudable in this account. In listening to my voice, you are also hearing theirs, for it was their voice within me that wrote this.

Chapter Descriptions

Chapter One is the personal narrative which chronicles the course I traveled between 1985 to 1996 which was the time between my first brain surgery to the time I began radiation, and received the Gamma Knife treatment at the University of Virginia. Data for this personal narrative came from personal journals from 1985 - 1996, medical and psychological therapy records, and interviews conducted of parents and other family members, other patients, and health care professionals. Also included are summarizations and observations gleaned through my use of information technologies.

The personal journal entries and interviews were woven into my personal narrative. To protect the confidentiality of the listserv and chatroom participants, names have been changed as well as any other identifying labels. The personal narrative
documents the events from 1985, after my admission to Loma Linda Hospital for the first brain surgery, and extends until April 30, 1997, which dates the first radiation treatment at the University of Virginia. The personal narrative, while descriptive of many events, focuses on the use of information technologies to compare the 1985 episode to the 1996 cut-off date.

Chapter Two is the literature analysis and review on information, the impact of technologies on information and communication, the role of information and health, the history of the Internet and the World Wide Web, and on-line resources for health, chronic illness, and brain tumor patients.

Chapter Three details the methodology, provides the reader with the rationale of using qualitative methods, the specifics about data collection, selection, and attributes. Also included is a discussion on triangulation and reflexivity. Detailed accountings of the collection of field notes, procedures followed for interviewing and data generation, and collection of the Internet data is also reported. Ethical issues that developed while conducting this research are presented. Recursive decisions are documented and the analysis system is explained. Chapter Three also includes the research question and documents the procedure leading to the research question.

The discussion section is presented in Chapter Four and includes a comparison drawn between the 1985 event to the 1996 event. This comparison focuses on the information needs and uses during this time period and the ways information technologies transformed, not simply influenced, the living context of my life as a chronically ill, oncological patient. A three-pronged, six-stage emergent model describing the information needs and uses for chronically ill patients is proposed, evidenced by my personal narrative, the narratives and interviews of family and physicians, and virtual health communities participation. Additionally, suggestions for physicians’ and patients’ use of information technologies, as well as implications for future research, are discussed.
CHAPTER I

PERSONAL NARRATIVE

I had forgotten what it was like to straddle the line between life and death. But the feelings of hopelessness and despair revisited me. The shot came none too soon. Arrogant of me to think that this second time would be easier and I would be unafraid. Anyway, I had to arrive yesterday at 4:30 a.m. to get registered etc. I really was fine through the registration and even during the two hours it took to hook me up to the monitoring machines. About one half-hour before the surgery, I lost it. My sister (only one family member was allowed to stay with me) was great. Kept assuring me that these machines were going to prevent strokes and problems that I had had in '85. My anesthesiologist came in, announcing that "we seem to having a little problem." "I guess I'm not as brave as I thought," I conceded. "That's what I'm here for," he said (I thought) smugly. It seemed as though it was me against them, and "me" wasn't winning. I remember hearing the clicking of the monitors and thinking that those really were my connections to life. I asked for more blankets and the next thing I knew I was hearing those clicks again. I wasn't sure if the surgery hadn't started or if it was over. My chart shows that the first thing I did when I "came to" was stick out my tongue at Dr. D. Of course, this in response to her telling me to; to see if it was paralyzed, but little did she know I had come to enough to mean it in another way. Well, I'm recording this so I guess I made it. Even my voice sounds stronger. But if I have to squeeze another doctor's finger, I think I'll tell her where to stick it!

Personal journal entry, September 26, 1996

My involvement in what eventually became my dissertation began much earlier than 1996. In 1985 I was first diagnosed with schwannoma brain tumors and had to have emergency surgery. The physical and emotional consequences of that surgery interrupted my life for years. My primary thought was to get through it, never realizing that the seeds of my doctoral research were being planted. I did keep a journal; not appreciative of the importance it would have ten years later.

I considered my medical experience in the past and though I knew that it had changed me, I tried to brush it aside and get on with my life. I have always been good at ignoring or not dealing with things that bother me or uncertainties that would get in the
way of how I wanted to live my life. But, as hard as I would try to shove my illness out, I felt it creeping in all areas of my life. I began to recognize that my illness was part of me, forever mingled in all that I’d do.

So what conditions would lead a 42 year-old, female, university teacher, doing what she loved to do and living in Southern California, back to graduate school in Ohio? The completion of the degree was some unfinished business that had to be settled and I never analyzed why. In one of those unexplainable coincidences of life, my need for closure came at just the same time my university was coming to terms with its commitment and responsibility for faculty development. Being professed “healed” by doctors and declaring myself “well” I applied for, and was granted study leave to complete the doctoral degree that I had begun 14 years earlier at Ohio State University.

Before returning to Ohio State, I knew that I wanted to focus my doctoral work on health communication. After my first class in telecommunications, and through discussions with Thom, my advisor, I realized that I was interested in telecommunications with telemedicine as my area of concentration. However, the more I studied and viewed telemedicine as currently studied at Ohio State I recognized that the questions I was asking and the ideas that I had for research were not representing my real concerns.

I kept returning to my experiences as a chronically ill, brain-injured patient, and I realized that I could not push these experiences aside. I felt awkward articulating this since several students had told me that the dissertation was a means to an end and I should not look at this as my life’s work. The only good dissertation, they said, was a completed dissertation.

But I felt very passionate about this, and one evening at Thom’s home I expressed these notions (foolish, I thought) that I could write a dissertation that would be meaningful. His enthusiasm floored me. And his agreement to be involved motivated me. He said we would learn together and I knew this is what a dissertation was really all about.

I formally began the dissertation research in a class where we were to design and complete sense making interviews. I chose to explore my own illness (brain tumors) and
how I made sense of that illness. I began by writing my story, a personal testimony, and conducting a sense-making interview on myself.

The personal testimony served two purposes. First, the testimony was an instrument of reflection, an “intimate relationship between the research and the researcher” and second, an examination of my perceptions of my experience. I extended the research, interviewed other chronically and terminally ill patients, and began to formulate ideas on a “culture of wellness.” The work led me to realize that this was what I wanted to explore in the dissertation research. Combining my original interest in new communication technologies and my lived experience as a chronically ill patient led me to question what influences the explosion of information technologies had on the wellness of chronically ill patients.

Personal Testimony
April, 1996

Once upon a time, my life was simple. I had come to expect getting most of what I wanted, and accept that somehow I would, more often than not, be a “winner.” I knew how to play the game, or at least pretend I knew. But my deepest fear was that all of what I was and had was attributed to luck—and that one day my luck would run out.

January 8, 1985 certainly seemed to be my unlucky day. I had been in the hospital one week with a white blood count of 2 requiring six blood transfusions. I was dehydrated, losing my eye sight, and was being fed intravenously because I could not swallow. But it was not until my right side was paralyzed that a brain scan showed what was wrong.

I remember the morning of January 8 so vividly. I was in that hazy hospital world where you lose all sense of day and night, let alone time and space.

It was 8:30 a.m. and a doctor friend of mine had just left after having prayer with me. I was surprised when she hugged me and started to cry. My first clue that something was terribly wrong. Enter Dr. Wisdom. Sitting down in a chair, a comfortable three feet away from me, and avoiding eye contact, the first thing he said to me was “Well, we’ll be doing brain surgery on Tuesday. You might want to ask your family to come out” (I was in California, my family back East). I guess I was a little surprised and I must admit I started to cry.

Never one to mince words, except in giving emotional support. Dr. Wisdom finally made eye contact and said, “Well, this certainly isn’t the end of the world.” I can still see him sitting in that chair. I had never felt so in need of someone to comfort me, to hold my hand and assure me that everything was going to be all right. And so, I was ushered into a world of foreign language, players that thought they were God and a very different set of rules to play their game.
A successful surgery did not rescue me from this world. My life consisted of therapy (my vocal cords had paralyzed during surgery and I could not walk, talk or swallow), insurance payments and rejections and those damn doctor visits (what a misnomer). For many months, I felt as though Dr. Wisdom had removed my soul as expertly as he had removed my brain tumors. 

I was on disability leave from teaching for over 16 months. I could not talk for 13 months, but I was walking with help after six months. I can honestly say that my “problem,” as my mother called the schwannoma tumors on my brain stem, turned out to be the best thing that could have happened to me. I was finally challenged with something that required more than luck to overcome.

I was so proud of taking those first steps on my own. My parents cried when I called them one year later and could speak. I could hardly wait for a new day when I could try to do something else. Those taken-for-granted took on a new meaning—no longer necessities but luxuries.

Like many who have had similar experiences, I began questioning who I was and what I was doing with my life. It was hard for me to go back to the life I was living—a husband, memberships in country clubs, trips to Europe. Instead, I went back to teaching at the university. I saw my students differently. I know that I was teaching differently—and better. For the first time, I felt I had something to share—not just content, but the excitement that I had for living.

My husband and I divorced in 1990, nine years to the day of our wedding. He had done some reexamining of his own and decided to join the Hells’ Angels. A little different route than what I chose, but we parted friends and with our lives a little better because of those nine years together.

Sometimes when I speak of these things people expect me to be angry and question “why me?” But I have come to see this “problem,” my survival, and my determination as turning points in my life. I am now more conscious of what living is. I wasn’t just lucky. I was strong.

I was truly amazed at the release of feelings as I wrote the testimony. I knew that I had tapped into something that I should have done long ago. I realized that this experience influenced changes in my life as no other. For some unknown reason, putting those words on paper gave me a sense of control, not just of the illness, but in the direction of my life. But I wrote this nine years after the initial surgery and certainly in a stronger emotional context. I was back at OSU in graduate school. I was physically closer to my family for the first time in fourteen years. I genuinely loved my life and was once again doing exactly what I wanted to be doing.

This assignment made me curious about what I wrote as I experienced the first surgery. Sensibly, I knew that there were dark underpinnings to the story I told in my personal testimony and I would only begin to grasp the totality of the experience by
deconstructing that account. This experience was not a cinematic, seamless story. I pulled out my journals and the letters and cards I had received, and began trying to piece together the story and the experience of this illness. The subjective meaning of my illness and self-concept lie in the events of 1985 and certainly even before.

**Hospitalization, presurgery**

As I remember and visualize the events surrounding my ‘85 illness encounter I see myself in the eye of the schwanoma storm in my head. I am reeling at a dizzily speed, trying to connect with someone or something which to anchor and give this chaos some semblance of order. I need information on not just what I can expect about the tumors or surgery, but to lessen the uncertainty about my future. I think the world is coming to an end, contrary to Dr. Wisdom’s declaration.

My first afternoon, after being admitted through emergency was very eventful. The hospital was overfilled and so I had to wait on a private room. I had been rolled into a room and left for about five hours. Orderlies came in to the patient behind the drawn curtain who had not said a word for those five hours. No wonder. The orderlies rolled him out with a sheet over his head. I had been in the room with a dead man for five hours. Not a good start on this roller coaster ride to hell and back.

Five minutes later a group of beginning medical students shuffled in to see the doctor at work taking my medical “history.” Conditions were not favorable for any type of information exchange, especially since I had given my medical “history” to the admitting nurse. I was not pleased to be used as a medical text, and so when the doctor smiled that feigned smile and ask if he could ask me some questions I said sure, as long as I could ask him some. In the moment it took for that smile to fade, I’m certain he knew he was in for more than he bargained. I never saw that doctor again. Unknowingly I had set the tone for my several-months hospital stay. Asking questions and searching for information gave me some power in this powerless role as patient.

I remember pulling out the papers and books to read long after the midnight “vitals” had been recorded. The effort kept me occupied enough to evade really taking in where I was and why I was there. But there was no one to discuss the information with. Nurses invariably responded “I just don’t know. Ask your doctor in the morning.” By
morning, I had to get up the courage to face another grueling day of tests—let alone add to my uncertainty by asking questions that would go unanswered.

Today Dr. Jones brought me the textbook I had asked for, to learn more about this lesion on my brain (lesion is just the medical term for tumor, used, I think, to make your condition sound not so bad). I have so many doctors, residents, and social workers, nurses, (and the list goes on) that I have made up my mind to do my own research. No one can give me a straightforward answer. I’m concerned that they don’t know what each other is doing. If they’re beating around the bush so I won’t be scared, it’s not working. Everything seems fragmented and I can’t pull the pieces together to make sense of this. I’m thinking of asking for a semi-private room just to have a roommate who may be able to tell me what I should expect.

Personal journal entry. January 10, 1985

Being in a hospital room, leaving only to be poked and prodded by a new “team” of doctors made my information gathering seemingly impossible. I was at the mercy of my “team” to provide me information resources, and as I came to find out, this was not an ideal situation. Wanting to take responsibility and learn about my condition, but not being able to was my first sense of the inequality of the patient role.

I confronted Dr. Nightpound with the book’s cited 80% patient mortality for brain surgery. He opened the text and pointed out that the cited study was conducted six years earlier and that advances in neurology were made every day. He seemed please to inform me that the “official” mortality rate had dropped to 40%, but somehow that wasn’t so reassuring. That, he said, was the reason he did not recommend his patients to read on their own. He really had no way of keeping up on the latest numbers. It was difficult enough to keep up on surgical methods--and that really wasn’t reassuring.

Personal journal entry. January 10, 1985

Before long I felt myself retreating into my self when I was being tested, x-rayed or scanned. If my doctors had noticed a change in my behavior, it did not change theirs. It seemed useless to ask questions and the technicians and doctors seemed much more comfortable when I would not ask. I was feeling like some laboratory specimen, especially when residents would ask questions about me as if I wasn’t there. Nurses seemed to be the only ones who wanted me to participate in this hospital milieu. But they were also hesitant to give me answers, afraid of speaking out of line or divulging some test result. Frustrating to say the least. I owned what they were testing and they controlled what I could and couldn’t know. I underwent a swift education in the
hierarchy of roles in the hospital, and felt baffled by the obvious institutional politics. I recognized that the status of the participants were designated by the type and amount of information that person knew, and the privilege to release that information.

As a patient, I knew the least about anything, and was not expected to demand to be given any information. Orderlies were just a notch above me, and then the pecking order was technicians, nurses, residents, and then the DOCTORS. One of the residents who had been with me from day one was suddenly reassigned to another case. I found out much later the reason. When my parents arrived from the East Coast, this particular resident was quick to point out to them “We know she has cancer, but we just can’t find all the tumors. But don’t tell her.” They didn’t tell me. They told my neurosurgeon. Dr. Smith was reassigned

I observed that doctors and nurses assigned roles to my family members, not by the social roles but by the type and amount of information they had. My father has extensive medical knowledge. Just by the questions he asked and the information he seemingly knew, hospital personnel thought he was a physician and invited him to participate in my consults. He declined, but it was obvious he was treated as “one of them.” They invested their trust in him, something sorely absent in their relationship with me. He was consulted on all decisions about my care, participated in discussions with other doctors and was asked his opinion on procedures. He also explained to me the tests that I was taking and would discuss the pain I would have.

My husband, however, was excluded from the discussions about my illness. I feel very guilty recognizing only now how he must have felt. He was given less information than I was and was not involved in decisions about my case. The sharing of information indicated status, and he was ignored. He had no one to share his feelings with. No role model as the despairing husband who had demanded to make all of the decisions in the marriage. He was struggling; his life was changing as drastically as mine was; yet, he was more alone than any of us. The social worker “assigned” to my family invited him to meet with a support group. I could have predicted his reaction. And the support group met from 9:30 a.m. to 12:00 p.m. Not ideal hours for a construction engineer. The solution? He was given Xeroxed copies of two articles to read and told to come back if he had questions.
Because of this code of secrecy, when I was given information I didn’t necessarily believe it. This was especially true after the surgery. During my month-long stay in intensive care, physicians and nurses were telling me I was recovering on schedule. I thought, “What are they hiding from me? What do I really have?” Their patterned behavior of not sharing made me distrustful of the few times that they did answer my questions.

Having no information isolated me from participation in my own well being and the process of being well. It was as though you had to be a member of this internal fraternity to share this exclusive knowledge. Just being the patient didn’t let you in. I felt almost a reckless desperation to find clear, simple explanations as to what was happening to me and what I could expect. I was totally dependent on what they decided I should know.

The morning of surgery was chaotic, to say the least. I lay in bed as six nurses prepped me. They seemed to move fast forward, talking so fast I worried I was missing something I should know, until I realized I was only the patient, the prop in the center of a drama. Ironically, I felt as though I was no longer the center of attention. My eyes darted as I kept looking between the blurred figures, trying to find my family. “Read and sign,” a nurse said as he thrust a form in my hand labeled “Patient Rights.” This was one of the few papers I had to sign that made sense. At least as much sense as it could make for someone passing over to the valium-laced world of “prepping.” I didn’t question, I signed.

It seemed forever, when they finally lifted me in one swift movement from hospital bed to gurney. As they rolled me into the elevator I felt a hand tug. The hand belonged to my husband. Little did I know we were saying goodbye to our life, as we knew it.

Hospitalization, postsurgery

After my surgery, I didn’t want to read about my condition. I wasn’t in the “investigative” mood I felt before the surgery. I didn’t ask questions. One reason was I didn’t know how I could question these people that had saved my life. I didn’t want to seem ungrateful and certainly didn’t want them to think I didn’t trust their judgement.
Besides, even from the short time I had been a patient, I knew I couldn’t get the information that I needed from a doctor or nurse. The questions I needed answered could not be found in a textbook, could not be answered by someone who had not gone through this. My illness removed me so far from ordinariness that those who were well could not understand. If you haven’t been there, you just can’t know.

_I can not concentrate and in the middle of conversation, I sometimes find my mind wondering, grabbing snatches of what is said. I use to be witty, snapping amusing responses. No more. It takes all my strength just to pay attention long enough for the conversation to be coherent. When Dr. N came in today, the only thing moving seemed to be his mouth. He seemed to speak so slowly. I’m afraid it’s just my mind slowing down._

Personal journal entry, February 4, 1985

As the doctors examined and reexamined, it occurred to me that the information they were collecting was going to be biased because of their surety of what they were going to find. I remembered reading that 80% of medical diagnoses come from medical histories. My diagnosis was going to be based on many nameless presumptions. My concern turned from them not knowing what the other was doing to concern about them not knowing to whom they were doing it to. But I didn’t have the strength to mention this; they would have to base their opinions on the physical, perhaps not even realizing that such was the least of my worries.

Everyone thought that because I didn’t die I was going to get better. All tiptoed around the obvious, that this was the way I was going to live my life. My religious background and common sense influenced my belief that if I didn’t smoke, drink, and did exercise, treating my body as the temple of God, that I would have a long life. I had followed these tenets with a blind faith. But now, I resentfully decided that all I had done was live my life guided by self-indulgent deprivation. This belief was embedded in nothing more than hopeful thinking, reducing my faith to a myth, a pretense, a sham.

I realized that chronically ill patients very quickly develop a sixth sense—the detection of deception. The indirect eye contact and carefully calculated words indicated a less than veritable answer to questions. Damn it! Couldn’t they understand that I wanted to know so I could make some decisions? I felt that just knowing what they knew must be so contemptible. This manner not only indicated they did not think I was strong enough to “hear the truth,” but also invalidated my concerns and feelings.
I found out from my parents that the reason I could not talk or swallow was that I had had two strokes during surgery. My vocal cords were paralyzed. They did not know if it would be permanent. Great, I may never talk again. And as if I needed more reminders I couldn’t walk, couldn’t swallow, couldn’t stand on my feet for more than 15 seconds -- a recipe for a not so fulfilling life.

I’m trying to imagine what my life will be like if I won’t be able to talk. I wonder if this is how I am going to be the rest of my life. I’m not as confident as I was before the surgery; that everything is going to be OK. And I don’t have so many reassurances from those around me. I wish that I could fast forward my life like I did those videos I was to watch about this “challenge” that is going to last a lifetime. One of the many ironies--I’m a speech teacher who can’t speak.

Personal journal entry, February 10, 1985

I don’t know that I have truly been able to characterize how I withstood this awareness, though I’ve tried many times. I do know that although I was alive. I seemed to be just existing, and I mourned the loss of the future I had planned.

For the first time in my life, I had physical difficulties that would limit my ability to do what I wanted to do. And for the first time, I started expressing my anger and sense of loss in passive aggressive ways.

Today has not been a good day. I woke up to another bowl of that damn green Jell-O for breakfast. But even worse was that I couldn’t swallow it any better than I couldn’t swallow it yesterday. I’m not sure why I reacted as I did. I threw the bowl across the room, trying to scream and of course couldn’t. I feel so bad. My mom walked in just as I was having my tantrum. The look on her face showed me that she knew things were pretty bad. I’m not myself, or at least how I used to be.

Personal journal entry, February 13, 1985

The issue of control was central to almost all of the routines. My actions were monitored as closely as the information I received. I was concerned that the only information the doctors were receiving was the three time’s daily “vitals” and what the equipment that I was coupled to disclosed. I started looking at the EKG charts as lie detectors, revealing the “inner” me that I tried to mask with claims of feeling OK.
When I woke up a few days after surgery, I had to buzz for someone to disconnect me from the restraints that made it impossible for me to leave my bed. My caretaker waited for me at the bathroom door, wanting to know if I was OK after about a minute. Measuring intake and output was an order I had not gotten use to yet. We clumsily made our way around the tubes and hoses that remind me of the balls and chains used on prisoners. Once again strategically positioned, my breakfast of cold oatmeal, warm orange juice, and runny eggs was pushed in front of me.

*I can’t understand why I’m being served food when I can’t swallow. And I told several, during those several “histories,” that eggs gave me migraines. I didn’t eat, and it was taken away. Dr. Nightpound came in this morning after the food was taken away and told me he would release me only when I started swallowing. I wanted to scream. Here he was accusing me that I was intentionally not swallowing. What made it worse was that I couldn’t scream. I panicked thinking that I will never be able to scream again. Or for that matter, talk again. Aren’t too many places where your “release” is dependent on something you do or not do. Only in prisons and hospitals. And I am beginning to think there is little difference.

Personal journal entry, February 10, 1985

This feeling of lost control was humiliating. People only lose control when they are weak, when they can’t determine right from wrong, when they’re just not bright enough to make the best decisions for themselves. It’s a primitive need to at least have the fantasy of control. By some quirk of fate I was in the role of a patient with my social reality expressed in the records and histories written by “professionals.”

I was described by the most superficial of traits; inferences made from very little personal information. The information they needed to know was taken from these records. They yielded the power to make decisions about me from the records; and with the records edited very heavily so that “I” exhibited the symptoms to meet their diagnosis. They did not reflect the Martie that was scared to death of not talking again, who was overwhelmed with the notion that she would not teach, who faced her future with such uncertainty that she was not so certain she could do it.

*The first thing I do each morning is quiz myself. What is the date? Who is the president? What did my mom wear yesterday when she visited me? What is 2 + 2? So far, I have known the answers, but I get nervous anticipating the day when I won’t. If I can’t answer these questions, how can I make everyday decisions?

Personal journal entry, February 11, 1985
Hospital. A fellow prisoner!

The best thing about being released from intensive care was that I finally got a roommate. Actually, Linda was my third. My first one died before we could even begin the relationship, my second one "Liz" was crazy and had to be admitted to SEVENTH FLOOR (the psychiatric ward).

But Linda seemed OK. The first night we talked all night. She talked and I whispered about how we found out, how we reacted when we found out, and all of our aches and pains. We tried to out do each other with pain tales. Who was more afflicted? Who could garner the most sympathy from the doctors? We had only just met but we had an unexplainable bond, a connection that drew us to each other.

My journal entry for February 12:

Finally, someone to understand!

With Linda, I was not embarrassed about my weak and strained voice. With her, I could be brutally honest about my feelings. I did not have to be strong, pretend everything was OK when, in reality, my world seemed to be crashing all around me. But even though we had spent two weeks together in the cramped, shared space of the hospital room, in spite of the disclosures made to each other and the intimacy of our relationship, I knew that once either one of us was "released" we would never see each other again. I realized that in order for me to get better I needed the connection to other patients who could relate on a level that no one else seemed to be able to do.

Connecting with my doctors and nurses was another story. Answers to my questions seemed elusive, the trend in their responses resolutely discomfiting. True to their customary roles, I felt them treating me as nothing more than a sick person at their mercy to get better. I began to see my body as their information source. The physical pain was overwhelming and I found my primary goal was to lessen that pain.

I felt that my only hope of lessening the pain was to turn control of my body over to them. This obviated my need to engage in information gathering. I felt little more than an object to be inspected every four hours by a convention that had become second nature. I had not had time to get use to the physical changes from the tumors or surgery, and was certainly not being encouraged to work on the emotional bewilderment.
It was as though the only time my doctors or nurses spoke to me was to give me orders so that they could inspect, stick or pound another piece of me. The immediacy of "we" as in 'Sooner or later' we will be up and running,' made me angry and determined to break away from their hold sooner rather than later. The question of "How are you doing?" became as meaningful as saying hello to a stranger passing you on the street. Rather than my verbal response, my vital signs answered the question and then I was left alone.

I am anxious to get home. I have reached my goal of walking to the nurses' station and now I want to walk to my front door. Dr. L cautions me that I should wait another week. By that time I should be swallowing, talking and will be much stronger physically. But I am determined to leave and am begrudgingly granted what I want. As I leave, Dr. N says he'll see me tomorrow, back in what I have been calling "This god forsaken place," but I just laugh, although thinking inside "I'll show him!" Sometime after midnight, I am back, and sure enough in the morning, I see the good doctor. I feel stupid and betrayed by my body. No one mentions my "little excursion." I admire how the doctors and nurses haven't pointed out that they were right; I was wrong. I feel as though we've entered a new phase in our uneasy relationship, easier for me to admit I do need them.

Personal journal entry, March, 1985

Home alone

I went home the second week of March, almost two months after I was admitted for what I thought was hepatitis. Dr. Nightpound had released me before I could swallow and I thought that was one small victory for me, not aware that the real struggles were just beginning.

I had spent most of the last month in the hospital believing that once I was home everything would return to the way it was before. The realization that things would never be the same threw me. Everyone's assurance that I "hadn't changed a bit" and I was "the same person" only served to make me question why they thought I would have changed.

My emergence into the "real" world, quite frankly, was a disaster. The consequences of the brain surgery were disturbing and oppressive. I had pretty much settled into a routine of silence. When I did talk I felt that most people were uncomfortable and it was easier not to have to repeat something three or four times and the person still not hearing. I had much to say, but I couldn't. I hated going out to dinner; I hated talking to my friends. I hated parties. I hated my life. I spent my life in
obsessive solitude, seeking liberation through separation. I endured under the weight of uncertainty.

I could not drive, so until 5:00 p.m. when my husband got home from work I was home alone. In addition to isolation, I was concerned about my students. I was nonproductive, which only added to my depression. I felt totally disconnected with the faculty at the university, even though I received cards and notes carrying messages of "get well," which I began to resent. As though as I was trying not to get well. I grew weary of the implication, I thought, that I was somehow slowing my recovery. I wanted my life back, at least a semblance of that other world. My world now was made up of MRIs, therapist and doctor visits, and of friends feeling uncomfortable because of my constant struggling.

I really did not realize how hard it is to talk about illness. I felt above those who were not "sophisticated" enough to talk about it. In fact, I took great pleasure in shocking friends and family with the direct, blunt talk of one who was living this illness. When asked how I was feeling, I was quick to answer in degrees of numbness, ability to eat without throwing up, and how long I could stay up on my feet without a shoulder to lean on. These were my measurements of getting well.

But my bravado fooled no one except maybe myself. My family was consistently agonizing over finding some common ground with an increasingly malcontented daughter and sister. I could not think of anything to say that they needed to hear.

It's hard to imagine feeling lonely when surrounded by everyone you love. Yet, I do. It's so emotionally wearisome, trying to remain nonchalant about the test results, which show the evil invasions in my brain. I feel pressed for time, not knowing if the present is my only future. I prioritize what I want to accomplish - the Ph.D., reading all of F. Scott Fitzgerald's books, going to Paris, getting up in the morning without a schedule to keep. Above all - be a better person, living, and believing as a Christian.

Personal journal entry. March, 1985

Though presumably exiled from my own life, I was also one of the elite who was authorized to enter the subterranean community which seemed to exist in a different world from the hospital above ground. For it was there, the technology that would inform my doctors on my physicality was kept.
The long, deserted corridors reflected an unfeeling environment that underscored the mysteries and sacredness of the brain. Following the signs visually screaming "AUTHORIZED PERSONS ONLY" I made my way to a hangar-like chamber which housed the casket which would become my home away from home.

Everything, particularly the technicians, seemed to be bathed in an incandescent mist. As I watched the technician scurry away after locking the chamber, I knew with certainty that my former life was over. The power of this technology and the intimacy for which it would have in my life was impossible to foresee; yet unsettling.

The existence of the "do-anything-I-want-when-I-want-to" life was now clearly gone. The claims this machine made about my physical state would dictate my life choices. Instead of freeing, I saw it as controlling and keeping me from the major changes in my life that I had already decided I had to make.

The technicians' demeanor belied the awfulness of the situation. Verbally applauding me for my mummy-like stillness only made this more surreal. I felt myself automatically holding my breath when the intermittent pounding of the MRI invaded the claustrophobic crypt. One push of the button would set me free for a minute, only to have to start the scan over. I willed myself to think I was in a tanning booth getting a jump-start on my "winter tan," burrowing my toes as deep as I could into the plastic pad that I lay on.

I had always believed in an ordered universe which implied an external "truth" which could be found through a systematic way of knowing. The mysteries of life would eventually be solved through searching and by following the dictums laid out by those in authority. Success in life was guaranteed if one played by the rules, and eventually rose to a position of making those rules. I could not tolerate chaos. I was confused by these occurrences which seemed to operate independently of any known rules, and upset that I would not acquire the role of "rule maker."

I'm beginning to realize the world is chaotic. events occurring without reason. My life is chaotic; no matter how much order I try to impose. I now make plans with family and friends with the unspoken qualifier, "...if I feel OK". Routines are interrupted by unexpected pain, moodiness, or financial responsibilities. Sometimes there are no reasons for things like this happening; but along with that, there is no blame. I didn't do anything to cause this and I am not being punished for things that I have done.

Personal journal entry, March 10, 1985
This notable "pattern of chaos" made it all the more important for me to gain control in some way. I had been victimized by these tumors for too long. I accepted that I had to fight this inertia just as hard as I had to fight this illness. I can't identify an instant or incident that prompted this resolve. I do know from my journal entries that I began imposing an order to my actions and a determination that I would be responsible for medical and health decisions. I looked to my doctors to explain my experiences rather than to solve my problems.

There is a routine I go through before meeting a new doctor. I sit down and write a list of my complaints, literally starting with my head down to my toes. I go over my history starting with being hospitalized in 1985, all the tests that were performed, and the subsequent surgery. Dates for MRIs, information on my strokes, descriptions of pain follow. I can talk schwannomas with the best of them. I sometimes see myself as one of those transparent overlays of the human body in medical texts. I wonder how other patients answer those questions on the "history" quiz given by the receptionists on every first day. Do the doctors even read them? How do they use that information? Guess I'm sensitive today on that issue. I saw a new doctor on my "team" and he began asking me questions about my history before realizing he was referring to another patient's history chart. Oh yeah—I am now, according to my medical I.D. band experiencing life as an oriental male.

Personal journal entry, March 15, 1985

It struck me that as I became more participatory in this medical melodrama three things were evident. One, my health care professionals were treating me differently; they asked my opinion and presented more options for treatment and pain management. Not all physicians were appreciative of this change. Unknowingly I had begun to develop criteria to use in evaluating health care professionals. If doctors were not open to the participatory role of the patient, I didn't want them on my "team." Dr. Tacky came with the top academic and professional credentials. He had graduated from Harvard medical school and had risen quickly through medical ranks to chair the neurosurgery department of a well-known medical school. I was looking forward to what I now knew to be a long-term relationship between physician and patient. I would receive the best of care, as well as the most up-to-date treatment. Instead, after one office visit Dr. Tacky and I parted ways. I was forced into being the one responsible for my medical and life decisions.
There are so many doctors and therapists. I've heard that if your illness won't kill you, your doctor will. And patients get well in spite of their doctors. That certainly proved true today. I have really been exhausted by the pain lately and Dr. Tacky decided to shoot cortisone directly in my head to decrease the swelling. Unfortunately, he did this before reading my charts, which indicate that I'm allergic to cortisone. I never thought the patient had to suggest that the doctor read the charts. Once the medication hit, I couldn't move. I was having a hard time breathing and was convinced I was dying as he was shouting "Code blue!" I just knew they would take me to the morgue so I kept trying to move my little finger so they would know I was still alive. Those few seconds seemed endless. I knew I was going to be OK when the doctor stopped pushing on my chest and when I heard him say, "...let's not tell her husband." I thought "Why? Are you afraid he'll kill you?"

Personal journal entry, May. 1985

The second change involved family and friends. They discussed my illness more objectively, with more openness and with less hesitation. Discussions were now largely centered on actively seeking information for us “to beat this thing” rather than assuring me that “it was going to be alright.” Before, when I would ask the “what ifs . . .?” that were answered with “Nothing like that is going to happen,” I was robbed of my feelings as well as the information that I needed. Now, their questions involved them in the answers.

There were the “warm fuzzies” of the strength gained from a common goal. At the same time they validated my fears and concerns which I had seen them denying before with their cliched proclamations when discussing “my problem.” I saw that by having information my role as patient was not passive, looking at healing as what the doctors do with me, rather than what doctors do to me. The energy exerted before in anger at the doctors or even the illness could now be directed toward getting well. And it was in this recognition that being “well” became the motivating force in my life.

The third major change was perhaps the most significant. I realized that active participation in information giving and getting encouraged me to stop thinking of myself as a victim and acting as one. I noticed as did my family and doctors, I began to treat myself better, both in words and behavior. I exhibited a sense of responsibility my situation. But most importantly, I saw progress in my living and hope for, and anticipation of, a better time.
It is only now, as I try to make sense of my wellness experience, that I see that this resolve to take control of my decisions developed in the process of getting well. At first, the mystery and perceived implications of brain surgery engulfed me, increasing the intensity of any decision to be made. Except for the initial information gathering in the hospital about my illness, my information needs were largely focused on emotional support from family and friends. In time, this support giving became symbiotic. Just as they had become a source of encouragement and support for me, I became the same for them.

When my mom finally left to return to Charleston, I felt as though I was losing my best friend. She had come to the hospital every day and she had inspired me in ways she couldn’t know. She doled out her love and compassion as generously as she had offered the baby food and mashed potatoes. As she drove away, I felt as though I was losing what little physical and emotional strength I had gained since the surgery. I had this awful terror that I was in this alone. Once again I saw how my illness was a communal condition affecting those close to me. This was not my illness: it was my family’s.

Traditional family get-togethers and even weekly phone calls could become emotionally exhaustive. We would speak of everyday things, but say nothing about my everyday pain. I purposively tried distancing myself to spare them these feelings. I isolated myself even more from friends. When our conversation slipped into the area of “my problem,” it became something of a cheering section. “You can do it.” or “Just keep your faith.” “Don’t think like that.” only increased my feelings of failure. “Oh, if only it would be that easy,” I said silently.

Not recognizing, perhaps selfishly so, the discord in my husband’s life, we became angry with each other and lived in a discontented marriage. It was depressing to think that we had to work so hard to make the marriage work. A very fragile relationship became even more fragile. It shattered and couldn’t be pieced back together.

I was angry at his non-attentiveness, rationalizing that he just didn’t know what to do. The anger only inflamed my other emotions—guilt, hopelessness, and even jealousy. Doctors’ appointments, friends and family visits or physical pain sabotaged what little
time we did have together. He became my chauffeur and I was his responsibility. I
failed to realize that this illness was his as much as mine, and he needed to become active
in this process of being well just as much as I did.

The anger we felt at each other was intensified by not being able to share our
feelings with others. We had no idea that this was a very normal reaction to the
circumstances now surrounding our lives. To us this was the stuff of movies and music,
not the stuff of life, certainly not our lives.

I chose to continue isolating him from my “medical problem” thinking this would
insulate this portion of my life; that he would prefer to be shielded from what I
considered to be a mess I found myself in. In reality, I really wasn’t use to talking about
what bothered me and closing him out was shutting the door on our relationship. This
insulation and his seemingly intolerable detachment compartmentalized my life, forcing
me into a dual existence. For several weeks we made stilted small talk and avoided being
alone together where we would have to talk. We began to communicate through notes,
left for one another as each tried to avoid this chasm. The remoteness of our relationship
could be traced from the paper trail of these notes.

_I really can’t understand why you think you are depressed. We need to get on
with our lives. The surgery’s a thing of the past—you’re fine, but we’re not.
The tumor is out. What’s the problem?_  
Letter from husband, April 1985

My almost daily notes from husband remind me that this was the lowest
emotional down I experienced.

_Why are you so miserable and hell-bent on making everyone around you
miserable too?_  
Note from husband (not dated)

In none of his notes did he ever tell me we could get through this. I often
wondered what it would have been like to hear those simple words. Resentment
increased and lingered for both of us.

I made my way back to the world of rules that I had followed before January
1985. I found myself in a system different from what I knew before. But the outside
world had not changed; I had. I couldn’t articulate how all of this had changed me. I just
knew that I wasn’t inwardly who I had been. From a place inside, I knew things that
others didn’t; a feeling of lost innocence only experienced by almost losing your life. My information seeking was now a matter of instinct rather than calculation. I didn’t question “why me?” but instead asked “what now?” I was startled to recognize that my life was precariously balanced; never knowing when or what would tip the scales.

It took some time for me to understand how angry I was at not being told about possible physical and emotional consequences of brain surgery. The doctors had not explained the very real chance of having a stroke until my third, immediately after surgery, paralyzed my vocal chords rendering me voiceless and unable to swallow. I wondered at the time if I could have been prepared for this impotence, or better yet, could the doctors have prevented this? I knew that the doctors minimized this “inconvenience.” but to me speaking was communicating; it was much more than my voice.

But more devastating was the depression and emotional turmoil that I was experiencing, even before going home. The feelings of my own inadequacy and failure were more intense than ever. How could I own up to these feelings when everyone was telling me I was so lucky, that I should thank God I was fine?

I would smile my crooked little smile (as my mom later described it) and nod my head in docile agreement. Each time I spoke the weak, grating voice reminded me of the emotional weakness that I lived with.

Looking Inward.

I can remember the exact moment that I knew that my mind wasn’t healing as fast as my brain. It is one of those few moments that are fully etched in my mind. I recognized that the MRIs were only showing the abrasions and swelling of my brain, not my soul, and I had to get help. I had been trying to pull my life together without my usual success. But these were the abstruse secrets that I could cover up by mimicking the rules of normalcy.

My on stage presence reflected the moods of those I was around, but I knew that was draining for them, and essentially gave my friends and family more responsibility. The few I trusted with my feelings and concerns were so ready to agree or believe me. I knew they were not listening to what I was telling them. I wanted desperately to spare my family these feelings that were causing me such pain. I no longer felt the resolve of
taking control of my life. I cringed inside when told how well I was doing. And I felt so guilty when told I should count my blessings.

I can't seem to shake this uneasiness. But now I know what it is. Today in church, I saw Dr. Nightpound singing in the choir. I can't stop thinking that he has been in my brain. I feel so foolish, yet at the same time violated. This has really made me realize how I've thought all along about brain surgery and I've got to talk to someone. Is this just me being crazy or do others think this too? It all makes sense now. The way people look at you when they find out about the surgery. They take that almost imperceptive step back and start "cliche(ing)". "Well, you certainly were lucky." NO, I'M NOT! And I'm not getting better.

Personal journal entry, May 9, 1986

But even in this darkest time, I had to laugh as I remembered George Bush's proclamation the 1980s as the decade of the brain. THE BRAIN, it holds all that you are, all you know, and everything you've done. A most sacred vessel, storing who you are and who you are going to become. It was hard for me to dismiss my obsession of the phantom-like world of thoughts and emotions, and both man and machine had physically touched mine. I hoped that my voiceless proclamation of "I don't want to live anymore" would shake me into action.

Something inside of me knew I needed to look inward for some answers, and even for questions. Each difficult moment I viewed as a revelation that brought me closer to my heart and soul. Both housed vital information about my self, information that had been shoved aside by the fear, the anger, and the confusion of not knowing.

Growing up I had imagined, as all little girls did in the non-not-politically-correct time of the 1950s, that my knight in shining armor would be my husband who would whisk me away from an ordinary life to one adventurous and problem-free. Instead, at the age of 30 I found him, in the guise of a therapist who had a cramped third floor office in an old Victorian house in Riverside California.

Reaching Out.

The path to Dr. Heap was somewhat circuitous. The Monday following the church episode I was in the waiting room to see my neurologist. Usual behavior for patients sitting alone is to intently read a year old magazine, probably one you have read on previous visits.
When I walked in the only seat available was beside a young mother with three kids. This is what all patients dread, much like sitting on an airplane by someone who wants to talk. And talk she did. After a while I really didn’t mind. Her middle son, who was 7, was seeing the doctor for his monthly checkup following brain surgery two years before. We talked about the real definition of patient (someone who has to be untiring with doctors) and then I found myself starting to talk about what had happened in church.

I had never met this woman, yet I could talk with her concerning things I was hesitant to talk about with my doctors or even family. She told me about a therapist who she and her husband were seeing for marriage counseling. His office was located in the same office building as my family doctor that I was seeing on Thursday.

I had been seeing a therapist at the hospital but his style of therapy and I just didn’t work. It was awkward for me to stop seeing him since he was in the same medical group as my neurologist. I was obedient to doctors and others who I perceived as knowing what was best for me. I was really frustrated at the role I had assumed not to cause problems for everyone else. Instead, I fell back into my habit of ignoring what made me feel uncomfortable and kept seeing him. I was actually jealous of the relationship Pat seemed to have with her therapist.

The timing of my encounter with Pat was auspicious. Yet, I did not think much more about it until Thursday when I had to wait for my appointment with Dr. Walker. I was leery of bringing yet another doctor into my world. Besides, Dr. Heap’s office was on the third floor and I knew I could not walk those stairs. While I was waiting at the desk for registration, an elevator door opened to my left. Without thinking I got on the elevator and pushed the third floor button. Seconds later I was in a poorly lit hall, standing in front of a 90 year old receptionist, and I started crying. Dr. Heap walked out and asked if he could help. Thirty minutes later I came out of his office and that dark hall seemed much brighter. I had a moment of quietness that I had not felt in months. I made an appointment for Monday, already comforted by the cloak of certitude that I had taken the first step on my road to being well.

This spontaneous act was my salvation. I wanted to be strong for me, not my parents or husband, family, or friends. It was my first step on the transitive course to
wellness. Notes included in my therapy records remind me that for the first few appointments all I did was cry. I noticed right away Dr. Heap didn’t always say what was on his mind. My journal reveals that I was angry with Dr. Heap for not making the pain go away. The emotional sadness was more real than anything else was. I anticipated each visit as the miracle that would make all problems disappear. I was disappointed and many times during those first few weeks I talked myself out of and then back in to meeting my next appointment a million times. After those first visits I would come home and try to wash away my confusion, my anger, and my despair by crying and further isolate myself from others.

I’m beginning to think that seeing Dr. Heap has just added another stop on my weekly rounds to doctors. I’m not ashamed to admit that I want someone to make decisions for me at this point. I’m also feeling a little uneasy with the direction this therapy seems to be heading. We are getting sidetracked and talking about my relationships in my family and more about my marriage. I would rather solve immediate problems than trying to piece together my whole life.

Personal journal entry. June 30, 1986

It’s ironic that my need to follow the rules and sense of guilt were really what kept me from giving up. Slowly, my journal shows I began getting better and thinking of myself as more valuable, charting my emotional growth in a self-account titled “Turning Points.” The redemption of myself, by myself was not easily attained. As therapy progressed, I switched into my information gathering state asking if my feelings about others and myself were typical.

But I then questioned what was typical? Were my thoughts about my marriage usual for someone in this situation? Was my deep-seated need for certainty healthy? I felt a disconcerted mix of courageousness and cowardliness. I spoke of my past in hushed memories.

Until now I had kept our problems a secret from family, friends, and even my doctors and therapists, thinking it was just a problem with us, especially given my husband’s reaction to the first attempt on my part to get outside help. Not wanting to add to my parents’ concern, I said nothing about our relationship. But sometimes no evidence is the strongest evidence.
Much earlier, not knowing where or whom to turn to, I began to view the relationships I had with my doctors as the most intimate, certainly the most time consuming. I disclosed the most revealing aspects of my physical being, and not having others around who seemed to understand my pain. I finally admitted to a doctor some of our problems. I felt completely alienated from a support system and needed to create a support group distinct from my family.

Dr. Nights was not considered the “best” in surgery, but he was the first to ask about my husband. Doctor Nights pointed out to me that most of my energy was spent on other family than on my husband. I was relieved, feeling as though we were going to work on this together, whatever “this” was. But my hopes were soon shattered. When he received the letter, he got angry with me for discussing our problems with Dr. Nights rather than him.

*Martie has told me some of the problems you two have been having with her medical problems. We’re not sure why this happens, but it does quite often. I know you’re going through pain that is just as real as hers. I want you to know that I’m your doctor as well as Martie’s. If I can help in any way please let me know.*

Letter to husband from Dr. Nights

Although his intentions were nothing but good, Dr. Nights’ letter showed that his approach was not. My husband’s question as to how the doctor could even think of writing him a letter without knowing “his side” was probably justified, at least in his eyes. His reaction made me recognize that he saw the equation as me + my illness + my family + his family + our friends + my doctors against him. When it dawned on me that his life was in disorder, I saw his indeterminate behavior, as in his note stating “I’m just being realistic, you’ve got to get over this,” as his way of “being strong” and he had similar fears of our future together.

The relationship with Dr. Heap was the first one that was completely my own since January 1985. He and my husband were the only ones in my life that I could say I chose for myself. I came to view those sessions as distant from my everyday existence and I shared those therapeutic 50-minute hours with no one.

These sessions were my weekly reality checks. I was in complete control in the therapy and the one who had become sidetracked in sessions was me. I made the
decisions as to what we were going to discuss and I appreciated, only afterwards, the importance of not being told what to do, something I resented in the beginning. And I started seeing that I was the one to make things better, not Dr. Heap.

The sidetrack issues that I had viewed as irrelevant were at the heart of making sense of my illness. I was acknowledging the importance of family in me getting well. As a learned attitude, the way I viewed chronic illness was embedded in the history of my own illnesses of the past. It seemed as though I had spent a lifetime fighting frailty. My past provided the passageway to my future. I deconstructed my past from evidence in the present: my spiraling dependency on others for my security, my avoidance of responsibilities and obligations, and my apathy toward my future. My therapy objective was no longer to “make better” the specific social symptoms of my illness, but rather to explore personal life issues and the possibilities of a happier and more fulfilling lifestyle.

I continued seeing Dr. Heap long after I was released from standing appointments with other doctors. Dr. Heap had asked me to consider joining a support group but I was not one to share my problems in that forum. I saw these issues as making me weak and vulnerable and the fewer that knew the better. I didn’t feel that I had the six months to invest that Dr. Heap said was usual to feel comfortable and accepted into a support group. I recognized the role of patient was a full time job and I recognized how fortunate I was to have the time and support to best play out this role.

Today, as I settled into what I now refer to as “my nest” (the huge leather chair that envelops you in Dr. Heap’s office) I couldn’t help but think of all that have claimed this territory as their own. We have all contributed to the history of this room, with the secrets shared with Dr. Heap. The comfort of familiarity nestles me. The chair whispers the illnesses of all its occupants. Does this stead give us the courage and strength to face our demons? Is it here that one begins to see a future, a light at the long, dark, tunnel that looms ahead?

Personal journal entry. August 20, 1986

In September of 1985, I won another small victory. I had convinced the ENT doctors to inject my paralyzed vocal chords with liquid Teflon. This was still an experimental procedure and had previously only been administered a full year after paralysis. Even with the injections a patient, at best, was expected to regain not more than 40% to 50% vocalic correction. On September 16 I called my parents and spoke to
them semi-audibly for the first time in over nine months. The doctors had told me not to try my “new” voice for 24 hours. Needless to say, I spoke immediately after the injections to my husband. Although my voice would gradually weaken through the day, I could start the morning with an 80% stronger voice than I had had for nine months. My oral voice was symbolic of the voice I expressed as I grew in self-acceptance and independence.

I gradually decreased the time I spent with Dr. Heap. I did, however, have one piece of unfinished business for which I needed his support. My journal entry for February 17, 1987 explains.

_I have not been truthful with Dr. Heap. He comments on how edgy I seem and asks if there is something I need to talk about. After denying there is, and feeling as though he can see through my hedging, I finally, through tears, relate the reoccurring nightmare. In my dream, I’m very young, coming home after school. I run the steep trail, through the old graveyard and spend time playing in the tower field with Connie and Melinda. Leaving each friend at her house, I walk the last quarter mile alone. I go into my house and pass both my younger brother and older sister who are stone figures. I run up the stairs to the top floor and yell for my mom and dad. I can’t find them and think they’re playing hide and seek. I go through each room, looking under the beds and in the closets. I find both of them in separate closets in their room dead. I freeze. And then I wake in tears. I have had this dream for three weeks and each time it seems to take me longer to wake up._

Personal journal entry, February 17, 1987

Although I had been seeing Dr. Heap for over nine months, we had never discussed death and dying. There was no need for him to explain my dream. I had not told anyone of this nightmare, feeling that in some way just by telling it, it may come true. But just to hear my voice describing it was healing. As with so many of my fears and anxieties, I wondered if this was normal. But normal for whom? Just who was my reference group? Dr. Heap hesitantly suggested joining the support group again, assured of my response. We talked more and I concluded there was only one thing to do. As soon as I got home, I made reservations to fly to Charleston. The nine-hour flight seemed an eternity, yet when the plane taxied to the gate the travel time seemed much too short.

Every time I had the nerve to approach my parents, there was always some interruption. We finally ended up at the kitchen table alone where we had celebrated so many birthdays and holidays. I cautiously broached the issue. I remember the silence
after I blurted out “If I died where would I be buried?” I can’t remember the answer or the ensuing discussion, but I did not have that dream again and my soul seemed to settle down. We all know that we are going to die, but graciously we seldom contemplate this. As with death, so many of my fears and anxieties could not be explained, and could not be discussed, even in the secluded and secure womb of Dr. Heap’s office.

Reaching In.

After a year, I was strong and confident enough to end the therapy. This time there was nothing awkward about terminating the therapy and I left with an enjoyment for living that I had not felt for so long. By the spring of 1988, I was making small strides in volunteering to work with oncological patients and their families.

This was one of the most significant aspects of my life, yet inconvenient. I had gone back to teaching and did not have the luxury of time required to meet when and where I was needed. But the rewards were so great that I did my best in eking out time from a daily schedule that included a full time teaching position at the university, three contract teaching positions at a community college and taking classes for an Ed.D.

I never thought a year ago that I would be enjoying my life so much. What an appropriate feeling for this time of year. I have such a revivification and an appreciation, which helps me to help others. I finally feel as though I can comfort others who may be in the winter of their life. I know I now have a healthy dependability on others, a renewed spirituality in my way of living.

Personal journal entry, April 24, 1988

Looking back it appeared that I had crammed each day with work and obligations, perhaps trying to make up the lost time I felt this illness had robbed me of. But an unexpected reward was the strength I gained from this activity. Once I had accepted this responsibility in getting well things changed. I recognized that being a patient was not a role separate from being a wife, teacher, student, or family member. The patient part of me fused with all others, changing my self-identity. The “patient” was no longer fighting with the others. My illness was not my identity, but integrated in my identity. Once the inner conflict waned, others seemed more comfortable with me. I realized that it was not my illness that made them uncomfortable, but rather it was their uncertainty of my feelings about the illness. And though I was living my life differently, I was living.
This acceptance was not achieved overnight. It was a long, arduous course, my appreciation an even much slower process. The acceptance that I felt in the hospital was necessary but in no way was it complete. It was important for that moment and I see it now as a tactic to gain some control in an inextricable situation. And this path to wellness resembled a bumper car game rather than the romanticized view of a long, slow journey. I was in that bumper car daily for the next three years, stalling and colliding at almost every turn with frequent pit stops. But I was the driver rather than a passenger. I came to view my family, friends, doctors, nurses, and therapists as co-pilots, recommending, but never taking full control.

Here We Go Again.

In August of 1989, my yearly MRI showed more tumors. The doctor had called my husband at his office before telling me. He then called me, and even though I had heard this before I still felt the same queasiness and lightheadedness as in 1985. This time, however, there was a new twist. These tumors were literally twisted closer to my spine. As the doctor spoke I kept thinking, “How odd to tell me this over the phone. I must be imagining this.” The words seemed to come from afar.

As much as I resented this impersonal communication, he was telling me something I already knew. Pain and anger that seemed incidental and slight at the time seemed circumspect now. Our lives had once again been touched by an unknowable horror and although this fear had a ring of familiarity, I felt exhausted before the fight had begun.

The news took my breath away and at the same time sent shudders down to my southern soul. The clock, sounding so loud, ticked away the seconds and the obvious analogy came to mind. I wanted my head to ache just to know I had feeling. I thought about everyone saying how lucky I had been; surely, a second chance at living was all you could be given. I hadn’t been good enough, had not gone to church enough, and had not kept all those promises we make in the middle of dark, lonely nights. There seemed to be an urgency to decide something but I didn’t know what. I felt as if I didn’t do things now they would never get done, but I couldn’t focus on what to do.
The harder I would try to think of details of my first intrusion, feelings, rather than facts flooded my mind. All the progress I had made was for nothing. I could feel my body, as well as my mind react to the putridness of this news. I saw my world being reduced, once again, to pain and incertitude. I called my husband and told him I was fine, not to come home; I needed some time to myself. Of course, he didn’t come home. And I finally cried.

*It’s hard to imagine that just this morning the tumors were the last thing on my mind. And then Dr. Nightpound’s phone call changed my world. I’ve been thinking how all this has sapped my strength, interrupted my living, and I don’t know the cause of it. I guess this is my fate in life—continually facing uncertainty, having to use so much energy to deal with this that it will eat away all the other parts of my life.*

Personal journal entry, August 21, 1989

For the next few days, I seemed to coast through living, almost ashamed of this physical weakness and even more embarrassed of the emotional weakness. I had adopted a patent response to questions of how I was doing with an assurance of being stronger, having met the challenges thrown my way since 1985. But now, it was though I was caught between two worlds, in limbo, waiting for my illness to choose my next move. The tensions between the feeling of hopelessness and assuring everyone I was fine became unbearable: my disorientation was palpable, if not to others, certainly to me.

*It’s as though I’ve been deceiving everyone—including myself with this “I’ve-learned-so-much” attitude. I’ve been operating by two opposite principles; the first surgery I had to go through was just to be safe, but at the same time, the odds at surviving the surgery were against me. The worst feeling is that I’m afraid to hope for a future. I can’t dream until I get out of this nightmare. I was given a second chance, but will I be given a third?*

Personal journal entry, August 24, 1989

Once again, my somewhat ordered life was thrown into turmoil. I didn’t want to face the drama of telling everyone and so I continued outwardly to live my life as before as much as I could. Gambling with my life was something I wasn’t ready to face again.

The deck was stacked against me. Inwardly, I was fighting my own anxiety and fear. Friends and family alike tried to console and encourage with observations of this kind, “This will probably be the last time.” or “Well, we knew these tumors usually come back,” all well-meaning but unenlightened as to the effect of such reflection. I had no
I didn't ask them. All were accommodating and favorable, perhaps too accommodating and too favorable.

I was so tired of this existence. I longed for the days when my headaches were migraines – or at least I thought they were. While waiting for test results before I planned my immediate future, I lingered in the past, thinking that if I had only known, I could have somehow prepared, or better yet, made different choices. The only language that meant anything was that of doctors, tests, treatments, and medical terms. My life was measured by the cadence of disease. I had become what I had resisted all along – my illness. I recognized the illusory reality in which I was living. My illness became my frame of reference for my identity. Forced to work around an undeniable illness, I felt it was time to uproot this physical and emotional scourge as the ruling factor of my life.

When I was younger and asked what I wanted to be when I grew up I immediately answered, “Davey Crockett.” But as I came to grasp reality outside of me, I knew I couldn’t; I wasn’t a boy and I didn’t have a horse. Answers seemed so concrete back then, either I was or I wasn’t. I had or I didn’t have. Now, I’m feeling as though I am starting all over, grasping a different reality, a reality without a history. I have to admit I don’t think in terms of when I grow up. Instead I live day to day.

Personal journal entry, September 17, 1989

Struggling to find some direction, I decided that it was time to start practicing what I had been teaching in my communication classes—the understanding of self through written accounts. From my 1985 journal, I read Dr. Nightpound’s mention of the progress that had been made in neurosurgery since 1980.

I realized then that to have any control of what my next year would be, I needed to know all I could. I drew strength from a line on a get well card someone had sent me that I had taped to my refrigerator, “knowledge is hope.” Anxious to get any information to help me, and not having any instruction on where to turn, I started watching a university physiology class on cable TV and went back to volunteering at the hospital. This time, however, I wanted to learn from the other patients and in some way, it seemed important just to connect with them. Whereas before I asked questions to be informed, I was now using information to make decisions. I no longer felt as though I had to fight these tumors, but rather find a way to peacefully co-exist with them.
I cut the number of doctors on my “team” from five to two. I did my “homework” before my appointments, researching the tests that I had had, and optional available treatments. No more shots of cortisone in my head, no more hours of voice therapy that only resulted in the doctor suggesting “just a couple of more tries.” Although I lived and worked close to several medical libraries, the research was time consuming and I often had to choose which part of my life would have my attention and time.

Materials in books were dated and the medical journal articles intimidated me. I found them hard to understand and relate to my illness. I noticed that the voice of the journals was as sterile and objective as some of the doctors I had to deal with. I wanted more than a medical conceptualization of my illness.

I became a frequent attendee at lectures and presentations at the medical school and talked to health professional friends, approaching as a friend rather than a patient. I was surprised at the interest of students and colleagues when they found out about my illness. Speaking to pre-med students on health communication, I found them to be much more involved and interested in my own experiences rather than the “objective” research.

I discovered the more I told my story, the more insight I gained. I had to be careful to not bring it up in conversation; I was so hungry for information, especially from the medical community, that it was easy for me to focus almost exclusively on my illness. Although I had heard positive experiences from participation in support groups, I still could not attend. My misgivings were probably a reflection of low self esteem but I continued to regard the groups as a combination of complainers or patients who had become obsessed with their illness.

I approached the study of my illness subjectively, taking ownership of it. Although research was tedious, I found the more I knew of brain tumors and available treatments, the more I participated with doctors, which gave me a sense of control. With this participation, there was a strange sort of emancipation. I took it as a compliment when I heard a doctor tell his receptionist, “Make Martie’s next appointment for 45 minutes so we can have time to talk.” In one of those rare insightful moments that all of
us have experienced, I understood that anytime the word “brain” and “surgery” are used together in a sentence anyone would be afraid, and to not be afraid of the feeling.

All this time I had to juggle my marriage, career, friendships, and family and all four suffered. I took advantage of being “ill” and then got angry when people responded to me as “ill.” I was acting out a societal sanctioned martyrdom which many times took advantage of my circumstance. I received notes and articles from newspapers and magazines from “friend of a friend” people I did not know. More often then not my family would pass along information from their beauticians, doctors, friends, and even my sister’s secretary. *National Geographic* published an issue dedicated to the mysteries of the brain. I was a celebrity in my circle, being the only one to undergo MRIs, which was the “big breakthrough” in brain surgery *National Geographic* touted. I received five copies of this publication, from five well-meaning friends and family members. I could not escape this illness, even if I wanted to.

**Psychological Cleansing.**

One of the roughest parts of the ride was my divorce in 1991. In a strange way my illness had brought us closer, yet was the primary contribution to our breakup. I can remember thinking that we had weathered the storm when I ended therapy. But I had achieved a sense of independence and a desire for major lifestyle changes that were quite different from my life before surgery.

Beyond love and hate lies apathy. I’m unsure which came first, the apathy toward our relationship or my determination to make these changes with or without him. I saw him as being very angry about my illness, concerned only in how it was affecting his life. He had little interest in what I was finding out from others and my search, and along with offering little emotional support, blamed me for interrupting a lifestyle that he had defined. He seemed to dismiss the seriousness of brain tumors, equating my illness with nothing more than tonsillitis.

It seemed as though every decision I made concerning my illness produced incessant tensions. I hid my fears in the long periods of silence. It was a silence I knew well. I was saddened by thought of failing in the relationship, but recognized that I, at
least, was very different from the person I was nine years previously, and I just wanted to get on with my life. I was determined not to live a life of uneasiness.

*I want to be there for you, but for some reason, I just can't seem to help. For seven years, I have been hoping to get back that life we had, but I know now that we can't. I've tried to understand you, to help in anyway I could, but you won't let me. I'm not sure what you want or what you need. Your life isn't the only one that has changed. I'm strong enough to face that it's over, but will always wonder how and why we let this happen.*

Letter from ex-husband received during separation, June 1991

What happened was that we just stop talking to each other – verbally and emotionally. By this time, I was struggling with the decision to end our marriage. Not remarkably, my disillusion with the marriage produced immediate and immutable stresses. My divorce was certainly not the footnote that I have presented here, but I now look at it as the psychological cleansing I needed to move toward wellness representing another token on this continual trek: a catalyst to the slow changes I was making in my life.

I look at our divorce probably different from most. I see it as a victory. This victory came at a price. However, without the divorce, I would not be where I am today, even if all other parts of the picture played out. My ex-husband played a critical role in what I now see as my culture of wellness for having traveled along side me those five rough years. With the divorce, my husband paid the price for what he didn’t do and neglected to do. The divorce became symbolic as the last tie to the life that I now needed to change.

**The coming of age.**

As I look back at these events it becomes apparent that underlying the pursuit of the new vision for my life was the search for information to reduce uncertainty, for negotiating meaning and for decision making. This fragment of my life experience is the predominant influence on my collective life. The way I lived my life and what I thought of myself before the illness shaped this single most defining landmark for my past as well as my future. I realized that there was more to me than what I had taken credit for and the question became what type of life did I want for myself?
When this all began in January 1985, I wasn’t happy with the way I was living. I had more or less settled for what now seemed to me a mediocre life. In the center of a life that many friends were envious of, I felt distressed. My life was active, but seemed empty, negligible, and wasted. Life had seldom been unkind to me. The news of my brain tumors came as a deterrent in thinking about what changes I should make. I had separated my physical life from my emotional and spiritual life. I had lost enthusiasm for all three and had passively accepted this as my lot in life. There was no emotional fabric; I was facing the end of my life with regret.

So, my illness was really a rebirth of my soul. I had somehow perfected the need to please everyone else. Now I would not be viewed self-indulgent if I concentrated on just myself for awhile. After the shock of hearing of my illness, this seemed almost a reprieve. I began to notice that even though the physical pain at times would be splintering, if I knew the reason for it, it became more bearable. I approached my emotional pain similarly; I began to understand the spiritual and emotional aspects of chronic physical illness.

By 1992, I had seemed to make peace with the tumors. They had settled into a dormant existence, interrupting my days very seldom. But every headache, each moment of lightheadedness, even the times when my legs prickled from falling asleep, sobered me. Every so often the pain would get so bad that I would go to my family doctor (I had really had enough of neurosurgeons for a lifetime) and be comforted by his insistence that nothing was wrong. The diagnosis of migraine was a relief. To live life with an infrequent migraine was a withdrawal from a protracted battle that had shadowed me for too long.

Though living essentially “tumor-interference” free, I occasionally received information from family about brain tumor management. I was managing just fine, thank you. Out of sight, out of mind – literally. I talked very little about my experiences and when I did, it was in the context of the effects of illness on family and relationships in interpersonal classes. One of my students could relate. He had recently undergone a new procedure for brain surgery. He talked about his experiences in his introduction to the
class; there was an unexplainable and unspoken bond between us. His experiences were so like mine.

Convincing myself I wanted to know more just for interest sake, I began quizzing Carl about this procedure. It was incredible to think that brain tumors could be eradicated completely with the Gamma-knife procedure practiced at the University of Virginia, without invasive surgery. I asked Carl to bring in pictures of his treatment and remember thinking how foolish he looked in his helmet. Throughout the quarter he would stay after class and give me more information on the procedure, lack of pain, but most importantly a return to his life within a couple of weeks.

Concurrently, my father was learning about the availability of this new procedure. He sent me medical articles and professional information on the Gamma-knife “wonder,” but it was Carl’s personal experience that gave me hope that I may not have to have more invasive surgery. Without realizing, I elected to value the voice of Carl over that of the medical “authorities.” Intuitively I knew I would need this information in the future.

That future was not a long time coming. When I thought I was facing another surgery in 1993, I traveled to the University of California, Irvine to see Dr. Lee, who was known to recommend the gamma-knife procedure treatment. Although I was experiencing tremendous headaches, Dr. Lee did not agree with my foregone conclusion that I needed surgery. I was amazed that he chose the MRI pictures over my chronicled chronic pain I relayed. I began feeling as uneasy as I felt he did as I tried to share the information I had garnered from studying and from Carl, but it appeared to me that he wasn’t particularly concerned with what I was telling him. I felt foolish for even making the appointment and left thinking I was exaggerating the pain. Once I had considered that I was the expert, after all, he did not have brain tumors, I concluded he had not passed the “patient-first test.” One more doctor crossed off my list.

One can never go home again

Nineteen ninety-five looked promising as the year to finally get on with my life. I had been reluctant of starting things I could not finish. I dared even to imagine finishing the Ph.D. Buoyed by the neurosurgeons’ contention that my pain was not caused by my brain tumors, I arranged to return to Ohio State University to finally complete my
doctorate degree. The commitment was for three years, but I had no reason not to do it; I was assured over and over that I did not have to have surgery and that my life was now, probably, surgery-free.

In the late seventies, when I was living in Columbus, many years before “surfing” meant something other than a sport, a long time before “chat” was associated with “rooms,” everyone was talking about television shows and banks that interacted with consumers. Shades of the 1940’s skepticism of television were voiced. “This is just a fad.” I sat on the sidelines listening, but never experiencing, interested, but not involved. During the mid 1980s, the university where I taught gave each faculty member a computer. Allotments were made over a three-year period, the year of the gift determined by the luck of the draw in a lottery. I was the last one chosen to receive the $2,000.00 the first year. I bought the best I could, but rarely used it.

Before I returned to Ohio State for graduate school in 1995, I used information technologies for little more than e-mail. In fact, the first e-mail I sent was to the graduate secretary at Ohio State when I knew I had been accepted. From the first day of class, I was overwhelmed by what looked to me as a compulsive, boarding on obsessive, use of information technologies for education. The first class I took in graduate school, “New Information Technologies” required me to quickly jump on the “information superhighway.” Actually instead of jumping, I felt pushed, almost resenting this “new education.” Just another requirement I would never use.

I formed a love-hate relationship with this technology, on one hand admiring the efficiency, on the other, thinking that technology had little importance for human communication. By September, the use of the World Wide Web and Internet for information was routine. It had taken some time to feel comfortable using information technologies. I did recognize, from classes and independent reading, the implications for human communication theoretically, but my primary use was for practical, factual information gathering.

My appreciation of information technologies and personal use for creative and communicative purposes was an example of just-in-time learning. For a project in a required technology class, I chose to design an application for distance learning.
Unfortunately, or so it seemed at the time. I also chose a group of students who was more limited in their use of technology than I was. Three days before the project was to be presented the group had nothing. On Sunday, I began searching the web for presentational ideas. Within two hours, I had conceptually designed the project. At 10:00 am the next day, I presented a nearly completed project to my group. I had, inexplicably, moved a little closer to the “love” side on the love-hate continuum. I had no idea how this would affect my life in other ways besides education.

Here we go again II

The immutable use of information technologies in my academic world naturally led to the Internet and World Wide Web as my primary information source for what I tried to keep separate – my health world. Once again, on June 13, 1996 my forty-third birthday, a MRI dictated my life choices. The news had unfortunately lost its shock value for me. Traces of time and real life, of guilt and of triumph tempered this time. But again it was time for me to take serious stock of what I had and had not done with my life.

Even before the “official” declaration that I had to have more brain surgery in September 1996, I had started an information excursion on the World Wide Web. My first primary use of this information in decision making was to develop a “physician profile” to guide in my search for a neurosurgeon in Columbus. I used the downloaded information to prioritize my needs in a physician and to develop questions on the treatment options and services available.

After calling my family doctor in California, and speaking with other physicians in Columbus, I made appointments with three potential choices. I viewed these appointments as interviews. Dr. Dullard was the second neurosurgeon, and before we ended the “interview,” she was my choice. Armed with web-vocabulary I grilled her about surgical techniques, possible problems, and probability of paralysis. She responded to the questions with my memorized answers and I thought that she was the one. But it was her question to me, when I was leaving that cinched it. “Martie,” she said, “Don’t you want to know if I’ll shave your head?” She knew the human fears, the thoughts that could sometimes keep you up all night.
I had been monitoring the progressive frequency and intensity of what I knew to be "tumor" headaches. I braced myself for the familiar diagnosis. The results of the MRI Dr. Dullard ordered confirmed what I suspected. Did I dare have the audacity of arrogance, presumptuousness, the innocence, or ignorance, that things were going to be the same as in 1985? The thought that things may not be the same upgraded my peripheral seeking for information on my health situation to primary. I knew from experience that I needed more than information about the brain tumors. I needed information concerning my emotional survival as well as my physical survival.

When I was told that I would have to have more surgery in 1996, my first thought was "I told you so," directed to the three neurosurgeons who chose the information from the MRI films rather than me that led to their conclusions. But soon I felt the initial numbness that was all too familiar. The news was more dismal couched in the concern that once again my education was going to be interrupted. It was as if I had had some control, if there was a problem that could be resolved, I could accept it with some degree of resilience. I had a repertoire of experiences to lessen the uncertainty I was facing once again. I called my folks tonight to tell them about the surgery. I have spent the day dismissing it as "a great chance to collect data" and I tried that on my dad. But he saw through it and asked if he and my mom should come to Columbus. I said no, keeping what I thought strength, but afraid I was testing the limits of what I was worth.

Personal journal entry, June 14, 1996

I had been given a reprieve, a stay of execution for three months. Certain that the tumors would not leave on their own volition, I waged a silent war, empowered by newer ammunition. I had lived on the edge for ten years, dreading this moment, when I once again become a number, lying in numbered bed, in a numbered room.

The game was coming to an end, and I was determined more than ever to be the winner. No more waiting, wondering when I have to give up freedom of choice to do what I want. Out of sympathy, many pointed out that this had not come at such a good time, with the end of graduate school in sight. As if there could be a good time for this.

My idea of what information was and my sources for information had changed. I realized that my role expectations of patient and doctor were altered. Most surprising, however, was my realization that the context of "being ill" had dramatically changed, in large part, by my usage of information technologies. The role of information technologies in my illness experience was ironic – the medical technologies taking away
my options, and communication technologies giving me more choice in how I would deal with this most unfair sentence.

\textit{Reaching out II}

But that didn’t make it any easier. I felt a gnawing, nagging feeling that I had very little time to learn all that was out there to know. Just having the information available increased what as I saw as my responsibility in making sure Dr. Dullard knew all of her options.

Though a frequent user of the Internet, I limited using it as an information resource – web sites and manuscripts substituting for other printed material. The ease and convenience of accessing web sites through browsers or published URLs prompted my initial information search on the Internet. I mostly visited URLs listed in other literature I had read or had even seen on television. I was still exhibiting the “download” syndrome – printing every bit of information that seemed to have something, anything, to do with brain tumors. I began logging these experiences in my journal entries.

\textit{It’s 10:00 p.m. and after two hours of webbing I have had to force myself to stop so I can get other schoolwork done. I was hoping that I would find the disorientation and dizziness I have been experiencing could be caused by something other than tumors. But from what I’ve read tonight, I don’t think that’s the case.}\hspace{1cm} Personal journal entry. June 22, 1996

While upset by the thought of once again having my time and energy diverted from school, when I thought about the situation I realized that I was armed with information and experience which I would use to interpret information. Just by having the availability and accessibility of information, I felt a responsibility. I knew more about schwannoma tumors and about myself, and as a result could be more actively involved in this experience from the beginning.

Nightly, I categorized the stacks of computer paper, hoping that one would hold the answers to my questions. From my random collection of information, four categories of information “type” evolved. There was information about brain tumors, specifically schwannomas. I collected information on living with chronic illness. The effect of chronic illness on family and available treatment for brain tumors each developed in to a substantial category. There came a point when I started to accumulate more information.
than I knew what to do with. There seemed to be a blur of information and as I collected more I got very frustrated. There was so much information. This frustration forced me to be more discretionary in what information I deemed worthy of downloading.

At first I was impressed with the designation of "award-winning web site" until I realized that practically every web site claimed this, and that the award was granted not for the quality of information, but the design of the site. As I became more selective, my information search became more goal-directed. I was purpose driven, not merely accumulating information in quantity, but quality. I had moved beyond merely information gathering; I needed to do something with this information.

I made a real effort today to weed through my bookmarks so the number is more manageable and more relevant to what I need. In this short time, I've bookmarked over 130 sites. I deleted 73 and now include only those web locations, which are updated continuously. I feel as though I've cleared away some of the haze that was created by all of that information. I feel there's a real method to my madness – I'm starting to see some direction and purpose in my information quest. It's as though I've moved from information to knowledge seeking. I bookmarked all that stuff because I was afraid I would need to look it up sometime. But I don't need to. I'm comfortable in knowing what I know and ready to move on.

Personal journal entry, July 2, 1996

I began to critically evaluate the information from the Net. Whereas before I almost automatically clicked the print icon when the words "brain tumor" appeared on the screen, I began applying some criteria to determine credibility. I found that the criteria for credibility that I had been teaching my communication students for years, was useful for this assessment. Just one more instance of a "real world" experience that I had always insisted my students consider. I humbly realized that I had not been practicing what I preached.

The Internet did only give me access to web sites. Even more important to my objective of active information gathering at this time, was the entrée it provided to the Library of Congress, and sites such as the Mayo Clinic and the Cleveland Hospital.

Up to this time, I considered myself conservative in my use of the Internet. I was not using the Internet as an interactive resource, but merely as a text resource. The most sophisticated use for me was clicking on the hyperlink link icons on web pages. For all I
was gaining from the web sites. I knew there could be more. As long as I was actively seeking information I was strong, I felt in control. Yet at night I was kept from sleeping by the thought of unfinished business. Perhaps, I thought, if I had chosen a different “linking” path I would have the answers, or at least the information that would help me get well. I was drowning in information and I didn’t sense any lifeguards.

It was around this time that Thom and I began seriously talking about my dissertation, discussing focus and design issues. Naturally, the discussion also centered on choosing my committee. Perhaps to compliment the qualitative nature of the research questions I had been proposing, I felt it necessary to work with faculty who represented both qualitative and quantitative research orientations.

Luckily, the faculty I wanted to work with were intellectually inquisitive, and I knew would be supportive and competent to direct my research design and implementation. I intuitively sensed that these faculty members were willing to work collaboratively, and more importantly bring the varied areas of expertise I knew significant to the “vision” I had for this research.

The need for such a committee became even more obvious when I began feeling uneasy about studying information technologies in the context of lived experience. I realized that my uses of information technologies, and my experiences, so far, were not as grand or even similar to what I had imagined. Using information technologies for a very real problem was not the same as studying what others wrote. I seriously had thought that studying the influence of information technologies on my experience would be easy; I found myself feeling “lucky,” an explanation for my life that I had worked so hard to discount. Now it seemed that the more I used the Internet and the Web, the uneasier I felt. Truth, I realized, was not just a “click” away.

I’m really discouraged about my dissertation topic. Thom keeps telling me that I’m focusing too much on my illness instead of information. I can’t seem to separate the two. Maybe I’m too close to this. I can’t make that distinction. I had thought that this dissertation was going to be my way to really make a difference. Now I’m not so sure. I worked all this holiday weekend on trying different approaches. Thom said to give it time. Let the ideas come from the experience. It seems that the experiencing is more important than the experience.

Personal journal entry, July 5, 1996
Reaching in II

My uneasiness, I'm now convinced, was because I was merely gathering information and the more information I found, the more uncomfortable I felt. By this time, my primary resource for information was the Internet and I saw the up-to-date information as a major benefit. However, remembering my talks with Carl about the Gamma-knife and my experiences with other oncological patients, I knew that I wanted to do more than read web sites. I wanted to take advantage of the interactivity of the Internet. I had a new found respect for this attribute that I had studied. The journal articles did not do it justice.

Up to this point, I had been gathering information, that for me was simply the something said about "stuff," the words that appeared on my computer screen. I wanted participation. I wanted to put this "stuff" in a social context. Besides experiencing information overload I was intrigued by the listservs from Cleveland Hospital where one could direct questions to neurosurgeons and neurologists.

I accidentally discovered a goldmine when I was browsing through Infoseek in June. OncoLink, sponsored by the University of Pennsylvania Cancer Center, maintained a web site that automatically submitted subscriptions to Internet-wide e-mail discussion groups (listservs) which relate to cancer. The web site met my initial question of credibility, sponsorship, so I subscribed to five listservs for brain tumor patients, BRAINTMR, CANCER-L, CAREGIVINGKIDS, CARCINOID, and CAREGIVERS encouraged by the indication that I could "lurk" on the premises until I felt comfortable enough to post a question or respond to one. I was surprised at my hesitancy to get involved, not really understanding why.

This morning when I checked my e-mail I found a welcome memo from the listserv I joined last night. Along with my password came instructions. I was glad to see a reference to those who may be hesitant to jump right into questions and participation. Makes me realize I'm not the only one who feels this way. My first thought is that if these feelings are common, then I may have found others who are experiencing their illness similarly.

Personal journal entry, July 7, 1996

Along with that welcome was 194 e-mail messages, which I initially saw as exciting. I did not consider that this was only overnight for only one listserv. It didn't
take long to begin understanding the difficulty that new members had with the number of messages. I begin to notice that the primary reason a newcomer would unsubscribe was because of being overwhelmed by the unmanageable quantity of e-mail.

Messages that were perhaps dismissed too easily as “weird” or “too needy,” over time became expected. These communities are built on a foundation of needs, ones, that for some reason, could not be met by friends, families, or physicians in the everyday, face to face communities the participants live in. Relationships become intimate very quickly, and an ongoing “life” in these communities requires reciprocity.

What I have concluded is that this accelerated process is related to the type of information you share. If you think of your world being turned inside out, survival needs, a sense of security being questioned, you may start recognizing the topsy-turvy undercurrent of this existence. It is easy to “forgive” those whom, if you met face to face, you would probably ignore, especially after knowing some of their story.

The group’s electronic messages were not that different than what I had written in my journal. I did find, in fact, that as I got more involved in these communities, my journal writing tapered off. I actually began thinking of this as an electric journal, and even better, an interactive journal.

Underlying all of the information sharing and receiving, not far from the surface, was the dismal reality of illness, very serious illness that had in fact brought us all together. Robin, who functioned as the “official welcomer” began her welcome message with a line that held our collective thought: “Welcome to the list I wish none of us had to be on.”

There was very seldom a day that I was not a little better for having participated in the electronic communities. That may have been because of some phrase, or an experience someone related. These words, at times were as profound as those of the “great philosophers,” who were distanced from the things they wrote by inexperience.

Instead of feeling jealous over others’ new cars or houses, jealousy was now over MRIs, Brain Scans, or a glimpse of the future that many dared not contemplate. I found myself congratulating others who seemed to have been “spared” the potential awfulness of these problems.
When I first started using the listservs and discussion groups, I primarily focused on issues such as treatments, doctors, and support. It was a natural extension for me to think about my family members and friends that I knew had been affected by this unhealthiness. All I had to do was review my journals and remember that this illness was not just mine.

These events that had so drastically changed my life certainly affected and changed the lives of family members and friends. Until now I had dismissed this as something unique to my family, and actually felt stabs of guilt when I felt they were overwhelmed, or at least changing their lives to cope and deal with this. The topics discussed and the issues that were constantly cropping up in the listservs assured me that "family ownership" was a common occurrence.

There seemed to be an irresistible pull, a surge of energy once I made that connection to the "netters." Where did this energy come from? Looking back, I have to say that technically it was from knowing that every computer that was connected to the Internet was continuously banded – the pressing of a few keys could connect me to anyone connected to the Internet. But the energy I felt within came from finding those who defined "normal" for me.

The initial encounter of a "peer group" was, and still is, like opening an unexpected present, the excitement of not knowing exactly what you are going to find. I felt heartened by a newfound exhilaration from this literal and figurative electricity.

I sit in the dark after my computer blinked off. I am able to be alone with my thoughts. My mind has so many things to think about, and now I start to put them together. As I stare at the darkened screen in front of me, those disjointed thoughts in my head are starting to take shape. I am in no way even close to understanding, or even beginning to understand what was going to happen. But I know the connections I made tonight are going to play an important part in whatever that was.

Personal journal entry, July 8, 1996

My trek into the use of the Internet as what I now consider communicative rather than informative was inspired, not only by my knowledge of what was available on the web, but also by some research I had previously been involved with at Ohio State. Shortly after arriving at Ohio State, I worked for a professor who was overseeing a program that provided on-line conferences, chatrooms, and e-mail connections for
hemophiliacs. My responsibilities included categorizing e-mail messages and charting frequency of contacts for specific persons.

Now that I look back on that research, I see it lacking in the essence of humanness that is possible in information technologies. I recorded and analyzed the written text. It was not as a researcher, but instead as a participant did I begin to understand the heart and soul of this technical world. A strange marriage to be sure, but nonetheless a marriage forged between technology and humanness.

_The Internet is more than the information you receive. It is a kind of energy. On one hand, you feel so powerful, knowing you are breaking free of the temporal and spatial restrictions of before. Yet, on the other hand you feel almost a sense of humility, recognizing the Internet would be, without your participation._

\ Personal journal entry, July 10, 1996

I found there to be almost an amatory quality to this experience. This reverence, generated by participation, leads one to consider the Internet as having the potential to create the truly collective human consciousness. With information technologies, I had, for the first time, the capability to be part of that consciousness.

Participating in and on the World Wide Web is more than sitting in front of 17” screen and putting up on that screen words, which when perceived turns in to information. I felt a sense of interactivity, sense, and sensibility, even though this communication was not face to face. There were the elements of interactivity, both aesthetic and rational, even though others were not physically present.

_I'm surprised and shaken at the same time when I realize I have been thinking of the netters throughout today. They truly have become friends and along with that comes the worry, the concern, the risk and vulnerability of knowing them. I have started to look forward to our nightly encounters even though I may have to wait days for their responses. My "real world" family and friends have commented on my referencing these virtual friends. I hear an almost begrudging acknowledgement by family that the netters are providing a calmness and encouragement to my soul._

Personal journal entry, July 1996

It is not unusual for patients with chronic illnesses to describe a divided existence, living in two parallel universes, the “real” world, and their “ill” world. Much of the exhaustion and frustration comes from endless attempts of trying to connect one world to
the other and the necessity of avoiding the collusion of what usually are two contradictory worlds. It is an uphill struggle, made even more difficult when feeling that one is doing it single-handedly.

Taking the reins

My use of communication technologies in my "ill world" evolved as a practical answer to enigmatic questions as I tried to make sense of and truly understand the experience of chronic illness. Whereas cyberspace may be overwhelming and complex to other users, I experienced this milieu a calm and safe environment in which I could perhaps find answers to these questions and in some way center my life in my reality rather than that of others.

When I found myself, once again facing what before seemed impossible; I turned almost immediately to the web for connections with those who shared a similar nemesis. This was not a well-thought-out plan devised to keep current on treatment options or advances in brain surgery. And as I soon found out, not something I was pioneering. I found a certain appeal to this reasonable, direct and borderless approach to experiencing chronic illness.

I had to find a way to live my life, not sacrificing any portion as previously, yet forced to work around an undeniable exigency. Once again, I found myself straining to make sense of something that did not. The Internet gave other brain tumor patients and me a voice, which webbed us together and provided strength and encouragement. Although we responded differently to the unknown, to the grief, to a world of discomfort and indignity, we helped each other reconstruct our lives into more than mere existence.

Although none of us had met in person, and we were not even sure of the others' real names, together we wore our badges of scar tissue and head indentations proudly. There was a shared sense of humility in the recognition that we had survived a hell on earth. The Internet, for me, changed the complexion of my life, my illness, and my relationships. It has changed the architecture of my illness.

I found that forging Internet relationships on listservs (sometimes called "message boards"), and in chatrooms helpful, not as a substitute or even supplement to my
face-to-face community. The wired connections in cyberspace did not provide a way to conduct my life from behind a computer screen. Rather, these relationships fostered experiences that before would have been denied and gave me ways in which to forge my real and ill worlds better. The Internet allowed me to touch truths that are centered in illness. At the same time, my feelings had been validated, not by the author of some book, or some empirical piece making claims of “reality,” but by my peers who had fought the same battles. won the same war.

For ten years, from 1985 - 1995, fiction had given me the acceptable and expected role I was to adapt as a chronically ill patient. Media portrayed doctors and even family members of patients as understanding what was best for the patient. If a patient was hurting physically or emotionally, it was caused by the patient not trying hard enough to get “well.” The key to living, for the patient, was a “road to Damascus” edification.

Most books on health and wellness emphasized the patient as relatively sedentary, submissive, and obedient to the “experts,” creating generally accepted myths that equated illness with disability. These accounts contrived a false reality for chronically ill patients, and unfortunately perpetuated untrue “rules” for which to play the game of illness.

These experts were the “truth bearers” and, for the most part, supported the mechanistic characterization of the body, largely ignoring the spiritual and emotional dimensions of illness. In the near past doctors were the “boss.” Patients responded to that. Patients believed in that—and so did the doctors. This “accepted” past contributed to the confusion of the “patient” role that I was, by no choice of my own, forced to play.

For a long time I felt as though I had been packed into a cauldron of acceptance. afraid to digress from the prescribed behaviors, concerned about violating the expectations of others, yet feeling removed from and minimized in this very personal-made-impersonal experience of illness. Not able to pinpoint the cause of the uneasiness I was feeling I began to resent friends and family.

I was offended being viewed as one to pity, an obstacle to better living, this feeling encouraged with remarks such as “When we get over this problem . . .” Worse, I found myself identifying with these perceptions. A strange ambiguity developed. The
“experts” embodied authority, and though resenting it, I warranted it. I had no one to blame except myself.

One can never go to the same home again

I soon understood that time, living, and an underlying desire to reclaim what I had before the 1985 surgery had tempered my experience. In 1985, I had no idea what to expect. I thought in terms of “reclaiming” rather than changing. I viewed getting well as merely getting rid of the symptoms of my illness. The Internet communities provided other “role” models for me as a chronically ill patient, suggested through the experiences and knowledge of those of similar circumstance.

It seems as everyone participating in this listserv has come here in search of those who have shared the fright, the vulnerability, the uncertainty of illness. My illness seems to be as much a social experience as a physical one. It’s OK to be angry, to be confused, and to be afraid. I haven’t felt this strong since seeing Dr. Heap

Personal journal entry. July 18, 1996

The discussion groups and listservs were almost narcotic and I found myself once again overmedicating. I logged on with more groups than I could possibly participate. Instead of downloading all information that I accessed as I had before, I submitted my e-mail address to almost any group that came up in my searchers, as if the more groups I joined, the faster I’d get well.

I can’t turn my mind off. I feel chaotic, struggling to find ground, caught up in a swirl of information. Not able to make sense of any of this. I’m stumbling around these Web sites as fast as I can, thinking that it might be the very next one that will tell me how to deal with all of this. I have to face it – for all of my experience, even with my education-- I’m scared. This is just as bad as when I had no information, and certainly made worse by feeling so strong one day, the next feeling hopeless.

Personal journal entry. July 20, 1996

At first there was no sense of my contributing to the groups, I just wanted to get any information I could from the postings. Although I had become involved in these forums for what I thought was communication, I was still using the groups for information gathering. I couldn’t help but feel I was cheating, clandestinely monitoring the participants’ conversation.
The coming of age II

My first attempt in asking for information was submitting a question to a neurosurgeon at the Cleveland Hospital. Earlier that day I had noticed that I was losing feeling in my right leg. The problem got increasingly worse throughout the day and by the time I walked up my apartment steps, I had to look to place my foot on the stairs. It was six o’clock; Dr. Dullard’s office was closed. I knew the questions I would be asked at the emergency room and I just didn’t feel up to it. I sometimes worried that I exaggerated these pains and I felt embarrassed not being able to just tolerate them.

After reading my e-mail I decided to read the messages posted at the listserv’s archives. I had found that many times the postings would address some of my issues, but I found nothing about the loss of feeling. I didn’t think twice about it. I just submitted the question to the “doctor on call” and knew that the next day I would have her response.

In retrospect, there were several things that prompted me to initiate this exchange. One certainly was the temporal dimension of the information need. Dr. Tech’s office at didn’t close. There was the exhaustion and repetitiveness in seeing a new doctor at the emergency room. There was a concealed comfort in engaging in a communication that was, for me, still very rule-governed. I knew how to play the role of patient, even linguistically. And probably most important was the anonymity of the request. I wasn’t afraid of the doctor saying it’s nothing and somehow invalidating my senses. I did, however, “perfect” the wording of my submission before sending, editing and rewording the question, thoughtful that the wording of the question would reflect on the validity of the pain.

I am an oncological patient with Schwanna tumors located on the brain stem. Today I have been experiencing an increasing loss of sensation in my right leg. I, of course, am concerned that this loss of feeling is being caused by the tumors. I wanted to know if this is a possibility and if I should take it seriously enough to make an appointment with my neurosurgeon. I am concerned that I make unnecessary appointments and I want to guard against that.

E-mail sent to Hospital Clinic listserv

I was surprised at the personalization and “doctoring” of the e-mail I received the following day from Dr. Tech, especially considering how little information I had sent in regarding my condition.
The condition that you described concerning loss of feeling may or may not be related to your tumors. But to rule out that possibility you do need to see your neurosurgeon. For specific problems such as the one you described it is always best to bring these to the attention of your neurosurgeon. You do need to consider why you are concerned about the legitimacy of your appointments. You should not delay in discussing this condition with your doctor.

Response to e-mail from physician on call, Hospital Clinic listserv

It was obvious to me that this on-line physician was not promoting this forum as a substitution for Dr. Dullard. In fact, he reinforced the importance of the patient-doctor relationship and the necessity for openness in the relationship. I immediately saw that there were indeed appropriate and inappropriate issues to be handled by on-line physicians and the physician quickly expressed this to the netter.

The practice of lurking was beneficial for a couple of reasons. First, by reading messages I could get a sense of the issues or topics that were discussed to determine relevance. Through lurking, I got a feel for the membership and an idea of the type of interaction that characterized the group dynamics. Messages from “newbies” announcing their own lurking indicated this was the practice many enacted before “voicing” their presence.

After lurking around the listservs and discussion groups for two days, I made another uneasy attempt at participation. I posted a question about “the second time around” to the participants rather than the “on-site” doctor, and asked what differences I might expect. I asked what I considered a low-risk information-seeking question, one that I may have asked of a new doctor, and one for which I knew what the answer would be. The question was innocuous; a question that I thought revealed nothing too personal.

I waited several hours before logging in to “collect” my answers, but was disappointed when I realized that I might have to wait several days before anyone responded. There was a difference in actually participating in this as opposed to reading about it. Understanding a little better how this worked, I ventured to the Mayo Hospital discussion group and posted the same question to a “visiting” neurosurgeon and the general listserv.
Two days later I returned to both sites. I was excited to find three responses on the patient listserv and a lengthy message from the neurosurgeon. I realized I was more interested in the responses from the participants rather than the physician.

When I initially “clicked” to submit a question, I realized how foolish I had been trying to assure anonymity of my questions by using a “pen name.” For the next few days I frequently visited the listservs and recognized the “obsession” that had made me hesitate to get involved in this. I continued to shy away from the questions I really wanted to ask, questions concerning emotional rather than physical pain. I was still testing the waters and I posted the same question to three separate discussion groups. It was interesting to me that members in one group were actually suggesting other groups to get involved in if they considered your questions more appropriate for other groups. Some members, I surmised, were actually recruiting for other listservs. I found a large crossover in the “vocal” participants in the listservs. It was not unusual to meet “Jerry” on “location” at two or three different listservs or chatrooms.

*I can’t understand why I’m backing off from participating with these people. I don’t feel this way with my doctors. I think I feel more responsibility. Part of it is wanting to help, to contribute to others. But a more selfish reason is that I’m going to be seen as my ideas. If they’re not good or helpful, neither am I.*

Personal journal entry. July 22, 1996

Within three weeks I was regularly visiting the two listservs I had chosen as the ones, from the seven I had been participating in, that I simply liked the best. I had found that the more participating members, the better the listserv. One group was for chronic ill patients or family of the patient, the second was specifically for brain tumor patients. Certainly one criteria for “liking” was the topics and issues discussed, but as important, if not more significant, was the membership of the group (at least those who participated). I felt comfortable by then and began to look at the conversations and the members, rather than just the responses to my questions.

My journal documents a problem that I now embarrassingly admit. I found myself, after reading the postings, convinced that I had similar, if not the exact physiological symptoms that others had described. This made me further consider an
already advanced concern, whether I exaggerated my physical pains and problems, convincing me that I was attributing minor aches and pain to the tumors.

I find myself wondering, after shutting down, if that tenderness or that ache is symptomatic of what Lisa found to be another "invaded" site, or what Mark is having an MRI for on Monday. Are we feeding others' neuroses? Is this some way to legitimize my participation, or maybe anticipate the worse? There are so many consequences to this "sharing." Do they come from a sense of obligation to the others?

Personal journal entry. July 28, 1996

Remembering the discussions I had with Dr. Heap oh so long ago about face to face support groups and my defiance in joining one, I realized that I was much more comfortable with the electronic support groups. These groups were certainly more convenient, allowing me to dictate the time and place of my attendance. I had initially been concerned about the waiting time for the responses, no spontaneity, and no validity checks on the responses that come from physical presence.

But I realized, at least for me, that this was not critical, because I knew, from my measured responses that the messages others received were closer to what I sent. There was a sense of responsibility for any information or feelings one sent, and an immediacy that belied the constraint of time.

I was surprised that the words on the computer screen soon took on the personalities of the authors of those words. As in any face to face group, the members had certain roles to play, and the participants consistently played the same roles. For example, Tom was one of the most "interesting" characters that most everyone, by the end of a week of participating encountered.

I cautiously began using this technology to "chat" with other oncological patients, and then with chronically ill patients. After loitering and submitting questions and responses to the listservs, I ventured into the chatroom that was scheduled for Tuesdays at 7:00 p.m.

To participate in chatrooms, I needed a new surge of confidence as before to get involved in the listservs. Once again, I couldn't understand my hesitancy but I now see it, not as a hesitancy to use the chatroom forum, but rather as the same reluctance anyone feels as the new person in any established group. The archives and opportunity for
lurking, which I thought of more as loitering, made it possible to construct some of the history and allowed me to get to "know" some of the participants.

The real-time factor chatrooms afforded, moved me closer to "interactivity" on the Net. Listservs and e-mail provided the equivalent of "snail mail" or phone calls in my other world. The anticipation of the weekly meetings was, I'm convinced, due to the interactivity with the other netters, rather than the information exchanged. I used the e-mail and listservs infrequently; I wanted to "hear" what was going in the context of the chatrooms.

*I was very glad that Shelly visited the chat room tonight. I was anxious to hear how her visit to her parents went. We had a lively "chat" last week about her standing up to her parents and doctor by telling them she was not going to have surgery again. Nina said that she would never question what her doctor recommended, but Nina is new to this. She's in for her first surgery in two weeks. She'll soon be comfortable enough with her illness that she'll be able to know what she needs. It's funny. Sometimes things that seem so alien to us, are, in a strange way, what make us stronger.*

Personal journal entry. July 1996

There were certain "flags" that announced a participant as a "new netter." The initial questions were frequently qualified with such phrases as "I'm not sure..." and "I was hoping." Questions from the "novice" were infrequent and I noticed that there was no interactivity between the new netter and the group; the rookie did not respond to the responses to their questions. From my own experience, I knew that they were probably loitering to evaluate the group before making more of a commitment through participation.

I detected there were several rites of passage before acceptance by the other group members. There was certainly the initial probing from the newcomer of the group, but once someone began to routinely "visit," the group expected an introduction of the newcomer through revealing his/her medical condition. Once that was provided, questions came from the group about his/her medical history, usually starting from the most recent.

This information seemed to provide "context" for the information from that person. New members seem to spend time as an apprentice, in the sense that it took sometime to determine the operating "norms" for that listserv or chatroom. The groups had individual cadences, a particular rhythm, and a "code." The harder to break that code, the less probability others would join.
New members were very important. As in any group, new members would offer new perspectives on issues discussed. Sometimes the questions they would submit would trigger something in my own experience that I had not realized. Perhaps because of the familiarity of members, or a sense of shared history, it was much easier for me to participate in chatrooms that were in someway connected to the listservs I belonged to. I use the word “belong” intentionally, because over time the chatrooms, and the listservs, to some degree, were “clubs” and took on the characteristics of associations.

Officers were not elected, but rather through their contributions and even suggestions on how to improve our group, roles were defined. Participants seemed to relish in their group role and most continued to play that role. These roles represented a continuity and certainty that we found in very little of our “real world” existence.

Though the norms varied for each group, there was some consistency among the groups. Many of the listservs sponsored by a hospital, health agency, or even insurance companies. As my participation increased, I felt a sense of obligation to the members, and it was as though we had an unspoken contract with each other to share information and advice. I would come from an appointment with Dr. Dullard and share our discussions. I also used the advice and information I garnered from the members in my discussions with Dr. Dullard. This was especially helpful in questions as to what I could expect from the upcoming surgery. So many of my concerns were those of the other member’s and I took comfort in knowing that I was not exaggerating the pain or problems that I faced or was anticipating.

I came to understand that the credibility of the listserv was tied to sponsors of that listserv. There were four primary sponsors of the groups I participated in, hospitals, managed care corporations, insurance companies, and shared interest groups, such as the Brain Tumor Association. I quickly retreated from those that were sponsored by the insurance companies and managed care facilities. There seemed to be an underlying assumption for most listserv or chatrooms participants that HMOs and insurance companies were “the enemy.” This seemed to be a fairly common reaction and for some
sites, it took awhile to figure out just who the sponsor was. I soon found myself looking for the sponsors' name or logo as soon as I went to a site.

Sometimes the only way to determine the sponsor was to trail the hyperlink, which eventually led you to the sponsor's web page. I learned to pass those listservs with hidden sponsors. Web sites, with slick designs, were no different than the wagons that delivered the cure-all tonics to the susceptible in the early 1900s; the potions in a travelling show.

It was not uncommon for a physician or therapist to contribute to the hospitals' and shared interest groups' sites. Listservs and chatrooms sometimes gave you the option of requesting the health care professional to answer your questions by e-mail, rather than posting the answer to the listserv. This was an attractive option for those questions that the patient considered disclosive or uncomfortable. When physicians' answers were posted "publicly" in the listserv, members would discuss and evaluate the physicians' responses.

I learned more from the members' responses than the physicians' and found myself asking for general postings more often. There certainly was a feeling of getting to know the other members and it was common for members to send questions to specific group members. There was no hesitancy for these questions to be addressed by other regularly contributing members in the group.

I feel that I have really found my cyberhome with this group from BRAINTMR. I'm not scurrying around to Web sites, downloading everything I can. I can't believe that I haven't even gone through one set of ink cartridges this month. I really look forward to our Tuesday evening chats.

Personal journal entry, August 1996

The "hierarchy" of what I liked best, or used most frequently, appeared to be related to the level of interactivity of the forum. In the beginning, I was most comfortable with web browsing, which certainly required no interactivity. I controlled the type of information I was exposed to, and was not obligated to do anything with that information. I decided to delete it, ignore it, or even read it.

At first I was non-discriminatory, downloading any and almost all of the material I found. However, I got more selective after I finessed my browsing by entering more
specific requests on Infoseek. I had chosen Infoseek as the browser to use after test driving the others. Infoseek provided more scholarly and academic web sites and information retrieval, which made sense. I seemed to feel more comfortable in the "medical mainstream" groups which were usually moderated by a physician or nurse.

When I registered for listservs, I continued to search web sites through Infoseek. What I observed, though, is that as my participation in listservs increased, my excursions to web sites decreased. The enhanced level of interactivity increased my participation, and even though hesitant, I was doing something with the information, eventually, responding to questions and giving advice, rather than just asking for information. This metathesis evolved, not on my own accord, but was sanctioned by the quantity and eventually, quality of questions directed towards me by other members.

My "specialty," ordained by my experiences, centered on relationships and communication. This was both a natural focus, as well as an academic one. I had made a decision before getting involved in this research, and after much thought and deliberation, that I would be open with the participants. There are, of course, sins of commission and omission, and I did not want to commit either.

I had included in my self-introduction that I was a graduate student in communication at Ohio State, and I was interested in the use of information technology for oncological patients. This "upfrontness" made me more comfortable, and I found, in no way, diminished my acceptance or participation in the groups.

As my participation and experience grew in utilizing listservs, I began getting involved in chatrooms. I had decided that it would be best to let this participation evolve, so I could study that evolution. When did I feel comfortable to participate in chatrooms? What were the conditions or factors that led up to this participation? What did it feel like the first time I participated?

I realized that none of these issues could be studied if I began participating just to have the experience. Similar to the decrease in using web browsing after I participated in listservs, my participation in listservs decreased, to some degree, after taking part in chatrooms. There was, however, a major difference. The chatrooms that I participated in
were linked to the listservs I joined in, so the listservs continued to be used as a communication format for the members.

What I found was that the interdependency of the chatroom to the listserv influenced the sense of community for me. Members had at least three ways to communicate, e-mail, the listserv, and the chatroom. These options were important when considering the type of question or information one wanted to share. Private e-mail was used for more personal responses, or concerns about specific group members.

Over time, this communicative format became the “socialization” medium. The listserv format served as the means of discussing the “bad” behavior and possible concerted ostracization of a group member. If, however, the group member continuously “flamed,” or said things hurtful or disruptive to the group, most members felt justified in carrying out the act of banishing the flamer on-line. Some in the group were quick to verbally “discipline” the violator. Once this was done, the violator either apologized on-line or unsubscribed to the listserv.

Participants in the chatroom communicated a familiarity with other members. The “context” or history of a voiced concern or problem could be traced, many times, to the listserv from which the chatroom evolved. This alliance that evolves appears to be linked to the interactivity of the forums. The sense of interactivity leads to participation, which increase feelings of obligation to other group members. These observations lead me to suggest that it is the interaction with similar others that draws one to these virtual communities; the attraction is not information you get, but rather the interactive process of information gathering, information receiving, decision making and communication.

There was a point where reciprocity was important to continue participation. If you were asking for information, you were expected to contribute and give information. The advice and information gathered from listservs or chatrooms is not that different than what a patient can read in a book, but with a book, of course, there is no interactivity.

Yet, in this interactive forum, the problems or concerns could be attributed to a “real” person, not just someone named in an article, or referred to in a television segment. I don’t think it is too presumptuous to say it is the communicative act, allowed by the nature of information technologies, that changes the context of “being ill.”
The sense of community in these groups does not happen instantaneously. I had not been involved in the inception or the beginning of the groups that I participated in. It did, however, take some time for me to consider, and be considered, a community member. Though some of the groups had been in existence for some time, active members were regularly contributing suggestions on how to improve the community. Some listservs encourage members to suggest “administrative hints.”

Through these electronic forums, I learned how to live my life, to integrate my illness into my identity and family. Many postings emphasized ways of living, and at times had the feel of “Dear Abby.” There seemed to be no particular pattern as to type of information requested. Some new members requested information about how to help their families first; others wanted information on treatments or diagnoses.

Though the benefits from participation in these listservs and chatrooms were many, there were still some negative aspects to the experience. There was always the sense that you didn’t really know these folks. But what I determined after some time is that the veracity of the stories shared was not important. What was important was the applicability to, or perhaps the validation of your experiences. As with any information, I knew it important to get several opinions or evaluation of any information before accepting it.

Though information requests or advice was not always focused on illness, it was difficult to know when the participants would be responsive to other issues. It was certainly easy to ignore postings if you didn’t want to get involved. While that may be attractive to the participants, it could be very annoying to the participant asking for the advice. It was easy to ignore, but difficult to accept being ignored. I noticed that, more often than not, being ignored led to discontinuous participation.

When participating in listservs, if I felt ignored for a period of time, I would unsubscribe, or at least minimize my active participation in that listserv. What is important to note, is that for most participants, their postings were focused on important concerns and when ignored, there was a feeling of implied invalidation of their concerns.

In the electronic communities there was, of course, no gage of nonverbal communication. This was especially problematic for those new participants. New
participants to chatrooms, if they did not engage in the listserv associated with that chatroom, many times were left out in the real-time chatting. It was difficult, at least for me, to be comfortable sharing problems, which I had learned were ones I let, or permitted to occur. Though no one wants to be known for their mistakes, it was important to share them if others could learn from them.

The Tuesday chat discussion before my September surgery was strained. It didn’t start out that way. I had come to know several of the group members fairly well. We had forged a world based on common fears and knowledge. It was a space I had carved out for myself, a space that I kept separated from my "physical" world as best I could. In fact, it was a relief to be able to leave that physical world for a short time and take up with the netters.

My sister and parents had come to Columbus, and I'm sure they didn’t understand when I went to the computer and tuned them out for an hour. I had not planned on visiting the chat room that Tuesday evening, but I felt a need to do so. In his typical direct approach, Paul brought up the impending surgery. The netters were very generous with their advice, their offers to help, even to the point of scheduling "contact" after the surgery. Not having to bother listing all of my feelings helped me to understand the importance of these connections. These were feelings we shared, a collective sense of what was going to happen. I did have something that I needed to ask, and I felt the same hesitancy that I had when I first began this.

I finally directed the question to all of the participants. A thought that made me feel guilty and foolish. There was a very good chance that this surgery, with the Gamma Knife surgery that I would be having, would make me tumor free. The first reaction, of course, was wonderful. No more headaches, no more lost time. Then I thought, no more attention, no more excuses for not completing what I should, or for doing things that I really didn’t want to do. I would no longer have a part of me that I had fought and pampered for ten years. In this decade of questions this is one I never asked – what is so frightening about being well?

It was a very common, and useful practice that group members would answer questions by providing links to relevant or inspirational web sites. Perhaps because this
question was on the minds of many participants, or because our own words could not express the answer, within minutes I had the advice from five participants to visit a particular web site. By this time I could read the URL well enough to know what I was going to find at the site. Sure enough, the article was "It's Not Over When It's Over." but surprisingly the author was "unknown." I wondered why no one took credit for articulating the fears that many hide from others. Perhaps this could account for the "bonding" that seemed to occur when meeting other patients, either face to face or electronically.

When I visited the web site of another listserv I joined, Cancer Care Group Programs, I found a similar service to that of OncoLink, offering registration to listservs. The following information was provided:

An on-line support group is very much like a 'face to face' support group — it usually numbers between 5 to 15 people, who have been through or are facing a similar situation, and have come together to share their experiences, learn from each other, and provide each other with a setting of emotional support. At Cancer Care, all groups, including this on-line support group, are facilitated by a professionally trained oncology social worker.

One feature that I particularly liked about Cancer Care was that the program offered four distinct, yet related discussion groups; two groups were for patients (General Patient Support Group, Brain Tumor Patient Support Group), and two support groups for family members (General Family Support Group, Brain Tumor Support Group). The number of participants were monitored, availability limited, and when a group was currently filled, the site provided information when the next group would begin. The benefit only became obvious to me as I "lurked" and began seeing that there was a crossover membership from families; the patient would register for a patient group, their family members would register for a family group. This allowed a participant the opportunity to compare and contrast the perceptions of the patients and their family.

The bookends of my day had been, for many months, the connections I had with the netters. Not all the talk was about illness. True, everyone wanted to talk about their illness, about their family, but conversation about work, assignments in school and even dates became common. I did notice stages of acquaintance similar to friendship development experienced in "the real world," although accelerated.
There was an initiation, a rite of passage, which forced new netters to the sidelines as the others talked about everyday things. I recognized the same hesitancy I had described in my journal for most new netters, a limited participation that did little more than ask for information concerning their illness. There was the safety in information gathering and at the same time trying out the waters of a promised land of understanding.

It may have been innocent to think, but it was reassuring to feel that the netters were an extension of myself. Forgetting the ether world of archived listservs and chatrooms, I sensed that nothing I told them would go beyond this circle. This feeling did nothing to ease my own misgivings about what I was doing.

I had, for the most part, participated in these sessions as a patient. There were times, however, when I would take notes, or download a chat session that I questioned my own ethics. My head and heart had to come to some agreement; some arrangement that would make me feel more honest with those who I had come to respect, and care about.

This was the first time, in a long time that I began thinking about my role as a researcher. Ethics in quantitative research, for me, are much clearer. You either behave ethically or you don't. A simplistic view, I'm sure, but one that I wanted to apply to this research. It was easy for me to change the names of the participants, and I toyed with even changing the names of the listservs. To me, I wasn't just collecting data. I, in some strange way, felt that I was capturing glimpses of souls, of the hearts of these people. They had given me advice and help in a secured forum.

In the beginning, I would often journal kernels of conversation in hopes of holding onto the experience. This practice situates when I began experiencing the encounters rather than just using this format as an extension of information gathering. It was only after experiencing, did I find the magic in this existence, the magic that seemed to nullify whatever was unsubstantial in my life.

Although there was a sense of change with every new netter, there was still a development of routines and rituals that personalized our "group." Though we came from different backgrounds, lived different lives, once connected we all shared two things, an unexplainable loneliness, and a desire to make things better for those who would follow.
I wanted to make things better and easier for my family who would be at the hospital. The day before my surgery, my parents, sister, and I met with Dr. Dullard. I had not been the only one living this illness for the past ten years. This experience had touched all of my family, and their living had been as disrupted as mine had. I had thought before the meeting that it would primarily be Dr. Dullard explaining what we all, for the most part, already knew. I had scheduled the meeting because of a discussion point that came up during a chatroom visit. Make your family feel part of this, give them a sense of responsibility, keep them informed.

I had expected my father to ask medical questions, almost “quizzing” Dr. Dullard, and I was right. When my mother started questioning Dr. Dullard on the location of the tumor, and from her “…understanding this location is dangerously close to the center for breathing,” I was shocked. Almost as shocked as when my sister asked questions on the gamma knife procedure, again things I didn’t know. Gone was the apprehensive fidgeting that I had observed in the waiting room. These people knew what they were talking about! I was the only one who didn’t ask questions! These observations only served to emphasize that I was not alone in this. This questioning made me realize that my family was actively searching for information, not just holding my hand for reassurance or emotional support.

The night before the 1996 operation was certainly not the calm before the storm. We had gone out to dinner staying longer than usual, I’m sure putting off the last night of sleep before the surgery. Friends and family called, feeling awkward, not knowing if they should wish me luck or say they would see me soon. I reacted in my usual way, making light of the situation in hopes of making them feel better. I thought for a second how different this was from the chatroom on Tuesday night. Maybe because we weren’t face to face, I could talk about how I felt openly. I had to say little, they just knew. Here I was, surrounded by family and I felt responsible, in some way, for making it easier for them. I didn’t resent this, I just felt at fault. I had thought I would spend the evening writing some important missive in my journal on how I was feeling, what life was all about. Instead, I talked and laughed with my sister until two o’clock in the morning. When my parents told us we had kept them up all night, I had to smile. That’s really what it’s all about.
The alarm went off at 3 a.m. For some strange reason, I had to shower and wash my hair. I was due at the hospital at 4 a.m. and we were right on schedule. As my dad drove, the object of our attention was the mini-cassette player I would use to collect my data. Much better than me being the object of attention.

The doctors and nurses told me later that they marveled that I was questioning them up to the time I faded away. Dr. Dullard told me I actually “went under” in the middle of a question. Not that the questions made sense. The voice was becoming more distant and the next thing I knew I was groggily stirring, seemingly playing tug-of-war with sleep and wake.

The first thing I did when I woke up was to turn on the recorder. I was determined to get this experience documented and not to miss any conversations with the doctors or nurses. Though I felt mentally removed from the event, I was reassured that my recorder was capturing this “Kodak moment.”

Hospitilazation. Post-surgery II

By 6:00 p.m. I was celebrating another successful surgery. I could swallow, I could talk, and therefore I must be fine. I kept my uneasiness to myself about having to leave after three days, on orders from my insurance company. The behaviors of being fine were those of someone who wasn’t. Surely, my insurance company had to know what they were talking about. After all, their name, Critical Care, implied as much. I just couldn’t imagine the application of a formula in assessing my health.

Perhaps no other battle in this war I was engaged in reflected the nature of the circumstances more than the one being waged by my insurance company. As one of the doctors told me, “Insurance companies are here to make the doctors look like the good guy.” I began to see the vulgarity of reducing my illness to dollars when I received the notice informing me that Critical Care had “authorized” three days for hospitalization after the surgery.

I was not “authorized” for admission until 4:30 a.m., the morning of the surgery. In 1985, I had barely come to after just three days after the surgery, so this “authorization” presented something else that I saw as a battle in this on-going war. I called my “representative,” and told her my concerns. She said that my situation called
for no more than three days, but it could be extended on a day to day basis if my doctor would call in and request additional days. The insurance numbered my days as well as the medication and health care procedures I would receive.

_I’m beginning to feel more and more like David gearing up for battle with Goliath. I’ve been reduced to statistical averages by Critical Care. They’re authorizing three days for hospitalization and no pre surgery admittance. Pretty scary considering I was barely waking up after three days. When I called to question I was told that my procedures were run through the computer and authorization calculated When I asked if they were concerned and considered individual cases, Mary complacently told me, “That’s not our job. You have other people for that.”_

Personal journal entry. August 24, 1996

I suspected from my Internet group that insurance was a primary, if not the major concern of most patients. The thought of being in debt for something I was not in control of overshadowed even some of the concerns of my wellness. I just kept thinking of the irony that the surgery would extend my life, yet I’ll be saddled with the costs for all of my extended life. I felt this was one struggle that I had to fight alone. So, I had entered this hospital two days ago with more on my brain than brain tumors.

This three-day hospital approval goaded everyone into action. I noted in the recorder that speech, as well as movements, seemed to be on fast forward. I was especially struck by the relationship my parents were developing with the family of my roommate. “Judy,” I learned from listening to their conversations, was fifty-two and had lived the last three years in and out of the hospital, mostly in.

This relationship evolvement defied the importance of history and time in “normal” relationships, similar to my observations of relationships developed on the Net. I weighed if this relationship acceleration was attributed to the “illness” context for these relationships, considering the face to face relationships development were as expeditious as the Net relationships. Names were never exchanged, but it was nothing to share intimacies about Judy’s health. Judy never did the sharing. In fact, Judy and I never spoke until the families had left.
Judy’s brother Ted was the source for this information about Judy. I thought this was curious until I heard my mother telling Ted about me. Ted reveled in this. He was a self-proclaimed “expert” in brain surgery since he had had one surgery, ten years ago at the Ohio State University Medical Center. It wasn’t too comforting for me to hear “That’s the hospital where she (meaning me) should have gone for this surgery. They have this place beat in know how and service. I would never have brain surgery here.” Oh, out of the mouths of fifty-four year-old babes!

Judy’s relatives were experts on the food served here, the hasty doctor rounds that were made “only two times a day,” and on which nurses were better. They just didn’t seem to be experts on Judy. They spoke about her, but very little to her. When I heard her sigh after they left, I figured that it was a sigh of relief.

This all rang true to my experience as a patient and to what I was sharing with those on the net. Patients were talked about as if they weren’t there. Patients were the “break-the-ice” topics when their families were forced to share cramped quarters, the hospital room. Patients learned to be comfortable with the silence that surrounds illness, a trait not yet learned by most family members. Families voiced concerns about the hospital or doctors were not even close to the patients’ concerns.

It was my last “authorized” night in the hospital when I finally heard Judy speak. She had heard me discuss the progress of my data collection with Thom when he had visited earlier that afternoon. I was surprised to hear my name from behind the pulled curtain. Judy said that she could really tell me some stories about being a patient and I knew she could, from the weariness and experience I detected in her voice. As I listened, I found myself wondering what the voice of the netters sounded like. I seemed to be able to tell so much from Judy’s and I wondered how I had come to know those in the chat-room and listservs through only words displayed on a screen. When Judy started talking I immediately reached to turn on the recorder. Once on, I at once turned it off. For some reason, I felt this was wrong. It just did not feel right. I was so glad that the recorder wasn’t on, when, after a few minutes, Judy pushed the curtain aside with the end of her cain. Judy apologized for Ted’s comments that day about the
hospital. She nodded her agreement when I said that they just don’t understand. Our conversation was really no different from the ones I had on the web.

It was a conversation that would not have taken place if our families were there. This, I realized, was what bonded patients, milled an understanding that could only come from a shared history, a secret club non-patients were not aware of. My conversation with Judy that night played in my head long after we had stopped talking. I sensed that she felt she was struggling alone. She had no connection to other patients, and was “protected” by her family not letting her know much about her illness. I realized that her silence I had observed when her family was visiting was not atypical from how she led her life.

I told Judy about my research and, of course, about the relationships I had formed over the web. She had no idea that this was possible. I was certain she had felt what we all did. We took comfort in finding our peer group. For the first time, I heard encouragement in her voice. She did not have a computer at home, but she was going to get one. She wanted to know about the people I had met, what they were like. For a while I had forgotten that I had never seen them. I described their personalities, the funny things they had said, the problems and concerns we had shared, just as if they lived down the street. I admitted that there was even a “Ted.” Judy said, with that sigh I had come to know, “Well, every group has one!”

Three days after brain surgery I was sent home. I knew I wasn’t ready, but I thought that maybe I just wanted to play patient a little longer. I had been told that this was what was expected and I didn’t want to argue, I just wanted to do it. If I didn’t, I would have somehow failed this process. Dr. Dullard came in to release me and I told her I just didn’t feel right. But my “vitals” said I did and three hours later I was riding in the back of my parents’ car, home to my apartment in Columbus and the next day on to my home in Charleston. When the orderly arrived with the wheelchair, I said goodbye to Judy. Her goodbye told me I had perhaps offered her some hope, “Meet you on the Internet!”
Once settled in Charleston I read my e-mail and was buoyed by the messages I had received from some of the "netters." It was much more personal to receive the private e-mails, rather than messages in the chatrooms. This was the first time I realized that I was part of a "netter clique." I was surprised that Kate had sent an e-mail, but then I realized that her net role was "peacemaker" and she wanted to make sure everyone felt OK. Kate was equivalent to the group members who send the birthday and anniversary cards to all other group members, whose contribution is characterized by the good she sees in others.

By the third day in Charleston, I was feeling so bad I was concerned that something was terribly wrong. I forced getting up every morning and doing something, although I really didn't know what I should be doing. I was pushed to continue by the information I had been given by the insurance company and my doctors and the information I had read in magazines on how the procedures were so advanced for neurosurgery that most people would be back to work in less than a week. I had seen a TV show which had chronicled a woman's recovery from similar surgery as mine and she was hiking in the Rockies one week after surgery. I remember telling Dr. Dullard this and she had laughed and said that while that sounded incredible, it certainly was possible. The hospital release papers indicated that I should take it easy for a week, and then slowly resume my regular activities.

I felt that everyone and everything indicated that this was the norm and there was no reason I why I couldn't be doing this. I was exhausted, I ached both physically and mentally, and all I wanted was to be all right. I wanted to be the one to get back to work in a week. I wanted people to think it was incredible I had the strength to pull through this quickly. I wanted nothing more than to be "normal," but I knew I was fading fast.

Dr. Dullard called that afternoon to see how I was doing. I told her fine, afraid to admit I wasn't, but again feeling certain that I should be. The next day my parents rushed me to the emergency room of a local hospital. I was admitted and was soon being "doctored" by our family physician from forty years ago. I remember the weekly appointments I had with Dr. Sharp when he had monitored my bout of diabetes when I was six years old.
Hospitilization, Post-surgery III

My parents and I told him the tale of this latest medical adventure. It may have been because of our history, or because of his “doctoring” technique, but this was the first time, during this whole mess, that a doctor took the time to sit in a chair, directly facing me and took my medical history. He probed for further information, more than a doctor could possibly know from the forms patients fill out in the waiting room. For once I felt as though the information was going to be used for more than words on a chart that were, more often than not, substituted for intimate knowledge of the patient. For a moment I thought how impersonal, and perhaps offending, history giving would be if doctors’ offices initiated “computerized” programs. This idea for efficiency would only distant the patient more from the physician.

Once again, I became a pincushion for the technicians. Dr. Sharp was limited as to what he could do until he spoke with Dr. Dullard. It was well into the following day when he finally had a chance to speak with her. Before he did contact her, I was surprised to hear his remark that some doctors don’t like to “share” their patients. He was hesitant to suggest anything before contacting her, but it was important to begin some treatment. At this point, he knew that I had a blood infection and I was not responding to the medicine that dripped into my arm from the IV.

I kept thinking how much more efficient this would have been if Dr. Dullard used e-mail. Dr. Sharp and Dr. Dullard could have exchanged test results, scans, as well as diagnoses through information technologies. I found myself angry with Dr. Dullard for the response she had given me when I asked if she used e-mail in her practice. “No,” she said, “why do I need to when I can schedule an appointment with a patient.” Instead, I found myself worrying that I would have to be the liaison between Dr. Dullard and Dr. Sharp. Once again, this personal experience brought into focus the possibilities of better health care through the use of information technologies.

For days I was hooked up to IVs, and gave bodily samples to whoever asked for them, but at least the room had a different view. The lovely folks at Critical Care just couldn’t resist getting involved. Dr. Sharp was told that he would not be able to treat me with the medicine he wanted. It was too expensive and was not covered in “my plan.”
Dr. Sharp was the first of the long line of successive doctors who stood up to Critical Care. He would, he informed them, continue using the medication. Ten days later I once again was "released," with the desire and the determination not to see the putrid green inside of a hospital or smell that antiseptic smog again.

It was during my second office visit with Dr. Sharp when I learned that I would not be able to escape. After being examined, the frantic calls began, trying to contact Dr. Dullard. It took over 45 minutes to track her down. As I lay on the bed in the office, Dr. Sharp and then my father spoke to Dr. Dullard. It was decided I had to get back to Columbus as soon as possible. Dr. Dullard, or her associate would meet me in the emergency room. It was already 5:00 p.m. when we began maneuvering those winding country roads from Charleston to Columbus. I had given up. I could care less what was happening. I had no idea that a most painful and serious two weeks awaited me.

The events in that emergency room seem almost farcical. My veins had collapsed so the nurses could not insert an IV. After two hours, an emergency doctor took me in a "private" emergency room (i.e. a room with a door), and attempted to insert the IV in a neck vein. He instead nicked an artery. When the blood spurted out, all I asked was, "Is that suppose to happen?" I could tell from his face, and the blood-red stain on his lab coat that the answer was probably no. I was detached from this activity, seemingly observing from the side. I didn’t ask questions and no one volunteered any information.

Eight hours after arriving, in a private room in critical care, a "critical care" doctor finally succeeded in lodging an IV under my clavicle. When the doctor told me he was a critical care doctor, I immediately asked if he was from my insurance company, those who I held responsible for this. I told him if he was he needed to leave. He wasn’t. and as he jabbed the needle under the bone, I survived it by momentarily imagining I was doing that to a select few who had made my revenge "list."

Three hours after falling asleep, Dr. Dullard was informing me that I was going into surgery immediately. I had meningitis and it was necessary to insert a shunt in my head. But this was overshadowed by what she then said. "This," she informed me, "was why I don’t like patients leaving the area." I knew it would make no difference to remind her that she had told my parents, during that visit to her office the day before surgery, that
it would be no problem for me to go to Charleston. I understood it would have no effect, reminding her how hard it was for Dr. Sharp to contact her. I was saddened to recognize that when something goes wrong, it was the patient who had caused it from not “obeying” orders.

Those ten days that I spent in the hospital only reinforced my recent recognition that the relationship that I thought I had with Dr. Dullard, in which I was participating in my illness and treatment, was not reality. As I look back on my journals and experience, it seems as though that relationship was fine, as long as things were fine. I found myself slowing blaming myself for this latest problem. My parents and I had both misunderstood what the doctor had said during that office visit. None of this would have happened if I had stayed in Columbus, if I had just paid closer attention to her counsel.

The farce of the emergency room admittance paled in comparison to the life I had those next ten days in Riverside Methodist Hospital. Nurses had no idea what the doctor ordered, or any idea as to who should be doing what. I was told for four days I was going home that afternoon, only to still be in the hospital the next day. For two days, I wasn’t served dinner because my room was on the corner of intensive care and step down care. No one knew who was to take care of me. Why did I put up with this? Why didn’t I complain and get some answers, as I would have a month previous? Because I stopped asking questions.

The lack of information and the lack of a climate where one could feel comfortable asking questions contributed to my silence. A silent patient, I understood, was a good patient. They had worn me down. “They” no longer was my illness; “they” were the doctors, the nurses, the technicians, and the hospital I felt I had inconvenienced.

*What I wouldn’t give to chat with the netters. They would understand how this feels. Someone would be able to tell me what to do. Instead of being asked how I feel, I want to be asked “Did you feel like I did when...” Maybe when I, if I, get out of here I can understand this. Hopefully, and this will be best, if I decide I don’t need to understand this. I know now that the progress I had thought I was making was more about the context of living with this, rather than my symptoms. You have a sickness, you live an illness.*

Personal journal entry, 1996
Leaving and not coming back!

I left Riverside Methodist Hospital with a cynicism and trepidation that I had not felt in a long time. I was discouraged; it seemed to me that the experiences and the enlightenment that I had gained from the contacts through information technologies were always going to be ignored by the physicians in the "real" world. But, I had a better understanding as to why. Many physicians still held on to the traditional dynamics between patient and doctor.

There was no need, according to these physicians, for the patient to participate in his or her illness. Patients would benefit if they left the "doctoring" to doctors. I had no sense of value as a patient. I felt as though Dr. Dullard and others merely tried to pacify my insistence of participation with words. I had in some way failed. not just as a patient, but in my mission to convert my doctors to the importance and benefits of incorporating information technologies into their "doctoring." But I had succeeded in being strong enough to make my own decisions, and breaking the dependency on the doctors for the final decision.

I also left with an appointment to go to the University of Virginia for the Gamma Knife treatment in six months. My thought those first days after getting home was that I didn’t want to know anything about the procedure. I would go to this appointment with no expectations, no understanding as to what was going to happen, and most importantly, NO QUESTIONS. I would do what I was told to do. After all, the only reason I had problems with this surgery was that I had not listened to what Dr. Dullard "was really saying."

That lasted for as long as it took me to return to the chatroom on Tuesday night. Almost immediately, I realized I needed to read the archived discussions to be able to participate. Though I had limited the number of e-mails to receive from the lists, there were still several hundred. I had not planned on being "away" for so long and I felt overwhelmed. This was turning into one of my time-consuming, do everything perfect quests. I saw that the same people were not participating in the chatroom. I had thought, foolishly, that I would just pick up where I left off. I had envisioned being welcomed back. I considered just how elusive, ethereal and even transitory these virtual groups are.
When I thought about the ebbing and waning of my own interests I began to understand. My previous experience had given me the rudiments of participation so I decided to jump right in. My hesitancy left quickly.

I logged on and immediately asked a question about Gamma Knife treatment. Pam responded that she had just received the treatment at the University of Virginia. I explained I was scheduled for the procedure in six months at the University of Virginia and asked her to e-mail me any insights she could. Perhaps this was because I was not facing invasive surgery in the near future, facing my own mortality. What I needed was information on the Gamma Knife treatment. I had made a contact through Pam to tell me her experience and I didn’t feel the need to “shop around” for others’ opinions.

I quickly logged off and went to the Cleveland Hospital listserv. I submitted a question to the on-call doctor and closed the connection knowing that I would receive a response in a couple of days. I’m not sure if it was because the novelty was no longer there, or if I knew exactly what I needed to ask. Probably a little of both, tempered with understanding of how things worked and a definite information goal.

I found the “in-charge” group still in charge, but noticed that some familiar names were missing. It is complicated to discuss or even think about this with the ways I had traditionally thought about information. When the difficulty of “fitting” the information I encountered into apriori categories of information needs, types of information, or even information resources to explain these changes, I began thinking about how “information” seemed to be viewed in a different way, in this experience.

My information needs and uses were dependent on the progress, or steps, I had achieved in this living context of chronic illness. Harder to explain, however, was that as my participation and decision-making increased, my actively seeking out information decreased. I was not actively looking for specific information, but rather taking information I received and fitting it into the “gestalt” of my experience.

Depending on relevancy to my context, I included as well as excluded information. I became more discriminatory in the information I would include. I felt I didn’t need the emotional and relational information that I had developed through the listservs and chatrooms. Though feeling selfish, I knew that I had used the netters for
guided evaluation of feelings and information evaluation. The netters were the “stepping stones” that bridged my dependency to independence of doctors and family. Not that I wasn’t going to need them, just need them in different ways.

In this stage, all of my needs, not just information needs, were practical. I saw this reflected in the way that I was leading my life. There was an urgency to get on with the rest of my life. The helping others mode I was in for months seemed almost disingenuous: it had served to make me feel better, that I had helped others. I knew I had because of the relationships formed through the Net. Close relationships, cyber-relationships, could be transitory, useful for awhile, and then discarded. There was no value judgement to be made, this is just the way it was. Much more inline with the way we sustain most other aspects of our lives.

After a week of home-nursing care, I returned to graduate school. The first day I stayed six hours instead of the two the doctor told me, but by now, I knew what to do better than the doctor could determine. My relationship with Dr. Dullard had changed, and I met my appointments only because my parents insisted.

During an appointment two weeks later, the relationship was further tested. I had told her that when I moved my head I still felt the same pain that I did when I had meningitis. “That’s not possible,” she insisted. “You can’t get it again, once the fluid is gone.” I felt myself get tense and asked her, “Have you ever had meningitis. Do you know what it feels like?” Her silence answered my question. “I want an MRI just to see.” Four days later the results showed her that I was right. There still was fluid on the brain. I didn’t “get” it again. I just never got rid of it.

There certainly wasn’t any satisfaction in knowing I had meningitis, but I must admit some degree of smugness, and a boost for my self-confidence. Those test results showed me more than that I still had meningitis. I realized that all I had experienced from the use of information technologies was not dependent on my physicians’ acceptance or use. Information technologies were improving my living context of illness and did not need to be “sanctioned” by others.

The use of these forums were more balanced with my other responsibilities. I still felt the strength and saw the necessity of using information technologies in this area of
my life, but I integrated the use into the rest of my living. I also began using the Internet for other uses. I became a participating member in several listservs for other interests. I enjoyed discussing antique Wedgwood collecting with the members of a small listserv and an international group, attending seminars on plein-air paintings, and even "previewing" items "on the block" at the California flea markets.

I visited the University of Virginia's College of Medicine's web site (University of Virginia, 1997, http) which linked to the Gamma Knife Web page. I was encouraged just by the fact that Dr. Right had a home page. This was a real sense of justice – I had finally found, at the end of this long haul – a physician who recognized the potential of using information technologies in his work. I e-mailed the staff and told them who I was, that I was a patient of Dr. Dullard's, and I would be coming in March for the Gamma Knife procedure.

Within two days, Becky had returned my e-mail with a complete description of what I would be doing, what they would be doing to me, and even an introduction to all that I would be meeting. I took a virtual tour of the facilities, read "testimonies" from previous patients, and even made reservations to tour Monticello.

Ironically, as with so many other events in my story, two days before being admitted to the University of Virginia Hospital, I saw a television segment my sister had alerted me to, on the "miracle" of the Gamma Knife procedure. So armed with information from Carl, my student, from Dr. Right's web site, information I received from the listserv and chatrooms on the "Gamma Knife," and the television special, I went in, for what I hoped would put my references to these brain tumors, permanently in the past tense.

I did have one little surprise. When you first arrive, you get a metal "halo" screwed into your head. The all too obvious remark on it probably "being the only halo I would wear" was made. I didn't laugh. This was one little piece of information no one had mentioned. But I was actually more upset to hear that I had to have an MRI, and the "procedure" was performed in an MRI tube. I envisioned that catacomb, with the familiar sense of claustrophobia, so strong I wanted to just leave. But of course, I didn't. I still trusted, though not without question, the "medical mainstream," just like I bowed to
most authority. This trust was sobered, however, with a confidence and responsibility to and of myself.

Though I had cut down my “net” time, I was always welcomed with messages of “Glad to hear from you,” and “It’s great you’re doing so well.” I was assured that they would be there if I ever needed them, and I am finding that to be true. When I logged on asking about experiences with the Gamma Knife procedure, I received over 20 responses within eight hours. I now recognize that this web netting is personalized to everyone’s needs, and everyone is accepted, even those with minimum participation.

From my tracing of the history of the BRAINTMR listserv and chatroom, I found that the netters who came on board in the beginning were the most “vocal,” participating daily, and some seemingly, hourly. As others came and went, Betty, Robin, Lee, and Paula were always present, welcoming, supporting, and encouraging those who visited and then moved on. There was a “proudness,” as well as “ownership” tone to their messages. Moreover, an intense desire to help others, if only given the chance.

Other participants logged on with a specific information need and left, never to be heard from again. I found that my patterns of participation seemed to be most typical, increased and more intense participation immediately before, and sometimes after, a “turning point” in their illness. Visits for them, as well as for me, became increasingly infrequent, yet I knew I could join in anytime. There is an acceptance that can’t be described, a level of support and optimism, yet realism, which defies imagination.

I have heard of people, who come close to death, speak of seeing a bright light at the end of a long tunnel. When death does not come, these people tell of “revelation,” a divine revelation that allows them to turn away from that light, and return to those who love them in this world. I can’t make that claim, of seeing the light at the end of the tunnel.

But I am reminded of the story that is told of a teacher, Mulla Nasrudi, who, while looking for a lost key on the street, was asked by a friend, “You lost the key here, Mulla?” “No,” Mulla replied, “I lost it in the house.” “Then why are you searching out here?” asked the friend. “Because,” the teacher answered, “the light is better out here.”
Information technologies, have, for me, illuminated the path, when I seemed to have lost my way as I traveled through this path of illness.

As I soon discovered, the illumination of “what is” shone much brighter from those with similar experiences. I had anticipated a significance to these encounters, but not such a profound enlightenment. Strangely, their stories changed the nature of my illness and provided a collective experience and knowledge for sense making. My ten years of disjointed experiences assumed a logic when compared to those I only knew through the net. It’s a light not to turn away from, but rather embrace. And Judy, I’m still looking for you on the Internet.
It is impossible to conceive of an information-based understanding of illness without considering the impact of information technologies on the experience of chronic illness. Specifically, this research focuses on what ways information technologies transforms the living context of a chronically ill patient, not simply influence it. Living an illness is information-based, but the patient is its center, focusing on how he or she creates, distributes, understands and uses of information for coping, understanding, and participation in chronic illness. This research illuminates the transformation of these processes by information technologies. Specifically, this review will cover 1) what information is, 2) the impact of technologies on information and communication, 3) the role of information in health, 4) the Internet and the World Wide Web (WWW) and, 5) health online.

Information

Information, though readily acknowledged as essential for communication (Littlejohn, 1983. p. 115) is, nonetheless, difficult to define. The principal conceptualization of information in information theory focused on measurement, the quantifiable units in messages between senders and receivers. It is, however, the issue of semantic information from information theory that we find most applicable to our use of “information” in human communication. “The net effect of semantic information (receiving messages) is to reduce the total amount of uncertainty in the situation” (Littlejohn, p.120).

Information has long commanded a central place in communication research. First introduced as a concept in the hard sciences, Schramm is credited for advancing information into the study of human communication. Schramm (1971) recognized the
importance of information by suggesting that "We have every reason to suspect . . . that a mathematical model for studying electronic communication systems ought to have some carry-over to human communication systems" (p. 135). This claim was not met without criticism. Shannon & Weaver's 1949 mechanistic model of information transmission, which Schramm heralded, failed to account for the "sociability" of human communication. MacLeish (1967) argued similarly "We are the best informed people on earth... We are deluged with facts, but we have lost, or are losing, our human ability to feel them. . . We know with the head now, by the facts, by the abstractions. We seem unable to know as Shakespeare knew who made King Lear cry out to blinded Gloucester on the heath. . . "you see how this world goes." and Gloucester answers: "I see it feelingly."

Griffin (1997) argued that Shannon & Weaver's linear model of communication, while limited in its adaptability to human communication, was, in fact, responsible for spawning communication as an academic discipline (p. 54). Even given the hesitancy of adaptability of the model, it is unarguable that information is the cornerstone for at least three human communication activities: reduction of uncertainty (Mischel, 1988), decision-making (Grunig & Disbrow, 1977), and the development of self identity and group membership (Meyrowitz, 1985).

The Impact of Technology on Information and Communication

Concurrent to Shannon and Weaver's development of their one-way model of information, Wiener visualized a time "when humans could use thinking machines (we call them computers) to combat chaos." Laying the foundation for the study of artificial intelligence, Wiener introduced the term cybernetics to academia (Griffin, 1997, p. 53). It is perhaps today, more so than any time previously, that information and cybernetics have converged to create the quintessential "information age."

Revolutionary and evolutionary changes in technology for accessing information are fundamental to the coming of the information age. It is impossible to discuss the "information age" without addressing these technological advancements. This has resulted in many pundits viewing technologies as distinct from culture and as simply a
way of doing what we have been doing more efficiently, or effectively, or conveniently.
Menser & Aronowitz (1996) warned

They (technologies). . .are bracketed off in such a way that they are mistakenly seen as distinct entities often deployed by certain cultures. . .to bring about specific changes (progress) within cultures. . .the nature and the role of technologies are more complex and ambiguous. . .than some critic of the enterprises of modernity claim. (p. 21)

Menser & Aronowitz continued, “Sociality, politics, perception and experience—not to mention love or friendship. . .many of our most fundamental categories have been challenged or changed by technology (p.p. 21-22) Slack (1989) developed a similar argument when she discussed “context” as “not something ‘out there’ out of which technology emerges and into which we can insert it.” (p. 339) and Ong’s (1996) reflections emphasized the same sentiment. “This vast load (information generated daily on the Internet and World Wide Web) is new. and growing so fast as to be in fact immeasurable. It is making of human consciousness something other than what consciousness use to be” (p. 11). Simply by replacing “human consciousness” in Ong’s argument with any human activity, practice or institution (i.e. health, education, religion) one can begin to see the validity of Menser and Aronowitz’s claim.

Zuboff, in her 1988 work which chronicled the impact of information technology on work and power observed

choices that are merely technical will define our lives together at work. This means more than simply contemplating the implications or consequences of a new technology. It means that a powerful, new technology, such as that represented by a computer, fundamentally reorganizes the infrastructure of our material world. It eliminates former alternatives. It creates new possibilities. It necessitates fresh choices. (p. 5)

In essence, technology changes what work is.

Other observers of the impact of information technologies on our living point view technology as more sinister. Hyde (1995) cautioned the lose of communities formed through face-to-face communication and Frisch (as cited in May. 1991) suggested that “Technology is the knack of so arranging the world that we do not experience it” (p.57). Davenport (1997) warns that the vast amount and variety of information, as well as the changes in everyday living resultant of this information can be overwhelming.
Ong (1996) concurs:

As preoccupation explicitly with information systems as such has recently overwhelmed our human lifeworld, entering in depth into our communications revolution itself, we are today flooded with processed information to an extent quite unimaginable only a few generations ago. Human beings have never had to cope with information even remotely so abundant as that with which we now live. (p. 9)

Information, communication, and technology in the information age

Observing, thinking, and writing about the information age and its impact on everyday living has created an unparalleled litany in many areas. Ironically, as interest and involvement increase in technology there appears to be a growth in the mindfulness to human communication. Ong (1996) suggested as much in his monograph on information and/or communication. Arguing for a distinction between information and communication, Ong set forth reasons reminiscent of those raised opposing the application of Shannon and Weaver’s linear model of communication to human communication.

According to Ong, “meaning” is what differentiates communication from information. Ong (1996) reasoned that information is something that is transmitted by a mechanical operations” and is not inherently meaningful . . . information (for example, a genetic code in living cells) does not of itself involve meaning. It does not involve human consciousness or conscious of any kind, including that of subhuman species. (p. 7)

Ong referred to the work of I. A. Richards (1987) in defining communication:

Communication takes place when one mind so acts upon its environment that another mind is influenced, and in that other mind an experience occurs which is like the experience in the first mind, and is caused in part by that experience. (p. 672)

Griffin (1997) cited Ong’s earlier work in which he directly addressed and debunked Shannon and Weaver’s information model specifically stating, “This model obviously has something to do with human communication, but, on close inspection, very little, and it distorts the act of communication beyond recognition” (p. 55).

Dervin (1977) distinguished information from communication stating:

Information is essentially seen as a tool that is valuable and useful to people in their attempts to cope with their lives. Information is seen as something that
reduces uncertainty. As the individual moves through time and space (i.e. the
time and space continuum that makes up a life), it is assumed that information
can both describe and predict that reality and thus allow the individual to move
more effectively... (p. 18)

Distinguishing information from communication becomes even more critical in
the information age than ever before. The distinction between information and
communication is critical in examining information uses and needs of chronically ill
patients and the impact that information technologies may have on their lived experience.
It is, in fact, the sharing of information and social interaction concerning this information
that creates meaning and engages the patient in his/her illness.

Technology has assisted the sharing of information throughout history.
Williamson (1987) stated

From the beginning of language and ... territorial markings on rock to the latest
generation of communication satellites and supercomputers, we have always used
a science of the practical to extend our transmission and reception of sights and
sounds, to record ideas, and to facilitate our thought processes. (p. 23)

The information age is the current context for information technologies. What is
of considerable interest is both the characterization of information in the information age,
and the result of the “glut of information” (Ong, 1996, p. 9) on human communication.

There are common themes running through the literature distinguishing the
information and communication in the information age from previous stages in human
thought and development. Gandy and Simmons (1986) discussed information technology
in the light of “combining information from a variety of diverse sources.” Kirby (1989)
 wrote about the shaping of “unique communication networks,” and characterized new
forms of culture. Zuboff (1988) affirmed that “information will be more integrated,” (p.
359) and new technology in this information age “fashions innovative methods of
information sharing and social exchange” (p. 7).

Davenport (1997), concerned with the narrow focus on technology and his
perception that the effective use of information has not improved at the same soaring rate
of technology development, extended his work to the study of information ecology,
emphasizing the “human approach to shaping, interpreting and muddying the
information” they receive from information technology” (p. 6). Chesebro (1995)
asserted that information technologies challenge the ways people think and process information.

Questioning new technologies and their effect on communication and behavior is nothing new. And many of the research questions asked previously concerning information technologies have simply been reframed to ask similar questions regarding the newest technologies. In the not so distant past television research questioned if television caused violence, for some illiteracy, and for others mass apathy for politics (Menser and Aronowitz, 1996, p. 22). Telephones were viewed as broadening community relations as well as fracturing others (Fischer, 1992) and more recently, the Internet’s availability to a select demographic groups have raised concerns about the haves and have nots and the power and control of information in societies (Harper, 1997, p. 1).

Campbell (1998, p. 51) posited that “the information highway could create economic tiers and classes of service. It could become a toll road rather than a freeway. with wealthy users buying many tiers of service” resulting in information classed as a consumer good, regulated by costs or supply and demand.

Biernzki (1996) in reviewing Perkinson’s 1996 work on risk aversion, cited Perkinson, who reasoned “that each of the four dominant media, speech, writing, television, and the computer, each in its own period of dominance - - have determined ‘the amount of control over information, and the degree of accessibility to information’” (p. 23). But rather than asking what new information technologies are doing to health, education or religion as was asked in the past, the critical question becomes what is health, education or religion in the information age? This representative shift in research focus denotes a primary “uniqueness” for those studying the new technologies of the information age.

What is uniquely characteristic to the information age is the amount of information available, the interactivity of the technology, technology possessing both mass media and interpersonal characteristics, and the ability for real time presence. Davenport (1997) maintains that most significant attribute of the information age is the ability of individuals to personalize the information search, exerting more control over
the flow of information. These distinctive characteristics beg for an information-centered approach to research, which focuses on how people create, distribute, understand and use this information (Davenport, 1997, p. 2).

**Information technologies**

Goe and Kenney (1990) defined information technologies as “Collectively, technologies combining computers and information processing equipment with telecommunications have become known as information technologies” (p.254). They continued in suggest that information technology is revolutionizing the ways in which information is disseminated, exchanged, and utilized…” (p 255). Davenport (1996) however, warned that there is a real danger in assuming, as so many do, that “technical progress means information progress” (p. 35).

The startling growth and use of information technologies in the private sector has contributed to information, now more than ever, becoming a commodity, not only in the financial sense, but commodity as power, especially in medical world where for so long docs have been the keepers of information. Information technologies have made information access much easier to many types of information (Davenport. 197, p. 11). Davenport cautioned, however, that with the information=power equation, along with that power comes responsibility. And there is a financial cost associated with accessibility of information.

**The Role of Information in Health**

In health communication, studies of information use by patients for reduction of uncertainty and decision making have received considerable attention. Recently, there has been an intensified interest in the patient’s knowledge and beliefs of their illness and the effect this may have on their health condition (e. g., Bradley, 1995; Naess & Malterud, 1995; Kleinman, 1988). Kleinman, Eisenberg and Good (1978) suggested that such an approach, which acknowledges the patient’s experience, should lead to patient satisfaction, compliance, and less criticism of the health care they are receiving. Additionally, research suggests that the chronically ill patient, their family, friends, and health care professionals collectively use information to cope and negotiate the meaning of the chronic illness.
Patients' information uses and needs are influenced by several things, among those being cultural norms and behaviors, accessibility to information and their past experience with illness. However, even given these differences, we can view information as critical for chronically ill patients and, as the literature suggests, empowering the patient in the medical experience. In this review I will look specifically at patient information needs and uses in a) the doctor-patient relationship, b) coping, and c) understanding and participation in health care. In particular, I will examine the informational needs and uses as manifested by the chronically ill.

The Chronically Ill Patient

The emphasis in this dissertation requires a distinction be made between acute and chronic illness. The "official" recognition of chronic illnesses distinct from acute illnesses began in earnest with the publication of the first volume of *Journal of Chronic Diseases* in 1955. However, this distinction was not without dissent. Conceptually and methodologically, the study of chronic illness was not compatible with the general study of "disease" rendering the interest "homeless" and seldom "encouraged or accepted" by mainstream medical journals (Feinstein and Spitzer, 1988). Writing as editors of the *Journal of Chronic Diseases* in 1965, Louis Lasagna and David Seegal politicized, "The editors have refused to confuse chronic disease with geriatrics, or with rehabilitation, or with public health, while at the same time welcoming articles about the aged, physical medicine, and the public health aspects of chronic disease." In spite of this declaration of "independence," there exist, yet today, confusion, and ambiguity about chronic illness, reflecting both lay and professional lack of agreement on the meaning of "chronic."

It is impossible to understand the chronic patient's informational needs and uses without exploring the context in which they live their lives. Goodheart and Lansing (1997) asserted that though "chronic" can be tied to various illnesses, from sore throats to cancer, there is a common psychological thread that binds patients of any chronic illness together. "The individual will never again return to the pre-illness sense of self, of options, of invulnerability, of obliviousness to the body functioning." For the chronic patient their life seems out of control, as well as their body and their sense of reality.
The chronicity of an illness disrupts any semblance of order that the patient had before the onset of the chronic illness. Though the intrusion on time is frustrating, that can be dealt with relatively easier than the embarrassment of not being able to fulfill roles. The change in relationships, both family and friends is more frightening than the discouraging changefulness of symptoms. The loss of self-identity harder to accept than the thwarting of goals and future plans.

Kleinman (1988) distinctly positioned chronic illness as more than the additive nature of illness flare-ups over time. "Chronic illness," he stated "is more than the sum of the many particular events that occur in an illness career; it is a reciprocal relationship between particular instance and chronic course." Chronic illness is so intertwined in the lived experience that "illness becomes inseparable from life history" (p. 8). Thorne (1993) provided yet another glimpse into the world of the chronically ill. "The social world discredits those with various health differences, rendering them incompetent and invalid if not invisible" (p. 7). Goodheart and Lansing (1997) suggested that these fears and struggles are more pronounced for the chronically ill patient in such a "sophisticated technological" era as we live in today.

(Chronically ill) patients are sick. They are not getting any better, and may get worse, which creates a psychological conundrum for people living in a sophisticated technological era. . .(There is) a fundamental dichotomy between the expectations of a technological society, which promises solutions and cures for problems, and the reality of chronic debilitating illnesses, which fosters confusion and regression to the superstitious magical things of the past. (p. 8)

The irony is as medical technology and advances increase life span, the study of chronic illness becomes even more salient. The 1996 statistics from the American Medical Association indicated that there were over 100 million Americans with chronic disease. In 1990 the number of premature deaths attributed to chronic illness was so high that "it costs the United States economy over $161 billion in lost production." In "the age range of 65 and over, 90 % suffer from chronic illness. aged 45 – 64, 70% have chronic illness. In the 18 –45 age range, 35% suffer from chronic illness. The American Medical Association (American Medical Association. 1996, http) reported that 25 % of those under 17 have chronic illness.
These figures don’t lie. They tell us a story that is frightening and sober. Yet, how many people take it seriously? This problem has been growing every year for decades, even with the growing interest in natural health care and nutrition. This means that the problem will not disappear. In fact, there is a lot of evidence that we will have to face a coming plague before things level off.

It stands to reason that people living longer will continually increase the number of those diagnosed with a chronic illness. Mechanic (1995) predicted that this “increasing prevalence” of chronic disease necessitates a reexamining and remodeling of traditional models of health care, which include promoting and maintaining patients’ quality of life through the acquisition, dissemination, and the use of information. Additionally, as it becomes increasingly important to focus on preventive medical measures, the study of the chronically ill permits us to examine long-term practices and strategies for information needs and uses.

At a time when health research has enjoyed a renewed interest, (Perry, 1990; Ong, de Haes, Hoos, & Lammes, 1995), Hayden (1993) and Mishel (1990) proposed that little attention has been given to the plight of the chronically ill patient. Though chronic illness has received some theoretical and research attention (Gerson & Strauss, 1975; Corbin & Strauss, 1988; Lindsey, 1996) the lack of a consensual definition of chronic illness impedes possible theory building or even a clear understanding of what living with chronic illness is like. The ambiguous use, and what some consider the overuse, of the term “chronic” only adds to the confusion and perhaps reluctance to specify the meaning. The literature does offer, nonetheless, some agreement on characteristics of chronic illness.

To be “ill” in the American culture is to be “abnormal” (Crane, 1975) with most persons being “abnormal” for short periods of time. Illness is viewed as “a temporary state” (Ballard-Reisch, 1991) and there is general agreement that the diagnosed chronic illness is not temporary, but will be with the person for most, if not all of their life. The distinction between being ill and being chronically ill is not, however, just a matter of being sick longer. A dark alchemy transforms the way one lives their life and results in “... live(ing) in a “different world.” It is a world separated from their “well” friends, families, and co-workers, and it is a world that can be known only within” (Hayden, 1993). Herzlich & Pierret (1987) observed that chronic illness can be “...a form of life as well as a form of death” (p. 23).
Living life as a chronically ill patient can begin well before the diagnosis is made. The undiagnosed illness can be seen in physical changes, perhaps weight changes or the loss of senses that we have all come to take for granted and which only compound the problems. The chronically ill patient surrenders control of their body (Register, 1989) to the various health care professionals and friends and family who have inherited the obligation of “taking care” of the those who are chronically ill, if not to the illness itself. Identities and roles are redefined (Burckhardt, 1987; Pitzele, 1986) and the chronically ill person senses others defining them by their limitations. The world of the chronically ill can be lonely, isolated, and restrictive.

Few things in life can be as potentially devastating as chronic illness. It affects not only the patient, but his/her friends, family, associates and most of all, the care partner. There are, however, many ways to learn to cope with, and, in some cases even triumph over chronic illness. These ideas and techniques deal with both the physical and emotional sides of chronic illness and can benefit the sufferer as well as those who support and love him or her. (neuro-chief, n. d., http)

It is very often the case that the diagnosis of a chronic illness comes after several doctors’ visits, tests and perhaps hospital admission in which information giving and gathering are the primary purpose. For the patient, it is a relief to finally have a name for their illness (Register, 1987). However, this temporal dimension to information exchange and diagnosis increases anxiety and fear for the patient and augments the uncertainty about their illness and their future. Additionally, time for the chronically ill seems to stand still. It is not uncommon how illness makes days seem longer, the interruption of everyday living seemingly endless. An ill person anticipate that very soon they will be “well.” There is no such anticipation for the chronically ill. Mischel (1990) suggested that the chronically ill live with continued uncertainty, at times the uncertainty being the greater illness. Just as important, the chronically ill see themselves as burdens to those they care for, with their illness rendering them incapacitated for sharing and giving in their relationships (Adelman & Frey, 1997, p.26).

Lupton (1994) questioned the applicability of Parsons’ concept of the “sick” role to chronically ill patients:

While the sick role concept fits acute, curable illnesses, it is not easily adapted to the features of chronic illnesses or permanent disability. If a person becomes ill with a chronic or life-threatening condition, which does not seem to respond to
medical intervention, he or she may be seen to flout the third and fourth conditions of the sick role as outlined by Parsons, by failing adequately to escape the 'deviant' state of illness, and also by failing to benefit from the socially sanctioned solution to illness. (p.p. 89-90)

This perception of failing could explain a commonly expressed feeling of the chronically ill; “I feel so guilty,” or “If I had only...” These feelings of blame and shame could also explain, in part, the motivation for the chronically ill patient to get involved and participate in their medical experience. It could very well be the sanction and approval of society that drives the chronically ill patient to solve their health problems.

Good, Good, Schafer and Lind (1990) wrote:

To despair, to lose hope are frowned upon as strategies of dealing with disease such as cancer. People with cancer are lauded if they appear to be brave, never allowing themselves to ‘give in’ to the disease. There is an emphasis on ‘will’ which argues that ‘if one has enough hope, one may will a change in the course of the disease in the body’, an emphasis which is related to notions of individualism, fighting spirit and the power of thought to shape one’s life. . . (p. 67)

Simply put, the patient has chronic illness, which is not temporary and has to be integrated into his/her life. This indicates a long-term need for information and an ongoing relationship between patient and physician, which Balant (1957) reasoned increases the necessity for the physician “to get to know the patient as individuals in health as well as in illness.” Though Balant’s work focused on the relationship between the general practitioner and his patient, the importance lies in the long-term relationship, which suitably applies to the chronically ill patient and their relationship to their physician. Although the periods of “health” for the chronically ill patient are not “disease free,” there are still relatively healthier periods of time in which the nature of the illness requires contact with the physician or health care team.

Lacroix, Jacquemet, Assal and Benroubi (1995) remind us that a chronic illness is one that can be treated, but not cured. Many chronically ill patients can lead “almost normal lives.” However, the illness brings “a series of difficulties...psychological, professional, domestic, social and financial.” Helman (1995) concurred. “A ‘permanent cure’ is not possible for the chronically ill patient, and long-term ‘care’ is the only option.” According to Lacroix et al. the lives of the chronically ill “bear witness to the difficulty of accepting a new way of life and, for many, the burden which treatment represents.”
The attention to the chronically ill patient is usually found as a footnote or included in the discussion section of research studies. While many researchers recognize the current need for research focusing on the chronically ill, most seem to leave it to "future research." This is further exacerbated by the interchange of "disease" and "illness" by most researchers. There are very real distinctions between these two constructs (Cassell, 1985; Mishler, 1984). Levenstein, Brown, Weston, Stewart, McCracken, and Whinney (1989) explained the difference as "Disease is an abstraction, the thing that is wrong with the body machine; illness is the unique experience of a person who feels ill" (p. 108). We can, nevertheless, begin our exploration of chronically ill patients by looking at studies, which have been designated research of the "chronically ill" by the illnesses they examine.

The Role of Patient and Informational Needs and Uses

The definition one holds of "patient" to a large degree, influences how information is viewed in the illness experience. Parsons' 1951 role characterization of the "sick" minimized the patient's need for information by excusing her from social and role obligations, essentially isolating him from everyday concerns and expecting the patient to get well by "seeking technically competent help and cooperate in the process of recovery" (Perry, 1993, p. 24). The patient was exonerated from the reciprocal give-take nature of relationships once medical professionals legitimized their condition (Lupton, 1994, p. 89) and delegated the patient to a passive role in the medical experience. There was no sense of patient responsibility or decision-making, precluding the need for information. The doctor was perceived as the expert and was responsible for all the decisions made concerning the patient's health care (Tmobranski, 1994). Physicians were the keepers of knowledge deciding what and when patients should know. This practice kept patients from being informed, and only added to the mystic and mystery of illness (Katz, 1984, p. 40). Cahill (1996) described Parsons' perspective of the patient as "a passive client."

Perry (1993) recounted that Parsons, responding to criticisms of his original work, amended his position in a 1979 paper in which he acknowledged the limitations of his view of the sick, particularly in patient participation. He conceded that "the degree of
patient participation is very much dependent on the patient’s state of illness: ‘the less acute the mediate situation, the more likely it is that participation will be substantial.’”

The chronically ill patient was more likely to assume responsibility and participate more in their illness management than acute patients were. Parsons acknowledged the role of family and friends in their treatment, but still argued for the asymmetrical relationship between patient and physician.

In essence, Parsons argued for an unbalanced power in the doctor-patient relationship by either the doctor withholding information from the patient, or the patient not actively seeking information about their illness. Whereas Parsons’ work primarily focused on acute patients, Balaint (1957) suggested differences between short-term and long-term doctor-patient relationships. Balaint prognosticated a long-term doctor-patient relationship built on “mutual influencing” but pointedly recognized the possibility of the unbalanced relationship Parsons suggested. Balaint argued that the practice of medicine was “more than the diagnosis and treatment of physical signs and symptoms” (Perry, 1993) and the role of the patient in a long-term doctor-patient association was elevated from someone uninvolved in their medical treatment to an active participant. With this participation was an assumption of responsibility and therefore the need for information.

Though recognizing possible patient participation, and suggesting the importance of the patient’s perspective on their illness, Balaint (1957), and later Engel (1977), still connoted a paternalistic model of doctor-patient relationships with little need for patient information and participation. The patient, for both Balaint and Engel, was not to question “doctor’s orders” which minimized and trivialized patient partnership. As the role of patient garnered more participation in the medical model so did the patients’ need for information. Szasz and Hollender (1987) described the “mutual participation” model which emphasized the “search” for both physician and patient for treatment strategies becoming “the essence of the therapeutic interaction” (Perry, 1993).

The differences that Parsons suggested in his 1975 paper between acutely ill and chronically ill patients received considerably more attention in Szasz and Hollender’s work. The depiction of the chronically ill patient as active participant implied a search for and sharing of information on diagnosis, prognosis, and treatment options with the
physician. Information was not only for reduction of uncertainty, but used for decision making. The marked difference among these models is the flow of information between physician and patient, and the use of information.

On surface, the literature appears to suggest a positive correlation between patient participation and need for information, with information use for reduction of uncertainty and, as implied to in the mutual participation model, decision-making. Evidence currently available suggests that patients who are actively involved in their medical experience have fewer limitations associated with their illness (Greenfield, Kaplan and Ware, 1985), exhibit higher levels of patient compliance (Craig, 1985), and share more disclosive information (Macleod and Latter, 1990). It should be added parenthetically that the mutual participation physician-patient model is not necessarily the "best." Some patients, for various reasons, and/or at varied times, desire a more passive role in health management.

Mechanic (1979, p. 42) argued that many patients do not want to assume responsibility for care of their illness and want very little, if any, participation in medical decisions. Due to minimal medical experience, more information about their condition or treatment options may, in fact, increase uncertainty as to decisions they need to make. Patients may be overwhelmed with problems other than physical that accompany their illness (Maseide, 1991, p.555) and may turn over complete responsibility to their physician for management of their illness. Patients who do not want to participate but are encouraged to simply go through the motions do not benefit in ways that the willing patient does by participation. For these patients critical pieces of information from the doctor may be conveniently forgotten or distorted.

Pollard (1993) argued convincingly that “The transforming effects of illness, which may radically change a person’s decision-making capacity, are commonly ignored.” Information is the foundation that enables a patient to make appropriate choices. There is, however a wide chasm in patient use of provided information. at least suggested in earlier studies on information needs and uses by patients. Fadden (1977) stated that although 93% of patients who had received information thought they benefited from it; only 12% actually used it in their decision making. Meisel and Roth (1981)
reported that patients had made decisions concerning their health care before information was received. Roling, Pressgrove, Keefe and Raffin (1977) found that 86% of patients said they would agree to any treatment that was suggested, seemingly to support the "physician as expert" perception which has become an increasingly defining characteristic of paternalistic models of medicine.

While recognizing the importance of the studies on patient participation, several researchers have noted the literature lacking in questioning the degree that patients want to participate (Biley, 1992; Barry and Henderson, 1996), when they want to be involved (Baker, 1995; Martelli, Auerbach, Alexander and Mercuri, 1987; Miller, 1987) and how patients need and use information (Luker, Beaver, Leinster and Owens, 1995; Beeney, Bakry, and Dunn 1996). These observations suggest that patient informational needs and uses are patient conditional, varying by virtue of individual differences in coping strategies and illness characteristics. More recently, attention has been directed at the exigency of the chronically ill patient, recognizing that their information needs and uses may differ from acute patients.

The role of information in the physician-patient relationship

A chronically ill patient and his/her physician develop a unique relationship, one that is intimate yet professional. Information exchange underscores this relationship and is determined by the patient’s need or desire to participate in their medical experience. Roter, Hall and Katz (1988) suggested 247 "unique patient and provider variables" identified by analyzing patient-physician literature. The variables were then categorized into six communication process variables: information-giving, information-seeking, partnership-building, social conversation, positive talk, and negative talk.

Wensing, Grol, van Montfort and Smits (1996) indicated that chronically ill patients consider primary in their assessment of quality care, doctor-patient relations, information, and support. Although the two elements are, for practical purposes distinct for discussion, in reality they are not mutually exclusive. In a conceptual analysis of patient participation, Cahill (1996) argued that although the notion of patient participation is accepted in medical practice, few researchers and physicians agree on its meaning. This results in confusion for physicians as to the role they should play in this partnership model of medicine (Clayton, 1988) and for the patient as well.
Even recognizing this, Clayton suggested that patient participation improves self-esteem and mental health, reduces alienation, increases patient responsibility, and enriches the patient’s quality of life. Although patient preference for participation is highly individualized (Clayton, 1988; Biley, 1989) for any patient to feel comfortable in the decision-participating role, (s)he must have information. Luker, Beaver, Leinster, Owens, Degner and Sloan (1995) suggested information as the possible “key to empowerment” and necessary “...for informed decision-making to take place” (p. 135). Biley (1992) warned of a patient’s total dependency without information and Brownlea (1997) wrote that without information patient participation is simply token participation.

Miller and Mangan (1983) pointed out, though, that information, in and of itself, does not hold the key to better doctor-patient relationships. Rather, it is the interpersonal dimension, initiated by the physician, which tempers the information exchange, establishes, and maintains effective doctor-patient relationships (Greene, Hoffman, Charon, & Adelman, 1987). Stain, Fleishman, Mor & Dresser (1993) indicated that interpersonal qualities of the doctor-patient relationship increase patient satisfaction as well. Dunkel-Schetter (1984) found that competent medical care by physicians was actually viewed as unhelpful when not accompanied by emotional support. The concept of patient participation provides a framework for us to study the interaction between information and the interpersonal dimension in doctor-patient relationships.

Inherent in the practices described is an implied power imbalance between doctors and patients, which is perpetuated through practices that often ignore information needs of the patient. However, power and role domination between physician and patient in the medical relationship is viewed differently, as either necessary or subjugating. The meaning of “good doctor-patient relationships” can be interpreted in several ways (Dubos, 1979) and exemplified in various medical practices. A recognition and appreciation of the patient’s needs and preferences, including informational needs and preference for participation in medical care is what underscores the appropriate doctor-patient relationship.

Various needs and expectations are reported by patients regarding their relationship with their physician; patient needs for expression of feelings and emotions
(Lacroix, Jacquemet, Assal & Benroubi (1995), partnership-building (Roter, Hall & Katz, 1988), and needs to develop and implement self-management programs (Day, 1995). A closer examination of the literature suggested that informational needs are the primary expressed concern, either directly identified or as the basis for other patient needs such as trust in their doctor or control in their illness (Koning, Maille, Stevens, & Dekker, 1995). Informational needs have also been noted as most important for patients’ family members. In a 1996 study of parents’ information needs concerning their childrens’ recently diagnosed illnesses, Kai (1996) reported that lack of information made parents feel disempowered, attributed to their physician’s inadequate supportive as well as knowledge information sharing.

Information is not only the foundation of the initial contact of patient and physician, but the purpose for the medical interview and consultation as well. Frederikson (1995) defined the medical consult as “the process of information flow.” She proposed an information-exchange model of medical consultation which, when tested in actual patient consultations, showed that information-exchange tasks are important to patients, and that doctors’ performance on such tasks provide a good predictor of patient satisfaction. Furthermore, Frederikson emphasized the importance of information for the physician, citing that 60% - 80% of diagnosis and treatment decisions are founded on the information gathered during the medical interview (p. 238).

Stewart (1995) suggested that the medical interview can be used for more than diagnosis. The quality of communication in both the history taking and management plan interview was found to positively influence patient health outcomes. Roter (1984) suggested that patient question asking in the physician-patient interaction can be viewed as promoting patient participation as well as information seeking. Evidence has been reported that patient compliance (Lane, 1973), patient health outcomes (Stewart, 1995), the patient’s view of the appropriateness of treatment (Frederikson, 1995) and patient satisfaction (Roter, 1984) are all enhanced by the physician’s engagement in information-exchange.

While there is evidence to suggest the universality of patient informational needs (Derdriarian, 1986), the literature does not suggest that the needs are the same for patients.
The positive results of information exchange between physician and patient in no way imply that all patients want all information or mutual decision making in their medical treatment. In a 1993 study of cancer outpatients, Borgers, Mullen, Meertens, Rijen, Eussen, Plagge, Visser, and Blijham reported that one half (58%) of the studied patients intended to discuss with their primary physician topics of the illness and treatment. Qualitative measures suggest that reduction of uncertainty; fear and dissatisfaction with information were offered as possible reasons for those physician-patient interactions. Borgers et al. also found that the physician or the person accompanying the patient to the appointment initiated 25% of those situations in which the patients indicated a desire for such discussions.

Catalan, Brener, Andrews, Day, Cullum, Hooker and Gazzard's (1994) study on decision making and information seeking for HIV infected patients found that health care professionals had a higher preference for patients’ involvement in decision making than the patients themselves, while finding the opposite case for information seeking. Asymptomatic HIV patients reportedly desired high involvement in their subsequent care by indicating a need for information seeking. Physicians and symptomatic patients however, reported lower levels of desired patient autonomy.

The desire for information seeking as exhibited by the asymptomatic patients. but less for the symptomatic patients may suggest that when options seem more feasible, patients will actively search for those options. Because of the severity of their illness. the symptomatic patients may still resist the responsibility that accompanies active decision-making on their part. Baker (1995) explained the reluctance for information seeking by patients may indicate that patients may have a “certain tolerance level for information” and may avoid information that is viewed as threatening or increasing their frustration for feeling helpless.

Degner and Sloan (1992) stated that patients may not want information so as to decrease their responsibility for possible failure of the treatment. Pollack (1996) proposed that information seeking occurs after the patient has accepted having the illness and suggests that a patient’s “information-seeking state is not necessarily constant” shifting because of various factors. Hardwick and Lawson (1995) agreed stating that
"information needs vary from individual to individual and are dynamic throughout the illness." Information may, in fact, signify a patient's acceptance of responsibility and self-management of the illness.

The results of the Catalan et al. study support the findings reported by Ende, Kazis, Ash and Moskowitz (1989). These researchers found that patients prefer that decisions be made principally by their physicians although they very much wanted to be informed. There was no correlation between decision making and information seeking preferences. The severity of the illness did affect decision making; the more severe the illness, the less desire to make decisions, contradicting Parson's 1975 amended perspective that the chronically ill patient will participate more than the acute patient. In addition, Ende et al. found that age affected the desire to make medical decisions; older patients indicated less need for decision making.

Beisecker (1988) discovered similar preferences. While all 106 rehabilitation patients indicated a need for medical information, older patients gave more decision-making authority to doctors. In the majority of times, questions were asked during the consultation, accompanying companions initiated the questions, rather than the patients. Age was also found to be negatively correlated with attitudes challenging physician authority, which gives rise to the question of perceived role expectations that older patients may have of the doctor-patient relationship.

Studies by Cassileth, Zupkis, Sutton-Smith and March (1980) and Amir (1987) indicated that younger, more educated patients diagnosed with cancer want to be more involved with decision-making regarding their health care. Luker et al. (1995) cautioned that though patients may not want to be involved in decision-making we should not assume that they do not want or need information.

Barry and Henderson (1996) advised that though patients may initially report that they do not want to actively participate in decision-making, as patients become more knowledgeable about their condition, their preference for participation in decision-making increases, underscoring the relationship between information and patient participation. By the same token, physicians need to be concerned with "information overload" for the patient. There is a real problem accessing just how much information a
patient wants or needs. Luker et al. (1995) cautioned that when asked, patients usually say they want all the information they can get about all aspects of their care and treatment.

Patients Not Wanting Information

There is support, however that some patients may not want information, thus indicating little, if any, desire for participation in their medical decisions. For a physician to encourage patient participation without information they may be encouraging a patient’s total dependency (Biley, 1992) and the tokenism Brownlea (1997) described. In a study assessing the degree of knowledge and attitude towards diagnosis information, Centeno-Cortes (1994) noted that 68% of the 92 patients interviewed had not been informed of their terminal diagnosis of cancer. Of this group, 60% anticipated a terminal diagnosis and 42% did not want to receive more information. These findings collaborate Catalan et al.’s (1994) study on information seeking for HIV infected patients.

Several researchers provide possible explanations for these misgivings. Cameron (1994) asserted that hospitalized patients indicated that they did not want more information because “their knowledge was sufficient,” referring to prior information they had been given in the hospital. However, there may be more to this articulated patient perception of information needs than just having sufficient knowledge. Thorne (1988) suggested that many patients perceive information from doctors and health care professionals as unhelpful as well as nonsupportive.

Baker and Stern (1993) discussed states of readiness and the consequence of these states on information needs. Mast (1995) argued that uncertainty of illness increases stress for the patient; the stress influencing acceptable levels tolerance, which in turn influence information needs. Righter (1995) contended that a strong reliance on credible authorities and “expert power” may influence patients’ perceived information needs. and Hack, Denger, and Dyck (1994) noted the effect of the patient’s activism or passivism on information needs. This evidence emphasizes the importance for physicians and health care professionals to understand what the informational needs of their patients are.
The Role of Information in Coping

It is argued by several researchers that patient information needs and uses can be explained as coping strategies (Martelli, Auerbach, Alexander, and Mercuri, 1987; Luker, Beaver, Leinster and Owens, 1996; Lazarus and Feldman, 1984). The notion that information has been found to increase as well as decrease stress figures prominently in the view of information use and need as coping mechanisms.

The question for the physician that leads this research is not, is there a right time to tell the right person the right information? Rather the question should be, why is there a right time to tell some patients something (Baker, 1995)? Seeking information has been shown to be paramount for cancer patients (Northouse and Northouse, 1987). However, Tuckett and Williams (1984) suggested that the focus of the research has been on quantity rather than patients' preference for type of information and the way the information is given. Differences in patients' informational needs and uses have been linked to patients' coping style.

Coping mechanisms refer to strategies people use to deal with stressful conditions. Coping styles may take many forms (Shipley, Butt, Horowitz and Farbry, 1978) and Rahe (1993) proposed that patients with acute illnesses who do not develop appropriate coping strategies go on to develop chronic states of the illness. With Lazarus and Launier's (1978) assertion that coping is a series of transactions between a person and his/her environment's resources and demands, one recognizes coping as more than a one-time action. Viewed within their proposal coping is a set of reciprocal responses occurring over time. The trajectory model of coping concurs with the trajectory of chronic illness. Cohen and Lazarus (1979) suggested information seeking as a primary coping strategy. Specifically, the researchers proposed that information could be used problem solving or emotional regulation, reduction of anxiety and/or used in decisions on future actions.

In the medical and health literature, the most commonly applied "theories" of information as coping are those of Lazarus, Averill and Opton (1974), Miller (1987) and Lipowski (1970). Lazarus, Averill and Opton (1974) proposed when a person is confronted with a stressful situation, how they respond is dependent on their ability to
cope. The coping response is an information-centered appraisal, a "mediating cognitive process." that influences how the person processes information, assesses the relevance of the information to his/her well being and then opts for a coping method. Lazarus et al. suggested that the two primary purposes of coping are emotion-focused coping and problem-focused coping.

The researchers proposed that emotion-focused coping may be used more widely in the first stages of coping and problem-focused coping more useful in the later stages. What this implies is that most individuals proceed through both stages. the emotion-focused and the problem-focused. Of particular interest is the influence of each coping stage on information seeking. According to Lazarus and Folkman (1984) information seeking is usually manifested in the problem-focused coping stage, but can be employed in the emotion-focused stage when information is needed "to bolster a decision already made and so to sustain morale." Information seeking in the problem-focused stage is to "find out what has to be done."

Martelli, Auerbach, Alexander and Mercui (1987) tested the applicability of the problem-focused coping, emotion-focused coping and mixed-focused coping information on patient satisfaction, anxiety, pain response, adjustment and satisfaction with oral surgery. Patients' preferred coping styles were measured by the Folkman and Lazarus (1980) Ways of Coping Checklist. Results indicated the mixed-focus information produced the best overall results for the surgery; the emotion-focused produced the lowest adjustment levels. Better adjustment and satisfaction and lower self-reported pain were obtained when high information-preference patients were given problem-focused information and when low information-preference patients were given emotion-focused material.

The results for the mixed-focus information can be explained by a 1996 study conducted by Wineman, Schwetz, Goodkin and Rudick who examined the relationships among illness uncertainty, stress, coping and emotional well-being. Information was identified as an influence on patients' emotional well being. Results indicated that health status, education, perceived stress, and illness uncertainty were the best correlates of emotional well being. Patients with high levels of illness uncertainty were more likely to
experience mood disturbances and feel less hopeful about treatment effectiveness. This finding concurs with that of Sofaer and Walker (1994) who reported that lack of information for chronic pain patients was the best predictor of negative mood.

In the mixed-focus information group Martelli et al. provided high-information preference subjects with additional information which helped to reduce their uncertainty even more, which resulted in better adjustment and satisfaction and lower self reported pain for this group. Following this line of reasoning, the mixed-focus information treatment for low-information preference patients proved more stressful by exposing them to information they would rather avoid. This finding actually provides more support for the distinction between problem-focused and emotion-focused coping styles. This makes sense if we consider Lazarus and Folkman (1984) position that information seeking usually occurs in the problem-focused coping stage, presumably after a patient has moved through the emotion-focused stage of coping.

Although the Martelli et al. study did not address the use of the specific information by the patients, these findings suggest an interesting direction for future research on patients’ uses and needs of information, rather than focusing primarily on general, overall evaluations and anxiety levels.

Miller’s (1987) monitoring and blunting theory has received considerable more attention in the medical literature. Information is evaluated as either helping to lessen anxiety or increase the patient’s level of anxiety. Miller proposed when “individuals are threatened with an aversive event, they differ in how they deal with information about it” (p. 345). This theory of information seeking is more useful since it presents coping strategies as consistent within the patient although individuals may exhibit both coping strategies as they move through illness. “Monitors” according to Miller, Leinbach and Brody, (1989) are those who seek information which orients them to deal directly with the threatening situation and “blunters” are those patients who avoid threatening information by “distract(ing) themselves from psychologically blunt threatening cues” (p. 333).

Baker (1995) suggested that the stressful “exacerbations and remissions” nature of chronic illness may indicate a difference in coping with a chronic illness rather than an
acute illness. Baker pointed out that few studies have focused on stress in the chronically ill, emphasizing “the need for research on the information needs and information-seeking behaviors of people with chronic disease” (p.24). In a study measuring coping for hypertensive and normotensive patients Miller, Leinbach and Brody (1989) did report the hypertensive patients were “significantly more likely to display a high-information coping style” and monitored information for “threat-relevant cues.” Baker pointed out that Miller et al. (1989) “did not discuss what information is needed by the patients and when they prefer to receive information about their disease” (p. 24).

In a study of female MS patients, Baker (1995) first identified the patients as Monitors or Blunters using the Miller Behavioral Style Scale (MBSS) (Miller, 1987). Baker reported that there was a significant interaction between general orientation to information and length of time with MS. Her hypothesis that monitors would find both general and specific information relevant to their needs and blunters would prefer general information was confirmed.

Her results also showed that monitors began searching for information as soon as they were diagnosed, and blunters looked for general information only after having MS for a period of time. Baker further concluded

In controllable situations such as MS, monitors will seek information whether they need it or not because the information will give them an idea of how their MS will become. If and when the worst happens they are prepared for it, and the effects of stress are less then if they had not collected the information. (p. 27)

Baker cautioned not to assume that blunters who have a chronic illness do not want information. She suggested that blunters “may seek information only when they know they can handle the stress the information may provoke.” In addition, Baker reported that information-seeking behavior and preferences were consistent over a period of three time frames, the newly diagnosed (diagnosis to 1 year after diagnosis), the active coping period (2 to 3 years after diagnosis), and the acclimated period (5 to 7 years after diagnosis) offering insight into the trajectory of a chronic illness and patients’ information-seeking behavior over time; monitors wanted specific as well as general information throughout their illness, blunters preferred general information through the illness.
In an earlier study Davis, Maguire, Haraphongse and Schaumberger (1994) researched the interacting effects of coping style and preferred type of preparatory information on cardiac catherization patients' anxiety. Working from Miller and Mangan’s 1983 proposal that patients will experience less anxiety if the preparatory information matches their coping style, Davis et al. hypothesized a patients coping style interacted with preparatory information material to effect the patient’s anxiety levels.

Specifically it was hypothesized that bluters would have lower levels of anxiety if given procedural rather than procedural-sensory videotaped modeling information. Monitors would have lower levels of anxiety when given procedural-sensory rather then procedural videotaped modeling information. It was also expected that patients receiving the videotaped information would have greater anxiety reduction than those receiving the information booklet. After assessing the patients' copying style by the MBSS and patients' anxiety by Speilberger’s A-Trait and A-State Inventory, monitors and bluters were randomly assigned to receive one of three preparatory informational treatments: 1) videotaped procedural modeling information; 2) videotaped procedural-sensory modeling information; and 3) procedural-sensory information booklet.

It is worthwhile to note the operationalization of procedural and procedural-sensory in this research. The type of information presented defined each. The procedural information presented focused on a same-gender patient model going through the steps involved in the catheterization procedure: being admitted to the hospital, awaiting the procedure, undergoing the procedure, returning to the hospital room, and being discharged.

The procedural-sensory information viewed an identical same-gender video, but included patient voice overs talking about how the patient would feel, and what they could expect to see and hear (p.132). These operationalizations reflect Baker’s 1995 hypothesis that bluters would prefer general information, whereas monitors would desire specific information. Results confirmed the hypothesized interaction between patients' coping style and type of preparatory informational treatment with monitors, after receiving the procedural-sensory modeling video treatment, and bluters, who received the procedural modeling video treatment, reporting less anxiety during and after the procedure.
In an extension of the study Davis et al. (1994) used the same patients and examined the effects of the preparatory informational treatments and preexisting coping styles on patient anxiety during the procedure, focusing on patient self reports of anxiety, physiological measures and a behavioral measure. Davis et al. found that patients receiving the videotaped modeling treatments did exhibit greater behavioral adjustment than patients who received the informational booklet did. However, coping style did not appear to significantly influence any of the measures of patient anxiety.

One explanation could be that patients' knowledge base coming into the situation was not measured and the medical history of the patients not considered. In addition, it was unclear whether the anxiety scores were a reflection of the actual procedure or patient expectations about the procedure. There is also the possibility that the differences in ideational content between the videotaped material and the booklet influenced the behavioral adjustment. Results from the two studies do point to the possibility that informational needs and type preference are different for monitors and blunters.

Davey, Tallis and Hodgson (1993) studied patients designated as having either information-seeking and information-avoiding coping styles and the symptoms they reported. Patients were categorized as either monitors or blunters using the MBSS. Blunters were found to report more physical and psychological symptoms than monitors do, with no significant relationship found between monitoring and symptom reporting.

Most interesting was that the relationship found concerning the blunters was independent of other factors, such as negative life experiences and levels of trait anxiety, that have been shown to influence health. Davey et al. argued, results indicated that blunters reported more illness symptoms as a result of failing to respond to initial illness cues (which monitors would have) or seeking treatment at a later stage in the illness. This explanation could be extended to account for the nonsignificant relationship found between monitors and their reported symptoms: monitors may have had enough information about their symptoms before the doctor's appointment resulting in fewer symptoms reported.

Though the findings of the reported studies appear inconsistent, one must consider the diverse methods in which patients were studied (Baker's questionnaire, Davis et al.)
measurement during a procedure. Davey et al. evaluations of actual patients’ reporting symptoms) which circumspect concluding the validity of the Miller Behavioral Style Scale. None of the reported studies attempted to measure base knowledge of the patients, as well as not studying actual information-seeking. What can be discerned is that patients seem to have different informational needs and uses which can be identified and used for more effective patient education.

Information has also been identified as an influence on patients’ emotional well-being. A 1996 study conducted by Wineman, Schwetz, Goodkin and Rudick examined the relationships among illness uncertainty, stress, coping and emotional well-being. Results indicated that health status, education, perceived stress, and illness uncertainty were the best correlates of emotional well-being. Patients with high levels of illness uncertainty were more likely to experience mood disturbances and feel less hopeful about treatment effectiveness.

In summary, theories of information use as coping strategies for patients suggest that coping can be categorized as either emotion-focused or problem-focused (Lazarus, Averill and Opton, 1974); monitoring and blundering (Miller, 1987); or conditional on the patient’s subjective meaning of his/her illness.

Lazurus and Folkman’s 1984 study suggested that problem-focused information seeking centers on the practical (what has to be done) whereas emotion-focused information seeking is directed at confirming and supporting decision-making. Miller’s 1987 proposed monitor and blunter theory recognized coping as a constant patient characteristic, consistent over time and situation.

Miller’s perspective on coping as similar to the information seeking practices advanced in Festinger’s (1957) cognitive dissonance theory. That is patients either seek or avoid threatening information concerning their health state with “monitors” confronting the threatening information and “blunters” avoiding perilous information. Monitors may in fact, through their information seeking practices, develop a “tolerance context” in which to process threatening information. As in Festinger’s idea of consistency in information, threatening information for monitors may still be consistent with their accepted view of their illness.
Skipper and Leonard (1965) documented a major complaint for patients was lack of communication between patient and physician. This is emphasized by Roth (1963) who reported a general practice was “that a doctor or nurse ‘never tell a patient everything’. . . there is always some information that is considered a threat to the control of treatment or hospital management if known to the patient.” Roth found that health care professionals were advised to “consider whether the patient may ‘misrepresent’ what he learns about himself (or about others that can refer to his own case), or whether he will act in an undesirable way to information given him” (p. 307).

More astounding however, is that Roth concluded his work with the observation. . . physicians are often reluctant to admit any uncertainty about diagnosis, treatment or control . . . because they are afraid that patients will interpret uncertainties and disagreements to mean that the doctors do not know what they are doing, that the treatment procedures . . . are mistakes, or that the patient’s guess is just as good as that of the doctor. (p. 307)

Though seeming to protect the patient, these practices resulted in information controlled by the physician and fostered a submissive and subjected role for the patient. This increased uncertainty and nonparticipation of the patient in his/her medical plight. Previous research on information needs of the chronically ill have yielded similar results: information, and perhaps the active role of information seeking, increases participation and involvement of the patient in their illness. Consequently, research has indicated, involvement and participation have both physical and emotional benefits for the patient.

The consequences associated with little or no information are even more problematic for the chronically ill patient. By its nature, chronic illness necessitates a life-long need for information and emotional support. By increasing the availability of and accessibility to information once considered the domain of the medical privileged, and by the broadening of support resources, information technologies have changed the face of chronic illness.

The Internet

The Internet has revolutionized availability and accessibility of information for patients. Thirty-two years ago the United States Defense Department launched an experimental project as a communication system to conduct sensitive top government research. Sharing similar characteristics with the government development of the
interstate highway system of the 1950s, the system was designed to function if parts of the system were damaged, even in nuclear war. This ability was made possible with automatic response of re-routing communications if one or more individual links were made inoperable. (Text Communications Decency Act, 1996, paragraph 9)

By prescripting multiple links to and from each computer information could travel a variety of routes, thus insuring delivery despite operational failures. The project, Advanced Research Project Agency (ARPAÔ), was called ARPAnet. The project was characterized as having no central authority and ironically, as Campbell (1998) pointed out, the most hierarchically structured and central organized institutions in our culture, the national defense industry created the Internet, possibly the least structured and most decentralized social network ever conceived (p. 36). The ARPAnet linked military computers and computer networks, defense contractors and university laboratories conducting defense-related research. Eventually, the network was used to directly access large supercomputers located at a few chosen universities and laboratories. Additionally the military computer system allowed, through leased telephone lines, the ability to send letters and memos electronically (email) and post information on bulletin boards, which are computer locations which distribute information on specific topics (Campbell, 1998, p. 37). These resources were made available to others besides government and defense workers, universities, corporations, and eventually people around the world. ARPAnet came to be called DARPA Internet, nicknamed the Internet and then the Net.

Simultaneous to the maturity of ARPAnet, which subsequently lapsed, was the development of analogous computer networks connecting universities, research facilities, businesses, and individuals globally. These networks included BITNET, CSNET, FIDONET, and USENET. Campbell likened the unlinked networks as “an enormous free-floating library without a Dewey decimal system” (p. 42). The World Wide Web, a system that organized and standardized information on the Internet, eventually connected these networks. The World Wide Web, introduced as a text-only data-linking system, eventually, through hyperlink, allowed users to navigate through the Internet and access information that was located anywhere on the Internet.
Internet usage became much easier through the feature of hypertext markup language (HTML) which allowed users to access information located on other computers by merely clicking on highlighted words, phrases, or pictures. Standardized software made possible access to other files besides text-only, which included photo images files, and video and audio clips. Hyperlinking allows flexibility in information access and organization. Links are used for leading from overview to more specific information, from tables of content to specific pages and can also be used as cross-referencing, footnoting, and new forms of information structure. Hyperlinks are what unify the web into a singular coalition of information, and uniquely characterizes the World Wide Web. The WWW Consortium, which is a joint initiative of CERN (the European Particle Physics Laboratory) and MIT (Massachusetts Institute of Technology) oversee the continual interoperability of the World Wide Web.

In less than three years there were more than 10 million electronic documents at a quarter million Web sites. Miller, (1995) contrasted this to the 195 years it has taken the Library of Congress to collect 14 million books. These sites have been developed by individuals, companies, and organizations and can now be designed on relatively unsophisticated computers and relatively inexperienced users. Campbell claims that “almost all national TV commercials include the product’s Web page address where more information about a company or its product can be found.” Schwartz (as cited in Campbell, 1998, p. 42) suggested that in 1996 new pages on the Web were posted at the rate of one per minute.

The “Findings of Fact” cited in the text of the decision on the constitutionality of the Communications Decency Act (Communications Decency Act, 1997. http, paragraph 3), part of the Telecommunications Act of 1996, advanced the following history and the basic technology of the Internet.

In 1981, fewer than 300 computers were linked to the Internet, and by 1989, the number stood at fewer than 90,000 computers. By 1993, over 1,000,000 computers were linked. Today, over 9,400,000 host computers of which approximately 60 percent located within the United States, are estimated to be linked to the Internet. This count does not include personal computers people use to access the Internet using modems. In all reasonable estimates are that as many as 40 million people around the world can and do access the enormously flexible
communication Internet medium. That figure is expected to grow to 200 million Internet users by the year 1999.

Business and commercialization have played an important role in the development and the attraction of the Internet though not the primary sector of the World Wide Web. Commercial use was cautioned when the Internet was first advanced for public use. However, many businesses and organizations maintain web sites to disseminate information about products or services. More prevalent are the locations for non-commercial purposes, which include email, bulletin boards, newsgroups, and chatrooms.

The fact that there are no owners of the Internet guarantees that each hub in the network has equal postures, independence, and dominion rights, assuring security in maintaining their position on the Internet. According to text of the decision of a special three judge panel in Philadelphia ruling on the constitutionality of the Communications Decency Act (paragraph 11)

No single entity -- academic, corporate, governmental, or non-profit administers the Internet. It exists and functions as a result of the fact that hundreds of thousands of separate operators of computers and computer networks independently decided to use common data transfer protocols to exchange communications and information with other computers (which in turn exchange communications and information with still other computers). There is no centralized storage location, control point, or communications channel for the Internet, and it would not be technically feasible for a single entity to control all of the information conveyed on the Internet.

Nineteen hundred and eighty-two marked the entrepreneurial emergence on the Internet. Campbell (1998, p.38) attributed this stage to the National Science Foundation's investment in a high-speed communication network designed to link computer centers around the country. The dissolution of the Soviet Union in the late 1980s resulted in the cessation of the ARPAnet military program, but not before commercial interests, computer programmers, researchers, and hackers had created tens of thousands decentralized intersections. Campbell suggested that as the military predicted, the lack of central authority meant that the Net could not be knocked out.

By 1993, the Net developed multimedia capability, allowing users to travel with pictures, sound, and video. In the same year, the web browser Mosaic was released. The Net, according to Hobbes's Internet Timeline (handshake, http) increased its annual
growth by 341.634% of service traffic. Today, the Net consists of fifty thousand regional computer networks called servers: individual host computer centers run (or hosted) by universities, corporations, and government agencies, all interconnected by special high-speed phone lines. Twenty to forty million individual and institutional users were served per day in 1996 (Campbell, 1998, p. 38).

It is arguable that the Net has provided the opportunity and challenges to reshape and restructure human relationships that captured our attention in the work of Marshall McLuhan in the 1960s. The notion that technological changes are interrelated, in fact determinant, of other social change has been parlored as technological determinism (Straubhaar & LaRose, 1997, p. 46). It is imperative in understanding this philosophical stance that one explores beyond the technical foundation of the Net to the ethereal province of the Internet -- cyberspace. The Emergence of Cyberspace

The term cyberspace first appeared in William Gibson's science fiction novel Neuromancer (1984) defined as "a consensual hallucination...a graphic representation" Campbell (1998) understood cyberspace as the mysterious regions where the global networks of computer communication take their users (p. 39). Though euphonious, these definitions did not provide an utilitarian conceptualization of cyberspace. More practical and working definitions of cyberspace are innumeious. Despite what appears to be limitless definitions, there is, however, a common thread which runs through all; the intangible and mediated space (through information technologies) which promotes interactivity and a sense of others presence. In Wired Style: Principles of English Usage in the Digital Age, cyberspace is defined by the editors of Wired as "information space... The place between phones, between computers, between you and me. Que's Computer and Internet Dictionary (AOL, 1996, http) distinguishes cyberspace as the virtual space created by computer systems. Accessibility and Content The infrastructure of the Internet provides the foundation for meeting the necessary conditions of information availability, interactivity, interpersonal characteristics and real time presence, the unique characteristics of the new information technologies. The reality of these conditions, however, gives rise to the issues of accessibility to and content of the Internet. The controversy surrounding the issue of accessibility focuses on who and how individuals
receive information or interact on the Net. Of particular interest are the costs associated with this access and the very real concern of status identification of the haves or have-nots. Once costs are incurred to receive information from the Net information becomes a commodity, to be bought and sold.

The Internet, as all information technologies, has received both praise and protest in predictions of its influence on human communication and relationships. There are, however, unique characteristics of the newly communication technologies. Maxwell and McCain (1996) highlighted these differences as new media are more decentralize in that supply and choice are no longer controlled exclusively by a technology provider. Secondly, in terms of capacity, storage and distribution devices can accommodate tremendous amounts of data; an order of magnitude unimaginable in previous epochs. Thirdly, new media support interactive or two-way communication; the receiver is no longer exclusively a recipient but now can select, respond, exchange and be linked with others. And finally, new media are flexible, offering users many more options in form, content, and use of communication technologies (p. 2).

Some argue that the internet provides the foundation for developing and maintaining a utopian global village rendering effete the temporal and spatial restrictions imposed on human communication without computer connections. Those advancing the reverse, argue that cyber communities equivocate to false communities characterized by isolation, challenging the rudiments of human communication and relationships (Campbell, 1998, p. 34).

Cyberspace connects people to one another. This doesn't ensure community, as the connectivity made possible by cyberspace is too often a one-way, broadcast flow of information, but where there is interactivity on-line, a mutual exchange, there, in a broad sense, community exists. Sometimes the community is as evanescent as a lightening flash, as when a group of strangers meet by chance and for one time only in a chatroom on America On-line. Sometimes it is longer lasting... (Zaleski, 1997, p. 244).

These bipolar views are fairly familiar going back at least to the discovery of electricity. Samuel Morse, in 1850, stated that he saw "no reason why intelligence may not be distributed throughout the planet by means of electricity." Campbell (1998)
reminded us that the circumstances surrounding the advent of earlier information technologies similarly encircled the development and advancement of the internet.

The social, political, cultural and economical climates of the twentieth century have been instrumental in the Internet emerging as technology that has reshaped and restructured patterns of social interdependence and every aspect of our personal lives (McCluhan, 1964). Bernstein and Kline reported the Internet as the most wide-ranging interactive mass medium in history (1995, p. 105) and it has been predicted by 1997, 50 million internet users with expected growth by the year 1999 to 200 million internet users (Communications Decency Act, 1996, http).

Though staggering, these numbers are somewhat misleading. The nature of the Internet is such that it is very difficult, if not impossible, to determine its size at a given moment. It is indisputable, however, that the Internet has experienced extraordinary growth in recent years. In 1981, fewer than 300 computers were linked to the Internet, and by 1989, the number stood at fewer than 90,000 computers. By 1993, over 1,000,000 computers were linked. Today, over 9,400,000 host computers worldwide, of which approximately 60% located within the United States, are estimated to be linked. On any given day 30 million people in 50+ countries connect on the Internet (Nosh Productions, 1998, http)

It is the Internet's "extremely resilient, flexible, and adaptable facts" that Nosh Productions attributes the attraction of the Internet as a new medium for communication. According to this report "Today, the Internet is a vast, continually expanding global network connecting more than five million host computers used by approximately 60 million people inside and outside government and educational institutions" (Nosh Productions, 1998, http, p. 2)

**The World Wide Web**

The original proposal for the World Wide Web in 1989 was submitted by Tim Berners-Lee to CERN (European Laboratory for Particle Physics) as an attempt to persuade their management of the necessity of "a global hypertext system" for the Internet (Stars, 1997, http). The proposal addressed the management of general
information, prompted by the problem of loss of information due to the turnover of
employees.

Berners-Lee described his vision of such a system, a system that, from its
conception, was an information management system. Quoting at length to show the
beauty in the astuteness of his thinking

the hope will be to allow a pool of information to develop which could grow and
evolve with the organisation and the projects it describes. For this to be possible,
the method of storage must not place its own restraints on the information. This is
why a “web” of notes with links (like references) between them is far more useful
than a fixed hierarchical system. When describing a complex system, many
people resort to diagrams with circle and arrows. Circles and arrows leave one
free to describe the interrelationships between things in a way that tables, for
example, do not. The system we need is like a diagram of circles and arrows,
where circles and arrows can stand for anything. (p. 2)

It is perhaps this inherent common sense that Berners-Lee brought to his project that
helps account for the wide and rapid acceptance and application of the world wide web
by users today. Recognizing that others were working on similar programs, Berners-Lee
continued

Meanwhile, several programs have been made exploring these ideas, both
commercially and academically. Most of them use “hot spots” in documents, like
icons, or highlighted phrases, as sensitive areas. Touching a hot spot with a
mouse brings up the relevant information, or expands the text on the screen to
include it. Imagine, then, the references in this document, all being associated
with the network address of the thing to which they referred, so that while reading
this document you could skip to them with a click of a mouse.

In 1980 Berners-Lee wrote a notebook program titled “Enquire-Within-
UponEverything” while consulting for CERN. Originally, the 1989 proposal was
shelved, only to be redistributed in May 1990, with no changes. In October Berners-Lee
and Robert Cailliau co-authored a reformulated proposal and the name World Wide Web
was chosen for the project (over Information Mesh, Mine of Information, and
Information Mine). Berners-Lee had proposed the development of Hyper-Text Language
Markup (HTML) as the shared language necessary for platforms to be linked together on
the “web.” As the World Wide Web developed, so consequently did HTML. A 1992
summary of the World Wide Web reads
The WWW world consists of documents and links. Indexes are special documents which, rather than being read, may be searched. The result of such a search is another ("virtual") document containing links to the documents found. A simple protocol ("HTTP") is used to allow a browser program to request a keyword search by a remote information server. (Stars, 1997, http)

The links within Web pages can connect to other documents besides other Web pages. They can indeed, link to graphic, sound, or video files through application programs provided by the Web browsers.

Cailliau, who co-authored the 1990 proposal for the Web with Berners-Lee, in a 1995 speech given at the launching of the European branch of the W3 Consortium, traced the historical movement that predated the Web and indicated the "acceptance" of the Web by the number of servers since 1992. In 1992, there were 50 servers worldwide. In 1993 the number had increased to 250, 1994, 2500 servers. At one point in 1995, 700 new servers were being registered daily, and the number of worldwide servers reached approximately 73,500. Today, in 1998 there are estimated to be more than 300,000 active Web servers across the world (Nosh, 1998, http).

It was in 1995 that Cailliau documents as the time when the World Wide Web is generally equated with the Internet. Yet there are some very practical differences between the Internet and the World Wide Web. The Internet was developed 25 – 30 years ago and is a technical system that operates on basic computer science concepts and rules. The World Wide Web is only one way to access and navigate the Internet. Others include gophers, ftp, the files exchange system, and email systems.

The World Wide Web system was conceived of eight years ago and is a system that is used to develop "the global field of texts (as well as images, animations, sounds, etc.)," with all texts cross indexed (Internetvalley, 1998, http).

The ease of navigation and access and the availability of software contributed to propelling the World Wide Web as the most popular navigational operation of the Internet, and has consequently changed, according to some, not just how we know, but who we are. Nicholas Negroponte (1995) suggested as much when he observed "Computing is not about computers anymore. It is about living" (p. 23).
Electronic Forums

Electronic forums are discussion groups which exchange asynchronous messages through computer networks. The Internet provides several forums for patients to access these online communities. Email, mailing lists, newsgroups, chatrooms, and web sites on the world wide web are the most frequently used forums.

Rojo (1996) suggested that electronic forums are used to bring people who have similar interests, but are geographically distant, together to exchange information, viewpoints, and ways of doing things” (p 1) at a comparatively low cost. Rojo does caution that participants may experience information overload, and that content irrelevance and poor quality of information have been reported by newsgroup participants (1996, p. 1). Some newsgroups are moderated, meaning that questions are submitted to a moderator who controls what message will be distributed to the newsgroups. Discussion groups can be synchronous, meaning real-time or “live,” or asynchronous, meaning messages are distributed and read when convenient.

The strength of electronic forums, according to Rojo (1996) is the interactivity of the forum, more specifically the reciprocal interdependence among users. Underscoring the concept of reciprocal interdependence is that the participants “cannot achieve the potential benefits offered by the medium on their own” (p. 3). Markus (as cited in Rojo, 1996, p. 3) has suggested that if initial submitted messages receive no response than the participant will likely leave the newsgroup. It is important to note, however, that interactivity is not a medium attribute. The medium only provided the tools to make interactivity possible. It exists only through the communication process; the participants “create” interactivity (Rafaeli, as cited in Rojo, 1996, http).

Rojo emphasized the on-line interaction being the drive of reciprocal interdependence. “It is on-line interaction itself that draws people in to contribute messages” (p 3) and cited Feenberg (1987) who offered that on-line messages achieve two goals: to communicate content and to stimulate the responsiveness of others. Rojo referenced Rafaeli in his contention that a “more active on-line communication setting is likely to increase participation.”
Email

The foundation for any electronic communication using information technologies is email. Email is the primary use of Internet services. Messages are sent worldwide instantly, with most messages being received within minutes. Email transmission is routed to the receivers' email address which is divided into two parts formatted as the username@domain. The "@" symbol is spoken as the word "at." The email address is analyzed by a mail server in reverse order for transmission. The domain in the address represents the specific computer which handles the mail for the receiver, the username the account of the recipient. Received email is stored in the "in" box of the computer until the receiver reads it.

According to a 1998 Internet survey email has contributed most to the development of intranets, internal networks for corporations or institutions. Fifty % of 3,000 surveyed indicated that email was their primary use of the intranets (NUA. 1998. http).

Mailing Lists

Mailing lists are distinguishable from the other forums mainly by the underlying technology. A participant does not have to log on to read messages, this being the chief benefit of mailing lists. Only subscribers receive the electronic mail if the mail list is restricted to authorized participants.

Mailing list messages are forwarded to the "In" email box, either as individual messages or as a digest or newsletter. Messages from moderated mailing lists are edited to send only "relevant" messages. The participants of unmoderated mailing lists are forwarded most any message on a topic. Forwarded messages can include information on medical trials or research a patient may choose to participate in, research findings, and on patients' experiences.

In October 1991, there were two mailing lists, namely www-interest@info.cern.ch and www-talk@info.cern.ch which were developed to network researchers and employees of CERN. Ogden (1998) (http://www.gretmar.com/webdoctor/ Articles/taming-lists.html) estimated that there are over 40,000 listservs, the number growing daily. He suggested two ways that may make it easier and more efficient in choosing a
listserv in which to participate. The first way is to access “Liszt” which provides a complete, up-to-date list of all mailing lists. Medicine-related mailing lists may be found under the “Health” hypertext link. The second way is to use an automated method exists to search for existing mailing lists using email. Send an email message to listserv@listserv.net with a blank subject line and the words “list global medicine” in the body of the message. A few moments after transmission of the message, a reply will be returned with a list of active medical mailing lists. All submitted responses or comments will be distributed to all subscribers. Ogden advised that by lurking or remaining a “passive participant” for a few days, the norms and rules of the listserv will be apparent.

Listservs

Listserv is the primary mailing list forum which manages mailing lists for specific groups, only one of several mail servers. A subscriber to a listserv will be forwarded information on relevant topics, or messages will be forwarded to all members on the listserv. Unfortunately, there is a very real problem of “electronic junk mail” when a computer program such as Listserv forwards the information. These forwarded messages take up reading time as well as memory in a computer, as the mailing servers.

There is also the danger, with unmoderated mailing lists, that negative and spiteful comments may be distributed. There may also be a flood of forwarded messages, many of which may be irrelevant. It is important to keep in mind that submissions are made public to all subscribers. If a participant wishes to address only specific participants, messages need to be sent to the others’ private email address.

Newsgroups

Whereas mailing lists forward messages only to subscribers, newsgroups offer a forum where messages are posted on virtual bulletin boards and can be read anytime by anyone. Newsgroups are asynchronous “conversation” between participants who can be linked by postings on an “electronic bulletin board.” Rojo (1996) specified four reasons for participation in a newsgroup, 1) Getting information and keeping updated, 2) to participate in or listen to the exchange of ideas, 3) network with others of similar interest, and 4) meet other people and to keep and develop contacts (p. 2).
Typically, the focus of the newsgroup is identified in its address such as <alt.support.depression> which indicates a newsgroup devoted to self-help and support for depression. The newsgroup forum allows participation in an ongoing discussion of the group's focus. Newsgroups are distributed through the conferencing system Usenet news groups and are sometimes referred to as USENET news. Net news, network news, or Internet news. Participants are required to subscribe to their chosen newsgroups. It is possible to structure a list of newsgroups which can be accessed by simply clicking on a "Read My Newsgroups" link.

Newsgroups are hierarchical and the level of a particular group is identified in the address prefix. For example, the address <alt.support.depression> identifies that newsgroup's level as an "alternative" application procedure. This refers to the alternative procedure that was utilized in the development of the newsgroup. The prefix "comp" indicates groups that focus on computer topics. "Soc" identifies social issue discussions and specific social groups, and "talk" groups connect "people who like to argue" with others who discuss current controversies (Ferguson, 1996, p. 202).

For most newsgroups, it is possible to subscribe on-line. After subscribing, the participant will receive a "welcome message" which will describe the content, purpose, and customs of the group with an I.D. or password to use when accessing the group. Once the connection is made, the participant will see a list of topics that are currently being discussed. The number of postings for each topic is also designated.

Newsgroup postings are basically email messages which can be read by all of the subscribers. Health Links, which is located on the Health Way site (HEALTHWAY, n.d., http) gives access to over 1,725 health oriented newsgroups. Newsgroups not only give access to patients with similar health issues and concerns, but to experts on a variety of topics. These experts can be physicians, health care professionals, or researchers. Ironically, the strength of newsgroups may also be their weakness. Because of ease of accessibility and participation, anyone can contribute. It is impossible to know if the person is who or what he/she portrays in their message.

Before posting to a newsgroup the participant should request and read a list of "FAQ" (frequently asked questions) if available. The list will provide more information
on what the group discusses as well as indicating what you should not post. One
"netiquette" rule: Don’t ask questions that have already been answered. Archived
discussions allow the participant to read responses to that particular question. The
newsgroup may post their “FAQ” list periodically for the group, or give an email address
where you can request the list.

Subscribers also received suggestions from other group members to make it easier
to respond to the postings, lessen the amount of email received decrease the problem
several group members have raised concerning personal emails being posted to the
listserv. Usually, members initiate the changes in netiquette after a “cyber” discussion.

Ferguson (1996) suggested options that the newsgroup participant has after
reading the postings. After you have read the postings of a newsgroup, you have several
choices. First, you can add an additional public comment to the existing thread. Second,
you can start a new thread with a new subject heading on a different topic. The third
option. Ferguson suggests is that you can send an email message to anyone who posted to
the newsgroup. Only the person who wrote the original posting will see your message.
Ferguson also suggested you can, of course, read the messages without responding at all
(p. 206). Ferguson also advises to think and proofread before you post. If your message
or question is not clear, you will probably receive no responses.

The “Help Seawyn” (Play/Seawyn. 1998. http) newsgroup is structured
differently from the conventional question – answer format of other newsgroups.
Participants are given a specific “question of the month” and are asked to submit
answers. A list of the submitted answers are sent email to all subscribers along with tips
on how and where to search for health/medical information on the Internet.

Chatrooms

Real time, both the defining characteristic and benefit of chatrooms, reflects
“live” interactions, synchronous “talk.” Chatrooms are the ethereal spaces where any
number of people can electronically gather to participate in exchanging messages on a
particular topic. Chatrooms are open at scheduled times when the participants log on.
These “virtual” meetings offer advice and information, and the opportunity for cyber
debating and sociability. The real time factor of chatroom communication distinguishes
this format from other CMC formats.
Chatrooms are the cyber equivalent of social clubs or organizations that meet routinely face to face. The advantage, of course, is that they operate without the time and space restrictions of those face to face groups. These electronic meetings provide visual anonymity, are not subjected to the stereotypes and prejudices found in face to face groups, and to some degree, provide a less riskier context for self-disclosure.

Participation in a chatroom requires a program that will allow the participant to join internet relay chat. The Internet relay chat server (IRC) receives messages, and then forwards all messages to other servers. Specific topics (or chatrooms) are channels in which conversations have been organized. As suggested with other electronic forums, passive participation such as lurking, allows the participant to observe the norms and practices of the chatroom before actively participating. Due to restrictions within America On Line, Compuserve, and Prodigy members of one service cannot "communicate" in chatrooms with another service. There is, however, a 24 hour chatroom at no cost, located on AnotherNet. Registration for a chatroom is critical for keeping the channel opened and the chatroom not dropped. Some chatrooms provide copies of the email an individual has sent if requested.

Many chatrooms are designed for communication among members of mailing lists, a number of them allow entrance to anyone. This has created "crowding" problems that limit and restrict the communication among the members that were orginally designated for the room. For example, PALS is a chatroom, started in August 1996 for children with serious illnesses or who have a family member with a serious illness. The original intent in the development of the PALS was that children would have a chatroom where they could discuss, share their feelings, and have fun with other children. PALS, though a "scheduled private" chatroom, is being visited by nonmembers, who arrange to meet others. This not only disrupts the conversations, but takes up time with irrelevant message to the children. The children who regularly meet have voted to change the name of their chatroom, hopefully to reduce the number of uninvited participants.

Web Sites on The World Wide Web

The world wide web (WWW) is but only one index system used to travel the Internet, albeit the primary one. The ease of access and the commercial success of the
WWW has positioned it above other protocols such as gopher, telnet, or FTP (file transfer protocol). Hypertext Markup Language (HTML), was the programmed language that was used to connect and make transmission possible from the individual computer servers. Originally, the world wide web was only text-based, meaning that the files accessed from other computers could only be read. Today, instead of hypertext linking, hypermedia makes it possible to link to world wide web sites that can include graphics, pictures, videos, and/or audio.

Through the WWW it is possible to produce, locate, and download on-line documents, such as Web sites or homepages rich in multimedia messages. A homepage is the point of origin or the surface layer point of reference, which may link to other layered information. A commercial server (i.e. America On Line, CompuServe) can access these homepages or web sites, as well as a direct Internet connection. These connections are driven by web browser software (i.e. Netscape Navigator). It is through network-wide hypertext that web sites can provide links to other web sites, discussion groups, or homepages by simply clicking on the link, usually displayed in blue.

The Graphics, Visualization, & Usability (GVU) 1998 User Survey, sponsored by The World Wide Web Consortium (W3C), indicated the following information about users' perceptions of the web. From a sample of over 10,000 web users, privacy is the primary issue of concern for web use (30.49%) surpassing censorship (24.18%); privacy being the most important issues for women, censorship for men. Over time (with experience) concern over privacy decreases, and censorship increases. The number of female respondents to the survey increased 7% over the previous years, with 42.64% having gone online within the last year. Supporting the idea that the Web has been considered the primary resource for information, 84% stated that the web was indispensable, 84% of that number indicating email as indispensable, chat 22%. Ninety-four % of the experts use the web daily, compared to 78 % of the novice. (Graphics, Visualizations, Users' Survey, 1998, http) To analyze the data, three categories representing length of experience on the world wide web were created. The "novice" category was assigned to respondents with a year or less web activity. The majority of the "expert" users have been active the World Wide Web four to six years (72.33%), the
rest for seven years or more. Fifty-six % of the respondents reported having more than one email account, and 74 % of “experts” access their accounts from multiple places. Forty-six % of the respondents have created their own home page.

In terms of personal search for information, the majority of the respondents reported that find useful information from five to fifteen minutes, and 24 % indicated that they found useful information in less than five minutes. Forty-nine % of the respondents noted they found the information they were looking for, 22 % located the information more than half of the time. An August, 1997 survey conducted and distributed by “Internet Valley” reported that Internet traffic is increasing by 30 % monthly.

**Health Online**

Driven by an increasing dissatisfaction with the quality of traditional health care, the consumerism approach to medicine, and an unprecedented societal attitude of self-help, on-line health offers to many the solutions to an increasing number of problems in the medical community. The world wide web, shaped by these factors has expanded the realm of possible support systems and interactions with medical professionals that in the past have been limited by time and space. Additionally, activity on the web sites dedicated to health and medical information has exploded.

Medscape, a leading medical information site on the World Wide Web reports that on January 29, 1997, its 200,000^{th} member registered for online services. That is double the membership of 100,000 less than five months previous. In January, 1997 alone, members viewed more than 1.2 million Medscape web-pages, and downloaded 300,000 full-text articles. In the same month, 120,000 unique visitors performed 200,000 searches of Medscape’s full-text, peer-reviewed clinical medical articles, daily medical news features, and MEDLINE and AIDSLine abstracts. New weekly registrants have increased by 625% and the sites are visited weekly by an increase of 430%. (Medscape, 1997, http)

Information, in and of itself is notable.

Paraphrasing Miller and Mangan's (1983) observation, information shared within a communal context characterizes the contribution of media technologies and illness. Time has become a friend and new information, as well as medical and information technologies, offers hope to chronically ill patients.

As family and community support is taxed with other obligations, decreasing their ability to help the chronically ill, on-line services can provide support and informational
resources traditionally served by family and friends. These on-line services do not substitute for traditional information and support resources, but rather enhance information gathering and dissemination, which are surely critical for quality living with a chronic illness. These virtual communities not only nurture cultural empowerment, but avail chronic patients communication with those of similar interests and concerns.

A January 1998 report of the NUA (NUA, 1998, http) entitled "Pathfinder: DIY diagnosis on the Web," suggested that the growing internet use for medical information and support is evidenced by the "recent explosion in web sites dedicated to medicine" (p. 1). The United States National Library of Medicine has provided free public access to an online database of medical information and references and has reported over 250,000 daily inquires. NUA warned, however, that there are some serious problems with access to this overabundance of information.

with so many websites on offer, surfing for specific information is time consuming and laborious. Furthermore, while many of the sites offer sound medical information and advice from both fellow-sufferers and members of the medical association, there are also those intent on selling supplements, bogus remedies and even miracle cures. (p. 1)

Indeed, some websites can be considered the equivalent of the modern travelling medicine shows of the 1990s. One consequence of this information overload is that the chronically ill are now using mailing lists and listservs "where they can ask specific questions and post messages to people living with the same diseases" (p. 1).

Telemedicine

The current seductiveness of the world wide web has influenced the upsurge in available health information, and increase in virtual communities that offer chronically ill patients forums in which they can connect with other chronically ill patients, their families and physicians other than their own. This coetaneous interest has obscured the fact that a primary catalyst for the Internet-health connection, telemedicine, is nothing new and that it came into play long before the emergence of the Internet and the World Wide Web for the public.

Telemedicine, according to the Telemedicine Information Exchange (Telemedicine Information Exchange. 1998, http) has been operating in some form for over thirty years. The National Aeronautics and Space Administration (NASA)
pioneered telemedicine in the early 1960s when the first men were sent in space. Physiological responses were telemetered from the spacecrafts and spacesuits. Soon, telemedicine projects were developed and implemented world-wide. The primary function of the earliest programs was to provide health care not only to astronauts but general medical care to rural communities, such as Indian reservations in the United States.

The Nebraska Psychiatric Institute instituted closed-circuit television in 1955, and in the late 1960s and early 1970s functions extended beyond general medical care to health education, linking specialists to general practitioners, and psychiatric group therapy. In 1967, a telemedicine project between Massachusetts General Hospital and Logan International Airport provided 24 hour a day medical care to passengers. Nurse-clinicians were physically there to perform necessary hands-on care.

Research by the Institute for Communications Research at Stanford University in the early 1970s indicated that satellite systems for telemedicine were effectively used by health aides at distant sites, and were useful for "practically any medical problem except emergency care" (p. 2). Accessing rural communities for general health care continued as the primary focus for telemedicine projects throughout the 1980s.

In 1989 the first international telemedicine program between the United States and the Soviet Republic of Armenia was implemented to provide medical consultation and care to Armenians injured during a massive earthquake. This project was a landmark in telemedicine development; it showed that medical consultation "could be conducted over a satellite network crossing political, cultural, social, and economic boarders" (p. 3).

Research has indicated that telemedicine projects can provide effective medical care to rural patients, can be used successfully for medical education for health care professionals, and can prove valuable in connecting medical specialists with medical general practitioners. More important, however is the research that shows that the majority of patients are satisfied with medical care delivered through this means. Huston and Burton (1997) evaluated 96 patients using the Kentucky TeleCare telemedicine network. Medical specialties included psychiatry (41), dermatology (24), clinical nutrition (20), anaesthesia (3), infectious diseases (3), rheumatology (2), internal
medicine (1), neurology (1), and paediatric pulmonology (1). Results indicated a high patient satisfaction level with a mean score of 6.8 on a seven-point Likert scale.

Bloom, Hunter, and Williams (1996) conducted in-depth interviews with telemedicine patients, family members and health care providers. Additionally, they conducted focus-group sessions with 20 elderly rural people who tested out the telemedicine program offered through the University of North Carolina School of Medicine, Program of Aging. The researchers concluded the following: 1) patients reported feeling freer to speak and less intimidated, 2) there is enhanced patient-physician communication, because physicians are less distracted, and because take-home videotapes help patients and their families understand what’s happening, and 3) involving the patient, referring physician, and specialist at the same time improves communication and may improve care.

Historically, the use of computers in hospitals or the medical profession was for information storage. This technology allowed faster, if not immediate access to patients’ records and “written” consultation among physicians. An important function of telemedicine was the relay of x-rays, medical imagery, and medical records to physicians, either directly from labs, hospitals, or other physicians. This promoted collaboration among physicians and “team” medical care, which brought together physicians, nurses, and other health care professionals to care for patients. This was an especially important function as hospital management organizations (HMOs) became major players in health care. Today, physicians are requiring more services be available in an integrated, cohesive, consistent, and effortless fashion (Greenes, 1990).

Swartz (1996) indicated that the on-line medical prototypes available to physicians did offer an effective and cost efficient practice that could be adapted as a cheap form of telemedicine.” These prototypes, sometimes referred to as critical pathways and practice parameters, provide a way to “insure the level of medical care, and to get control of the costs (of telemedicine). . . By keeping protocols up to date and available on-line, tertiary medical centers can export their expertise to rural physicians using telecommunications – a form of telemedicine.” (p. 3)
According to the American Medical Colleges (1984) a primary function of the information technologies in telemedicine was to provide continuing education for health professionals, including physicians. The principal health care reform proposals recently argued have included a form of telemedicine.

Telemedicine revolutionized medicine in several ways. First, the programs improved access to care, providing health care to previously underserved or unserved areas, increasing the speed of diagnosis and treatment, providing immediate access to health care, and allowing access to specialty care. Additionally, telemedicine programs were credited with reducing professional isolation and improve quality of health care.

The critics of telemedicine programs pointed to the "technologicalization" of medicine, which prompted Sanders (1994) to suggest "In the final analysis it will be the human component at each end of the system—not the technology—that will determine whether it is successful or not." Telemedicine projects laid the foundation for electronic transmission of medical data and the application of such programs to the Internet. The application of the world wide web to telemedicine forged yet another furtherance for health care, and has ironically increased the "human component" through technology.

The Influence of the World Wide Web to Telemedicine

As the World Wide Web prompted changes in most aspects of daily life, it continued to influence and change telemedicine. The state network of West Virginia (WVNET) forged partnerships between private corporations and government to provide healthcare and education to rural communities. On-line medical records were included in enhanced telemedicine programs. Telemedicine programs were advanced to retrieve important patient information from a stored record and package that information with radiology information systems.

Swartz (1997) referenced the growing importance of the Web to telemedicine and the necessity for physicians to accept and embrace the global distributed platforms for medical information accessible through Web browsers. Results of a 1997 American Interactive Healthcare Professionals Survey documented that physicians were "slower to adapt" the use of email and the Internet in their profession, but such practices are expected to increase. In a 1997 on-line issue of the Canadian Medical Association...
Journal (Canadian Medical Association Journal, 1997, http). Lampitt estimated that fewer than 8% of Canadian physicians use the Internet regularly. Responding to this disappointing percentage, Breeck (Breeck, 1997, http) addressed the various ways she used email in her cardiology practice (p. 1). Though she described several fairly routine uses of email, all were related to communication with other physicians, no practice utilized to communicate with patients.

During a typical day in my office, I have little time to stop everything and pursue each problem as it arises. Fortunately, most of the family physicians and specialists in my area have email addresses. At the end of the day, I simply craft a precisely worded response to my messages and forward it to the intended address—I can even dictate the message and have my secretary send it. The recipient can then prepare a response that will be waiting for me the next day. And there's no telephone tag! (p. 1)

In the 1997 article Breeck also documents a specialized email-based system, CardNet that is specifically used for connecting physicians in northwestern Ontario to cardiologists in Sudbury, the district's referral center (CardNet, 1997, http). According to Breeck “Nonemergency questions can be forwarded to participating cardiologists and a response is usually provided within two working days. CardNet shows how email can help coordinate communication between 40 physicians and two cardiologists, separated by wide distances” (p. 1).

Though Breeck, in 1998, (Breeck, 1998, http) wrote on the usefulness of the World Wide Web for patients, there is an obvious exclusion of the use of email to connect patient and physician. The results of the 1997 American Interactive Healthcare Professionals Survey are not surprising considering it is common practice for the medical profession to restrict access to medical publications with limited circulation. There is a sense of risk if complicated medical information is offered to the public, especially those made vulnerable from illness or disease. The benefit of patient accessibility is that patients would be better informed as to treatments and their health conditions, thus making them more participatory in their medical experience.

The literature suggests three primary concerns of Internet distribution of medical information: 1) Medicolegal implications of Internet distribution of medical information, 2) the risks from possible misinterpretation of information (by either the patient or physician), and 3) the possibility of interception of confidential patient information.
An interesting example of the mediolegal implications can be found in the Telecommunications Act of 1996 which included the Communications Decency Act (CDA). Language and content of communications over the Internet were restricted by this act, and any online material deemed indecent or patently offensive to minors would be considered a violation of the act. Among the offensive language, the word “Breast,” which made illegal frank discussion about cancer. The ACLU filed suit in federal court to overturn the ruling and, in June, 1996, the CDA was overturned (American Civil Liberties Union, 1996, http). This prompted Janet Reno to declare the Internet “the most participatory marketplace of mass speech that this country – and indeed the world – has yet seen.”

Responding to the risks from possible misinterpretation of information (by either the patient or physician) most hospital and medical universities sites include a disclaimer or qualifier. The qualifier states explicitly that a reader must not use the information provided as a substitute for their physician or hospital care. Health care professionals who contribute to listservs or chatrooms emphasize the same.

Physicians’ reluctance and some patients’ ardent use of the Internet for medical information and support, prompted a 1996 editorial in the Journal of the American Medical Association, in which Editor-in-Chief, George Lundberg addressed the lag for physicians’ use of the Internet and computers in general in their education and practice. In 1982, the American Medical Association implemented a program to induce physicians to use the Internet by developing information and computer access for physicians. The program AMA/NET was dissolved in 1990 after monetary loses (American Medical Association, 1990).

There has been a renewed interest in such a program due to the accessibility provided by the Internet and the World Wide Web. Preliminary research for the new project, Physicians Accessing the Internet (PAI, 1997, http) is currently being conducted at Loma Linda University School of Medicine. Workshops are being developed and include objectives from advising physicians on equipment to go on-line and how to get on-line, identification of information sources available on line, to granting continuing medical education credit for completion of the workshop.
Additionally, the AMA is developing programs that enlighten physicians on the principles of information security and communications ethics on the Internet. What is of note in Lundberg’s editorial is that the medical profession expressed concerns similar to most users of the Internet, the issues of accessibility, costs, and privacy. Lampitt (1997) suggested that reason physicians have not incorporated the Internet into their professional world is that “the Internet, when described in the cold language of computer science is, well, boring” (p 1). Lundberg recognized the availability of high quality of medical information on the Internet and argued that this forum could be beneficial for patients as well as physicians. Besides sponsoring condition-specific Web sites, a number of medical journals are available on-line such as the Journal of American Medical Association (Journal of American Medical Association. n.d., http). Several more are developing Web presence including New Media Editor (New Media Editor. n.d., http) and American Medical News (American Medical News. n.d., http).

There are several other on-line resources developed for physicians. Among these is MedWeb (MedWeb, 1997, http) which functions as an on-line medical library linked to medical websites, medical journals, and newsletters. Met Health Resources (Met Health, n.d., http) (categorizes homepages of international and U.S. health agencies. Medscape (Medscape. n.d. http) is an on-line medical textbook subtitled “The On-line Resource for Better Patient Care,” which houses peer-reviewed, practice-oriented information edited by leading clinicians. The site also provides annotated links to relevant Internet resources. Health On the Net Foundation (HON: Health on Net. 1997, http) is a non-profit organization dedicated to “build and support the international health and medical community on the Internet and WWW,” availing physicians, healthcare providers, patients, and individuals the current medical treatments and information.

Lundberg (1996) recognized the present as the opportune time for the American Medical Association to once again support the effort to encourage physicians to look to the Internet and World Wide Web for medical resources. He attributed this renewed support to a number of facts.

More than 200,000 new physicians have been graduated in the United States since AMA/NET began, most of them computer literate, and many computer aficionados; equipment and software are better, much less expensive, and easier
to use. And we now have the information superhighway (the Internet) and the World Wide Web offering instantaneous free information exchange to virtually every continent in the world. (p. 2)

Advising “physicians, access the Internet,” Lundberg, while recognizing the efforts of the American Medical Association to support physician use of the Internet, acknowledged the reluctance of physicians, to date, to consider the Internet as a viable medical resource.

We pride ourselves on our Web efforts to date, as well as ownership of the PAI initiative and in putting forth this plan. But we do not “own” the national effort needed to accomplish it. This will involve hundreds of thousands of people as students and teachers. We call on all interested physicians to participate in a massive education effort for the good of their patients and their own professional well-being by developing their ability to gain new information in this manner. (p. 4)

Recent medical resource sites on the web are much more sophisticated than the text only files previously constructed. For example, the “visible human” project is a complete, anatomically detailed, three-dimensional representations of the male and female human body. The current phase of the project is collecting transverse CT, MRI and cryosection images of representative male and female cadavers at one millimeter intervals (Visible, 1998. http). Additional movies can be downloaded from http://www.nlm.nih.gov/research/visible/mpeg/umd_video.mpg. The National Center for Biotechnology Information (National Center for Biotechnology, n. d., http) is a databank that contains the annotated collection of all publicly available DNA sequences.

Breeck and Lampitt (1998) argued that the principal concern for “net-savvy physicians” is not accessibility, but rather the skills and practice of choosing the relevant material from which could be considered an overload of irrelevant information. In recognizing the traditional view of the physician as the source for “authoritative” medical information, Breeck and Lampitt advised that the availability and accessibility of the same medical information by patients will create an “unbalanced information” situation. This obligates and necessitates the physician teaching their patients critical evaluation skills of Internet medical information (p. 1). Physicians can access Breeck’s and Lampitt’s work, and additional help, from basic searches on the Internet for medical
information to accessing on-line postings of medical positions on “Job Board.” at the Webdoctor web site (Webdoctor, 1997, http). The Webdoctor site documents 450,000 monthly requests, though it is not indicated how many requests are from physicians.

Breeck and Lampitt proposed that consequent of the patient, under the guidance of the physician, using the Internet as a medical resource, can become “positively involved in the healing or coping process.” Dr. William Lavalley (1997) concurred in the article “Educating your doctor: Your doctor has a few things to learn – from you.” Dr. Lavalley suggested visualizing the doctor-patient relationship as that of a captain and a navigator. The captain, in his perspective, is the patient and the physician the navigator, dissimilar from the traditional view of the relationship.

In almost all instances, the Internet, for physicians, has been designated as an information source to the exclusion of the Internet as a communicative forum to promote interchange between physician and patient. Medscape. (Medscape. n. d., http) one of the most active medical web sites, reported that medical professionals compromise the bulk of Medscape’s membership – 71% are physicians, physician assistants, nurse practitioners, researchers, managed care executives, or other health care professionals. Every seven minutes a doctor joins Medscape.

Even when patients can interact with physicians, the exchange is categorized as “informative” rather than “communicative.” Ron Sauders. (1997) director of Johns Hopkins Office of Consumer Health Information emphasizes this function allowing, “We’re not making diagnoses,” he says. “We’re not prescribing drugs or treatments. We are providing information rather than advice. I don’t think it is any different from the Q and A columns written by physicians in many newspapers.” Medical informative web sites routinely post qualifiers as such for legal and ethical reasons.

**Patients’ Use**

Though physicians are hesitant to use the Internet as a medical resource, their patients are not. Patients have more readily embraced the Internet and World Wide Web as a primary medical resource, and have extended its use as a communicative forum as well. According to the April, 1997 issue of the *Johns Hopkins Magazine* (Johns Hopkins Magazine, 1997, http)
There was a time when people got their health news mostly during intimate chats with their doctors or neighbors. Now, in what may be called the new version of those intimate chats, you can receive a multimedia windfall of medical information every day with just a few computer key strokes. (p. 2)

A recent survey cited in a 1998 on-line journal (Webdoctor, 1997, http) reported that 40% of the people who surf the Internet are searching for information on personal health. This percentage is alarming, considering the varied quality of the information on the Internet. Whereas physicians are encouraged to use the Internet and World Wide Web strictly for information and informative exchange with patients, chronically ill patients have found sanctuary in the on-line communities of other patients, family, and even physicians. Additionally, the Internet provides the chronically ill the opportunity to attend healthcare related conferences and events, to participate in medical projects and research, and download papers and other information relevant to their illness.

Starting January 1, 1998, California enacted a law, which requires the California State Medical Board’s website (California State Medical Board, n.d., http) to make public doctors’ histories that had previously been kept private. By simply accessing the web site and typing in the physician's name or license number, patients can find information including disciplinary actions by hospitals, as well as all court and private judgements against physicians, even if the State Medical Board has not acted against the doctor. The information on the California web site is still not as inclusive as the information provided, by law, in Massachusetts. Information provided by Massachusetts includes malpractice settlement amounts, felony and misdemeanor convictions that involve incarceration, honors received, hospital affiliations and insurance companies accepted.

It is in the use of information technologies as “patient connectors” that perhaps have indeed revolutionized the experience of chronic illness. Today, the connection to other patients is just a click away on the Internet. The more meaningful uses of information technologies for the critically ill patient include the accessibility to information about their illness, accessibility to patients with similar medical and health experiences, and the influence of this connection to empowerment for patients and their families. Brennan, Moore and Smyth (1995) report on ComputerLink, a computer network which provides information for caregivers of persons with Alzheimers.
ComputerLink was evaluated by a one-year study period examining specifically the effects that ComputerLink had on confidence in decision making and social isolation. Access to ComputerLink enhanced decision-making confidence and postings to ComputerLink’s public electronic bulletin board included both information seeking and supportive messages.

Kleinman (1988) emphasized the confidence factor for chronically ill patients. By definition, the chronically ill suffer and resuffer the symptoms of their illness. Each time the cycle of the symptoms begins, the sufferer loses faith in the dependability and adaptability... that the rest of us rely on for our general sense of well-being. This loss of confidence becomes grim expectation of the worse, and, in some, demoralization and hopelessness. (p. 43)

At present, there are several forums for patients to communicate with others from around the world. According to a column article in the April/May 1995 edition of the Canadian Medical Informatics (The power of USENET. 1995. http) the power of the “USENET” is the way it enables patients with similar interests and experiences to communicate regardless of time, geographical or cultural differences. The Usenet groups provide access to an extensive and valuable knowledge base for a patient, family member, friend, and even health care professionals.

Since coming on-line almost half (46.1%) of respondents in a 1997 Graphics. Visualizations and Users’ survey poll (Graphics, Visualizations. Users’ Survey. 1997, http) felt more connected to people who share interests and concerns. The Internet is more than an information source, rather it is building new communities based on common interest and experiences instead of common geography. Particularly noteworthy are the medical web sites such as The Med Help Patient Network (Med Help, n. d., http) which states its mission is “putting patients in touch with other patients, for the purpose of sharing information and support.”

Computer Mediated Communication

To go beyond mere description of these options, it is important to consider the augmentation of computer-mediated communication in society. The investigation of online communities and the use of the Internet by the chronically ill can be examined through the lens of computer-mediated communication research.

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Wood and Duck (1995) observed that computer-mediated communication (CMC) continues to grow as a prevalent mode of communication and suggested that “we are fast approaching a time when the computer will be as ubiquitous a communication medium as the telephone is today” (p. 200). The ease and convenience of CMC has spawned the use of the Internet for more refined uses other than information resources, chronicled in the work of Marshall McCluhan (1989) and has revolutionized the conceptualization of communication and the way we communicate.

Advanced by the early theorists of computer-mediated communication, information technologies were viewed as disrupting the “fabric of community life” (Straubhaar and LaRose, 1997, p. 440). Straubhaar and LaRose decreed the concept of “social presence” to account for the “something missing” in computer-mediated communication. Those missing elements (nonverbal messages) resulted in low levels of social presence delegating computer-mediated communication as “an inferior means of establishing interpersonal relationships” (p. 440).

Others argued that computer-mediated communication can contribute to the development of interpersonal relationships, as well as change the characterization and dynamics of interpersonal relationships. Additionally, recent research has documented CMC relationships as gratifying and fulfilling as face-to-face relationships (Walther, 1993).

Virtual Communities for the Chronically Ill

The isolation and the dual citizenship in the “ill” and the “real” worlds for chronically ill patients can contribute to the attraction of and participation in on-line communities. As chronically ill patients struggle to achieve equilibrium in this dual existence, the connection with like persons becomes even more important. Information technologies have removed time and space constraints that previously limited the boundaries that separated a patient from others with shared interests and common problems.

These virtual communities share expertise or even companionship. For the chronically ill patient on-line doctor “visits” and participation in virtual support groups are available. Critical information from physicians or other critically ill patients can be
sent by email. This access is not only more immediate than previous methods, but may, in fact provide a “safer” environment for discussion or participation in support groups.

There has been an expanding awareness that information is critical for patients, as well as physicians, in quality of living with a chronic illness. More importantly, however, is the constitution of community to share, discuss, and negotiate meanings of the illness from information. Virtual communities offer a sense of belonging to what may be an increasingly insular life. Rheingold (1997) suggested that the Internet represents a form of freedom for some people who are otherwise limited because of physical and mental obstacles in their everyday living.

Ferguson (1996) suggested that the unique contribution of on-line health resources is that information can be “shared in the context of community.” Madara (1996) suggested that “on-line support communities made up of informed, empowered, supportive” persons with similar interests and concerns provide not only information, but can transform patients with problems into “providers and supporters” of health care. The on-line virtual communities provide the chronically ill the “shared space to mingle” that Etzioni (1993) noted in his conceptualization of the spirit of community (p. 129). These acknowledgements reinforce the recognition of media technologies as more than information resources.

As the accessibility for connections to others and to “more” information increases, so does the potential for misuses of information. Health or medical information is available unedited and uninterpreted by the traditional sources of medical authority. Patients may feel so overwhelmed by the quantity of information and the possible connections to other patients that they hesitate in making critical health decisions. Kai (1996) points to a major source of frustration for parents of chronically ill patients was the disparity in physicians diagnosis. It is easy to extend this same argument to disparity of views and suggestions offered by the many “authority” sources available on the Internet. Issues focusing on how and for what purpose will the information be used, and the vulnerability that can characterize the chronically ill, need to be carefully thought about.
The Internet is increasingly challenging physicians as the "truth bearer" of health information. As the use of the Internet for health information and support by patients increases daily, physicians are cautioned not to ignore their patients' reliance on the Internet for medical information. In an on-line article "Working with the Internet-literate patient," (Webdoctor, 1997. http) physicians were advised to improve critical appraisal skills in their patients for evaluating information form the Internet. The authors suggested the information be assessed with five criteria - accuracy, authority, objectivity, currency, and coverage. A list of questions reflecting these criteria should be generated by the physician and given to the patient to use in his/her information gathering.

Summary

It is tempting to consider the use of media technologies as universally beneficial for the chronically ill patient, nevertheless it is essential to avoid doing just that. While the Internet may offer expanded communities for participation in by chronically ill patients, they should not be automatically considered utopia. The use of information technologies by the chronically ill must be approached cautiously. To be actively involved in their medical experience requires a commitment, and for some, major changes in lifestyles, which may have psychological and relational consequences. The social context and the communal dimension of welling must be considered as powerful elements in a chronic patient's life. Any recommendation for chronically ill patients use of media technologies must be offered with due precautions.

There is no doubt that the amount of information available through the new information technology is staggering, and increases daily. Designated as "on-line" information sources, the sites offer not just information but an extended community and a context for sharing that information. Since the 1970s there has been growing vigilance over technological determinism (Winner, 1986). Does technology take on a life of its own and follow a course of its making? Alternatively, is technology shaped by social and cultural factors? In essence, does technology work independently of social norms and, due to the universal community of the Internet, whose societal norms would be questioned? It is unquestionable that the explosion of media technologies is changing the face of medicine and health as it has all other aspects of living. Information technologies
are, however, not mere additives, that allow us to do the same things in a different way. “Doing it” with technology changes the face of “it.”

Ironically the criticism of Shannon and Weaver’s mechanistic model of information failing to account for the “sociability” of human communication has been levied at what some consider the invasiveness of media technologies in our everyday lives. What needs to be considered is what media technology may be changing. Given the rapid acceptance and advancement of information technologies, it is impossible to think that any social practice or institution being restricted by time and space, and medicine and health are no exceptions. Information technology may allow the definitive social process, encouraging interactions beyond our limited geographical “world,” challenging the long held conceptions of “being ill.”
CHAPTER 3

METHODS

Maybe I’m angry
But I want to know,
Could anyone do better than I have done?
No one is perfect.

Will You help me???
I think you would if You
Had gone through it.
Today You didn’t help me.

“I’m Angry”
poem submitted by Arnell,
Brain Injured listserve, www

Background and Conceptual Framework

I understand from my own lived experience and those of other chronically ill patients that the patient’s voice is often silenced, or even ignored in research. The poem by Arnell is not anomalous of the feelings shared by the citizens of the electronic communities I participated in, during my meanderings for meaning. Family and friends, as loving and supportive as they are, and doctors and nurses, for all the care and concern they show, cannot relate in the same intimate way as those who share a similar medical experience. As Arnell so aptly stated in another verse of her poem “No one understands. Even fair and smart people.”

My academic roots led me to the scholarly quantitative research on chronic illness in my information pursuit, and I was uneasy at what I was reading. I had always defended quantitative research to the exclusion of qualitative, but as I studied doctor-patient communication and scholarly prescriptions for attaining wellness, as a chronically
ill patient for over a decade, I felt “No one understands. Even fair and smart people.” A circled number on a scale could not represent the feelings of isolation, of looking at myself as “abnormal,” or relating the social and physical pain of my being. And just the thought of someone suggesting that they understood me “statistically” was offensive.

*I have to imagine what it would be like to have a panel discussion with the panel being patients and the audience being doctors. I know of several times when I have asked one of my several doctors if my pain or symptoms are common with other patients. They admitted they did not know. I guess I’m looking for a way to be “normal” in this abnormal world. Today I asked my roommate Judy what she would like to ask other patients. “Just how do they get through the day?” “Do they feel so weak, but they have to be strong for others?” “When do they not feel on display?”*

Personal journal. September 28, 1996

Ever so slowly, I was recognizing the integration of my identity as a chronically ill patient fusing into the intellectual, emotional and physical domains of my everyday living. The fundamental ways I viewed the process of knowing and meaning were challenged; I acknowledged a growing sensitivity to the subjectivity and reflexivity found in qualitative research methods. To accept only quantitative methods in studying the experience of illness was as faultful as accepting the doctor’s diagnosis as the illness itself. The questions I was asking and my lived experiences directed the choice of the research methods for this research.

I was encouraged by the works of Miles and Huberman (1984) who stated that qualitative research data are presented “in words rather than numbers,” (p. 21) and Smith (1988) who emphasized qualitative methods as “deriving verbal rather than statistical conclusions . . .” (p. 187). Cegala (1996) (personal communication May 8, 1997) observed that the advantage of quantitative research is to show that there are patterns in the data; qualitative research provides interpretation of that data and, according to Cegala, the frequency of occurrence is not as important as the sequence of events.

In the summer of 1996, three events coincided which influenced the research questions I began to formulate. I had completed two qualitative methods classes and was beginning an independent reading class in qualitative theory. I used media technologies
Little did I know that Dr. Dullard’s phone call on June 21, 1996 would change my life entirely from what I had known for 43 years. Dr. Dullard’s diagnosis of invasive brain tumors really came as no surprise. You see, the symptoms had been coming gradually and I had done my best to ignore them. However, when I closed my eyes, or had a minute of rest I could see those tumors invading the crevices of my brain, braiding down my spine. True, I had been through this before, but as they say, you can’t put your foot in the same stream twice. I considered myself “well” from the ‘85 surgery and had just returned to graduate school 2,500 miles away from home to complete my doctorate, which I had begun 14 years earlier. I can remember thinking, after reading accounts of brain injured patients and after ten years of soul searching, after knowing “me” on a deeper level, I wish I could do it all over again. Like they say, be careful what you wish for. One week after my 43rd birthday that wish came true. I would have to do it all over again. The doctor scheduled September 26 for more brain surgery. Even as I was hearing the results of my MRI I tried to envision this time completely different from the first. In 1985, I had no time to ask questions, no time to prepare myself emotionally or intellectually for the surgery. One minute I was told I had hepatitis, serious, but manageable. Then suddenly I was whirling, feeling out of control when given the news of the brain tumors. And that was exactly how I felt when I hung up the phone.

Personal journal entry, June 25, 1996

These three life experiences directed my attention to three primary areas to study: information technologies, chronic illness, and communication. I was surprised that the intersection of these three areas had not received attention in the literature. The influence of technology on the practice of medicine and seemingly all other aspects of living had been documented in numerous studies, in various academic disciplines, and with disparate methods, but had not been related to information and chronic illness in an academic study. More important, my initial probing into the literature on chronic illness and information convinced me that my personal medical situation allowed me to contribute more than examining as a researcher without patient perspective, fashioned after Konner’s (1987) research in which he documented his medical school experiences.

The research literature seemingly offered a most simplistic view of a very complex event. Even the interpretation of data seemed to lose an important elegance of the patients’ accounts. Who better to act as the “cultural go between” discussed by Katz
and Shotter (1996) to present "the unique nature of their (patients') inner world of pain?" (p. 919) or the informant "to act as guide to and translator of cultural mores . . ." (Fontana and Frey, 1994, p. 366) than the patient/researcher? In the introduction to her text *Negotiating Health Care: The Social Context of Chronic Illness*, Thorne (1993) pointed to the problems that can arise for a researcher studying chronic illness:

Despite efforts to have chronically ill patients and their family members described their own experiences without interpretation, the accounts were always full of analysis and explanation. . .In other words, they made it clear, that if I truly wanted to find out what it was like to be chronically ill, I had better look closely at the system in which these people were immersed.” (p. 12)

It stands to reason that by being one of “the system in which these people were immersed” gave entrée to the culture members, the history among the participants and with the patient provided context for the data and the “full involvement and identification” emphasized by Punch (1994, p. 93).

**Research Question**

At the core of qualitative research is the research question. The tenuous nature of qualitative research led Morse (1994, p.226) to suggest that the investigator begin with a broad research question, and as the study progresses, the research question is fine tuned:

The researcher should state the question so that he or she can later refine it to make it appropriate to maximize the research effort. The researcher can do this as soon as he or she begins to understand “what is going on” in the setting and what is possible given the constraints. (p. 228)

Writing the research question(s) for this study proved to be one of the most arduous tasks in the research process, requiring constant revision. My early attempts at writing the research question, though broad as Morse suggested, focused not on the communication process, as it should for a communication study, but rather on the illness process. I attribute this, primarily, to the fact that the lived experience was so intense and personal that it was difficult to interpret the experience. Additionally. I was letting the experience and my assumptions about the experience override the data.

I was frustrated, confused, and intimidated by what I perceived to be daunting responsibilities. I held on to the notion that this was going to be my contribution, not just to the communication discipline, but to the chronically ill. I recognized that my situation offered rare opportunities. I thought of this study in magnum opus proportions, and I was
concerned that I would fail. My committee members' direction and constant prodding helped me “ramble” through this period, and guided me with questions concerning my research purpose and my audience. Feeling off track I would refine my research question, resulting in a revived direction, a better direction.

Instead of reading scholarly research on chronic illness, I began the literature research process by reading personal accounts of living with illness. Cousins’ 1979 *Anatomy of an Illness As Perceived by the Patient*, and Kleinman’s 1988 *The Illness Narratives: Suffering, Healing, and the Human Condition* were invaluable in giving voice to the patient, and consequently, giving voice to me. There was a ring of universal truth to the patient accounts and I began to be more comfortable with the dual role of patient and researcher. This dichotomy was essential to guard against, what Morse refers to as “familiarity with the setting,” which results in dulling “the researcher’s awareness,” in essence rendering the researcher ineffective.

There were three watershed landmarks in the research process that I identify as points, which required major changes to the research question. Crabtree and Miller (1992) addressed the “flexibility” of the research question in qualitative research:

The initial question or problem allows for preliminary decisions about the boundary of the investigation. The investigator concerns herself with questions like: Which data sources are information rich? Whom should I talk to, or what should I look at first? As theory develops, additional questions arise: Which data sources may confirm my understanding? Challenge my understanding? Enrich my understanding? (p. 33)

The boundaries, provided by the research question(s), naturally lead to the “types” of data, which, according to Crabtree and Miller can include “events, places, persons, artifacts, activity, and time” (p.34).

The first research question was constructed from my lived experience and focused on the illness rather than communication and information technologies. I struggled for sometime to conceptually differentiate the two, but writing the personal narrative facilitated this understanding. Though on the surface the research question seemed indicative of the research purpose, it was when I tried explaining the focus to Thom that it was obvious the emphasis was not only on the illness rather than communication, but
focused exclusively on my experience. The first research question was: How has information technologies changed my experience as a chronically ill patient?

The second landmark which resulted in a revision of the research question was the completion of the review of literature for my dissertation prospectus. The literature I reviewed ignited a theoretical and conceptual notion of “wellness,” and resulted in the formulation of the following research question: How has the explosion of communication technologies influenced the wellness of chronically ill patients?

This question begged the difference between illness and wellness, and emphasized the importance of information technologies. Furthermore, this led to the conception of an information-based “culture of wellness,” which highlighted the influence of family, friends, and physicians to the chronically ill patient. This is the research question I used to guide my observations and data collection immediately before and during the 1996 surgery period.

The third point in time that resulted in further refinement of the research question was my candidacy exam and prospectus meeting. Morse’s 1994 representation that the researcher should have his or her proposal “reviewed by seasoned experts” characterizes this meeting. While supporting my proposal, the committee members suggested that it needed more focus, and that I should consider taking advantage of the 1985 and 1996 surgeries, exploring how information technologies influenced these two events. Furthermore, the committee suggested investigating the influence of participation, as a chronically ill patient, in on-line communities to face to face communities.

This event, coupled with Wolcott’s 1992 position of the possible emergence of qualitative research questions from both literature and personal experiences led to the development of the following research question:

**Research Question:** How have information technologies changed or influenced information management for the chronically ill?

The specific focus of the research was on information interchange, information needs, and information uses. The underlying theory reflected in this question is that information technologies have changed, but society has also changed technology. That
is, societal and cultural needs give rise to technological changes and advances and in turn, these technological changes are reflected in the cultural ways of doing. The history of my use and study of information technologies constantly influenced the course of this research.

Qualitative Methods

The proposed research questions to study illness as the lived experience of a chronic state pointed to the use of qualitative methods. Nelson, Treichler and Grossberg (1992) indicated that the “choice of research practices depends upon the questions that are asked, and the questions depend on their context.” (p. 2) LeCompte and Preissle (1993) maintained qualitative research strategies are chosen to provide “what information most appropriately will answer specific research questions, and which strategies are most effective for obtaining it” (p. 817).

The societal ambience of the research question connoted a descriptive and interpretative analysis of information practices of both on-line and face to face communities. Morse (1994) suggested that such questions lend themselves to ethnographic strategies, employing methods of unstructured interviews, participant observation, and field notes. Data sources can include documents, records, and social network diagrams.

Holstein and Gubrium (1994) described the goal of ethnomethodology as a “. . .focus on the ways that the life world—that is, the experiential world every person takes for granted—is produced and experienced by members” (p. 263). Recognizing this, the research strategy for this study enveloped three components: 1) self-reflection through personal narrative, personal journals, and medical and therapeutic records, and 2) research interviews and personal narratives of others. The ethnographic methods of narrative, reflexivity and open-ended interviews of others were suggested for this study.

Qualitative Methods in Studying Illness

Considerable attention in recent medical and communication research has been directed at issues, which can best be addressed by qualitative research methods. Lyons, Sullivan, Rivito and Coyne (1995) offered the following description between qualitative and quantitative research in chronic illness:
The quantitative literature characterizes the individual in his or her solitary struggle to overcome the limitations of disability with the goal of minimizing the experience of emotional distress. The qualitative literature paints the picture of an individual within a relational environment struggling to maintain functional abilities in order to meet social and relational responsibilities. (p. 82)

Kai (1996), addressing the issue of medical care, suggested that qualitative methods could contribute to the understanding of patients' and providers' preferences. Peterie, Weinman, Sharpe and Buckley (1996) concluded that patients' initial perceptions of illness are important determinants of aspects of recovery and advanced that specific illness perceptions need to be identified at an early stage in health care. Shaul (1995) reported that qualitative methods led him to determine that living with a chronic illness was characterized by periods of uncertainty, of learning about the illness, discovering strategies that allowed patients to meet expectations of their perceived roles, and the establishment of new patterns of daily life. Heskestad and Tjemsland (1996) advocated giving renewed attention to patients' stories in dealing with chronic illness and Goodman (1995) insisted that it is critical to understand the chronic patients' attitudes, views, and life style for effective outcomes.

The 1993 work of Hayden and the more recent work of Geist and Gates (1996) investigated the communication of chronically ill patients with qualitative methods: Hayden, studying the perspective of chronically ill patients and their "communication with those who are well," and Geist and Gates, addressing the human dimension in the hospital experience. Moreover, the heightened awareness of the importance of the meaning of illness to patients implores methods that capture the essence of these meanings. Quantitative methods can actually strip away meaning by assigning numerical correlates whereas qualitative methods allow researchers to study in-depth what cannot be subjected to statistical analysis. "Fundamentally, qualitative researchers seek to preserve the form and content of human behavior and to analyze its qualities, rather than subject it to mathematical or other formal transformations" (Lofland, 1995). Support for qualitative research in health communication is strengthened in Miller and Crabtree's (1994) observation of several medical journals' acknowledgement and inclusion of qualitative research.
Qualitative clinical research is now appearing in clinical journals. ... *Qualitative Health Research* and *Culture, Medicine and Psychiatry* are bridge building publications with an almost exclusive emphasis on qualitative clinical research. All of the primary care journals now have reviewers trained in qualitative research, and all have published examples of qualitative studies. (p. 347)

**Questions of Validity in Qualitative Research**

Of particular concern to me in designing and conducting qualitative research were issues of validity and reliability. Coming from a quantitative background, I viewed research validity in the perspective of “measuring what you are saying you are measuring” through content validity, criterion validity, or construct validity, which served only to increase my skepticism in valid qualitative research. By addressing this concern through literature research and discussions I concluded that validity, although not conceptualized as is in quantitative research was still a primary issue that needs to be addressed with qualitative research, yet in a different fashion.

Taft (1988) described validity as being a “quality of the conclusions and the processes through which they were reached” (p. 61). Taft’s issue that validity is “dependent on the apparent accuracy of the data and the way it is communicated to the audience” led me to study Constas (1992) who instructed, “Qualitative researchers make many choices when conducting research, over the trajectory of the research on assumptions, logics and choices when conducting a research study.” Constas also expressed a major concern how these choices were not disclosed in many qualitative studies. For this reason, Constas suggested the qualitative researcher present the story of method construction in his/her work.

Bateson, (1972) concurred with his recognition that there are two studies in qualitative work, the “official” research project and a “study about the study” which details the choices that were made by the researcher in the construction of the study. For example, Atkinson, Heath, and Chenail (1991) suggested inclusion of items such as the steps in forming the research question(s), selecting a site, generating and collecting the data, processing and analyzing the data, and selection of data for presentation aids in “the process of establishing trustworthiness of any study (which) comes down to the quality of the relationship built between researcher and the community of readers and critic who
examine the study." Janesick (1994) insisted that validity in qualitative research "has to do with description and explanation, and whether or not a given explanation fits a given description. In other words, is the explanation credible" (p. 216)?

Janesick (1994, p. 216) turned to Patton to address and evaluate credibility in qualitative research. Patton suggested credibility be examined by three questions: (a) What techniques and methods were used to ensure the integrity, validity and accuracy of the findings, (b) what does the researcher bring to the study in terms of experience and qualifications, and (c) what assumptions undergird the study? These three questions guided my study and were constantly considered and addressed throughout the research process.

For discussion of proof required to support claims by quantitative and qualitative research, Smith (1988) differentiated the methodologies. For quantitative research, Smith argued "Only if scientific research can be replicated can it be confirmed by other scientists. Among other things, this requirement compels the researcher to articulate explicitly all research protocols so that others can faithfully duplicate the research." (p. 245). Smith indicated that for qualitative research "Although much humanistic research is replicable, it need not be. Indeed, if a given analysis concerns some unique and therefore nonrecurring conversational event. . .precise replicability maybe impossible" (p. 246).

Replicability is even more of an impossibility in studying the first hand account of a brain injured patient. "The goal of qualitative research is not "to make generalizations on the basis of generated data" but rather to uncover an idiographic knowledge of the world" (p. 248). Kennedy (1979) maintained that generalization of qualitative research is the responsibility of the reader rather than the researcher: Clearly, the study of a single case with no replications limits the strength and the range of generalization arguments considerably. . .But in fact, the range of generalization simply cannot be known to the evaluator. That range cannot be known, however, does not mean that a range does not exist. . .the range of evaluation is a matter of judgement. For studies of single cases, however, the judgement should not be made by the evaluator. Instead, it should be made by those individuals who wish to apply the evaluation findings to their own situations. That is, the evaluator must should produce and share the information.
but the receivers of the information must determine whether or not it applies to their own situations. (p. 662)

Denzin and Lincoln (1994) argued that issues of validity “all turn back on the crisis of representation, and involve, in one form or another, the problem of how the Other’s perspective and experienced and expressed in a text” (p. 759), and Glaser and Strauss (1967) indicated that “criteria of judgement be based...on the detailed elements of the actual strategies used for collecting, coding, analyzing and presenting data...” (p.224).

Kincheloe and McLaren (1994) noted

Some analysts argue that validity may be an inappropriate term in a critical research context, as it simply reflects a concern for acceptance within a positivist concept of research rigor. To a critical researcher, validity means much more than the traditional definitions of internal and external validity. . .Trustworthiness, many have argued, is a more appropriate word to use in the context of critical research. . .because it signifies a different assumptions about research purposes than does validity. (p. 151)

In reference to Lather’s work, Kincheloe and McLaren (1994) offered the suggestion of catalytic validity, research which “moves those it studies to understand the world and the way it shaped in order for them to transform it” (p. 152). Fundamental to all discussions concerning validity in qualitative research is the presentation of the “inquiry process,” necessitating the researcher to thoroughly document the steps taken in the research, noting changes throughout.

Questions of Reliability in Qualitative Research

The interdependence of validity and reliability naturally lead to fundamental research reliability issues (Lincoln and Gubba. 1985, p.2). As with validity, reliability issues are salient considerations for qualitative research but “criteria defined from one perspective may not be appropriate for judging actions from another perspective” (Lincoln and Gubba, p.293). Criteria for reliability for quantitative research is based on naïve realism, “something tangible and changing “out there” that can serve as a benchmark if this idea of replication makes sense” (Lincoln and Gubba, p.293). Murphy and Pilotta (1983) expounded upon possible research implications:

When data are inadvertently misinterpreted through the use of methodologies which contain “reality” assumptions that may not be true for the people that are
surveyed, the data that are collected do not have much validity. . . It must be remembered that qualitative methodology understands data to be valid only when they reflect the beliefs, values, and general life orientation of the individuals from whom they were generated. (p. 173)

Both validity and reliability issues can be addressed by being open with what the researcher is going to do. Details of the design and implementation are imperative. If during the process, you decide it would be better to change some design feature, change it and note the change. Chenail (1994) suggested including the following in presentation of qualitative research: what you did to create the project, what your choices were along the way, what else you considered doing in the project but chose not to, and note guesses, even if the guesses are intuitive.

Salient to data presentation is the order established for the display. The chronological pattern I chose for this research allowed the reader to follow the developmental process of the experience in a similar fashion as I, increasing the understanding of what I experienced rather than what I did. This order also conformed to the "storied" approach reflected in the narrative methods in the design of this study. The qualitative researcher should consider the reader at all times in the designing, implementing, and presentation of the research.

In presenting data, the data must be given context providing the embodiment of the data. From contextual information, the reader gains perspective in the interpretation of the data. This calls for detailed setting and characterizations. Janesick (1994) concurred by declaring "Description of persons, places and events have been the cornerstone of qualitative research . . . and it will remain the cornerstone because this is the qualitative researcher's reason for being" (p. 216) These observations prompted me to include as much of the data as possible for the reader. Yet, it was important to keep the presentation simple so as not to overshadow the complexity and richness of the data. Verbatim excerpts from personal narratives, in-depth interviews, and virtual community interactions, as well as details from field notes, would subsequently be used support the research conclusions.
Ethics

Before beginning this research I had studied and discussed research ethics in qualitative research, and in computer mediated communication (CMC). Ethical considerations for both qualitative research and CMC were similar in nature to those of quantitative research, but as I found, in so many aspects of this study, uniquely dissimilar. Additionally, I acknowledged that ethical considerations might also be unique to a particular research experience.

More often than not, specific ethical decisions were made during the research process. Of continuous concern was the public-private nature of the communication in on-line communities. Though I was a “legitimate” member of the chatroom and listservs in which I participated, I had to consider the unique issue of forfeiting the potential health benefits through participation as a brain tumor patient or observe without fully participating, to minimize influence in the on-line communities. Additionally, getting prior consent from the participants would certainly influence, and may disrupt the group, or even make participation impossible. I initially emailed moderators or sponsors of listservs and chatrooms in which I had decided not to participate, to gage the “acceptance” of a researcher participating in the group. Two contacts suggested that participate in other groups, indicating they would prefer me not to participate in theirs, and the third contact did not respond.

What I found, however, after getting involved is that I soon abandoned my role as researcher and became completely involved as a patient. My researcher role was maintained by continuing my journal writing and field notes, which were audio-taped and then transcribed. I had made the decision not to influence the interaction as a researcher, such as initiating discussion on specific topics or creating specific interpersonal dynamics that were of interest to me as a researcher.

This decision not only enhanced the authenticity of the experience, but also resolved some of the ethical concerns I had about conducting research on the virtual communities I was participating in. Additionally, I decided not to analyze chatroom, listserv, or email communication from on-line communities until after the cut off date of March 1997. In order to delay analysis I at first downloaded communication to a disc but discontinued this practice after discovering chatroom and listserv archives were data
depositories, which, for a time, would be accessible. The journal entries and field notes would supplement these archived records and provided accurate personal observations.

Over time, I began to understand that participants typically understood the “public” nature of their participation in listservs and chatrooms. When a participant “voiced” concern that some of the messages shared in these forums were “personal,” as in the BRAINTMR ASSOCIATION chatroom, the on-line community decided that as a communal norm private and personal messages should be sent through email.

My “legitimate” participation in these on-line communities also guarded me against “objectifying” the on-line communities’ members. Being “one of them” allowed a natural reflection on how I was presenting the communities, and my participation in them.

Research Design

The choice to study the information technologies and the lived experience of chronic illness suggested approaching this research as a participant observation study. Bogdewic (1992) stated that the participation continuum, that is inherent in participant observation research, “connotates some form of active involvement.” (p. 55) Jaeger, according to Bogdewic, suggested that there are three levels of participation that the researcher can employ: the active participant, the privileged observer, and the limited observer. Junker has also categorized levels of participation, in participant observer research, (as cited in Bogdewic, 1992) as four social roles in which the researcher can engage: complete participation, participation as observer, observer as participant, and complete observer.

Smith (1988) suggested that in participant observation research, “the investigator contributes actively to the communication processes being observed. The communicators may or may not be aware that a “participant observer” is actually a researcher studying their communicative behaviors.” (p. 181) Crabtree and Miller posited that it is not the goal of participant observation research “to see how many different ways the researcher can become involved in the activities of the organization,” but rather “Participation is a way of establishing rapport,” and “is concerned primarily with data collection” (pp 56 – 57).
It is Jaeger’s concept of “active participant,” Junker’s category of “complete participant,” and Smith’s position that those being observed may not know the participant’s research goals that apply to this research. Though “complete participant” typically describes the researcher joining a group professedly as a regular member, but surreptitiously a researcher, Konner’s 1987 research, which chronicles his education as anthropologist in medical school, exemplifies work where the researcher has participated as a rightful member of the group he or she is studying.

**Triangulation and Reflexivity**

The proposed research strategy for this research is a combination of qualitative methods with an emphasis on triangulation and reflexivity. The first issue to be addressed was the appropriateness of use of multiplicity of methods to incorporate my lived experience as a chronically ill and brain injured patient into the study of information and information technologies. Secondly, the concept of reflexivity for researcher and others was examined.

**The Method of Triangulation**

Denzin’s (1978) treatment of triangulation identified four basic methods of triangulation: data, investigator, theory, and methodological triangulation. It is the fourth category of methodological triangulation that applies to this study. According to Denzin, methodological triangulation is the use of multiple methods to study a single problem. The use of multiple methods reflects Lincoln and Denzin’s (1994) observation:

The use of multiple methods, or triangulation, reflects an attempt to secure an in-depth understanding of the phenomenon in question. Objective reality can never be captured. Triangulation is not a tool or a strategy of validation, but an alternative to validation. The combination of multiple methods... is best understood, then, as a strategy that adds rigor, breadth, and depth to any investigation. (p. 575)

The triangulation employed in this study is literature, reflexive methods of self and of others, examined through fieldwork, personal “lived” experience, and my research experience. Morse’s 1994 work further illuminated the concept of methodological triangulation. She proposed that “a more holistic view” of the research interest could be achieved through the use of more than one method in the research. The proposed multiple methods would function similarly as do the number of subjects for quantitative
researchers. Stake (1994) did propose the use of triangulation of methods for "researchers who are concerned about the validity of their case study."

To reduce the likelihood of misinterpretation, we employ various procedures, including redundancy of data gathering and procedural challenges to explanations. For qualitative case work, this is called triangulation. Triangulation has been generally considered a process of using multiple perceptions to clarify meaning, verifying the repeatability of an observation or interpretation... triangulation serves to clarify meaning by identifying different ways the phenomenon is being seen. (p. 241)

It is important to note that the research phases were not isolated from one another. That is, I continued observing and interviewing my family and physicians as I was conducting the virtual communities work. The influence of the interviewing, observing, and virtual community participation was noted in journal entries.

**Reflexivity of Self and Others**

Reflexivity can be viewed as the "up frontedness" of qualitative research. Crabtree and Miller (1992) viewed reflexivity as a means to identify observer biases, which could lead to the discovery of "preconceptions and assumptions that may have influenced data gathering and processing..." (p. 79). From the personal account of my experiences, I began to observe patterns of thought and behavior, which encouraged me to explore other issues concerning my lived experience. One observation which repeatedly garnered attention was that my interpretation and meaning of my illness experience was negotiated through factual and supportive information from my own information seeking as well as that of others, which included family members and the online communities in which I participated.

However, I also understood that there was more. I was not only defining my illness from the information I collected, but also in terms of how I saw myself in relationship to those "others." Kerfoot and Sarosi (1993) acknowledged as much in their observation "we see ourselves compared to those around us, and through the eyes of family and friends..." (we) get from community a sense of hope, trust, (and not to be) afraid of illness."
Reflexivity of Self Through Narration

A primary consideration was to engage in self-reflection, in order to reveal the communicative implications of the three constructs guiding this study, information, chronic illness, and information technologies. Thomas (1993) cautioned that ethnographic researchers “are active rather than passive recorders of narratives or events.” Ethnographic researchers must engage in reflection throughout the research process to repeatedly consider the influence of personal involvement (p. 46). As Clark Moustakas (1990) suggested:

The heuristic researcher is not only intimately and autobiographically related to the question but learns to love the question. It becomes kind of a song into which the researcher breathes life not only because the question leads to an answer, but because the question itself is infused in the researcher’s being. It creates a thirst to discover, to clarify, and to understand crucial dimensions of knowledge and experience. (p. 43)

Given the above, the first component of this research was to incorporate my own experiences in a personal narrative. Stake (1994) contended the following personal narrative provides opportunity for vicarious experience, readers extend their memories of happenings. Naturalistic, ethnographic case materials, to some extent, parallel actual experience, feeding into the most fundamental processes of awareness and understanding...We come to now what has happened partly in terms of what others reveal as their experience. (p. 240)

Personal narratives tell what the respondents experience and what has influenced that experience. The “storied nature of human conduct” (Sarbin, 1986) provide meaning and a context from which to interpret. The personal narrative did not just provide an accounting of relevant events in the study of my research question, but as posited by Carr (1986), recounted the experience overtime in story form. According to Carr, stories are the closest to actual experience. Clandinin and Connelly argued (1994) that “a story has the sense of being full, a sense of coming out of a personal and social history” (p.415).

The writing of the personal narrative proved to be cathartic as well as a means of storytelling. As I wrote I began to connect what previously had seemed disjointed experiences, and the construction of the story helped to give context to these experiences. The personal narrative seemed to take on a life of its own, and several times, I would
have to put the writing aside because of frustration or being overwhelmed by the recounting.

When I began the narrative, I had no idea what direction it would take me. I had decided to write the lived experience, editing and excluding very little. Though I was focusing on information processes and information technologies I felt that a complete narrative, not limited to information events, was needed to provide the context in which these processes occurred. I also took care not to incorporate a priori categories of information uses and needs in which to fit my experiences. It was important for information themes to emerge from the narrative, which I planned to use in the design of an emergent model of information needs and uses.

I incorporated in the personal narrative the 1985 – 1996 journals that I had written, the journal writings of my parents, letters from my ex-husband, my “official” hospital and doctor records, including those of my psychiatrists, internist, neurologist and neurosurgeons, personal testimony and a self-interview. Additionally, I read the letters and cards from friends and coworkers and included the journal entries and direct observations and interviews from hospital stays and doctors’ appointments surrounding the 1996 surgery. These documents were included, not only to provide distinguished data, but also to authenticate other evidence. Data also included downloaded web sites, listserv “conversations,” chatroom interactions, and email from the Internet and World Wide Web, documenting my participation in the on-line communities.

The cut off date for data collection was March 1997, which marked the period I began radiation treatment at the University of Virginia. The data I collected allowed me to explore the “individual, cultural, and medical maps Hellman (1993) suggested chronically ill patients use to define themselves and their illnesses. The multiple data approach advanced Yin’s 1994 claim that this approach would serve to increase the validity of the study, and the position that all data pertinent to the research question be included.

The serial narrative provided the “upfrontedness,” the explicit statement of where I am coming from for the readers and also provided the means that Thomas (1993) suggested in his observation of the necessity of continual reflection needed for the
ethnographic researcher to examine the influence of his or her own personal involvement. This continual reflexivity allows process development that may prove serendipitous (Altheide and Johnson, 1994). The narrative provided context, in support of Mishler’s 1979 argument for the importance of adopting a “context-sensitive” approach (1979, p. 3).

Development of personal narrative

The 1985 data was viewed as the starting point of this research. The self-interview that I had conducted after the personal testimony of written in April 1996, provided a historical perspective to my personal context of illness. I began to construct a personal narrative focusing on the impact of information technologies and my experience, realizing that there was much more to my interest than my curiosity of how I experienced my illness and its aftermath.

To provide appropriate context, the personal narrative included internal observations, the settings which couched these observations, communication with and personal observations of others, including family, on-line communities, friends, and physicians. Yin (1994) supported the use of multiple sources of evidence in his contention that this would serve to increase validity.

To cite Clandinin and Connelly (1994) “Experience is messy, and so is experiential research” (p.417). My experience was so messy, in fact, that my first predisposition was to include everything. I recognized that the “unique” data I had access to would define my contribution to the study of information technologies and chronic illness, and I could not imagine ignoring the richness that my experiences offered. Thom kept pulling me back on track when I would maunder. His continual prompting me to remember my research goals and audience helped to make these very critical decisions concerning appropriate data. This struggle would describe a primary necessity of the advisor-advisee relationship throughout the research.

My accounting of what I experienced suggested patterns of intrapersonal, interpersonal, and extrapersonal (Lipowski, 1983) interdependency that helped identify those individuals who became active participants in my lived experience as a chronically ill patient. Recognizing active participants highlighted family, friends, and physicians’
participation in the illness experience as going beyond giving support. There were three involvement functions which I used to identify those I would include in this study: 1) the impact of my chronic illness on their everyday living, 2) actively participating in information exchange and 3) involvement in the negotiation of the meaning of my illness. These original observations encouraged me to propose a “culture of wellness,” which could be used explain the relationship that I sensed between these significant persons, information and information technologies, and my illness experience.

The literature I reviewed supported this conceptualization. However, while living this experience, and from the personal narratives I collected from family and physicians, I began to understand that I could not meet some basic assumptions I had designated in this conceptualization. For example, I had chosen to view “culture” as an organizational model that emphasized interaction among and between all members. The “culture of wellness” I envisioned included health care professionals other than my physicians. However, the surprising course of my illness, which included meningitis and blood infections, added so many specialists and therapists to my “ill care” that the research soon began to lose focus, so I limited the research to my primary physicians, Doctor Dullard and Dr. Sharp. Additionally, I was seeing three stand-alone groups: that of family, the community of physicians, and the virtual communities I participated in.

Though not entirely abandoning the “culture” model, I was not comfortable with the observations I was making regarding the characteristic of interaction among the three groups. Borrowing from the information technology literature, I conceptualized the three groups as “communities,” rather than a “culture.”

**Reflexivity of Others Through Narration**

Through personal narrative, I was able to turn inward and use my experience to crystallize the research question for this research. As I wrote my narrative I emphasized my information needs and uses, and use of information technologies, which were relevant to the research question. The lived experience of others furthered the analysis. I did not experience my illness in a vacuum, isolated from friends, family, and physicians.

Given the complexity and exploratory nature of this research and the intricacies and idiosyncrasies of those individuals I included, I engaged methods that allowed
reflexivity of other participants that were necessary to explore the proposed research question. Acknowledging the importance of story-telling in accounting of my experiences, and recognizing how powerful telling my story was for me, I required methods that would allow for the others to tell their story. To accomplish this, personal narratives and in-depth interviews of each member were the most appropriate means to gather background and experiential data. Both the narratives and the in-depth interviews provided an understanding of this experience through the lens of each participant and a collective perspective of the experience. Moreover, the procedure of reflexivity of others suggested themes and concepts that I could investigate in the on-line communities I included in this research.

Development of others' narratives

Having others write personal narratives addressed Janesick (1994) position that the importance of qualitative design include more than interviewing or observing. She asserted “Simply observing and interviewing does not ensure that the research is qualitative, for the qualitative researcher must also interpret the beliefs and behaviors of participants.” Erickson (1986) addressed the use of narrative specifically in accessing the participants’ beliefs and behaviors:

It is important to emphasize at the outset that the use of continuous narrative description as a technique...does not necessarily mean that the research being conducted is interpretative or qualitative in a fundamental sense. What makes such work interpretative or qualitative is a matter of substantive focus and intent, rather than of procedure in data collection, that is, a research technique does not constitute a method. (p.60)

Family members wrote personal narratives which focused on five issues: the communal experience of my illness and how they are involved, the practices and patterns of information exchange, how they negotiated meaning of this experience, their thoughts and use of communication technologies in general, and the potential use of communication technologies in this particular lived experience. These personal narratives provided “an explicit statement about ‘where the author is coming from’” (Altheide and Johnson, 1994, p. 490).

Although these questions covered more than my primary interest of information technologies, the additional information contributed to contextualize and characterize the
situation. The personal narratives of others also functioned to provide what Fontana and Frey (1994, p. 371) discussed as a "shared meaning" that both the interviewer and respondent used to understand the context of the interview.

To facilitate the narrative writing, each participant was given a list of the above items to address in their narrative with instructions to tell a story of their experiences in this event, focusing on the broadly designated items. The focus items for the narratives were purposively general rather than specific to guard against setting a priori categories or researcher influence on the written accounts. This procedure also was used as the "member check" Lincoln and Guba discussed in their 1985 work by providing a framework for the in-depth interviews.

Additionally, the personal stories were used in much the same way that Janesick (1994) recommended for the "first interviews with participants" (p. 229) by letting the participants tell their story and using these stories as background for the subsequent in-depth interview. Narrative "assignments" were faxed or given in person. Each participant was encouraged to ask questions, regarding the instructions. Members were given four days to write their narrative and upon completion participated in an in-depth interview. Participants were assured anonymity for both their personal narrative and in-depth interview.

Though the original research design indicated personal narratives to be submitted by family and physicians, time constraints, interest and involvement levels, and personal factors negated the primary physicians to write personal narratives. To accommodate the need for this information, and to work around the above-mentioned constraints, this information was collected through questions asked during the in-depth interview.

The physicians' importance to this study was twofold. First, the physicians were interviewed to discover their general impressions of the importance of information for their patients, and their personal interest and possible use of information technologies in their practice. Second, physicians' data would be used to determine their view on patients' use and needs of information, and their impressions of patients' use of information technologies and the implications for their health care.
Data from the on-line participants were collected differently. For ten months (from June 1, 1996 – March, 1997) I participated in three on-line communities (two listservs and one chatroom) as a brain tumor patient with doctors and other brain tumor patients, and chronically ill persons. Participation in the chronically ill listserv was discontinued in September 1996, two weeks before the scheduled brain surgery.

There were several reasons that prompted this change. These three on-line communities had been selected from seven original communities, which were favored by topics discussed, group activity, and community sponsorship. I had initially planned on continuing participation in all three groups for the duration of the research. The decision to drop the chronically ill community was, however, a natural one. As the date for the surgery neared, I found I lost interest in this particular focus, and chose to spend more time participating in the listserv and chatroom for oncology patients.

My concerns at this point were not with managing a chronic illness, but rather, dealing with brain tumors and proximate brain surgery. Topics and discussions in the oncology listserv and chatrooms were more relevant to my pressing situation. I also enjoyed the groups from these communities more. The chatroom had actually grown out of this listserv, which resulted in at least three ways to communicate with each other: personal e-mail, the listserv, or the chatroom. Additionally, the oncology patients shared a more specific history and I related better, both psychologically and communicatively, to them.

On-line culture members did not write personal narratives or participate in in-depth interviews. Rather, the on-line data were used to describe issues and relational aspects among members, reflecting the information needs and uses and the role of information technologies in the members’ experiences and was incorporated in the personal narrative.

In-depth Interviews

In order to explore specific aspects of this experience for family and physicians, I chose to conduct open-ended ethnographic (in-depth) interviews of each participant. Because the interviews were conducted during the research process and not at the
conclusion, the reflexive nature of this approach allowed for refocusing and making changes throughout the research.

Fontana and Frey (1994) outlined several characteristics of the open-ended ethnographic interview. These interviews are appropriate when the researcher has general topics he or she wants information about and will not “use closed-ended questions, or a formal approach to interviewing” (p. 366). This interviewing format allowed me to respond to questions from the interviewee. Most important, Fontana and Frey suggested the open-ended ethnographic interview as most appropriate when the goal of the researcher is “to understand the complex behaviors of members of society without imposing and a priori categorization that may limit the field of inquiry . . . (when) the desire (is) to understand rather than to explain.” (p. 366)

Dobbert (1982) addressed the ethnographic interview specifically:

Because the researcher’s aim is . . . to uncover patterns and not to get questions answered, the researcher cannot, like the interviewer, direct the conversation. Indeed, by directing the conversation, the researcher can only uncover patterns predicted in advance. . . . [T]he basic aim is to determine what patterns the informant sees and considers important enough to bring up. (p. 114)

Interviews were scheduled for two, two-hour blocks which allowed flexibility, but also insured additional time if needed. I was concerned about the convenience to the interviewee, especially the doctors. This time factor forced the in-depth interviews of the doctors to be conducted when time was available. Consequently, information was gathered during office visits, hospital rounds, and hospital visitations. Family members chose both time and place for interviews to take place, but they were conducted only after I had received the personal narrative from that group member. Follow-up questions were discussed over the phone or by fax.

The interviews were unstructured allowing the respondent to ask questions. This, I felt, was especially important because the goal of the interview was to understand rather than explain. I was sensitive to not ask leading questions or to indicate a “right” or “wrong” answer. The areas indicated from the members’ personal narrative were central to the in-depth interview, although participants were not cut off if they strayed from the
specific question. This allowed additional information to be recorded which could be used in interpretation. Interviews were recorded on micro-cassette and then transcribed.

As previously indicated, though the physicians initially agreed to write personal narratives, after receiving directions it became apparent that this information would have to be collected another way. Physicians’ in-depth interviews were conducted when and where it was convenient for the physician. After discussion with the physicians, it was decided to adjust the procedure and a “verbal” personal narrative would be recorded during available times and then transcribed.

Though in-depth, the interviews were informal, allowing the physician to direct the focus and emphases. Dr. Dullard’s personal narrative information was essentially collected during office visits, hospital rounds, and infrequent hospital visits. Dr. Sharp would frequently sit in my hospital room and audio record his personal narrative for 45 minutes. Though these procedures did not result in a neatly transcribed interview, important information was obtained that could be used in interpreting the physicians’ experience.

What were limited, however, were the context, personal history, and personal perspectives, although more of this information was gathered from Dr. Sharp than from Dr. Dullard. Interview “areas” and prompt questions emerged from the personal narratives, which generally addressed the role of information in their professional practice and for their patients. There were questions included in the interview that focused on the use of information technologies for the medical profession, their personal professional activities, and for their patients.

**Family In-depth Interviews**

Completed family in-depth interviews ranged in time from two hours to four hours. Only one of the interviews had to be interrupted for any length and time and resumed later. Time, setting, and description of relational dynamics to indicate application of selection criteria were noted at the top of each transcribed interview. Transcription was not verbatim, but both question and answer was recorded when included, and questions and answers were kept in sequence. Statements that were not relevant to this study were excluded from the transcription.
I incorporated Denzin's 1989 suggestion that field notes should contain distinct references to participants, interactions, interpretations, and social organization. Journal entries and field notes were written immediately after my participation in listservs and chatrooms and documented both the activities and feelings concerning the participation. After a participatory session, the field notes were processed and saved as individual documents in a designated folder in the computer. It was very important to naturally experience the participation in these communities, and not to direct or influence others' participation by incorporating my research interests in my taking part.

This was difficult in the beginning of the research so, I designed my field notes to include participation as "patient" and as "researcher," which helped me distinguish the observations. Necessary changes in the field notes emerged throughout the study. Three weeks into the study the field notes allowed, what I considered, thorough documentation of the data.

Field notes were also written after interview segments, and incorporated in marginal notes that were made during the interview and audio recordings during breaks in the interviews, out of view of the participants. Additionally, after the interviews, I noted observations on field note forms which noted participants, interactions, interpretations, and overall general observations.

Virtual Communities Data

Participation in the virtual communities for this research lasted from June 1996 to March 1997. Downloaded discussions from the Internet produced over 5000 pages. This data included on-line discussions from listservs and chatrooms I participated in, conversations in which I did not participate, and web pages. When possible I would download archived material to provide context for the discussion I was interested in.

Units of Analysis

The objective of the analysis of the virtual health communities messages was to investigate the "realities" of the illness experience, produced "from within," which views reality as a self-generating (italics theirs) procedure (Holstein and Gubrium, 1994, p. 265). Holstein and Gubrium continued to suggest that the study of meaning through talk
necessitated this analysis include the context of the talk. "It is only through their situated use in talk and interaction that objects and events become concretely meaningful (p. 265).

Guided by Holstein and Gubrium's 1994 work, I determined that the unit of analysis for the virtual communities data include context rather than a single word or a single phrase. Initially I read the complete message to categorize the interaction. Most of the data did not require this, especially after "knowing" the style of certain participants. Consequently, the context of the talk could be identified by varying amounts of a participant's message. For example, Jim had a tendency to ramble, or to spend an inordinate amount of "verbage," a preamble, before getting to the focus of his message. He regularly insisted on providing the "history" that led him to his question.

Before I begin, let me just thank all of you for being here for me. You know I was really concerned about family this time. I'm sure you remember the long period of time when I did not "visit" our list for quite sometime. I was out about two weeks and told you when I returned that my parents were not taking this as good as the last time. Many of you told me, during the chatroom session, that I should get them involved in this listserv. Well, I worried about doing that and your responses during that chat convinced me that I should do it. What I really want to know is do you know of other listservs they can belong to?

Kevin had a different "style," getting right to his question or comment.

Any ideas on what I can have my sister read to help her with this latest diagnosis?

It was not only the influence of a participant's style that varied the amount of "context" needed to understand the participant's message. Some could only be interpreted through tracing the "thread" of his/her messages by looking at that participant's "history," which required me to go back in the archived documents of the listserv.

Data from participation in virtual communities changed over time as did the field note documentation. Initially, immediately after the participation, which included reading and responding to listserv messages or participation in real-time chatrooms, I would document "overall" perceptions which included personal feelings and evaluations, topics discussed, perceptions of "tone," and observations of other participants. As a researcher I would note observations on communication dynamics, and community roles, such as "leader," "antagonizer," or "peacemaker." I would also note who participated.
I did not find the literature in computer-mediated communication helpful in
developing a procedure for data collection, and consequently the employed procedure
evolved out of my data collection. In the beginning of the study I would categorize the
downloaded data approximately every four days, and would then chart the categories.
After recognizing the potential amount of the downloaded material, I began categorizing
after every session.

Three weeks into the virtual communities data collection, I was familiar enough
with the data to develop a chart to categorize the interactions directly from the computer
screen. I had tried to use the “subject” identification from the email transaction list, but
quickly determined that this procedure could not be continued for two primary reasons.

First, many times the email entries were replies to the original email document
and would be identified as the original identification category, and quite often, the
identification category did not fit into the categories I had developed. I became more
selective as the study progressed, partially because through interaction I came to “know”
the regular participants and recognized their “identification” categories. Simply by
categorization, the possible richness of the data was lost.

Though reading the individual emails was time consuming, the downloaded
material was considerably less. I continued to download communication that I thought I
would want to quote directly, or those interactions that could not immediately be
categorized. The procedure proved to be effective and efficient. From these selected
materials, relevant ones were used in my personal narrative and some were referenced in
journal entries.

As important as the data from the virtual communities were, participation in the
communities was critical to furthering the study on virtual “health” communities. Raw
data, in the form of transcripts, could have been downloaded from the archives.
However, the participation was necessary for the participant observation method as
defined by Junker (as cited in Bogdewic, 1992), allowing me to experience the
“community,” affording opportunities for observing the interaction and development of
the participants’ roles, studying others’ interactions, as well as chronicling my
experience.
Analysis

The analysis of qualitative methods allows for establishing the response of people and communities to critical events by “casting problems, purposes and intentions in a new light.” (Crabtree and Miller, p. 190) According to Altheide and Johnson (1994, p. 497) it is the context that gives validity to the interpretations. My personal narrative provided both context and data to be evaluated for meaning. The stories told in the narrative and by others were analyzed as a “form of truth seeking.”

Clandinin and Connelly (1994, p. 423) addressed the method of analysis which transforms field texts to research texts, which I incorporated in the analysis. Clandinin and Connelly reported that “a research account looks for patterns, narrative threads, tensions, and themes either within or across individuals’ personal experience” (p. 423). According to Clandinin and Connelly this search is created by the researcher’s experience.

The results of the analysis of the stories from three communities (self, others, and virtual) were looked at both individually and collectively to produce a more complete “picture” of the use of information technologies in the context of chronic illness. A six-stage emergent model, which detailed the information needs and uses from my personal narrative, was developed. The model was used to compare the information needs and uses of face to face communities and virtual communities. Further, the model was utilized to compare information uses and needs from the 1985 surgery to the March 1997 cut-off date, in order to examine how information technologies influenced the concept of information and information needs and uses.
CHAPTER 4
RESULTS AND CONCLUSION

I approached this study with three goals in mind. I first wanted to identify themes of information conceptualization, uses, and needs, emanating from my personal narrative, which chronicled a decade of living with a chronic illness, brain tumors. Second, these themes were used to develop a model depicting the role of information in this life experience. In addition to actuating the examination of information needs and uses in each stage, the model provided a framework to examine the role of the three communities (online and offline) in conditioning information needs and use, and ultimately communication.

The third goal of the study was an examination of the role of information in virtual communities of chronically ill and brain tumor patients and an analysis of the influence of information technologies on these information factors. These three goals addressed the research question: How have information technologies changed or influenced information management for the chronically ill?

The Emergent Model

The proposed model is a functional representation of information needs and uses that emerged from an analysis of my personal narrative, giving order and meaning (Smith, 1988, p. 10) to the lived experience of chronic illness. Though initially discerning gross categories, a closer examination of the data suggested a more refined classification system. Data driven analysis, derived from “the emergent nature” of the findings, as proposed by Johnson (1990, p. 27), suggested a three-pronged category system of information uses. Additionally, six stages, differentiated by information needs, depicted the role of information during the ten-year trajectory of chronic illness. These stages were Orienting, Opting, Inquiring, Ensembling, Integrating, and Advancing.
Six Stage Emergent Model of Information Needs & Uses for the Chronically Ill

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Figure 1: Emergent Model of Information Needs & Uses for the Chronically Ill Patient

This model focuses exclusively on information that the chronically ill patient has initially evaluated as relevant and does not consider information that the patient has ignored or discarded as irrelevant. The information needs and uses categorized in the model emerged from my personal narrative, the narratives and interviews of family members and data collected from participation in virtual health communities. The three "uses" categories that emerged were "Internal Assessment," "Cognitive Assessment," and "External Assessment."

Each uses category designated options that a patient has to apply or adopt the information. For instance, a patient may choose to further externally assess information by asking others, discuss the information with physicians, virtual health communities, or family. Choosing to cognitively assess the information, the patient compares and contrasts that information with previously obtained information. The patient may critically assess the information, or work to evaluate that information using their belief structures or value orientations. Internal assessment is characterized by the patient’s
internalization of the information and personal adjustments to accommodate the information, not just "adopting" the information which may be the result of the external or cognitive assessment uses. Identified as "assessment," the categories imply a purposive, goal-directed "use" of the information by the patient which is necessary for the patient participatory perspective.

The six stages of information needs represent needs that occur from the initial diagnosis of the chronic illness, which is characterized as chaotic, to an accommodating, advancing stage, which promotes personal growth. Though these stages emerged through my personal narrative, the literature on chronic illness suggests some model attributes. It is the specific goal of this research to explore the influence of information technologies on each of these stages in the living context of chronic illness.

Kleinman's 1988 assertion that "chronic illness...is a reciprocal relationship between particular instance and chronic course" (p. 8) suggested that the six stages are not mutually exclusive. Stages do not just overlap. Patients can experience more than one stage simultaneously, which can add to the general inconstant temperament of chronic illness. For example, a patient may have reached the fourth stage, Ensembling, for the physicality of the chronic illness, but may be experiencing stage one, Orienting, in emotional coping of the chronic illness.

The literature on chronic illness suggests that patients will vary in time to move through the stages. Thorne (1993) surmised as much with her observation that for the chronically ill, there is no single sequence in which onset and diagnosis of chronic illness occur,” and there is a “great variety of onset and diagnosis experiences” (p. 15).

The remainder of the result and discussion section will, 1) describe and provide evidence, of the six stages of information needs proposed in the emergent model, 2) examine information, from participant observation analysis, in each stage of the model, 3) examine the communication of the virtual health communities, in which I participated, in light of the proposed stages, and 4) discuss my participation in the virtual health communities, and the influence of participation in living as a chronically ill patient. Additionally, the influence of information technologies and participation in virtual health communities on information needs and uses of the chronically ill patient will be
discussed. These segments will be validated and evidenced by personal narrative excerpts, data from in-depth interviews and others’ narratives, and electronic communication from virtual health communities. Consideration for future research will conclude the results and discussion section.

The current status of information in chronic illness

Currently, information is considered, primarily, to be used by chronically ill patients for decision-making and reducing uncertainty. There exists a time-honored perception that with information a patient becomes more involved and participatory in his or her medical care. From these activities the patient is transformed by his or her illness, hopefully benefiting the patient in getting well faster. Immediately upon hearing my diagnosis of brain tumors, I thought as much.

But I recognized that information seeking and discovery did not “make things better.” What I did note in my journals, and in my personal narrative, that it was the action, not just the act of information seeking that affected me. I begin to think more about this emphasis on information for the patient. As I looked at my own situation, it was not the specific type of information that seemed important, and there seemed to be no relation to the type of information and the “need” it was fulfilling. I had always been intrigued with the application of Schramm’s information theory, and Shannon and Weaver’s model of information to human communication. Intrigued, but not convinced of it’s attunement. Suddenly forced into a life context where I did not have the luxury of being intrigued, but rather had to be practical, some of the haze seemed to clear in relative to information meshing into the life of chronic illness.

The Six Stages of Information Needs

The emergent model of information needs and uses suggested six stages of information needs: Orienting, Opting, Inquiring, Ensembling, Integrating, and Advancing. Each stage is distinguished by the information need of the patient, and is not mutually exclusive. Stage descriptions will be augmented by data from the personal narrative, in-depth interviews and personal narratives of others, listservs, chatrooms, and e-mail from the virtual communities I participated in.
Stage One: Orienting

Circumstances surrounding the diagnosis I received of brain tumors were not typical of the way most chronically ill patients receive their diagnosis. I had been in the hospital over a week, had had several blood transfusions, and there was no “history,” either family or personal, that would suggest this medical verdict.

What initially came to mind was that the diagnosis of brain tumors usually indicated the end to an actor’s television role. The diagnosis was reserved for those who would not be around much longer. This was so foreign to me that I had no idea that this would not be the end of my life, but rather the end of my life as I had known it for 32 years. I was not prepared for the extreme changes that would occur. Overwhelmed by Dr. Wisdom’s announcement, I felt as though I was detached from the situation, observing from a distance, the sentence I equated with death.

My major concern was the impending surgery, not how or if this condition would influence how I would live my life. The unnerving of the situation would color most of the time I would be in the hospital and would dance in and out of my life for years. I had no idea what any of this meant. I felt dizzy even lying down, and there seemed to be a hundred questions, but I had no idea where to begin.

Observations noted in my personal narrative support the characterization of first stage as chaotic, filled with uncertainty, and a dread of finding out what I did not want to know. There are references to “the schwama storm in my head,” a search for information to provide some anchor in the midst of this storm, and an emotional void that made it impossible to focus.

Information, in the orienting stage clearly served other purposes than information for decision-making or knowledge about the diagnosis, those being emotional and relational support. Data from my personal narrative indicated that information functioned in four ways which are characteristic of the first stage of the model “Orienting.” These functions were 1) reducing the state of uncertainty, 2) a distraction, 3) relational messages, such as control or power, or 4) validating or invalidating self worth.

What is surprising is that the data, when viewed in context as presented in the personal narrative, do not suggest that information was used for understanding the
diagnosis or decision-making. The physician's perceived information need of the patient, however, is for understanding the diagnosis and/or decision making. Though my communication seemed to indicate that I wanted to be informed, the contexts surrounding those requests indicated I asked for information to be used in other ways. The non-use of information for decision-making or knowledge distinguishes "Orienting" from the other stages suggested in the emergent model.

**Information to reduce state of uncertainty**

At first, the need of information to reduce the state of uncertainty suggests that the uncertainty is because of the lack of understanding, but uncertainty can be attributed to more. The diagnosis was not the only unsettling aspect of the situation. I was forced into the role of hospital patient for which I had no "map." Following the "rules" was a strategy that I could always rely on to make me feel safe. However, I found myself in a world in which I did not know the rules, this only adding to the surreal nature.

I knew just enough information about the tests I was given to "be dangerous." For example, when I was told that I was going to have a spinal tap, my reactions were largely because I "knew" that was one of the most painful procedures to have (it really wasn't that painful). The thought of blood transfusions worried me more than the tumors, and I received six. I was spared advanced worrying when told I was going to have an angiogram, simply because I had only heard of that for heart problems (this was the most painful).

**Information as distraction**

There are references in my journals and personal narrative to information searching. I read material the residents would bring me. I tried to engage nurses in conversation, and kept asking the doctors questions about the surgery. However, rather than providing information that would be used in decision-making, or even in understanding my illness, the importance in this information seeking was as an activity that accomplished several things. First, asking questions and gathering information was a distraction from the fear I would feel whenever I allowed myself to think of where I was and why I was there. There was also the sense that this is what I should be doing. After all, I taught at the same university in which the hospital was located, and a "scholarly"
approach to this situation would be “dialoging” with the “authorities” about my condition.

**Information as relational messages of power, control, and validation of self**

My personal narrative supports the idea that I did not ask for information for answers, rather the reciprocity of giving and getting information validated my status in this event. The most frequent function of information in the orienting stage was to indicate power and control; these being the foundation of hospital organization and operation. From the first night in the hospital I noted that the act of “Asking questions and searching for information gave me some power in this powerless role as patient.” I observed that knowing information and the legitimacy of giving that information ascribed status in the hospital, to health care personnel, as well as my family. The hospital hierarchy was structured around information knowing and giving. Doctors were at the pinnacle of the structure, the patient on the bottom rung. Residents were banished from my “team” for divulging information they should not have.

Information as relational messages only served to increase my feelings of dependency on the physicians, residents, and nurses. “I was totally dependent on what they decided I should know.” The observation that “my actions were monitored as closely as the information I received” was dehumanizing and resulted in an invalidation of my pains and concerns. “I was feeling like some laboratory specimen, especially when residents would ask questions about me as if I wasn’t there.”

Information was also important in acknowledgement and participation of my family members. I wrote, “...doctors and nurses assigned roles to my family members, not by the social roles but by the type and amount of information they had.” Because of information, my father gained the trust of the physicians, was “treated as one of them,” and the physicians “invested their trust in him.” Lack of information exempted others from decision-making in the hospital. My husband “was excluded from the discussions about my illness.” His information was regulated to the support group he was encouraged to attend.
Validation of "Orienting" through Others' and Virtual Community Data

The claim that informational needs in the Orienting stage focuses on emotional and supportive information rather than factual information is supported by the experience of other chronically ill patients and their families. Consider the following messages exchanged through listservs, chatrooms, and private e-mail between participants in virtual health communities, which focused on the emotional aspects of on-line relationships. It is important to note that these messages were either from or to new members of the electronic community. An important element of many of the messages to new members is that he or she has found the promised land of understanding and caring. The "we" in many of the messages is the collective we of the listserv.

I just wanted to welcome you to the list and let you know we are glad to have you here. We’ll do anything we can to help you. It’s so important to know you are not alone in this. This list is a wonderful place for emotional support, so if you feel you’re ready to talk about it, just let it out. We’re all here to listen.

Hi! I just wanted to take a moment to thank everyone who took the time to welcome me. Doctors app. This [sic] afternoon and I’m going with a list. I feel so much stronger, just from your help. The site on T.N. was great, many thanks. My good thoughts and prayers to all.

I am new to this list and am a new user to this type of list. I need help in coping with my situation. My 83 year old [sic] mother has just been diagnosed with a brain tumor and is not expected to live long. She was living independently until this crisis. She has had to leave her home of 30 years and move 140 miles away to live with us. This has been a big transition for all of us and we all are trying to find ways to cope with the illness, the changes, the future.

Hi. I don’t know if this is going to make sense but we just found out our 14 yr. old [sic] son has a brain tumor on the brain stem. We don’t know what to do or where to turn. Can any of you help us?

Help!!!! I’m not getting any mail from any of you. I sent 14 long messages yesterday including a prayer list. Did anyone get them?? Can you help me? I have no one here to talk to. Check in with me so I know you’re OK.

We all need to take our minds off our problems esp. [sic] in the beginning. Don’t turn away from those who need to talk. If you need to talk just leave a message on this list. If you’re new we understand. We’ve all been there.
You've got our positive thoughts. And I'd be bold enough to say that positive thoughts will be forthcoming from people on this list, whether they say it in writing or not. And we are here for you, any time, in any way.

My need for prayers and support and encouraging words is undeniable. I'd appreciate any healing thoughts and prayers you could send our way to get us through this tough waiting period. I'm so grateful this list is out there for me and I'm so proud of all of you doing a good job of surviving/thriving.

“Talk” data from the virtual health communities suggested that the language the netters used could be categorized as “orienting.” Theirs’ was the language of illness that worked to bond the participants together, the rhythm that created a collected meaning of the shared experience. The sharing of these words was even more important in the sense that a brain tumor patient could communicate with the words only with a select few, their health care professionals and other patients. Family members who used these words seemed at least once removed from the experience.

With the MRI many times the doctors cannot differentiate between necrosis (dead tumor), active tumor, and edema (swelling). A spect scan allows the doctors to specify certain areas in grids and then look at the chemical composition within those grids. Active tumor has a certain chemical fingerprint quite different from dead tumor or swelling. Sometimes MRIs do not show active tumors, but the spec scan can show more select areas.

Both gastrin and genetic factors were suggested to underlie the pathogenesis of multiple gastric enterochromaffin-like (ECL) cell carcinoids. To assess the role of genetic alterations in carcinoid tumorigenesis, loss of heterozygosity (LOH) at the locus of the multiple endocrine neoplasia type 1 (MEN-1) gene was studied in gastric carcinoids of patients with MEN-1 and chronic atrophic A gastritis (A-CAG), as well as in sporadically arising intestinal carcinoids.

The personal narratives and in-depth interviews of my mother, father, and sister, indicated that emotional needs were primary, when they first heard of the diagnosis though the needs were directed toward the family. My mother indicated that if she could see me and talk with me everything would be all right. My sister’s first thought was for the family to be together.

I could only think that all I wanted to do was to hold your hand. I knew that you’d be strong for everyone else out there and I worried no one would know what I knew, you needed us. I can remember your dad coming home and thinking something must be wrong since it was the middle of the day. He sat on the stairs and held his head in his hands, crying. We didn’t know anything, except we had to get out there.

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I called Dr. Z as soon as I got home, but couldn't even think of questions. Amazing since I had had to deal with patients for years. He actually told me the things I should focus on when I got to California.

When I heard, there was a rush that accelerated everything. I remember thinking how could I help you cope with this? It really never occurred to me to ask more about the brain tumors. I didn't know what good that would do me, knowing about the tumor size, or location. The only reason that was important for me to know was how it was affecting you.

Though patients and family members seek out emotional support after the initial diagnosis, physicians insist that their role is to provide factual information concerning the illness. When discussing the responsibilities of the physician to the patient, Dr. Dullard suggested

Facts about the illness are what I can offer the patient. That is my role. I really don’t see more that I can say than what my experience and studying suggest. We can’t get personally involved at that level. Patients may grab on to something I say and won’t be informed about their medical condition.

Though Doctor Sharp’s friendship with my family influenced my treatment, he still saw his primary role as providing the factual information of the patient’s medical condition:

Dr. Sharp: Now I’ve seen most of my patients for years. I’ve brought their kids and their grandchildren into this world. I tell you, sometimes it gets me that they call me about every little thing. But they need me for that, and I’d rather have them asking me then getting information on their own. I do realize now how important the doctor’s relationship with the patient is, and I’ve tried to foster that. But I can’t forget that I’m the doctor and I have got to give them the best care I can.

MP: And that care is . . .

Dr. Sharp: Mainly giving them medical information.

**Stage Two: Opting**

Though I had inherently understood that information could give me some power and control when I was in the hospital, I was not ready to deal with that before the 1985 surgery. My personal testimony shows an insistence for, at least an appearance of, taking
responsibility in my medical treatment. Looking at the experience through my personal narrative, I now realize I could not have handled any responsibility.

It was when Linda, my roommate arrived, that I, as well as my family, noticed changes that indicated I was getting stronger, emotionally as well as physically. My personal narrative and the data from others suggest that this is the time that I moved into the second stage of the model, “Opting.” The importance of my relationship with Linda was with her “I was not embarrassed about my weak and strained voice.” “I did not have to be strong, pretend everything was OK when, in reality, my world seemed to be crashing all around me.” The contrast of how I felt with Linda simply underscored the discomfort I felt with physicians. “True to their customary roles, I felt them treating me as nothing more than a sick person at their mercy to get better.”

This perception I had of my physicians was not shared with my family. My sister indicated in her narrative and in the interview that the “doctors asked you continuously if you had questions.” She also wrote that once I was admitted, residents and physicians would come to the room at night and explain procedures. She remembered that I did not have questions for them, but would complain that they didn’t care if or what I knew.

It was only after I began talking with Linda, my roommate after the first surgery, that I began to realize that my life had been altered. I knew, or at least finally accepted, that the problems I had with swallowing, and the vocal cord and right side paralysis were permanent, only to be corrected by more surgeries, rehabilitation and luck. Linda’s story, however, made me recognize, for the first time, things could be worse. She had, at that time, ten brain surgeries to correct a “leaky tube” in her brain. By the time she left the hospital, she already had a date for her eleventh surgery. She had not only won those “battle scar” arguments, she had my respect.

The personal narratives of my family provided a more complete picture of that time. I knew I was feeling guilty putting my family through this and the narratives of others supported this. My father noted that I kept asking him how he thought my mother was holding up. My mother wrote that I “drove her crazy” making sure she was okay. Yet, there was a strange calm characterizing this time – perhaps a resigned feeling to the surgery and whatever was my fate. I did not search for information while at home a few days before the surgery, but asked my father those “what if” questions.
Information seeking is characterized, in this stage, by analytical thinking and the need for specific medical information. I am convinced that it was the connection and bond with Linda that gave me emotional strength to deal with the physical problems. Though my personal narrative emphasizes a strong resentment toward my physicians, I had, by this time, resolved to take responsibility and participate in my health care. The resentment of the physicians, however, was curtailing. Ironically, I found that the more I actively sought information on my own, the more “healthy” reliance I had with the doctors.

My personal narrative indicates that becoming more participatory in this opting stage influenced my relationships with health care professionals and family. Physicians and therapists asked for my opinion more often, and actually presented more options for treatment and pain management. My discussions with family were more open about my pain and even my test results.

My father particularly took note of this in his personal narrative and in his in-depth interview.

I was so glad when I felt you were more honest with us about your health. All I wanted to do was make this go away for you. Since I couldn’t do that I knew the best thing was you having someone to talk about this with. I just knew things would be better and you could take anything when I saw that fight back in you.

The narrative also documents that in addition to engaging in more open communication, I also began receiving information about treatments and medical “advancements” in managing pain or in brain tumor treatment. There seemed to be a surge of interest in the media on brain tumors and brain surgery. Diagnosis of having brain tumors was no longer regarded as “the end” as previous thought. Health reports on the morning talk shows, and program specials touted the advancements with guarded optimism, but the coverage raised the comfort level in discussing brain tumors. Information was available, it was out in the open, and this could not help but change the course of physician-patient relationships.
Validation of “Opting” through Virtual Community Data

It is not surprising to see similar direct information seeking, which characterizes “Opting” in the electronic messages of the virtual community members.

I vaguely remember someone talking about “mystery” fevers while they were on chemo...my fever keeps coming back. I’ve had two injections and 2 anti-biotic pills, but still the fever. It comes back in the afternoon. Was diagnosed with acute bronchitis on Sunday. If anyone has had similar reactions, please let me know...thank God the oncologist will be back in town this afternoon.

My tumor sounds so similar to yours. Presented first with a seizure. The tumor was also on the right temporal lobe extending into the frontal. I seized. In May and because of a missed diagnosis by the neurologist, we did not discover the tumor until Sept. when it was 6 cm. It has grown from only a small spot to a 6 cm mass in only 4 months. GBMs double their mass every ten days if I’m not mistaken.

I’m starting my second week of radiation treatment for an AA III. I’m trying to find as much information as I can regarding Temozolomide. My oncologist told me that if I choose to do chemo after radiation that he would suggest PCV, which would be one year. I have heard many good things about Temozolomide and am presently searching for some printed material on the subject. Any help would be greatly appreciated. You may send it directly to me at XXXXXXXXXXX.

The electronic records also indicate that family members of my virtual colleagues exhibit the information searching that characterizes the opting stage.

I have a 27 year old [sic] brother who was DX w/ GBM eight weeks ago. He had what was considered a total resection and has completed week 6 of radiation 5Xweek and his second round of Topotecan 5Xweek every third week. This is a phase II clinical trial. I am interested if anyone else has had a loved one who has been in this clinical trial. Also any information on younger adults who are battling this GBM 4. [sic] I did find a website that is incredible. It is a GBM survivor, and I know those are few and far between. Give it a look see.

Jim is starting a taper of the dreaded decadron this week and I therefore wonder if this puts him at risk? Also, as in asthma, wouldn’t it make more sense to deliver the steroids right at the site of the damage for better protection without the systemic havoc that decadron incurs? If this is the reasoning in asthma, why does it not follow for BCNU complications? Thoughts? I just want to understand this.
My sister asked me if anybody out there knew about or heard of Santa Monica Hospital in Mexico? Sounds like a holistic approach maybe similar to Dr. Burman's in Texas. I know we've talked about him on the list, but I must admit I wasn't paying much attention. General info on him is appreciated as well. I don't want to start a debate (I remember last time) I just need general information to pass along.

Dr. Dullard and Dr. Sharp both commented on their patients being more active in information searching and bringing outside information to discuss during their appointments. Dr. Dullard reported that several of her brain tumor patients used the Internet, but she could not see how it was helping them. "They really do come in with some crazy ideas," she said as she seemed to dismiss it. She did say that she could see how it might help to have the connection to other patients, but she also said that she was concerned that patients were not critical about the information they received.

Given Dr. Dullard's personal use of information technologies and medical informatics in her practice, it was surprising to hear her reluctance in advising patients to use the Internet for health information. She did know that physicians routinely participated in listservs and chatrooms, and was aware of hospital-sponsored listservs and websites, but voiced concern that patients may begin substituting office care and their primary physician as an information resource with Internet resources.

Dr. Sharp reported he had never had a patient even mention using the Internet, but he was quick to point out that his patients were from rural towns, not "the big city Charleston." Dr. Sharp was also quick to point to concerns he had about patients' use of the Internet but was much more interested and curious about the Internet playing an important role in health care than was Dr. Dullard. Though not as sophisticated in either his personal or professional use of information technologies. Dr. Sharp could "envision, and looked forward to the time, when patients could connect with other patients."

This would be one of the best "doses of medicine" a patient could get. "Increasing a patient's participation could help not only the patient but the doctor." He assured me that this was a major point of discussion in the state medical association, but they focused exclusively on information technologies for telemedicine. He agreed that patient to patient contact could be an important element of telemedicine, and seemed more comfortable when virtual health communities were couched in the arms of "health care professionals."
The concerns of patients using the Internet for health, addressed by Dr. Dullard, could be minimized if the doctors would enter into the relationship of physicians and patients described in the third stage of the model, "Inquiring."

Stage Three: Inquiring

The information needs and uses of chronically ill patients in stage three "Inquiring" indicate a willingness or desire to be actively involved in their health care. Although my personal narrative depicts some behavior suggesting this in stage one, the context of that behavior disputes that I wanted to participate. Rather, information seeking functioned as a distraction from what I was experiencing.

More important, however, is that in "Inquiring" the relationship between patient and physician is cemented with mutual respect and acknowledgment. The information the patient "discovers" in the "Opting" stage is now coupled with a reliance on the physician, and without the physician's willingness to interpret and communicate with the patient about the information, the patient can become overwhelmed, more confused and unsettled, resulting in a withdrawal from participation.

Observations from my personal narrative testify that I entered this stage after I left the hospital and experienced "a disaster" in reentering "the real world." The categorization of the "ill world" and "real world" suggested the duality with which I was coping. It was the "pattern of chaos" that resulted from this duality that urged me to get more involved in my health care. Instinctively I knew, as I knew in the hospital, that information was the key to this involvement. Using information, "I looked to my doctors to explain my experiences rather than solve my problems."

This participation not only influenced my relationships with my doctors, but my family as well. "My health care professionals were treating me differently; they asked my opinion and presented more options for treatment and pain management." I used information to make choices for physicians as well as treatment. "Unknowingly I had begun to develop criteria to use in evaluating health care professionals."

With family and friends, we discussed "my illness more objectively, with more openness and with less hesitation." They began "validating my fears and concerns which I had seen them denying before with their cliched proclamations when discussing 'my
problem."

In this stage, I now sought factual rather than emotional information, which was used in "negotiating" the relationship between physicians and myself. Unfortunately, it was at this time that I began to resent my husband in the role he chose, or rather, did not choose, in this experience. His not giving emotional support was easier to rationalize. His family background, I told others, could explain this. However, it was more difficult to explain his obvious disregard of this factual information. "His seemingly intolerable detachment," his "non-attentiveness," "the remoteness of our relationship" characterized my building resentment of him.

Validation of "Inquiring" through Others' and Virtual Community Data

Documentation of the "Inquiring" stage can be found in the messages from the virtual health communities. There was one obvious difference. Whereas I relied on my physicians to interpret and clarify information, the Internet provided the opportunity to communicate with other patients, as well as health care professionals.

We have had four doctor's say my tumor is inoperable. My tumor is a low malignant-infiltrated-astrocytoma that is located at the base of the skull around the spine. Has anyone seen or heard of this being operable?

I had something that happened today that terrified the b'jeezes outta of me. In the last month I've seen little, hmmm, how to describe... speckles of like glitter, if you will in my field of vision. Not really too annoying until today. Could this be related to my lesion, which is adjacent to the occipital horn of my left lateral ventricle?

My mother-in-law was just diagnosed with a Brain Tumor [sic]. Glioblastoma? We would appreciate your expertise in dealing with this matter. Please E-mail [sic] me with info.

Thank all of you for your information. I am making my own collection data. I need it to make the best decision possible.

It was not uncommon for netters to ask others to question their doctors about something, or to comment on advice other doctors had given other patients.

Could someone ask their doctor about a fibrillary Anaplastic Asctrocytoma? My tumor is located in the midbrain and the Dr. in Houston said it is burrowing in the brain stem. I've been on Chemo protocol but I am questioning this as well as whether we are just being pacified by the Dr.s in that we are "doing something."
One question I would be grateful if you asked Dr. Know on behalf of the diffuse, infiltrating faction of all of us: Since diffuse, infiltrating tumors are so closely intermingling with normal cells and are probably nourished by their blood vessels, would ANY of the antiangiogenesis drugs (either angio/endostatin or Poly ICLC) be effective on them? Specifically, would these drugs be effective against pontine and brain stem gliomas? Please post your answer to the whole list.

Has anyone been treated by this doctor? Hey, he's a bit radical, but then so was I at one point. Could use any feedback. . .And will be sharing whatever I find out in regard to this treatment. I don't want to volunteer Dr. XXX, but he was just incredible to me and found me trial results on the one my mom is in. I believe he ran what is called a Medline and got several. Perhaps he or another who has access to this service can help.

I find Dr. YYYYY's followup mail offensive. Anti-Angiogenesis provides real hope. Not just in the form of anti-angiogenic products available right now (in the clinical setting or off-trial on an experimental basis). Finally Dr. WW, I don't mean this as a low blow, I liked your book for the most part, but you made some statements in there which seemed fanciful compared to those asserted by Dr. V., etc. I really think you should reassess your views on the subject. I just want to warn everyone of a dr in Michigan that has an experimental drug called antineoplaston and has reported success with brain tumors. The fda has tried to close him down for at least the last dozen years. If you go to the excite search engine and type in ******** you will find the clinic's homepage.

MMM's session was poorly titled and he blew an opportunity to discuss a very vital topic. I was very disappointed with is talk, or what I stayed for—which was more than most of the others in the room that made their get-a-way before I did.

Participating health care professionals in the listservs and chatrooms were quick to point out that they were not diagnosing or recommending a specific treatment, the "netters" did not shy away from either, participants unabashedly advising, and even diagnosing.

Some cancers can be cured and when I say "some" I don't necessarily mean. [sic] A particular type but if found early and in a good location they can be removed and treated. However, there are still many people dying. Unfortunately, modern technology has just not solved the riddle of tumors, and although they can be slowed down and treated for awhile, it is common for them to come back or start growing again. I'm sorry to tell you this, but we are all facing possible death and trying our best to come up with a cure, but it's not that simple.

I realize we are trying to be positive with this. But I think the rule is really: Every tumor is operable, its just how much damage you have to do to the surrounding brain in operating on the tumor. Even the deepest benign tumors are "operable" if you want to put that person in a coma by doing so.
I advise patients to hire physicians that say what you want to hear. Phrases like “We’ll do all we can to treat the tumor...yadda, yadda, yadda” Not to expect a doc to tell you that you will become perfectly healthy with this one itsy bitsy treatment.

Participants expressed an “indirect obligation,” insisting others learn from their experiences.

Through this experience with Ellen, I have gained a lot of insight into the health profession and brain tumors in general. If anyone has any questions about Ellen or anything else, or just needs a [sic] ear to listen, please feel free to contact me.

Thanks again—everyone here is wonderful!!!

Dear family,
It has been two weeks since Ben was taken from me. This is something that always is on all of our minds. Now that I have actually experienced this, I would really like to stay with the group. No matter how you prepare, you are never ready. Maybe, just maybe I can help.

Another MRI in two months. This should drive me to drink trying to get authorizations from Secure Horizons for out of plan treatment. It’s crazy. They drag it out to the last day. I’m keeping notes so I can answer any of your questions. As if this illness is not bad enough, you have to feel like you’re begging for everything. Reading the digest regularly, all BT-Listers are in my prayers.

Both Dr. Dullard and Dr. Sharp addressed information needs and uses that characterize the “Inquiring” stage of the model. Throughout her interview, Dr. Dullard made reference to controlling the information of her patients in various ways. For example, her statement that “I really want to make sure that the patient understand the information they are receiving,” and her concern that “much of the information from the Internet is not credible,” implies this control, as well as her inexperience in using the Internet for health information.

It is interesting to note that this element of control of information seemed just as important of the information her associates had of her patients. This is more critical than simply her need of control. When I had to be admitted to Riverside Hospital through emergency for meningitis, her associate, who was there to meet me, had to get most of the information about my situation from my parents or myself. This was not only
disruptive, it made the situation more stressful, and there was more information than we knew needed in this situation.

There are several instances in Dr. Sharp’s interview where the issue of information and the importance it played in physician patient relationships were alluded. Dr. Sharp commented on his “jealousy” of his son’s future in medicine. He was intrigued that physician’s would be able to collaborate with other physicians and health care professionals. He saw the Internet as playing a critical role in telemedicine.

From his own experience in telemedicine in rural West Virginia, he knew that there could be many benefits in using information technologies, other than videoconferencing. He spoke of what he thought would be beneficial for patients. He had clearly been thinking and discussing it with other physicians in the state medical association. He asked if I would be willing to attend a meeting and discuss some of the same issues we had been discussing.

Dr. Sharp did not only voiced his belief, his behavior supported the claim that he saw information as crucial for the patient and their family. In addition to suggesting reading material to help us understand my illness, he brought in several Xeroxed articles, and medical journals. He discussed, very openly, the serious blood infection that had brought me to the hospital in Charleston. Dr. Sharp kept me informed of his battles with my insurance, assuring me he would take care of everything. His remark, after trying for two days to get Dr. Dullard on the phone was very telling. “I’ll keep trying, but you should know some doctors don’t trust other doctors.”

**Stage Four: Ensembling**

It is in this fourth stage “Ensembling,” that the chronically ill patient emancipates, physically and psychologically, from their physician, and becomes less dependent on others for clarification and validation of information received. It is in this stage that the patient truly feels empowered by information and participation and involvement in their health care includes decision-making, as well as information seeking. It is also at this time that that emotional strength is regained, and the patient begins fusing the intellectual, emotional, and spiritual dimensions of their new identity. In essence, the patient finds their voice, not merely adopting the voice of the medical “experts.”
What began as a reaction to uncontrollable fear and self-questioning after the 1985 surgery, resulted in my association with the one person I credit with the strength and insight I needed, not only to get through this ordeal, but to acknowledge its relevance to who I am. When I read my journals, I realized I had never given him the credit he deserved; my therapist, Dr. Heap.

One indication of the importance of working through the stage of “Ensembling” is that it is the only stage that I did not activate in the 1996 surgery episode. The emotional weakness that I identified, after reacting as I did when I saw my neurosurgeon in the church choir, was even more disturbing because I was feeling much more assured and in control during the previous stage of “Inquiring.” This stage-shifting perhaps offers an explanation to the roller coaster of emotions a chronically ill patient experiences. The information in the “Inquiring” stage was factual, and it now seemed important to readdress the emotional dimension of my identity. Though frustrated at the physical limitations after the surgery, the emotional weakness was almost shameful.

The most surprising aspect of this stage was that I entered it as a “spontaneous act.” “I wanted to be strong for me, not my parents or husband, family, or friends.” At first, the decision to start seeing Dr. Heap only added more confusion. “For the first few appointments all I did was cry.” “I was angry at Dr. Heap for not making the pain go away.” “I would rather solve immediate problems than trying to piece my whole life together.”

I had been disillusioned with sharing and disclosing emotional information by the few appointments I had had with another therapist, and the false security I had with Dr. Night. But Dr. Heap provided a safe haven, a place where no one could second guess or pity me. “I came to view those sessions as distant from my everyday existence and I shared those therapeutic 50-minute hours with no one.” Although I was initially frustrated because Dr. Heap was not “solving” my problems for me, after awhile I noticed I was getting emotionally stronger, ready to accept responsibility, not just for information, but responsibility of my life. “My therapy objective was no longer to “make better” the specific social symptoms of my illness, but rather to explore personal life issues and the possibilities of a happier and fulfilling life.”
My family noticed this transformation. My sister wrote, “You seemed to able to
discuss other things besides the tumors. Your voice was even more expressive. The
bottom line, you were a lot more fun to be around.” “ I knew that you were strong
enough now, to get divorced, and I was so relieved.” My mother commented in her
personal narrative, “I’ll never forget noticing, for the first time that you laughed like you
use to. When we hung up, I felt so calm. You were going to be OK.” “ Oh boy, I told
your mother,” my dad wrote. “she’s back!”

Validation of “Ensembling” through Others’ and Virtual Community Data

In order to analyze the listserv and chatroom communication for “Ensembling” it
was necessary to examine more than current communication. There were two methods
that used to determine the stage of “Ensembling.” Through lurking in the archives and
following a participant’s history unfolding in the participation with the group, I was able
to establish a time, if present of the emancipation from others which characterizes this
stage. The main reason for this is that the “emancipation” communication that a
participant may exhibit is similar to the messages in the previous stages. It was also
important in determining “Ensembling,” that the unit of message to analyze had to
contain more than a single statement. For example, the following statement

I have thought so often of the help you have given me. I’ve just recently noticed
how I have come to count on you for any major decision I have to make. This list
is so interesting and informative and fun! Even our kvetching is cute. We love
each other, and most of the time our squabbles are a family thing.

If these statements are the only ones considered, it certainly appears that the
participant is overly-dependent on the group. However, when taken in context with the
next statement, it can be seen that the participant is stating that this dependency is in the
past, and now is strong enough to break away.
I am going to go back to school (can you believe it!) and I’m building my strength up again. In no time I know I’ll be going back to work. I am going “no mail” for awhile. I’m a lot busier than I use to be and I know school is going to take a lot of my time. I’ll check in in a couple of weeks. Thanks of [sic] everything.

The primary concern I have regarding virtual health communities is in the “Ensembling” stage. I noted that participants seemed to feed off of other’s neuroses, and that even though support was given by emotional messages, it was difficult to gain emotional strength as evidenced by Sandra in the previous message. When Karen wanted to leave the group for awhile, Jenny responded:

Dear Karen – Oh no you don’t. You can’t leave us hanging like that!! Who would dare make you cry?? Let me at ‘em!!! I’ll chew their ankles to shreds.

Sally, you know you can’t make it without us. We give each other the strength we need to fight the foes. If you don’t feel like writing, that’s OK. Just stay with us.

I have never found support like I have found here. This list sure helps me through the rough times. Thank you everyone. I just can’t find the strength to leave.

Stage Five: Integrating

Possibly, the most common feeling among chronically ill patients is the desire to help others. Through helping there is a sense of balance, perhaps a way to eliminate the “messiness” that that accompanies the illness. Though the patient may engage in “helping” behaviors earlier in their experience, it is in the Integrating stage that patients recognize the reciprocal help that they receive as well.

In my personal narrative, I recognize this feeling, “I wanted to learn from the other patients and in some way, it seemed important just to connect with them.” “I discovered the more I told my story, the more insight I gained.” “One of my students could relate... There was an unexplainable bond between us, right from the beginning of the quarter.” “Without realizing it, I had elected to value the voice of Carl over that of the medical ‘authorities.’”

The aversion of an earlier recognition “that I had become my illness,” was expunged in this stage. There was a sense of control, a calmness that comes from that control. “I was no longer fighting these tumors. Instead I was finding ways to peacefully coexist with them.”
My mother noted, “You didn’t talk so much of your health. I think I was worried more than you. In fact, I can remember having to call you about MRI results. You used to always call us immediately, and I would hold my breath as you told us.” I not only thought of myself as valuable, but I was, more important, valuable to others.

**Validation of “Integrating” through Others’ and Virtual Community Data**

There exist in most chronically ill patients an undeniable “chronic” urge to help others, an ongoing responsibility to help each other and those who come after. The listservs and discussion groups extend this opportunity to an infinite number of “others.” This wired connection also grants access for the patient’s family to other families. When looking at the archives of discussions available on the Internet it is interesting to note that family members have emotional, supportive concerns in the beginning of the diagnosis or treatment. Participation in the virtual communities provide opportunities for helping others that seemed to be a pressing need of the participants. This was usually not the reason, however, to begin participation. I noticed that it was only after awhile that participants got comfortable with giving advice although getting help would be mentioned quite frequently as the initiative for joining.

I really want to address what I see as a real problem for some of you out there. We can all relate, unless you’re independently wealthy. How do we pay for the treatment we need? There are several ways you can get coverage that you may not have or thought about. Many community hospitals will treat you, but we know they don’t have what we need. And something else. Sometimes you don’t get any encouragement in getting well. I have worked at two community hospitals as a social worker, and no one in those hospitals was offered any hope as far I could tell. Amazingly, no “big name” neurologist I worked with EVER was as arrogant as the big fishes in this one small pond. Those of you who have gone elsewhere in search of hope and healing, how many of you revisited the original team to let you know how you are doing? I’d be curious to hear about it.

I think we should start a list directory so we can get to know each other better. I’ve mentioned this before and the response so far has been very positive with one person even volunteering to do the technical stuff. For the sake of those who raised questions my thought was to include name, address (could be just the city, county, state etc) and the relationship with the bt. [sic] Recently I’ve been wondering about professions seeing that there may be some common ground professionally as well.
There is a corporation who will provide free nationwide air transportation to and from treatment centers for bt [sic] patients. They use empty seats aboard corporate aircraft operating on business flights.

**Stage Six: Advancing**

Whereas the previous stages may result in adopting behaviors or practices gleaned from information, in the sixth stage, “Advancing,” behaviors and beliefs are adopted and incorporated in the patient’s living context. There is an ongoing process of information gathering and evaluation. Change that was made before may have occurred because of the tension of uncertainty, spurred on by the promise of immediate relief, change in the “Advancing” stage and appears more fluid.

The “Advancing” patient develops criteria to use in the selection and evaluation of information, treatment, and physicians. Decisions are not made hastily, and the urgency once felt in decision-making is not present. There is the recognition of “orderliness” that has escaped the chronically ill patient’s life for so long. The chaos noticeable in earlier stages, although easily attributed to the illness, could be caused by other factors. It is this understanding that characterizes the sixth stage of the model.

“When all of this began in January 1985, I wasn’t happy with the way I was living. . .Life had seldom been unkind to me.” For years I looked back on that unhappiness and attributed it to the my illness, “There was no emotional fabric; I was facing the end of my life with regret.” Because of that attribution, I strove primarily to “get rid” of that illness. I had not made adjustments in my life, merely adoptions of behaviors that seemed to offer remedies to my physical and emotional pain. Though touting “integration,” there was still the perception of a dual life.

Information that I sought, and even gave others, focused on information specifically addressing brain tumors or chronic illness. On the cusp of the “Advancing” stage, I was appreciating information that suggested philosophical positions on illness and wellness. I ventured out of the familiar information terrain of treatment and tests, and felt a startling positive sense of chaos. I had for so long thought only of searching for information that confirmed my beliefs; I had incessantly insisted on information that would not challenge those beliefs. My entrée into the “Advancing” stage I credit to information technologies and the opportunities that they have extended.
As my personal narrative shows, I did not jump on the information superhighway agreeably. My biggest concern about reentering the Ph.D. program at Ohio State University was being too old. It was assuring to see that other students, much younger than I, felt the same uneasiness of this requirement. There was even more hesitancy in my acceptance that information technologies were a viable area of studying in Communication. “I formed a love-hate relationship with this technology, on one hand admiring the efficiency, on the other, thinking that this technology had little importance for human communication.”

It was not until I was faced with brain surgery in 1996 that I fully began to appreciate this technology. Originally used for information gathering from websites and other text documents, I soon moved on to the participatory experiences of the Internet. “I had moved beyond merely information gathering; I needed to do something with this information.” “It’s as though I’ve moved from information to knowledge seeking.” Participating with this technology for a purpose so intimate as sharing your illness with others was not easy. “I realized that my uses of information technologies, and my experiences, so far, were not as grand or even similar to what I had imagined. Using information technologies for a very real problem was not the same as studying what others wrote.”

I hesitated before every advancement in my use of information technologies. I originally was feeling overwhelmed by the quantity of information I was finding. “My uneasiness, I’m now convinced, was because I was merely gathering information and the more information I found, the more uncomfortable I felt.” “Up to this point, I had been gathering information, that for me was simply the something said about “stuff,” the words that appeared on my computer screen.”

Once I ventured “into the land of interaction,” there was no going back. “There seemed to be an irresistible pull, a surge of energy once I made that connection to the “netters.” “The Internet is more than the information you receive. It is a kind of energy. On one hand you feel so powerful... on the other hand you feel almost a sense of humility, recognizing the Internet would be, without your participation.”
As I compare segments of my personal journal, I see that the strengths I observed from my participation in virtual communities afforded similar strengths to those I wrote about Linda, my roommate in 1985. There was an immediate, not-quite-understandable bond between participants, and a cloak of anonymity that made it easier for me to participate.

**Participation in Virtual Communities**

The importance of the connection to other brain tumor patients that I had experienced in the decade between brain surgeries encouraged my participation in virtual health communities. The known benefits outweighed the hesitations I felt as I took those first steps. There are some steps that we take in life that we know, before we take them, they will lead us to places we want to be. And so it was with this adventure.

**The Role of Information in Virtual Health Communities**

Data from the virtual health communities (VHC) indicated that information in these communities served similar needs and uses for chronically ill patients as information in face to face communities. These needs and uses were grossly categorized as factual and emotionally supportive. There were, however, unique roles for information in the virtual groups, as well as unique characteristics of similar roles for information, as found in face to face communities. What follows is an examination of the roles of information in the virtual health communities, a description of those roles, data to support the suggested roles, and a description of the unique possibilities of information use and needs in the virtual communities.

**Information as Entrée**

Information for entrée into the VHCs is used for two distinct purposes, to give a potential participant specific information about the virtual community before actively participating, and as an introduction of the participant to the VHC. Before actively participating in the listservs several patients spent sometime “lurking” similar to my own behavior as noted in my personal narrative. I wrote

The practice of lurking was beneficial for a couple of reasons. First, by reading messages I could get a sense of the issues or topics that were discussed to determine relevance. Through lurking, I got a feel for the membership and an idea of the type of interaction that characterized the group dynamics. Messages from “newbies” announcing their own lurking indicated this was the practice many enacted before “voicing” their presence.
David, in announcing his status as a new member revealed “It took me several days to figure out just who the “List” was. I thought... boy!, what an active participant.

Mindy admitted, “I have been reading messages on the list for about a month now. I finally decided to introduce myself. I am Mindy, I am an undergraduate at West Virginia University... I would like to inform you all of a very well written book I have just finished reading...”

Introduction of Participant to VHC

“Newbies” had various ways of introducing themselves to the group. Some, like Cherrie, asked for help for posting.

I know I’m probably not following the rules for doing this, but I’m going to try.

Sonnie stated she was new and then immediately asked for specific information

I’m new to this list and I need information on how to help my friend who is going through radiation. I hope you folks have some tips for me. I am very worried for her.

It was obvious Matthew was a newcomer from his second posting:

Well, I really screwed up. I didn’t read the FAQs until just now and I did everything I wasn’t suppose to do with my first message. Hope you guys forgive easily.

When the new participants did not provide their medical status information, regular members requested that information “up front.” Even though the list discussed other issues besides the illnesses, the need for the “history” information is understandable considering that the illness was the link between members. The following excerpt exemplifies this:

Cindy, Your message about feeling lost is something I can relate too. Especially in the beginning. [sic] I am not so new around here but I can remember when I started. I’m very happy to belong to this group. It is a tremendous emotional support group and provides an amount of information (first hand information) that’s not possible to find somewhere [sic] else. If you don’t mind telling us about your “head” problem we can probably be more helpful.

Sam just what kind of tumors do you have and how long since your diagnosis?

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Oh Gary,
My earlier message was a bit premature – I thought I was sending a message for Gary K. Do you still live with your parents? How often do you have chemo and how much do you get in a shot? I’m [sic] don’t want to give you’re the wrong advice.

Though I felt hesitant to participate in virtual communities at first, the first result of typing in “Brain tumors” in the Infoseek browser made me much more comfortable. I visited a website, which automatically submitted subscriptions to Internet-wide e-mail discussion groups (listservs) which relate to cancer. The website was OncoLink, sponsored and maintained by the University of Pennsylvania (http://oncolink.upenn.edu/forms/listserv.html). The website met my initial question of credibility, sponsorship. so I subscribed to a five listservs for brain tumor and chronically ill patients, BRAINTMR (braintmr@mitvma.mit.edu), which promotes itself as an online discussion group for people affected by brain tumors, with about 1000 members. I found the list to be an informative and supportive resource. The appeal of Cancer Care (CANCER-L@WVNVM.WVNET.EDU), is that it is facilitated by professionally trained oncology social worker. Cancer Care describes the online forum as “An online support group. . . usually numbering between 5 and 15 people, who have been through or are facing a similar situation, and have come together to share their experiences, learn form each other, and provide each other with a setting of emotional support. Cancer Care limits the number of participants, and if the group is full, the potential participant can register to be considered for the next on-line support group. It is possible to participate in private conferences with the on-line facilitator.

CancerNet <cancernet@iciicb.nci.nih.gov>, provides access to information from the National Cancer Institute’s Physician Data Query (PDQ) system. Caregivers’ listserv <CAREGIVERS@LISTSERV.ACOR.ORG> provides active forums for the chronically ill patient as well as family members. Forums are separate providing privacy for the patient and family. Steve Dunn’s CancerGuide <http://bcn.boulder.co.us/health/cancer/cancerguide.html> is an outstanding guide to addressing specific issues such as “The Pros and Cons of Researching Your Cancer,” “Cancer and Statistics.” How to Research the Medical Literature,” and “Steve’s Guide to Clinical Trials.” As a cancer survivor, Steve presents practical as well as philosophical material for the patient.
I subscribed to all five groups the same day. I had received 878 e-mail messages by the next morning, confirming the warning from OncoLink that subscriptions "could generate a lot of e-mail." I had no idea what it really meant to have a continual, throughout-the-day, message reception. Obviously, I wasn't alone in this feeling of saturation.

Just joined the group and I'm finding it difficult to keep up with the mail. Hopefully, I can learn to limit the response I receive. Need info [sic] on Adult brain stem glioma: inoperable with fast progression. Everything I read is for pediatric patients. What is current for the adult (24 yrs)? Also, does anyone have any info [sic] on Roswell Park, Buffalo, N. Y. as far as who to contact, etc?

One obvious solution as exemplified by Maria was to clearly state what specific information she needed. I did observe that Maria only received three responses. Maria was definitely not part of the "group," and her direct message was not the "conduct" appropriate for a newcomer.

Jon had another solution.

STOP SENDING ME THIS CRAP.

Although this may appear harsh, Jon was following the instructions given when you are accepted into a listserv, to sign off formally.

Bob responded more appropriately:

Laura,
I need to drop out of the chat room for awhile. I will be spending most of the time this week at the hospital with my son. The e-mail is just getting too heavy. . .

Steve admitted that he was probably one of the "offenders" with the following posting:

Dear John: OK you caught me. I recognize myself as one of the 4 or 5 listers [sic] who are posting like there's no tomorrow, but you have to understand I'm new at this and very excited. I promise to limit myself. It's just that when Ralph posts, it gets me so riled up I post right back. Does one 4 [sic] page post count as 4 [sic] posts? Because I have a good idea for people like me with limited self-control, I could write just one long post a day, answering everyone I would otherwise have posted to one at a time. I'm going to do it today.

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Needless to say, Steve proceeded with a four-page post.

“Giddy Girl” acknowledged the problem with the sheer volume of e-mail:

I understand the "lot of mail" bit! My inbox usually hovers around 500 – ARGH!! [sic] I’m a refugee from another high volume list, so a lot of the mail is still there. Please forgive me (and this goes for everyone) if I don’t post too much. I’m the only net-junkie in the family, so I have to sneak onto my ‘puter [sic] when the hubby and kids are in bed! . . .

Bill, though acknowledging the overload of e-mail, summarized the feelings of many participants:

Life is too damn peaceful without e-mail.

It was not uncommon for listserv members to belong to more than one list. One observation I found interesting was that participants would “chat” with those who belonged in other chatrooms on what they thought of a current thread of discussion that was currently being conducted in the other forum. Participants also recruited for other listservs. For example, responding to the overwhelming number of generated e-mail, Maxx suggested the following:

Facing-Ahead gets around 25 – 30 messages per day. You can subscribe to it or any other list as a digest and get only one large message per day. This listserv may be more appropriate for your needs. It is certainly more manageable.

Sally also “cross-listed” and attempted to recruit for another listserv:

Paul,
Some of your answers might better be addressed in the brain tumor listserv located at braintmr@mitvma.mit.edu. There is more of a discussion on family perspectives of going through all of this. If you get a chance, tune in. Families participate just as much as patients. Specifically look for Valerie. She has had to deal with similar problems.

New members were encouraged to participate, and were made more comfortable by the acknowledgement of the hesitancy, and the messages of understanding of that hesitancy. Autumn’s message to Melinda illustrated this:

Melinda, If it helps just lurk around and read what others are writing. You’ll see we won’t tease you for too long.
Some new members brought in sage advice, succinctly summing up the best advice instead of “philosophizing,” as many of the “seasoned” members would do. For example, June introduced herself with the following posting:

I AM NEW HERE ALSO BUT IF I HAD A LESION OF ANY KIND I WOULD GET ANOTHER OPINION.

Information as Relational in VHC

Members, for various reasons, would drop out of the group and then rejoin. Reasons for this included critical stages in their illness, a much-needed vacation, work, or wanting to spend more time with their family. When they returned, many would post a lengthy report on what happened to them while they were “no mail.” Most would ask specific updates of problems that were discussed when they left, with sentiments expressed like “I missed you,” “I realize how much this group gave me,” “I couldn’t stay away.”

The returning members were for the most part, welcomed with open “arms” with the collective “we,” speaking for the entire list.

Tina,
We’re so glad you’re back. We all sent our prayers to you and kept wondering about how things went. Please give us a report when you feel like it.
Good to hear from you!!!!!!!

It was common to read very intimate, personal messages that some members complained should be kept personal by sending messages through private e-mail. Though infrequent, messages that offended some and were angrily evaluated as “disgusting,” or “inappropriate,” would continue as a thread of conversation. Some of these were “private” jokes or stories and when these continued I got a sense of the influence of the appropriateness of content to the information technologies. For example, several women began a conversation centered on the “bitchiness” of other members. One of the women, Gail, continued to fuel the fire by posting:

Dear Kate,
I accidentally deleted your long post where you mentioned bitchiness and described some posts I didn’t see. I wonder if the AOL monster is not sending all of the posts to me?? Sounds like the list is heating up!
Kate in VA addressed the issue of this “bitchiness” and with her posting brought the issue to a close:

Connie, Elizabeth, everyone, this has gotten crazy. Don’t we all have enough problems to keep us too busy for this kind of bitchy stuff? I’m not interested in all the posts about people whose fingernails are looking strange, but I just skip on and don’t stop to say “Hey, guys, don’t you have better things to worry about?” The point of this list is to inform and comfort one another, not to nit-pick over petty things. . . Did any of you NOT like the Elizabeths [sic] posts about their virtual vacation? If so, did you feel like posting to complain they were being frivolous? No, you either laughed with them or skipped to the next message. God help/forgive us if we can’t have a sense of humor here—here, of all places, where we can be free to say anything. I mean, what the Hell [sic] is going on here? Aren’t we hurting enough without hurting each other? Isn’t there some room on this list for teasing and bantering as well as consoling? The LAST thing we need is to get in cat fights. Space for all of us to reconsider this craziness and resolve to quit it and get back to our real job of helping/comforting each other.

Five regular participants “voiced” their agreement with Kate. Connie, however, saw the message in a completely different light. Connie wrote that she would be leaving the group and several of the group reacted. Along with Matthew’s declaration of the importance of Connie to the group, Paula added her sentiments:

Seriously – I tried to write you last night after I saw Kate’s post – I had a feeling she had cross-posted. I have been wondering how things were with you, but I found that I didn’t have your address. Thanks for writing and when you are ready please let is know you are. I think the thing I love most about this list is – NO FLAME WARS!! For those who haven’t experienced one, they are not pleasant and IMHO defeat the whole purpose of a support list.

AHH, CRASH, BANG, OWWW – Sorry, just fell off my soapbox. Hope to hear from you Connie and love to you and Carol.

Not all of the “conversation” focused on the illness, or emotional support. I learned about Sylvia’s acceptance into UCLA, Grace’s Master’s Degree, and the search for long-lost patients known in early stages of illness. It was fascinating to watch the efficiency and effectiveness of these listservs in locating people. Within 30 minutes, Tera had traced down the location of three people he was interested in.
Hiya y'all...
I need some help remembering... There was someone on the list (I think it might be Sam and Susan) that were from Nevada. Are they the right people? If so, does anyone have their e-mail address?
Thanks in advance!
As Always...
Tera

Dear Tera,
Roger Cobb used to live in Nevada, but is now on the East Coast someplace. Phil Erwin (Phil's e-mail) is in California someplace up north. I'm in Nevada. Sam and Susan Rielly are in the Oregon area, Portland I believe, but I think Sam died recently.

Messages of death and dying were expressed with much sympathy, but with almost an air of "matter-of-fact." Though Patsy would often resurrect the importance about discussing death and being alone, usually the only time it was mentioned was in comforting family members of those who died, or the threads initiated by some relative or friend of a patient that was dying.

I know we don't want to think about this, but there are some things we should be planning. If you can, talk over funeral arrangements with a loved one. I know that's hard to do, but it really will be much easier for them if it comes to that. Check on your insurance, make sure benefits are made out to who you want to have them. Having said that, live each day to the fullest. We never know..........

I guess you remember me. I'm Brandy's aunt. She passed away last week, a brave little girl of twelve. It's hard enough losing someone this way, but especially hard when they are so young. If it's alright I'd like to stay with the group for awhile. I'm trying to get my brother to join.

It was usually soon after one of the missives on death and dying that "distractions" were submitted. These distractions were anything from exercises, riddles, and even political humor, which frequently could be labeled "black humor" because of the focus on healthcare, doctors, and even death. The "distracters" were usually members that had been participating for sometime and had established roles to play in the group.

I was struck by the political nature that would sometimes characterize the group discussion. This can be best described by the "scandal" concerning patient manner of treatment at the Burman clinic, and controversial medical practices. Listserv and chatroom participants had reported "unquestionable toxicity and wrong information.
regarding tumor response” issued through this clinic. A listserv participant, Larry Cullum decided, on his own, that he would submit an e-mail, which he shared with the group, to the “FDA and copy lots of congresspeople and media (including the Dallas Morning News) in a couple of days. Please review it and give me any comments you have as soon as possible.”

One of the “comments” that was posted was from Dr. John Button, M. D., from the Department of Radiation Oncology at the University of Iowa. Dr. Button raised objections, which were quickly voiced by others, that Cullum had no right or privilege to send an e-mail that purported representing all members of the listserv. Button posted:

I would not want the letter sent as a letter from this list nor do I agree that Mr. Cullum should present a letter as from the over 500 participants as reflective of our joint views. I have reported my own personal experience with several patients who received treatment at the Burman clinic... My personal view is that Mr. Cullum does not represent my perspective nor does he have the authority to report that this list which includes me supports his letter...

Just the fact that Dr. Button responded symbolized the divisive and explosive nature of the debate. Harriet Howe offered this to Button’s posting:

While I responded privately to Cullum/Burton situation, you are correct when you say that it should not represent the list in general. As not every one has the same views. Maybe he should reword the letter a bit.

The thread continued with a posting from Dave:

I don’t get! [sic] Would not the answers help serve to put it to bed once and for all, assuming we get straight answers?
I support the letter.
Dave

Liz Shelton responded:

It is not now appropriate to frame the letter in language that suggests it has been endorsed by the list members. I certainly resent the idea of someone using my presence on the list as a cannon fodder to pursue their own individual agenda. I have no felling one way or the other about the subject matter, which is to say, it doesn’t matter to me whether or not it’s Burman’s trials that information is being sought on—for all it matters to me, it could be green cheese. I just find it highly presumptuous that someone should speak for me to advance their own agenda.

‘nuff [sic] said?
One of the owners of the listsev voiced her concerns:

I am one of the owners of the list and I have not yet been able to confer with the other owners about this so I will be silent specifically about Mr. Cullum’s letter. But it brings up interesting issues about the nature of the group. Who can speak for the group? Is it an entity unto itself or merely a group of e-mail addresses with distributing software? What is the role of the owners and how is the group governed?

Before my participation in these electronic communities, I would have answered that listservs and chatrooms were “distributed” e-mail, not understanding the “nature” and characteristics of the VHCs. Relationships evolved from this interaction, and in these groups, characters matured. Rules and regulations were developed, independent of the “netequeitte” regulations received upon registration. These rules developed from the exchange of information, both personal and factual, among the participants.

Before participation, I assumed that the listservs and chatrooms were resources to “visit” for specific information, accessing only when needed. However, through participation, I sensed the obligations and responsibilities a participant accepted upon registration. Other participants depended on you, and indeed worried about you when you did not “show.”

((((((Kathleen))))))
It’s so nice to hear from you. I have been thinking of you and wondering how you are doing. I think you still have much to share and contribute here. I hope you stay with us for awhile at least
Love Judy

(Husband Ray, dx 06/95 Stage III right side cc, colon resection followed by 1 year of 5fu & levamisole, suffered through some unexplained fluctuating CEA levels, clear colonoscopies & CT scans to date!! We live with our 4 children on a horse farm in Riverside. Next onco appointment July 3)

Participants wore their “signatures,” like Judy’s above, as battle scars. The longer the signature, the more admiration participants seemed to have of each other. After participating for awhile, most dropped their signatures as if they had finally become known and they had been legitimized in the group.
Relationship Development

Relationship development seemed to include stages similar to those in face to face communication, but was accelerated. It was common to be met with phrases that seemed too intimate for the time of participation. For example, when I sent my first messages I was told “It’s great to have you here,” “I’m sure we’ll get to be best of friends,” “You have just found the only people who can understand what you’re going through,” “Please stay with us a long, long time.”

As I lurked around the list I could not understand how anyone could send a message, such as Betty’s to Jill, someone she had only known through the computer. Oh, Jill.

I never cease to be amazed by the strength and courage I read on this list. And I’m so very proud to feel myself among the list buddies you feel very connected to tonight. You’re a light in the so often dark world, Jill. God bless. Betty

What I have concluded is that this accelerated process is related to the type of information you share. It was so easy to “forgive” those whom, if you met face to face, you would probably ignore, especially after knowing some of their story. Their electronic messages were not that different than what I had written in my journal. I did find, in fact, that as I got more involved in these communities, my journal writing tapered off. I actually began thinking of this as an electric journal, and even better, an interactive journal.

Through participation, it was possible to see the formation of cliques in the group and practices that maintained these cliques. Private language and jokes were used to preserve these relationships within the VHC. Phrases such as “drink du jour,” “buttcrack man,” and “frozen sperm” were obviously understood by Phil, Jamie, Pam, and Seth and used to continue running private jokes. Interestingly, rather then sending these messages through private e-mail, this group chose to play out their relationship in “public.” The clique was recognized by others and very few outside of the clique commented.

A unique opportunity offered from participation in listservs was the outlet for creatively dealing with grief and anger. In the prose simply titled “Mommie’s Prayer to Daddy,” Ida expressed her concern for having to tell her children of the seriousness of their father’s illness:

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I'm up, sitting here in the middle of the night... Can't sleep. Wondering what I am going to tell them tomorrow. You've been in the hospital for too long. Every morning, the little ones come in looking under the pillows. "Daddy, where are you?" He's not home yet, guys. "When? "Soon," When's soon?" "You know that Daddy would like nothing more, than to be sitting in his favorite chair, with you on his lap, watching Barney over and over and over again. or helping you finger paint just on more picture, just for mommy to put on the fridge, or helping sister with that last math problem that has to wait for dad, 'cause mom has no clue. Or helping your brother put the dryer back together, That he took apart, trying to help out. I want you in our bed, snoring all night. Keeping me awake. Come home soon daddy. We miss you.

Several participants developed their own web page and provided the address for the others. This implementation of information technologies has become fairly common: the web pages not only "introducing" the participants, but providing links to other sites, listservs and chatrooms as well. The web pages include illness history, philosophies on illness and health, introductions to family members. There has been a recent trend of scanning not only pictures of the patient and their family, but pictures of MRIs, x-rays, and brain scans. The interpretation of these medical informatics produce new threads of conversation among listserv participants. I have observed three instances where the VHC participant invites participating physicians in chatrooms to view these films and then comment on their interpretation.

Through these virtual communities, I was privy to Julie's problems with her neurologist and traced her experience, asking the "group" what to do, the discussions with her psychic, and everyone's agonizing during her search for another doctor. I knew the moment that Lisa's first grandchild was born, and saw a picture of Eliott she had scanned.
on her homepage. Murphy urged all of us to contact our legislator weekly to “fight for our rights.” These events were not amazing, nothing I had not witnessed or discussed with face to face friends and family. But these experiences were of those who were like me.

These wired relationships became my support group and the primary “factual” source. I had finally found those who recognized some of what I face when I walk through the front door each morning. Those people figuratively held my hand, gave me information for decision-making and emotional support. I connected with them soon after I found out I would have to have surgery in 1996 and I very slowly weaned myself from them. Group members came and went, but some stayed connected to some degree for awhile. There was an unspoken agreement on the roles that each would play. Due to the importance of reciprocity, most members contributed by giving information just as much as asking for information.

The listservs and discussion groups available on the Internet solved the time and space issues that prevented me from participating in 1985. I had access to the group when and where it was convenient for me. This convenience allowed me to give attention to the other aspects of my life—I could go on living as I ordinarily would, with the wired connections still possible to maintain.

Group connection is only one way that communication technologies have influenced the role of patient for the better. I have attended conferences in real time presented as far away as Australia. Discussions with doctors other than your own are available. I think back to how I was concerned about offending the doctors who I saw as saving my life in 1985 if I asked too many questions. The technological forums have allowed me to do just this and even receive quasi second, third and fourth opinions without this worry. I have traveled to national and international medical universities and libraries which before were of course restricted by spatial, chronological and financial obstacles. I truly feel empowered by this availability. But there are some very important issues raised by this availability.

Self-responsibility includes evaluation of information, not just obtaining it. There has existed a real problem for some time of patients accepting most information from
their physicians without question. This problem can be intensified when the computer becomes the forum for information exchange. As with all forms of alternative healing, these wired appointments should be used not as a substitute for traditional doctoring but rather in connection with. We should generally regard these forums as cautious implements of patient empowerment.

There are some stories that we never tire of telling or hearing. The stories that seem to cross-cultural barriers, age gaps, and gender differences. In the case histories of chronically ill and brain tumor patients you will find similar accounts. The stories we share and the way we tell our stories is the experience tying us together. The meaning of my illness was and is derived from the interactions of those who share a similar fate as I. It is information technologies that provide these opportunities.

**Future Research**

Though pervasive in our lives, the study of information technologies influencing communication, as well as a communicative situation, has a short history. The fairly recent focus on health communication, and a commitment on the part of communication scholars to advance understanding and an improved life for the ill, encourages a closer investigation that the role of information technologies can play in this advancement. It is time to reconsider the notions held in regard to patient participation and involvement in their illness and health care. I would certainly argue that information is vital for patients, but would encourage further examination as to the operationalization of information in our health care system.

Cegala, Soscha McGee and McNeilis (1996) suggested that information exchange between physician and patient consists of three components: information-seeking, information-giving and information processing. Cegala (1996) extended his work on perceptions of communication competency of physician and patient to include relational messages. It is these relational messages that I suggest are critical in the first stage “Orienting,” of the emergent model, as well as throughout the trajectory of the illness. This perspective suggests that the qualitative nature of information merit our attention.
According to Cegala, "There is a clear indication from the data in this sample that doctors will provide information if they are directly requested to do so" (p. 22). I propose that, in addition to the claim Cegala proffers that "Doctors should be trained to recognize these efforts at indirect information-seeking and respond to patients' needs as appropriate," future health communication research examine the importance of the action of information seeking and information giving of patients, as well as information itself.

Citing Roter and Hall (1991), Cegala posited that the division of relational and information exchange functions of communication. The emergent model proposed in this study emphasizes that information be looked at in terms of what that information is used for, rather than the type of information that is exchanged. In other words, it is the patient's stage that he or she uses to evaluate the information, rather than the type of information that is exchanged. This places the needs and uses of the patient in the forefront of the examination of information in health care. This perspective may present a more appropriate and effective way of studying relational as well as factual information in health communication.

I was privileged to be afforded the opportunity to examine a living context that benefited me not just as a researcher, but also as a chronically ill patient. I was, however, discouraged at the minimal involvement, and interest most of my personal physicians and health care providers expressed, in their active encouragement and use of information technologies for and with their patients.

Ironically, it was only recently that I found a physician, and a university clinic that has incorporated the Internet, video-conferencing, and e-mail into their program for their patients. The website for the Gamma Knife program at the University of Virginia provides not only detailed information about their program, but uses hyperlinking to connect interested patients with relevant material and medical literature. A patient can view video of the procedure, can read the testimony of other patients, and have ongoing connections to the health care professionals, including the physicians, who participate in the program. This provides the continuity and order that is sorely missing in the life of a chronically ill patient.
Dr. Dullard is not alone in her concern that chronically ill patients will substitute "Net care" for traditional face-to-face care. Speaking from experience as a chronically ill patient and as a Virtual Health Community participant, I can insist that most chronically ill patients would not jeopardize their physical and emotional health by doing this. What is notable is that the use of information technologies provides an opportunity for relationship development between physician, patient, and family, and increases patient and family participation and involvement in the illness.

Establishing e-mail contact between patients and doctors would not only serve as a more immediate information resource for the patient, but would promote the relational messages of care and concern for the patient. Though a physician may be concerned of time demand, and an over-dependency on the doctor, e-mail may provide an answer to the perception of impersonal medical care in the world of managed care and hospital maintenance organizations. Some may argue that each technological advancement removes us one more step away from "humanity." However, using information technologies in the living context of chronic illness may, in fact, put some of the "humanness" that seems so often missing back into health care.

Concluding...

Distinct patterns of communication emerged, which could be examined by theoretical perspectives of human communication. Griffin (1997) posed theory as "maps of reality" and segmented theoretical perspectives of human communication into five categories differentiated by the "symbols they consider and the primary context in which they operate" (p. 1). The five theoretical categories Griffin suggested are 1) theories about messages focusing on verbal and nonverbal dimensions, 2) interpersonal theories focusing on one-on-one interaction, 3) group and public communication theories which cover face-to-face participation in decision making, organizational communication, and rhetoric, 4) mass communication which explores the effects, and the uses and needs that electronic media addresses, and 5) theories about culture which consider the influence of culture for the construction of the meaning of the self, events and of reality (p. 1).

Some scholars of computer-mediated communication have advanced the idea that these categories are outdated and need to be reexamined in light of CMC (Newhagen and
It has been suggested that computer-mediated communication is not limited to a theoretical category, but necessitates researchers to reexamine the central questions of mass media (Morris and Ogan, n. d. http). Morris and Ogan argue that “The computer as a new communication technology opens a space for scholars to rethink assumptions and categories, and perhaps even find new insights into traditional communication technologies” (p 1). Aligned with Griffin's five categories of symbol/context. I suggest that the reexamining and adjusting of Griffin's five categories or considering them obsolete is neither necessary nor desirable.

CMC is not a substitute for other media contexts. Rather, CMC should be designated as a sixth category in Griffin's system: one using multi-media symbols similar to those used individually in other theoretical positions. The context, however, is unique to computer-mediated communication. The context is varied depending on choices the participant makes concerning number of interactants, level of interaction, attributes of anonymity, responsibility, veracity, synchronicity. In other words, to consider CMC a sixth category on the basis of symbols/context, or a paradigm shift, is not enough to advance the study of CMC. Rather, it is the transmutation of communication concepts in computer-mediated contexts that evince the importance of studying computer-mediated communication by communication scholars. The theoretical approaches signified by Griffin should be used as comparisons or points of reference, rather than considered obsolete. Newhagen and Rafaeli (1997) concurred in suggesting that research paradigms on the Internet need to be couched in “communication as we have known it (p. 1).”

This section addresses observations made concerning communication concepts within the framework of this study. Specific communication concepts to be discussed are 1) the public and private space and discourse in CMC, 2) the presentation of self in CMC, and 3) communication appropriateness and expectations in CMC. I chose these concepts for further examination primarily for two reasons. First, all three concepts can be characterized by the symbols used and the context placement. Second, the three concepts have been developed and maintained by communication theorists for a long time. These observations, which are outlined below, will lay the groundwork for proposing communication concepts that can be used to identify or describe patient Internet
communication and information processing. Additionally, these observations will allow comparison of computer-mediated communication to face-to-face communication and the implications for brain tumor patients. Finally, I will offer specific applications of these observations for three groups: communication scholars, physicians, and brain tumor patients.

**Verbal and nonverbal symbols, social presence context**

From the year or more of participation in CMC, and a decade of living as a brain tumor patient, I have been struck by the importance of verbal and/or nonverbal symbols in communication. These constitute the channels used to transmit messages between sender(s) and receiver(s) in the three concepts of the uses of public and private spaces for discourse in CMC, and the presentation of self in CMC. In traditional communication studies, verbal messages have been suggested as only part of the communication, emphasizing the duality of communication messages: verbal and nonverbal. Goffman (1959) suggested people transmit two types of messages in face to face communication: information they deliberately purvey and information provided through nonverbal or body language.

The lack of traditional nonverbal symbols in CMC has led some to suggest that the CMC context is low in social presence and is therefore task oriented and impersonal (Walther, 1992a; Culan and Markus 1987). Walther (1992b), however, amended his position on the impersonality of CMC stating, "It appears that the conclusion that CMC is less socioemotional or personal than face-to-face communication is based on incomplete measurement of the latter form, and it may not be true, whatsoever, even in restricted laboratory settings." Additionally, the "participation over time" factor may contribute to these inconsistent findings.

Nonverbal messages that have been stressed as the elements in the communication process which render the quality and effectiveness of interpersonal communication. It is the nonexistence of immediate and two-way nonverbal feedback that has been designated as a key distinguishing characteristic of mass media and interpersonal communication. The difference between interpersonal communication and mass media communication is not just the number of participants in the communication,
but can be found in the quality and functions of communication as well. These differences of quality and kind have been attributed to “social presence” and any discussion of the typology of communication types necessitates a discussion of social presence as a context variable.

As early as 1976, Short, Williams, and Christie suggested that “communication media vary in their degree of social presence.” Though originally discussed in terms of interpersonal communication contexts, Rice (1992) suggested the application of “presence” to media by evaluating a medium’s “capacity for immediate feedback, the number of senses involved, personalization and language variety” (p. 4). Nonverbal messages have been viewed as necessary for social presence and Walther (1992) suggested the lack of nonverbal and visual cues in computer-mediated communication renders that communication very low in social presence when compared to face to face. The conclusions of the effects and uses of computer-mediated communication research, however, challenge this accent on nonverbal communication as a personalizing agent in communication.

The lack of nonverbal messages in computer-mediated communication has been problematic to those studying CMC as a communication context. Research indicates that computer-mediated communication does not fall into the distinguished category of either interpersonal communication or mass media. Morris and Ogan (The Internet as Mass Medium, 1998, http) suggested that this difficulty has prevented researchers from “seeing the whole picture” and Cathcart and Gumpert (1983) argued that the traditional divisions of communication type cannot contribute to an understanding of computer-mediated communication. “We are quite convinced that the traditional study into interpersonal, group and public, and mass communication is inadequate because it ignores the pervasiveness of media” (p. 268).

Rice and Love (1987) argued the emergence of social presence as an integral part of CMC despite the lack of nonverbal messages and herein lies the enigma: CMC functions and provides a communicative situation rich in what the users epitomize as interactivity and what communication scholars have traditionally assigned to the category of interpersonal communication. The evidence is so overwhelming that CMC represents
a uniquely different communication context that Poole and Jackson (1993, p. 282) suggested “With the new technologies, the line between the various contexts begins to blur, and it is unclear that models based on mass media or face-to-face contexts are adequate.” Morris and Ogan (no date, http) concurred, suggesting that the “current uneasiness of the terms themselves seem to indicate that the old idea of mass media has reached its limit” (p. 3). The researchers call for a rethinking, rather than abandonment, of definitions and categories in mass media research.

**Difficulty of Categorizing CMC**

It may be this difficulty of categorizing CMC as either mass media or interpersonal that can account for the hesitancy that many CMC participants describe in their initial foray into CMC active participation. If communication scholars feel uneasy with this, there is every reason to believe that participants can experience similar uneasiness. I was curious to my own hesitancy to participate in listservs and chatrooms. I noted that this hesitancy was common, the welcoming from the listserv after registering indicated that "Many of you may not feel comfortable enough, for awhile. to post to the listserv. We recommend "lurking" around the site until you do. It is very easy to lurk. Simply log in and read the messages. Messages can be accessed by topic or date." As I noted in my personal narrative "...My first thought is that if these feelings are common, then I may have found others who are experiencing their illness similarly." The only "cure" for this uneasiness was to get actively involved and begin posting messages.

Lacking the engagement of nonverbal cues to gage the meaning of their communication or the expectations of the receiver to evaluate and adjust messages and get a sense of the interaction, participants cannot rely on the conventional nonverbal cues that communicators use in face-to-face communication. I remember thinking, as soon as I pressed the "send" icon, "Did I use the right words? And my spelling..."

The lack of nonverbal messages in CMC allows participants to know others only through the text of their participation, and requires the participants to create a physical context only with words. One consequence is evident in analyzing the messages sent in listservs or chatrooms. Relying solely on a text medium, messages are rich in description of feelings, behaviors, and descriptions of illness.
My mother has accused me, not only in words, but her behavior, (sic) that I have somehow caused my father's relapse. She barely acknowledges me in the hospital room and has even moved away from me when we are in the lobby. I feel guilty enough about using drugs again, but the anger and frustration of knowing my father is going to die soon is hard. I wish we could comfort each other during this time, but I see little hope in that. (Participant 40)

You can't believe how mad I am at Shelly for starting all of this. I can't even think straight so I'm going no mail for a couple of weeks. You guys deal with this how you want to. I'm sick and tired of being nervous anytime I send a message. I'll probably come back when I get over this. I can't understand what she gets out of this except breaking us up. (Participant 41)

I'm very concerned that I am going to have to go to the hospital again. My temperature is running between 101-104 and my vision is blurry. Yesterday I couldn't keep anything down and I'm getting really weak. I called my doctor yesterday and when he finally returned the call this morning he told me to wait to see how I felt tomorrow. I can't believe this. Has anyone else experienced this with their neurologist?

( Participant 42)

Menges (Feeling Between The Lines, 1996, http) chronicled the development of online symbols which were created to address the problem of lack of nonverbal usage in electronic communities.

There is much to be conveyed in the turn of a bit of punctuation or case, I have learned. An exclamation point can transform a simple statement of fact into a declaration, often changing the whole flavor of the sentiment transmitted. Can you feel the difference between someone saying, "I'm swell." and "I'm swell!!" In the first instance you would be wondering if the person was being facetious, in the second you are quite sure of his mood. An experienced virtual communicator might interpret the ambiguity of the first statement as an effort to deceive or reveal a mood or attitude not articulated. The second simply reinforces the obvious words. As well, upper case letters serve to accentuate certain words or phrases in an exchange. You cannot raise your voice in a virtual conversation but you can RAISE YOUR VOICE! And your favorite smiley emoticon can entirely transform the implied meaning of the words used. Sometimes, just as in face-to-face communication, it is difficult to tell when someone is joking. In the conventional venue, you can catch a twinkle in the eye that reveals the teasing nature of the words, "You're awful." In the virtual world you might be offended by these same words were it not for the emoticon that punctuates them ("You're awful! :-)").
Social presence and public and private space

The difference of public and private space in CMC compared to face-to-face effects CMC in two ways. First, the notion of private space has traditionally addressed the “location of others” in relation to the location of “self.” Second, the designation of “private” and “public” space influences what is talked about, how it is talked about, and the difficulty with which it is talked about. Lombard and Ditton (1997, p. 5) suggested a common thread among various definitions and operationalizations of “presence:” the perceptual illusion of nonmeditation. “An illusion of nonmeditation occurs when a person fails to perceive or acknowledge the existence of a medium in his/her communication environment and responds as he/she would if the medium were not there” (p 9).

When I first began CMC, every time I made the phone lines would signal my connection I felt almost an excitement, thinking about what I was able to do. I would visualize what each sound represented, and I was disappointed when the connection didn’t go through. It wasn’t too long until this didn’t happen. I logged on, left the room if the connection was delayed and then returned to log on. My web activity decreased, almost to a manageable level. This was when my netting became as normal as reading a book. I would get just as involved in CMC that I did when talking on the phone. There was not a feeling that this was better than other forms of communication. I did not see CMC as the answer to all of my problems. It became a choice out of several options, chosen when it was most appropriate.

The impact that social presence has on CMC and private and public space can be evidenced in the location of the “other,” the topics discussed, and the language employed. Lombard and Ditton indicated three possible scenarios involving the placement of the other, “You are here,” “It is here,” and “We are together.” It is the third scenario, “We are together,” that the researchers suggest as the characterization of presence in CMC. In this category of presence, there is a perception of sharing space with an other. The perceptions of participants such as “It felt like a real face-to-face meeting” or “It felt as though we were all in the same room” are unique to CMC experiences, either videoconferencing or Net participation. These perceptions of presence have been
attributed to the interactivity and the shared virtual space that characterizes forms of computer-mediated communication such as listservs and chatrooms (Muhlbach, Bocker, and Prussog, 1995).

Participatory evidence in my study suggests that "presence" may account for the fact that as interactivity in CMC forums increased, my use of less interactive forums decreased. Language of the messages indicated that this notion of "shared virtual space" and the "togetherness of the participants" were prevalent. In messages of emotional support or in rallying for social or political activism the collective "we" unified the participants. Newbies received messages representing all of the group.

Most received a "personalized" message, which included similar thoughts as "...we are glad to have you here. We'll do anything we can to help you. It's so important to know you are not alone in this. This list is a wonderful place for emotional support, so if you feel you're ready to talk about it, just let it out. We're all here to listen." Reminders of our segregated suffering were sent frequently, "... We all need to take our minds off our problems esp. [sic] in the beginning...We've all been there."

This "presence" could also be offered as an explanation of the acceleration of relationship stages. If virtual space can be considered physical, it can also be considered emotional or spiritual. This resulted in sharing intimate, disclosive information quickly, which extended the public sphere to include what, for others, would be very private information. It was not uncommon for me, when I first began interacting, to chide myself for "telling" something I had been keeping from others.

The enactment of the interpersonal concept of reciprocity was so apparent. Just as involvement could vary in face-to-face communication, it varied in the Net connections. Validation messages such as "I know exactly what you mean, last week I had the same problem in ..." made it easier to continue. Nothing that was discussed was ever ridiculed by the group. It was almost possible to "feel" the sincerity or the fear through the words. I could only understand this thinking of the interaction in terms of involvement, so involved that the public nature of the Net was for a moment forgotten. Biocca and Levy (1995) suggested that though virtual reality may share common characteristics with face-to-face reality (in this instance virtual health groups and face-to-
face health groups), the virtual presence “wraps itself around the senses” of the participant. The participant “is swallowed by the story.” Short, Williams, and Christie (1976) pointed to the importance for analyzing mediated communication by indicating that the variations in “presence” are important to determine how individuals interact in using that medium. One indication of a high level of presence in virtual health communities is the responsibility the participant feels to self and others.

The sense of responsibility to those on the Net could explain some of the hesitancy in interacting. When I first began interacting I would read responses and could not imagine having such wisdom to share. Relational, as well as factual messages from others seemed profound. It was easy to forget that this communication was not real time. It was as though “we” were all seated at a huge dining table, the words of wisdom out of the mouths of the learned ones, rather than being composed on the computer, edited and reedited, being sent only when created to the sender’s satisfaction. I knew that this was the way I participated, but I felt as though this was almost cheating. There was a sense of responsibility in getting everything right, including the spelling of treatments and physicians.

The notion of public and private space raises some interesting implications on the research which points to CMC used by more men than women. Is there something about women’s communication that does not shift easily from private to public space? The linguistic differences between men and women (i.e. men speaking longer, conveying information, less “emotional”) may work differently in CMC. A woman’s shown use of emotional and supportive communication may seem “frivolous” on CMC compared to the men’s “analytical,” information packed communication style. I was struck by my hypocrisy when I looked over the messages sent to me regarding the Gamma Knife procedure. Beulah’s message read

I know this is probably silly but I couldn’t keep thinking about how cold I was in that machine. It really helped knowing that my husband was just outside the door. You’ll probably be real nervous, but you can get valium. It doesn’t affect the test so I would take some even if you don’t feel as though you need it. The MRI doesn’t take the same time for everyone. I was in there almost an hour. I did ask and found out that the length of time is based on tumor location, so don’t worry if you are in for sometime…”

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Ben wrote

You'll first have an angiogram around 5:00 a.m. so that they can get some base readings. After an hour or so you'll be wheeled in to "THE MACHINE." Just like an MRI so if you take valuim for those just tell them and they'll give you some. Not sure how long your treatment will be, but afterwards the doc will talk to you, ask you how you feel. You'll be in the hospital 2-3 days. You need to have an MRI every 3 months for a year. Good luck!

When I read Beulah's response I did not think she had told me much about the procedure. She had told me how she felt, but nothing to answer my question on what was going to happen. From Ben's message I could visualize the procedure and immediately thanked him for the information. It was, however, Beulah's rendition that I remembered as I complained about being cold, asked for valuim because I was so nervous, and was concerned when the doctor told me my treatment would take about 90 minutes.

Whereas Ben's message answered my "worded" message, Beulah's posting told me the experience, rather than procedures. Both postings were useful, but certainly illustrated two takes. While the gender of the participants was not the only explanation for the types of messages constructed when reading the messages again, it struck me how differently the men and women used the medium.

The presentation of self in CMC

Lacking in the ability to incorporate traditional nonverbal messages in CMC has resulted in virtual health community participants developing ways to include nonverbal elements in their messages. For example, nonverbal symbols such as :) has been used to emphasize the "goodness" of the message, just as :( represents a negative message. I had no idea when I began posting that these were "nonverbal" practices. I had not seen any during my lurking, at least that I can remember.

I learned of these practices from a question posted asking about "the way to do things." I would get upset when participants would ask technical questions on the listserv. I thought that there certainly wasn't any reason why they should ask such questions. It was my opinion that the listserv was to be used for important (important to me) communication. Thank goodness I waited to blast the submitter. I found out, after Jeremy had complained about a similar posting, just what the participants thought of this.

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I really don't want to waste my time reading about computer memory or where I can get the best deal on a modem. If I wanted to find that out I'd join a listserv. This is not a class in COMP 001. Jeremy

Jeremy,
You don't seem to get it. We're here to help each other. If that means walking someone through using their computer, we will.

J-- You may want to consider joining another listserv anyway.

Through postings such as these I learned experientially the "netiquette" of the listservs practices. In the Net dos and don'ts I received when I registered I had read that the purpose of the listserv was to help others experience their illness better. I had no idea that it went beyond the factual and emotional support from the group.

This use of nonverbal strategies extends from mere expression to enabling Net participants to present "self" in CMC. This self-presentation can be examined in both content and style of the patient-created homepages. It is becoming common for participants to post their own homepage and provide the URL in their signature or an open invitation to visit their page. The homepages are getting more sophisticated including video segments of weddings and births, and audio messages as well as still pictures. There is a trend for these homepages to include MRI pictures, brainscans, and even doctor reports.

Tim was one of the first to document his surgery and recovery from brain surgery through his MRI films. In the account of his recovery he said that he did this so that it might be easier for others to "objectify" their surgery. He also wrote about how difficult the hospital was in "giving him permission" to post the films on the Internet. He spoke the common rhetoric of patient against hospital that was familiar to all of us. I was very interested in what prompted him to do this considering I had done something similarly.

Several months after my 1985 surgery, my therapist and I watched the video of my surgery and it was helpful because it did exactly what Tim had suggested. It "objectified" the operation. We watched this video just a few weeks after the church episode, when I saw my neurosurgeon singing in the church choir. It helped me so much that I had Dr. Dullard's video recording of the 1996 surgery. My parents watched the video the day after surgery. My mom's reaction was the same as Tim's and mine -- to
borrow a phrase from Thom regarding a live birth shown on the Internet this morning, "The mystery needs to be taken out of childbirth. If people don't want to watch, they don't have to." I predict that in a few months, maybe sooner, brain tumor patients will include quick time movies of their surgery or link to the web pages that show surgeries that anyone can access.

Homepages offer patients the opportunity for creativity and expressiveness that is sometimes obliterated by constant monitoring, questioning, and testing interpreted through science. The web has offered places to "publish" patient poetry, such as that reported in the results section of this paper, which may be understood only by other patients. One aunt conducted a web memorial service for her seven-year-old niece who died last year from brain tumors. The memorial service was interactive, incorporating real time broadcast and chatroom, and provided a page where the niece's friends could visit and contribute to the site.

The selected links on the homepages may suggest group membership and interaction, additional aspects of self-identity, and indicate values and beliefs of the developer. It seems safe to posit that as CMC technology advances, so will the content of the participants' homepages. The homepage offers a depository of information the patient thinks is important, but more than that, the nature of these spaces link the patient to information rather than link information to an "authority."

Communication appropriateness and expectations in CMC

Successful or effective communication in social contexts relies on the appropriateness of the communication and, for the most part, the non-violation of expectations others have for the interaction. Until recently, most expectations of social contexts have been examined in the context of face-to-face communication. These expectations may foster changes in roles of physician and patient and may influence the communication in these relationships. Expectations for CMC are grounded in "netiquette." A violation of these norms may result in sanction of the violator. These expectations, however, differ in focus and function from social expectations derived from interpersonal interaction. Rice and Love (1987) suggested that the lack of nonverbal messages in CMC might increase tolerance of violations because of "the lack of social
control that nonverbal cues provide.” The level of tolerance of violations of expectations may vary depending on source characteristics, the issue violated, and the notion of “paying one’s dues.” For example the violation by Ted of “appropriate” non-sexist cues in the specific listserv I participated in may have been tolerated simply because of the history Ted had with the listserv. Ted had a history with the listserv. This history was referenced in his, as well as others’ messages. It was fairly easy to trace the participants’ history through the archived discussions. He had “paid his dues” by contributing to the listserv, his illness experience, and the overwhelming amount of activity participation time. Contrast this to the concern the “newbies” have in following the norms and rules of the group. Violations can be extremely grave, even influencing some to carry on electronic, public discussion about the offense or the offender.

In this study one finding addresses a possible expectation violation in relationship development. In contrast to Walther’s (1992a) suggestion that relationship development in CMC takes more time than in face-to-face, I found, as did Hiltz and Turoff (1978) that relationship development was accelerated when compared to relationship development in face-to-face context. I noted several instances of this in my personal narrative. When I first met Linda, my roommate in the hospital in 1985, “We had only just met but we had an unexplainable bond, a connection that drew us together.” “With Linda I was not embarrassed about my weak and strained voice. With her I could be brutally honest about my feelings.” Soon after my interactive participation on the Net began I observed that the relationships became “intimate very quickly.” One explanation is that there seemed to be permission given, almost an expectation, to introduce yourself with private information, both about your illness and your feelings. After a short time, I began to expect this from “newbies.” When Ellen introduced herself by her symptoms and her diagnosis, John went right to the point. “Ellen, how do you feel about this? What about your family? What do you need RIGHT NOW?”

The questioning of contradictory research findings in CMC can lead to a more complete picture of the online world. Walthers (1992a) explained the need of extended time for CMC participants for relationship development by suggesting the “hyperpersonal” effect that considers the reliance of words for impression formation and
management. How can I account for the difference in our findings? Words were primary in getting to know the others in the virtual health communities, yet were not primary in the face-to-face relationships in the hospital that I experienced. The finding of acceleration, however, occurred in both contexts. The difference may be attributed to type of forums studied. Whereas Walther spoke of task-oriented groups who worked together on identical tasks in cyberspace and face-to-face contexts, the listservs in which I participated were involving, personal groups, as well as the intimate relationship experienced in the hospital. This suggests that the accelerated friendship stages may be characteristic of intimate, interpersonal forums, such as found in virtual health communities, more so than task-oriented, impersonal groups. As described in my personal narrative, there was sense of this acceleration in relationships with hospital roommates as well as descriptive of relationships in virtual health communities. These observations suggest that the shared context of chronic illness, and in particular brain tumor patients, may account partially for this acceleration.

There may be, however, some unique characteristics of the CMC context that influences this observed social acceleration. For example, the lack of nonverbal cues which has been suggested contributing to minimized social presence, may also influence or lower inhibitions in communicating. The anonymity provided in the CMC context increases "feelings of safety among users" (Reid, 1994). When I realized, from Dr. Dullard's office manager, that the doctor knew several of the online physicians from Cleveland personally, my first thought was that she was going to find out that I felt uncomfortable going to her for a concern I thought she would dismiss. Feeling a little guilty, I was concerned she would know that I was talking to another doctor about her, even though I did not give her name. When I realized the anonymity of the forum, I took comfort in my complaint would not matched to my doctor's name.

The acceleration of relationships may be attributed to the commonality that draws participants to the listservs. Members of the listservs in which I participated shared a history of illness, either chronic or kind specific which influenced assumptions about background and experience, possibly allowing "skipping over" some stages in the acquaintance process and probe relationships more expeditiously. This could be a
function of why an individual chooses to participate in the CMC context and/or the nature of CMC.

It was fairly common for participants to talk about their family members, both in positive and negative lights. There were instances that I felt very uncomfortable reading some of these general postings. The history surrounding Participant #40 illustrates. Participant #40 had been a listserv member before I joined and I gathered from the first postings that she had not participated for almost a year. When she returned she was greeted by the original four participants of the listserv who I now saw as the "welcoming wagon."

For a time #40 participated fairly regularly, and "normally." But then she posted that her father had almost died around the time she left the listserv but was doing better until a week ago. She elaborated on the problems she was having with her mother "My mother has accused me, not only in words, but her behavior, (sic) that I have somehow caused my father's relapse." The postings, primarily from these five participants discussed her mother's alcoholism, her jealousy, and her hatred for her daughter. Though other participant's requested that this thread be continued through private e-mail, the participants continued to play it out on the "public" stage. This led to several participants unsubscribing and number 40 going offline. Though the "offenders" were asked to continue in a private forum, when they chose not to I felt as though I was interfering or eavesdropping when I would go online.

Involvement and Activity for Information Processing

Three constructs that help understand brain tumor patients' Internet experiences are involvement, community maintenance, and activity. Though at first these constructs appear similar, they are used here in three distinct but related ways. Involvement indicates the degree to which a participant is amalgamated with their illness, and this concern instigates their net participation. Community maintenance is viewed as a concept which grows out of the concepts of social construction of reality in CMC, the public and private space and discourse in CMC, the presentation of self in CMC and the notions of communication appropriateness and expectations previously examined in this
research. Degree of activity represents time spent engaged in net participation. The three constructs can be designated as "high" or "low."

The academic linking of information and communication is, of course, nothing new. Almost fifty years ago Shannon and Weaver published their work on the information model of communication. Today the link between the two constructs is emerging everywhere, in organizations, private industry, government, and in academia. The discipline of human communication once again enjoys this partnership which has survived for so long. Inserted in the context of the information age, the importance of information to communication is unarguable. Information and communication are the foundation for the reformation in the society's economic, social and cultural lives. The relationship between communication and information has furthered been strengthened by the emerging technologies which have been necessitated by the information age. It is imperative for people to have the ability not just to access or retrieve information, but to share it as well. In health, information technology and the ability to access and use it can literally save one's life.

The research in information processing has provided results, which indicate that though all individuals use information processing everyday, there are varying styles. The literature in communication and information, and experiential data suggests that "Involvement" is a factor influencing information-processing styles. As used in this study, involvement indicates Internet behavior related directly to learning or "teaching" others about factual or relational information of the illness.

High involvement indicates a concern and focus on the individual's illness and this instigates Internet activity to communicate this involvement. Low involvement signifies the participant who may spend time in net practices but does not know enough about the illness to choose to actively participate on the net, who may be lurking before active participation, or who participates for reasons other than learning or disseminating information about their illness.

"Activity" is a factor, which can influence information processing and communication. Activity, as used in this research, represents the amount of time an individual spends in participating in CMC. High activity represents a substantial amount
of time in net participation. Low activity indicates little time in participation. The practice of lurking or passive participation is difficult to determine, but is recognized in the lower level of activity. This levels can be indicated qualitatively by a participant's own reflective statements or by observations of frequency of postings and reading postings.

Table 1 is a matrix, which provides data from this study, which represents the interplay of the two constructs, involvement and activity on patient Internet information processes. In each quadrant message examples are given that illustrate this principle. Communication messages were chosen as the exemplifies for two reasons. First, this was a qualitative study, which privileges the data. The examples provided were actual data collected in this study. Second, the data represent the "symbols" chosen by the participants. The data was collected from the researcher's Internet participation. Message examples were identified by information processing concepts, which provide some since of the processing used.

It must be noted that the examples in each quadrant did not come from the same participant. In other words, Quadrant 1, which is the upper left quadrant, represents the participants who were high in activity and high in involvement. These participants spent considerable time in net participation as well as be highly involved, or focused on their illness. The lower right quadrant has no direct data since an individual low in both involvement and activity would have minimal, if any net presence.

Another factor, which the data spoke to, was that of community maintenance. Participants in net forums have indicated that these forums operate as communities -- a sense of place-- in which they negotiate the meaning of their illness with other patients or participants, they develop or maintain their self identity through this communication, and data suggests they develop relationships and enact roles similar to face-to-face groups. High levels of community maintenance represent participation that develops, implements, and/or consciously contributes to the community structure of the net establishment.
Table 1: Patient Internet Information Processing for INVOLVEMENT

<table>
<thead>
<tr>
<th>INVOLVEMENT</th>
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</thead>
<tbody>
<tr>
<td>HIGH</td>
</tr>
<tr>
<td>LOW</td>
</tr>
</tbody>
</table>

**HIGH INVOLVEMENT**

**INFORMATION RECEIVING**

**GOAL DIRECTED**

EX: I need to find out any information on shark cartilage. Susan, you mentioned a chatroom discussion you participated in. What's the URL for the archives list?

**GIVES, ASKS FOR "SOUND" INFORMATION**

EX: Mary, you mentioned Keith saw a Dr. Kaller at ****? I read an article in the paper last week which featured his work. How did you and Keith like him?

**STAGE FOUR: EMERGING (EMERGENT MODEL)**

EX: Dr. K did not convince me that we need to be concerned about taking that medicine. I'm still going to take it.

**SPECIFIC INFORMATION SEEKING**

EX: Terry, I didn't understand the message you sent on your second insurance carrier. Did you say they were going to pay the balance on the medication you were taking in the hospital? We need to let Stan Fanley know.

**MULTI-FORUM USER**

EX: Be sure to visit the Health Chatroom tomorrow from 8a.m. - 4:00 p.m. located at http://www.geocities.com

**INFORMATION GIVING**

EX: I just read the latest information on the clinical trial at Johns Hopkins. If you're interested <http://www.virtualtrials.com/papers/books.html>

**INFORMATION GIVING -- RELATIONAL & FACTUAL**

EX: Jill, you didn't tell us where your dad lives. It might be helpful for him to have his primary oncologist contact another specialist in the area. Stay with him. Your support is the best help right now.

**STAGE FIVE: INTEGRATING (EMERGENT MODEL)**

EX: Well gang. It's been four days since I had a smoke. I'm sure my blood count is going to improve with these lifestyle adjustments. Hope I can make it through the weekend. Pray for me!

**VERY ACTIVE IN NET PARTICIPATION**

EX: I'm taking my laptop with me on my trip to Canada. I'll let you know what's going on at the conference.

**INFORMATION DISSEMINATION**

EX: Wanted you to know that The Berweski Clinic investigation is going to go to the FDA on Friday to ask for an indictment. Register any complaints you have before Thursday 1 p.m. at the website. We need to be concerned about this.

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**LOW INVOLVEMENT**

**INFORMATION RECEIVING THROUGH LURKING**

EX: I've been seeing what you've been discussing and I'm ready to get involved. I read the Norman Cousin's book you recommended. I can't tell you how much it helped. Can't believe how similar our experiences are.

**ILLNESS INFORMATION SEARCHING: RELATIONAL**

EX: My daughter Sara is afraid to leave me since I've been diagnosed. Can anyone tell me how to help her? Where do I start?

**INFORMATION SEARCHING ON CMC FORUM**

EX: My sister told me about your listserv. Our brother was told two weeks ago he has an inoperable brain tumor. Is there anywhere we can go and find out more? Jim's doctor told us to contact you.

**BEGINS MINIMAL INFORMATION SEEKING INTERACTIVITY**

EX: I can see how this can become addictive. Do you have any suggestions on the best way to get and stay involved?

**INFORMATION GIVING -- RESPONSE TO DIRECT QUESTIONS**

EX: Jenny, I saw your question on the Gamma Knife procedure. I'd be happy to share what I can with you.

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There are no discernable postings from this quadrant. The following list are possible information processing activities the individuals in this quadrant, low activity, low involvement:

- Information seeking on Net websites
- Information seeking from non Net resources
- Illness Concerns — Ambiguous
- Stage 1 Orientation on Emergent Model
- High uncertainty, chaotic
- Nondirective information search
- Lurking listservs
- Not Net interactive in information seeking or receiving

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Table 1: Patient Internet Information Processing for INVOLVEMENT

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Applying the construct of activity in the same fashion, as with the construct of involvement we can see from Table 2 there are message differences between and among the participants' profiles. Reading the upper right quadrant, the participant is low in involvement, but high in activity. It is thought that these participants have been involved for sometime in the forum. They have "paid their dues" and have earned the right to "monitor" the other participants in their behavior or communication, but at the same time their "dues" may have paid their "right" to violate the group's norms.

The interface between information and communication suggests that communication constructs should appear in the data. The communication perspective, however, needs to focus on the elements of the communication process, which are reflected in Table 3. Once again applying the constructs of involvement, activity, and community involvement, Tables 3 and 4 illustrate the communication constructs exemplified by the participants' Internet messages.

Quadrant 3, located in the lower left corner, houses the participants who exhibited, through their communication, low activity, high involvement. It was thought that these participants are in the initial stages of diagnosis, have perhaps been "lurking," but begin their foray into Internet communities, exhibiting hesitancy which may be attributed to uncertainty of their illness, the hesitancy associated with many beginners in net work. These participants are high in involvement— their diagnosis is what motivated them to become involved in CMC. Each quadrant provides a listing of possible communication constructs or information processing constructs, which can be used in the development of research questions or hypotheses focusing on brain tumor patients' use of Internet Interactive forums.

The nature of computer-mediated communication

I was going to develop, in this section, a list of computer-mediated communication characteristics to compare face-to-face communication characteristics. But I get somewhat uneasy "comparing" the two. It is easy to slip from comparing to evaluating. Instead, here are some descriptions that I have concluded about the nature of computer-mediated communication. These characteristics are experientially based and may serve to help others understand the experience of participating in computer-mediated communication.
<table>
<thead>
<tr>
<th>High Community Maintenance</th>
<th>Low Community Maintenance</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Questions NORMS</strong>&lt;br&gt;Ex: Barry, don’t you think it’s time to start a new chatroom session so that more can participate?&lt;br&gt;Net Community Listserv Loyalty&lt;br&gt;Ex: I’ve been asking my friends at my support group to join our chatroom this Tuesday night. I think several will join our listserv.</td>
<td><strong>Norm Development</strong>&lt;br&gt;Ex: My granddaughter gave me a great idea Sunday. Why not start an “electronic” memory quilt? Maybe not even for our members that have left us. Let’s celebrate all the good things that have happened to us! Anyone interested just e-mail. I’ll bring it up in the chatroom this Tuesday.</td>
</tr>
<tr>
<td><strong>Innovator: Political Activism, Community Service</strong>&lt;br&gt;Ex: We need to get going on our plans to get involved in the insurance investigations and let Washington know our concerns and problems we have had.&lt;br&gt;Suggests Web Sites &amp; Other Listservs&lt;br&gt;Ex: There are two discussion groups you may be interested in in kuring. One is dealing with genetic health issues and the second one is on possible dangers from the Gamma Knife radiation. There are links on my web page.</td>
<td><strong>Primary Social Exchange</strong>&lt;br&gt;Ex: Just an update on our trip. Going to London on Monday. So nice not to have blood test and all. Be sure to look at the pictures on our homepage next week.</td>
</tr>
<tr>
<td><strong>Provides Social and Emotional Support</strong>&lt;br&gt;Ex: Sally, I want to make sure you understand what Walt was suggesting you can do to help your brother.</td>
<td><strong>Ownership Strategies</strong>&lt;br&gt;Ex: I’m having a listserv reunion at my homepage. Let all our past members know, and even “bring” some new members. There’ll be a chatroom from 6-9 p.m. EST. Be sure to leave a post if you can’t attend. I want to start a “history” of our list.</td>
</tr>
<tr>
<td><strong>Norm Understanding Information Needed</strong>&lt;br&gt;Ex: Can someone tell me when we should send private e-mail instead of using the listserv? I do need to talk to someone about some personal things and I don’t want to offend anyone.</td>
<td><strong>Netiquette Enforcement</strong>&lt;br&gt;Ex: I was really offended by the posting from ANXIOUS NIGHT. There is no place for this kind of discussion on this listserv. Those rules we have are meant to prevent this. We need to do something about this.</td>
</tr>
<tr>
<td><strong>Self Introduction (First Community Activity)</strong>&lt;br&gt;Ex: Hi. My name is Karen. My mom Estelle is 67 and just found out she has a brain tumor. I joined the listserv so I can connect her with you guys. I’ll be participating too if that’s alright. We’re both pretty afraid.</td>
<td>There are no discernable postings from this quadrant. The following list are possible information processing activities the individuals in this quadrant, low activity, low involvement.</td>
</tr>
<tr>
<td><strong>May Not Be Active Participant</strong>&lt;br&gt;Ex: I want to thank Jeff for the article on IVIG. I haven’t been able to join in as much as I’d like and will probably not have the chance in the near future. Thanks for all the help and advice.</td>
<td>Searching for forum community norms&lt;br&gt;Minimal expectations – Need information to develop expectations&lt;br&gt;May check out netiquette suggestions for particular CMC forums&lt;br&gt;Little, if any, experiential knowledge&lt;br&gt;</td>
</tr>
<tr>
<td>HIGH INVOLVEMENT</td>
<td>LOW INVOLVEMENT</td>
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<tr>
<td>------------------</td>
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</tr>
<tr>
<td><strong>HIGH INVOLVEMENT</strong></td>
<td><strong>LOW INVOLVEMENT</strong></td>
</tr>
<tr>
<td>NO CONCERN OF TECHNOLOGY USE</td>
<td>NO CONCERN OF TECHNOLOGY USE</td>
</tr>
<tr>
<td>EX: Many of you will enjoy the chatroom presenter Tuesday night. Just log on using your assigned password.</td>
<td>EX: Let’s think about redesigning our web page. ***’s page is so much better than ours.</td>
</tr>
<tr>
<td>HIGH EXPRESSIVE</td>
<td>HIGH EXPRESSIVE</td>
</tr>
<tr>
<td>EX: If we’re going to make a difference, we must do it NOW.</td>
<td>EX: We’re doing such a GREAT JOB keeping our attendance up in the chatroom. I’m ready to PARTY!!</td>
</tr>
<tr>
<td>ADVISOR ROLE/INFORMATION GATHERING</td>
<td>ADVISOR ROLE</td>
</tr>
<tr>
<td>EX: Everyone should consider having their family explore their concerns in the new listserv located at FAM@CON. I’ll send more information by Thursday.</td>
<td>EX: I think we should all call MSNBC and demand a full story on this awful mess with aol.</td>
</tr>
<tr>
<td>MOVE TO ACTION</td>
<td>LOW SELF MONITORING</td>
</tr>
<tr>
<td>EX: I’ve written a form letter you can run off to send to your senator. If you think insurance problems are bad now, just wait if this reform package gets voted in.</td>
<td>EX: O.K. O.K. Sorry about the joke about the cloning of the brain tumor. But if you want more just click to <a href="http://www">http://www</a>????</td>
</tr>
<tr>
<td>INCREASING INTERACTIVITY</td>
<td>SOCIAL</td>
</tr>
<tr>
<td>EX: You may want to participate in this new web site located at <a href="http://www.BRAINWAVES.com">http://www.BRAINWAVES.com</a> You’ll be able to experience an MRI from inside the machine.</td>
<td>EX: Anyone in Portland Oregon interested in getting together next week? I’ll be in your fair city Tuesday through Friday.</td>
</tr>
<tr>
<td>COST /REWARD — High Cost, high rewards</td>
<td>COST /REWARD — Low Costs, High Rewards</td>
</tr>
<tr>
<td>EX: You should not complain about Dr. m’s presentation. He ran overtime but his ideas were very useful.</td>
<td>EX: Susie, you know it wouldn’t take long to check out that U of Penn site out. You should see if you can stop by.</td>
</tr>
<tr>
<td>IDENTITY TOLERANCE</td>
<td>IDENTITY ACCEPTANCE AND PRIDE</td>
</tr>
<tr>
<td>EX: No, we should not just ignore Josh. He wants to be part of this group and he deserves a chance.</td>
<td>EX: It’s really an honor being able to be part of this list. I was so scared when I joined. I can’t imagine leaving.</td>
</tr>
<tr>
<td>DECREASING CONCERN OF TECHNOLOGY USE THROUGH INTERACTION AND EXPERIENTIAL LEARNING</td>
<td>There are no discernablepostings from this quadrant. The following list are possible communication constructs the individuals in this quadrant, low activity, low involvement, ENGAGE IN.</td>
</tr>
<tr>
<td>EX: I ventured out to the CHRONICILL@AOL last night. Now it looks like I’ll be on this machine even longer. I have to sneak down to the ‘puter when family is asleep.</td>
<td>No community identification or communication</td>
</tr>
<tr>
<td>PERIODIC AFFIRMATION</td>
<td></td>
</tr>
<tr>
<td>Is everyone getting their mail? I sent out five posting and didn’t get a return. Is it just me or are you guys having trouble?</td>
<td></td>
</tr>
<tr>
<td>EX: I sent out five posting and didn’t get a return. Is it just me or are you guys having trouble? Guess I can thank AOL.</td>
<td></td>
</tr>
<tr>
<td>COST /REWARD — Low costs, high rewards</td>
<td></td>
</tr>
<tr>
<td>EX: Does anyone else feel like they are going crazy trying to make all kinds of decisions? I use to think I was pretty good at being able to not second guess myself but I can’t even feel comfortable knowing what to tell my doctor. Is this common?</td>
<td></td>
</tr>
<tr>
<td>IDENTITY COMPARISON</td>
<td></td>
</tr>
<tr>
<td>EX: Do you feel you don’t know who you really are anymore?</td>
<td></td>
</tr>
<tr>
<td>RECIPIROCITY</td>
<td></td>
</tr>
<tr>
<td>My family sure is having a hell of a time with all of this. I feel so guilty not being able to be a good mother or a good wife. I’m just so tired all of the time.</td>
<td></td>
</tr>
</tbody>
</table>

Table 3: Patient Internet Communication Constructs for INVOLVEMENT

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Table 4: Patient Internet Communication Constructs for COMMUNITY MAINTENANCE

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The first characteristic that I offer is that there is always an element of surprise possible when participating in computer-mediated communication. There are "social conventions" for CMC, but as in a face-to-face communication context, not everyone follows those conventions. Although several CMC participants that I interacted with admitted to lurking before becoming actively involved, group dynamics change very quickly, depending on the mix of interactants, at a particular time. Most participants were consistent in their CMC behavior but the listservs and chatrooms were constantly subscribing new participants.

There were personal acceptable levels as to what would be tolerated. Those who would violate the community's level of tolerability could face "public" sanctioning. The communities did have multiple ways to handle various types of communication. I found private e-mail available for communicating any participant "in private" and the messages I received via e-mail were considered the same as letters through the post. Some participants indicated they did not want to receive e-mail so communication with them was limited to the listservs and chatrooms. If forum members were offended by messages, it was accepted for members to discuss publicly, through open listservs, the message, and name of participant if that was available. More typical, members suggested that personal or intimate discussions take place through private e-mail, and the request was usually followed.

There is, however, an openness to CMC that can be attributed to several characteristics of the virtual context. Communication in virtual communities seems less bound by social conventions and ideas of appropriateness. Though registrants are provided a list of netiquette dos and don'ts, most norms are set through the interaction of the participants. The rules and norms in the listserv in which I continued participation were largely disseminated and enforced by the original four members of the listserv. They expressed ownership of the listserv by both reminding others of the operating norms such as being cognizant of the length of posts, and yet also violating some rules of netiquette such as appropriateness of talk.
For example, Ted seemed to relish the role of “dirty old man,” verbally hitting on every female that joined the group. There were women that initially played along, but would eventually ignore his postings to them. Only five women, during the time that I participated for this study, immediately expressed their disdain for his communication. There were two women that continued this relationship with Ted and they played this out in “public virtual view.” What started as what most would consider harassment degenerated into discussions on sperm donation, sexual positions, and pointers on picking up men and women. No participant however publicly objected to this and the messages continued.

Violations in expectations or netiquette may be more readily accepted, or at least tolerated because there is less regulatory feedback during the participation. Sanctions are not typically imposed synchronously to the violation. It may be several days before the offender receives such a message. If a participant intentionally wants to sabotage the group by violating, he or she can simply change their participatory name and log in as if a new participant.

The second observation I make on the nature of computer-mediated communication is that CMC can provide anonymity, which can be used in several ways. Participants can choose “nicknames” for most participatory forums, allowing them to submit personal or disclosive questions or situations without feeling at risk. The nicknaming also allows the opportunity for participants to try out different personalities if so inclined. But the practice of anonymity is more than using a nickname. The cloak of anonymity provides a safety-net for some that may not otherwise participate in CMC. When I started this research I was somewhat sanctimonious; I was so concerned about the veracity of the stories that were told that I almost missed the benefits of this experience.

I could not imagine when I would not use my real name. After all, I was open and truthful, nothing to hide. Until that first posting to the Cleveland clinic. The situation was true, the pain felt, but I felt safer holding back the name. The importance of net anonymity is not in holding back a name, but in allowing one to share even more of their experience with others. The security of anonymity allows one to keep hidden his or her
sex, physical appearance, and age. I realized that veracity is always in degrees, no matter in what communication context you participate.

I found that relationships developed faster, the acquaintance process seemingly accelerated from what I experience in face-to-face communication. As previously mentioned, that finding contradicted earlier findings, specifically by Walther. My explanation centers on the purpose or the reason for the group's existence. By selection, the groups I participated in were chronically ill or brain tumor patients. The members had a shared history of illness, although that experience was different for each. There was a personal, involving nature of the association. In contrast, Walther's groups were groups assigned to complete a task by CMC and face-to-face. What this contradiction in findings suggests is that the nature of the group affects the dynamics of the group. That suggestion is limited to the nature of the groups studied, but points to possible areas of research in CMC.

Computer-mediated communication offers new ways of relating, learning, and playing. The sense of community is very real for the coalesced, kindred kind that segregate. These communities can share a language, for my communities, that language was of illness, a set of unifying beliefs, such as beliefs on the responsibility and the accountability for one's own illness, negotiation processes for self-identity, and the emotional bonding of people to people, people to things, people to place. At first blush, the only available symbol system to achieve these connections is the word. But, there were several times when the communication to the netters occurred in the absence of words. Thoughts and feelings could be expressed with fewer words as during the days before my 1996 surgery. It was easier, not as complex, to communicate with the BRAINTMR listserv than with family.

Finally, there was, for me, a deep sense of responsibility to the netters. In both the 1985 and 1996 contexts I felt responsibility to other brain tumor patients, and to others as well. The deeper responsibility in 1996 could be explained in several ways. I was older, this was my second surgery, I was living a different life. But I attribute this primarily to my participation in the Internet communities.
Even though my Internet connections are less frequent, my feeling of responsibility to them has not minimized. It has, in fact, increased. I am struggling now, trying to decide my responsibility, if any, to share this research with my electronic community, just as I struggled in making research decisions for the past year.

Notes on Methodology

I approached this "experience" with mixed feelings. I had to make certain choices because of factors, which were out of my control. Once again, I find myself grateful for a life event that served me well -- brain surgery. It was a constant struggle for me as I went through this. I was unsure about methods that did not give me numbers. I was far from believing that others could learn from such a personal and intimate excursion. What I have concluded is this: the methods I used became part of the story. The methods that made me question every choice, rather than providing me a design where many questions could be worked through before beginning the study, made me uneasy. Just when I thought the hard choices had been made, another one was there to make. Did I have the right to use my experience involving others as "a study?" What are my obligations at this point? What do I have at this point? Answers? No. Questions? Yes. But maybe an experience a little less messy than when it began.
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