Changes in Communication after the Diagnosis of an Illness

Kimberly M. Sniderman
Western Michigan University

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CHANGES IN COMMUNICATION AFTER THE DIAGNOSIS OF AN ILLNESS

by

Kimberly M. Sniderman

A Thesis
Submitted to the
Faculty of The Graduate College
in partial fulfillment of the
requirements for the
Degree of Master of Arts
Department of Communication

Western Michigan University
Kalamazoo, Michigan
June 1996
CHANGES IN COMMUNICATION AFTER THE DIAGNOSIS OF AN ILLNESS

Kimberly M. Sniderman, M.A.
Western Michigan University, 1996

A cancer, HIV, or AIDS diagnosis may alter a person's life. This may be exhibited communicatively, particularly when people with illnesses (PWI) disclose their diagnosis to people without illnesses (PWOI). The present study examined the premise that communication between PWI and PWOI was likely to be affected by illness disclosure. PWI were asked whether and how (positively or negatively) they perceived communication to change in family, doctor, nurse, other health care professional and their own contexts. Results indicated that PWI communication did change, though this was not found across contexts. Specific types of communication changes PWI experienced included greater openness, information-seeking, discussion of health and illness, emotional talk, restrictions on some topics, and fear of communication given the illness. Positive and negative communication perceptions showed that PWI perceived information seeking, illness predominance, communicated caring, affirmation, and other to fit both categories. Negative communication indicated that PWI may experience mothering and condescending patronizing communication similar in nature to elderly people or people with disabilities since all are stigmatized groups. Research findings are discussed based on uncertainty reduction theory, predicted outcome value, social identity theory, and communication accommodation theory. These theories show that PWIs’ disclosure to PWOI ultimately can have positive and negative interpersonal and intergroup ramifications on the relationship.
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ACKNOWLEDGMENTS

With heartfelt appreciation and gratitude to my advisor and mentor, Susan Fox, for providing inspiration, encouragement, guidance, and constant academic challenges. Thank you for introducing me to the illness topic and for sharing your enthusiasm and spirit for learning, researching, and writing. This has been contagious—and often exhausting—but never lacking in academic stimulation. Susan, I have learned immensely under your auspices, both in writing my thesis and throughout my graduate school career. I am confident I have become a better scholar from these experiences. My committee members Jim Gilchrist, Peter Northouse, and Shirley Van Hoeven were also important in the development of this thesis. Thank you for the comments, suggestions, and your accessibility for questions during my thesis preparation and accelerated graduate career.

Most of all, I am indebted to my family, Jon, Fran, Jeff, Tracy, and to Todd Skaggs, without whom this endeavor, my dream, would not have been possible. Thank you all for listening, reading, coding, advising, brainstorming, and for the sanity breaks during all stages of the thesis and school. These were enormously helpful but are downplayed by the love and emotional support that you so tirelessly provided that enabled me to make it through this writing journey.

Finally, the motivation for my thesis and applied research comes from a passion for helping others, which was inspired by my grandmother, Lavine Tomasi. This thesis is dedicated in her memory.

Kimberly M. Sniderman
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CHAPTER I

INTRODUCTION

"Cancer," "HIV," or "AIDS" are words which may bring to mind media representations reflecting the emotional and physical impact on a person with one of these illnesses. What it may not bring to mind are the communication changes that may occur between people with illnesses (PWI) and people without illnesses (PWOI) because of the illness. In this context, PWI are defined as people having any form of cancer, HIV, or AIDS. PWI may experience communication changes because of the uncertainty or uncomfortableness PWOI have in communicating about the illness in general. Stigmas or labeling an illness may reinforce negative attributions PWI receive based on PWOI's perception of cancer, HIV, AIDS, or the types of people they believe contract these illnesses. These possible misperceptions PWOI have and may communicate about an illness may lower PWI self-esteem and self-concept. Further misperceptions may lead to isolation as PWOI distance themselves from PWI, those whom they perceive to be different.

The National Cancer Institute reveals that 1 in 8 women will get breast cancer, with that probability increasing in women over 50 years of age (Health ResponseAbility Systems, 1994). The National Commission on AIDS estimates that "three million years of life will be lost to AIDS by 1993 with more than 200,000 individual deaths, surpassing cancer, heart disease and stroke." This is because "one in every 100 adult men and one in every 600 females in the United States are infected with HIV or AIDS" (Ratzan, 1993, p. xxv). The impact of the AIDS virus is further magnified by a tally from the Center for Disease Control (CDC) which reports that "as of October 31, 1995,
a total of 501,310 persons with acquired immunodeficiency syndrome (AIDS) had been reported by state and territorial health departments” (CDC, 1995, p. 849). Because the number of these illnesses are increasing, particularly HIV and AIDS, there is heightened need to know how to communicate effectively with someone with an illness.

Given the increased likelihood of knowing someone with cancer, HIV, or AIDS, it seems plausible that knowledge of the illness could translate into communication changes as PWI and PWOI react to and cope with this new and potentially serious variable that has been introduced into their relationship. Thus, the purpose of this research study is to examine if and how PWI perceive communication to change once PWOI have knowledge of their illness. It examines positive and negative communication as well as the likelihood that communication changes are manifest in the form of patronizing speech, as found in intergenerational (Ryan, Hummert, & Boich, 1995) and interability contexts (Fox, 1995). Since people in these groups may be communicated with differently because of the stereotypes associated with the stigmas of age (Ryan et al., 1995; Giles & Coupland) and disability (Braithwaite, 1993; Braithwaite, 1991), PWI may also incur the same experiences because of stereotypes associated with cancer, HIV, or AIDS stigmas. The intergroup and interpersonal theories found in elderly/young and disabled/abled communication research may aid in understanding whether and how communication changes occur because of a cancer, HIV, or AIDS illness diagnosis.

**Literature Review**

In intergenerational and interability studies changes in communication between elderly/young and people with/without disabilities have been found. Yet, little research has been done in illness context to know whether changes in communication occur in
this context. There is some research regarding supportive and non supportive behaviors that suggests they may influence communication. Non supportive and supportive behaviors will be examined, followed by cancer, HIV, and AIDS stigmas. These examinations lead to an application of intergroup and interpersonal theories, including social identity theory (Tajfel & Turner, 1979), communication accommodation theory (Giles, Mulac, Bradac, & Johnson, 1987), uncertainty reduction theory (Berger & Calabrese, 1975), and positive outcome value (Sonnafrank, 1986). Intergroup communication contexts and behaviors as well as patronizing communication are then discussed. Finally, hypotheses and research questions explore any communication changes proceeding PWI disclosing their illness to PWOI.

Non Supportive/Supportive Behavior

Non supportive and supportive behaviors are defined as behaviors PWI exhibit once they have knowledge of the illness, to help PWI cope with illness changes (Dakof & Taylor, 1990). In some instances, these behaviors may exist prior to knowledge of the illness but may increase or decrease towards PWI following illness disclosure. In interactivity research, Braithwaite (1993) found that an able bodied person who became a person with a disability following an accident was inclined to receive greater supportive behavior through increased contact and presence at the outset of the disability than when the "newness" or the immediacy of the accident wore off.

Avoidance, withdrawal, and isolation are well-documented behaviors resulting from the uncertainty and fear people without cancer (Wortman, 1984) or people without disabilities (Braithwaite, 1993) feel preceding interaction with someone necessarily different from themselves. In addition, apprehension, anxiety, and emotional conflict may result. For cancer patients, these behaviors, initiated by avoidance, are manifested by PWI's uncertainty in how or what to say to them (Dunkel-Schetter, 1984;
Wortman & Dunkel-Schetter, 1979; Dunkel-Schetter & Wortman, 1982). In turn, this may begin a communicative downward spiral of decreasing social support, where PWI overemphasize their emotions and illness effects in an attempt to get more attention, subsequently leading to more withdrawal from PWOI. From there, PWI may begin to experience lower self-identity which may lead to lower self-esteem (Ward, Leventhal, Easterling, Luchterhand, & Love, 1991). Cobb and Erbe (1978) continue the downward spiral concept by indicating that PWI are likely to experience denial, decreased decision making skills regarding their illness, a need for greater emotional support, a decline in activities, isolation, and ultimately, reduced social support. All of these supportive and non supportive behaviors are facilitated by the communication quandary “What do you say to a cancer patient?” (Cobb & Erbe, 1978, p. 25).

Non supportive and supportive behavior constructs have been applied to research on people with cancer. Within the cancer construct, Wortman (1984) suggested that behaviors may be manifested as well as interpreted differently towards a cancer patient depending on the source emitting the behavior. Dunkel-Schetter (1984) and later Dakof and Taylor (1990) expanded on this premise by studying the behaviors cancer patients found supportive and non supportive and the source who provided them. In both studies, non supportive (unhelpful) and supportive (helpful) actions or behaviors were congruent with the social support taxonomy (Cobb, 1976). These studies also concluded that some actions are seen as more helpful when provided by various sources than when provided by others. For example, emotional support was seen as more helpful when provided by more intimate others such as spouse (Dakof & Taylor, 1990) whereas “emotional support and tangible assistance were reported as equally helpful across sources, that is from family, friends, and medical professionals” (Dunkel-Schetter, 1984, p. 85). More unanimous results in these studies revealed that unhelpful support is deemed as the absence of or misguided attempt at providing social
support, including minimizing the impact of the patient’s cancer (Dakof & Taylor, 1990; Dunkel-Schetter, 1984). The implication of this research for people with cancer is that the type and extent of social support they received may be influenced by PWOI feelings’ about the illness, affecting the helpful or unhelpful support PWOI are able to provide. It may then follow that the types of social support people with cancer received could be predictive of the type of communication people with HIV or people with AIDS may experience as a result of PWOI's knowledge of the illness.

The Illness Stigma

“Stigmatizing,” “ostracizing,” and different are all words that are used to describe types of behavior toward someone not fitting into society’s “norm” (e.g., PWI). These subjective words describing PWI also characterize the nature of the communication interaction between PWI and PWOI. This inference is made based on findings from intergenerational (N. Coupland, J. Coupland, Giles, & Henwood, 1988) and disability studies (Coleman & DePaulo, 1991; Emery & Wiseman, 1987). These studies support Goffman’s (1963) assertion that people with stigmas are devalued in society. He reasoned that the stigmatized person recreated their self-image based on society’s labels. Thus, behavior may be seen as patronizing, a perception which is in the “eye of the beholder.” Fox (1995) found three types of patronizing communication people with disabilities experienced: depersonalized talk, where the person is seen as an object and not an individual; baby talk, where people with disabilities are the recipients of special talk, as characterized by a different vocal pitch and intonation; and third party talk, where they are spoken to through the non-disabled person that may be accompanying them.

Fox’s (1995) results, paired with Goffman’s (1963) premises, indicate that society may perpetuate stigmas simply by speaking in a way to characterize people who
are different, whether by physical disability, chronological age, health status, racial orientation, or other distinctions (Barbarin, 1988). As a result of the covert and overt stigmatization, intergroup situations may develop by creating two distinct groups, with each viewing their own group as superior to the other (Tajfel & Turner, 1979; Giles & Coupland, 1991). Of course, it is possible that only one person in an interaction may view their group identity as salient to that interaction. However, this may still perpetuate the group distinction, as one person may communicatively work to convince other group members of the group identity.

**Cancer Stigma**

"The word 'cancer' conjures up in the minds of many people a sense of futility, despair, and death" (Barbarin, 1988, p. 167). Because of this, people with cancer may be stigmatized. Media portrayals validate this perception of cancer, where cancer is depicted as "mutilation, excruciating and disgusting suffering, and finally death" (Clarke, 1992, p. 115). Other reasons for stigmatizing people with cancer include PWOI's discomfort of being around people with cancer (Stahly, 1988) or because of the uncertainty in knowing how to relate to them. Fear of contagion is also a reason for avoiding people with cancer, people who are different (Gibbons, 1993).

Just world hypothesis (Lerner & Simmons, 1966; Lerner & Matthews, 1967) and victimization (Stahly, 1988; Stahly, 1992) are explanations which have been applied to explain overt and covert stigmatization of the person with cancer. They are based on the premise that people get what they deserve. PWOI are inclined to blame PWI for contracting their illness, believing and perhaps relaying to PWI that they could have controlled getting their illness. Part of the attribution in this alleviates PWOI fears of getting the illness. Victimization then results when PWOI consider PWI victims by blaming them for their illness. As a result of victimization attributions, communicative
reactions may be strained causing PWI to socially withdraw and isolate themselves (Sharf & Freimuth, 1993), ultimately impacting their interpersonal (Wortman & Dunkel-Schetter, 1979) and intergroup relationships.

Yet another perspective of cancer stigma demonstrates the limited experiences people without cancer may have in communicating to people with cancer. One analysis of a portrayal of a television character with ovarian cancer served to destigmatize cancer for the public as they could follow the progression of cancer, coping, and adjustments created by the cancer (Sharf & Freimuth, 1993). Although some media representations help to diffuse stereotypes, there may be few positive communicative role models from which people without cancer can learn.

**AIDS Stigma**

“AIDS is so imbued with fear that even loving family members are afraid to visit dying sons and daughters, professional caregivers ostracize patients, and those who assist the dying in their search for meaning are ill prepared to help” (Adelman & Frey, 1994, pp. 3-4). The feelings of medical professionals regarding AIDS, including its transmission (Cline & Boyd, 1993) and fatalness, can also inhibit the communication, amount, and type of care a person with HIV or AIDS receives (J.A. Kelly, St. Lawrence, Smith, Hood, & Cook, 1987; Wiener, Fair, & Pizzo, 1993). In sum, this explains why and how communication is (negatively) affected by AIDS stigma.

**Summary**

Regardless of the type of illness, the extent to which a person is unable to control their illness may be indicative of receiving greater stigmatization. This occurs due to the high value society places on being in control (Freund & McGuire, 1995).
Society assumes that if someone has cancer, HIV, or AIDS they are no longer “normal.” Because of this, some people may feel that PWI should automatically be placed in the marginalized group, as far as possible from the “normal” dominant group (i.e., PWOI). This is exemplified by parents who do not want their children to be exposed to children who are HIV positive. The dominant group searches and strives for separation and differentiation from the “different” group, achieving it by marginalizing these people based on their illness and their perceived ability to control it. Many people in society (albeit an acknowledged Western society) tend to peripherize and overlook people who fit the category of having one of these illnesses. Therefore, marginalization and stigmatization can manifest themselves communicatively.

Application of Theory

Intergroup theories have not yet been applied to the context of communication and illness, but can be useful in defining the intergroup saliency that diagnosis and knowledge of an illness may create. This research builds from the foundations in intergenerational and interability research regarding potential communication change, utilizing the theories found therein. Social identity theory (Tajfel & Turner, 1979), communication accommodation theory (Giles et al., 1987), uncertainty reduction theory (Berger & Calabrese, 1975), and predicted outcome value (Sunafrank, 1986) all aid in establishing the conceptual framework for the illness context.

Social Identity Theory

Social identity theory explains the individualness between people with differing identities (Tajfel & Turner, 1979). Since a social identity is relevant only in comparison to other groups, a group member must perceive that his/her membership is a unique and distinct entity apart from other groups. People do this in order to maintain
a positive self-identity and have a positive self-concept (Tajfel & Turner, 1979). Nevertheless, group distinction may be predominate through language, including using certain words, dialects, symbols, or their own unique language to communicate with each other (Tajfel & Turner, 1979). Social identity then, is shaped by the values of a group such that self-esteem and self-concept are based on the group goals, beliefs, and values (Giles & Coupland, 1991). Framed in communication and illness context, PWI and PWOI are the groups with differing social identities.

Social identity theory is relevant as PWI seek their new social and personal identities as defined by their illness (Pinder, 1990). In some cases, PWI may not seek a new identity but have one thrust upon them because of their illness. A new identity, whether created voluntarily or forcefully, changes the “healthy” intragroup context to an illness-health intergroup (PWI-PWOI). Potentially, PWI may restructure their life to accommodate the illness by redefining their roles (Jacobs, 1990; Rosen, 1990; Melamed & Brenner, 1990). L.L. Northouse (1984) characterized these changes as familial information gathering, adjustment, and coping.

**Communication Accommodation Theory**

This theory explains specific ways in which the communication interaction may be mediated by intergroup identities. Depending on a person’s goal, they can choose to converge or diverge to another person’s way of communicating. Communication accommodation theory is also characterized by perceptual communication differences in intergroup contexts, where there is likely to be greater divergence between people of differing social identities (Giles et al., 1987). Intergroups diverge to establish distance to avoid interaction. A feature of divergence is overaccommodation, which indicates that one of the intergroups will change their syntax and forcefully change their communication patterns to negatively accommodate members of another group.
Convergence however, suggests that one group will attempt to change their communication to be similar to another group. Symmetrical convergence is one facet of convergence which occurs when the intergroups adopt the same linguistic styles. That is, members of either group are not trying to adapt a different style but communicate with each other in a similar manner.

Divergence and convergence may also be affected by the context in which the communication occurs. In communication and illness contexts, communication accommodation theory suggests that there is likely to be less divergence between PWI and their family than with the doctor, based on each person’s status regarding the illness. For example, doctors are perceived to have greater status by virtue of their medical schooling and expertise while PWI may know comparatively little about medicine. Moreover, the doctor may regulate the interaction (Seale, 1984) by making the illness diagnosis. At least initially, this may represent control that the patient cannot exhibit because of the lack of knowledge about the diagnosis and disease (see communication section p. 13). Thus, the doctor may be more likely to lower his/her doctor-speak to accommodate the PWI although, it is also probable that the patient may try to upwardly converge to match the doctor’s level. Through this explanation, communication accommodation theory helps provide a rationale for understanding how communication transpires between PWI and PWOI.

**Uncertainty Reduction Theory**

Uncertainty reduction theory is based on the premise that uncertainty in an environment can influence a situation (Berger & Calabrese, 1975). It posits that when a person meets a stranger both people work to reduce their uncertainty about the other. The more uncertainty is reduced, the more communication is likely to persevere because
the interactants are learning more about and possibly becoming more comfortable with one another.

This same principle is applicable in interpersonal relationships between PWI and PWOI. The intergroups may seek to reduce their illness uncertainty by seeking and acquiring information about it (Wortman & Dunkel-Schetter, 1979). In fact, the more open and honest communication between PWI and PWOI, the greater information disclosure can result (Pinder, 1990). According to Albrecht and Adelman (1987), “supportive communication helps people because the process functions to decrease the anxiety and stress caused by the experience of the unknown” (p. 24). Open communication can help decrease apprehension and uncertainty about the illness, potentially helping PWI and PWOI to better cope with the illness.

One questionable factor is the sincerity level of PWOI in the uncertainty reduction process. While PWOI may seek information by asking PWI about their illness, they may really only want to hear a one to two word reply instead of an entire narrative about it. In essence, PWOI's lack of interest in seeking information may be attributable to not wanting to reduce uncertainty about the illness but may simply be their own way of coping with it (Oberst, 1993). Based on uncertainty reduction theory, it seems that the more communication there is about the illness, the greater the predictability and therefore, the less uncertainty there is likely to be about it.

**Predicted Outcome Value**

This theory is based on the premise that if uncertainty is reduced there will be predicted positive or negative outcomes. Specifically, predicted outcome value posits that individuals are working to maximize their positive outcome and “are more likely to form relationships with available others who enable them to do so” (Sunnafrank, 1986, p. 9). Conversely, when negative outcomes in a relationship exist, the communication
interaction is more likely to diminish, possibly to the point of termination. Positive and negative outcomes relate to uncertainty reduction theory because they show a relationship between the amount of uncertainty or uncertainty reduction to negative or positive outcomes in an interpersonal relationship.

Applied to an illness context, predicted outcome value suggests that the illness may impact communication, where PWI are more inclined to communicate to people (PWOI or other PWI) who enable them to openly talk about their illness or related issues. If PWI are unable to communicate openly with another person or perceive that the possibility of doing so will have negative outcomes, PWI may be less inclined to communicate with them. Because of the saliency of the illness in their life, PWI may feel that the negative outcomes of the relationship are not beneficial for them, whereupon they may consider terminating the relationship.

Summary

Overall, these four theories show that diagnosis of an illness can create differences, both psychological and communicative, between PWI and PWOI. Social identity theory provides the rationale for the distinction of the illness by explaining the concept of differentiation that the illness creates between PWI and PWOI. Relatedly, communication accommodation theory explains the communication process that may occur in the intergroup as a result of the illness. Divergence and convergence help to explain how the illness can create communicative distinctions between the intergroup. In the open communication process between PWI and PWOI, symmetrical convergence may result. If PWI and PWOI demonstrate open communication, it may be construed as a positive outcome about the illness (uncertainty reduction theory), enabling each to feel comfortable in discussing it. This may further imply that PWI and PWOI are experiencing a positive outcome in their relationship interaction (predicted outcome
value). Although these theories may seem autonomous, they are intimately intertwined in their ability to help explain communication changes cancer, HIV, and AIDS illnesses create.

Communication

Communication seems to be pivotal in the illness experience. After all, it is the means by which PWI, and later PWOI, acquire knowledge of the illness. Because the illness is seen as a stressor (Jacobs, 1991), it may lead to communication changes as PWI and PWOI react to and communicate in this new context. It is also possible that the illness may enhance or impede communication between the intergroup participants. Within the present study, the intergroup and interpersonal communication between PWI to family, doctor, nurse, other health care professional, and PWI own communication is examined. From here, positive and negative communication is explored, with emphasis toward potential communicative effects. All of this unites to form the basis for the following hypotheses and research questions.

Communicative Behavior

Communication behavior is that communication which aspires to and may have an impact upon the behaviors PWI and PWOI exhibit. More explicitly, it is the way that communication affects PWI and PWOI conduct or actions in a helpful or unhelpful manner.

A positive manifestation of communicative behavior is inherent in the efforts PWI and PWOI make at open communication which may lead to increased information seeking (P.G. Northouse & L.L. Northouse, 1987) and coping. Gotcher and Edwards (1990) identified imagined interactions as a coping technique cancer patients used to prepare for actual interactions with their family, health care professionals, and others.
They found that this technique, where cancer patients mentally prepared and rehearsed what they were going to say and how the other person may respond, enabled cancer patients to reduce their fears, receive more information about the illness, ask questions of health care professionals, and receive more emotional support, facilitating positive coping. Kupst and Schulman (1988), in a longitudinal study of children with leukemia and their parents, found that coping was facilitated by such variables as having family support, open communication, the ability of other family members to cope with the illness, the quality of the parent’s marriage, and the absence of other family stressing events. These behaviors and communications can be important because they may lead to positive social support outcomes which may be manifest as improved health, psychological well-being (Wortman, 1984), or self-esteem (DiMatteo & Hays, 1981).

The stigmas surrounding the illness may be created by the uncertainty in not knowing how or what to say to someone with an illness (Cobb & Erbe, 1988), fear of contagion (Gibbons, 1988; Cline & Boyd, 1993), or anxiety PWOI may have in relating to someone with an illness (Dunkel-Schetter & Wortman, 1982). Anxiety may lead to what Barbarin (1988) calls ambivalence, “often reflected in uneasiness in the voice, tentativeness in statements, and a patronizing approach to dealing with stigmatized individuals” (p. 178). Thus, knowledge of the illness can cause communication to change (McCann, 1992; Cohen & Eisdorfer, 1986; Cobb & Erbe, 1978) and subsequently may lead to negative or unhelpful speech because of PWOI uncertainty or uncomfortableness in communicating with PWI.

**Doctor/Patient Uncertainty**

The primary frame of reference in doctor/patient communication occurs because of the uncertainty PWI and their doctors may exhibit with regard to the illness. For PWI, uncertainty is characterized in not knowing about the illness. PWI may look to
the doctor or other health care professional to provide answers to their questions so as to enhance their understanding and ability to cope with the illness (Sheer & Cline, 1995). For the doctor, the issue is what or how much to tell PWI about their illness. Forthright or open communication between PWI (or parents if PWI are young children) and their doctor can be beneficial for all participants (Binger et al., 1969) and may serve to minimize or reduce the uncertainty that each may exhibit as a result of the illness (Nan & Maguire, 1988). Maguire and Sellwood (1988) demonstrated that doctors can reduce their own and breast cancer patients uncertainties with the illness through listening to patients verbal cues which suggests the amount of information patients may want to hear about the illness. These researchers also demonstrated that openness and honesty was the most satisfying communication for the patient, even when the doctor was uncertain about the illness or the prognosis of it. Research by Shedletsky and Fisher (1986) affirmed the belief in reciprocal openness, indicating that in hospitals “almost all staff (97%) believed that the patient should either usually or always be told the nature of their disease” (p. 18). Overall, better health has been equated with patient information seeking (Kaplan, Greenfield, & Ware, 1989; P.G. Northhouse & L.L. Northhouse, 1987).

P.G. Northhouse and L.L. Northhouse (1992) indicated that the patient and the doctor seek the dominance or submissiveness they desire in their interaction. They defend the point that both parties assume responsibility for the interaction since communication is a “two-person process” (p. 6). Their premise is that both the health care professional and the client work towards the same goal of “maintaining current health” (p. 20).

Meanwhile, von Friederichs-Fitzwater, Callahan, Flynn, & Williams (1991) found that the doctor tended to talk more than the patient, to the point of controlling the communication in certain health care settings. The greater implication for this study is
that through communication accommodation theory's characteristic of divergence (Giles et al., 1987), the doctor will attempt to distinguish him/herself through status, position, and power. Generalizing von Friederichs-Fitzwater et al. (1991) research to communication accommodation theory shows the doctor may be relying on these variables to deviate linguistically from PWI. In addition, when PWI are confronted with their illness diagnosis they may experience shock, denial, or a host of other emotions (Cohen & Eisdorfer, 1991) that may otherwise impede the communication process.

**Family/Patient Renegotiation**

One facet of change for families and PWI is the renegotiation of roles (Jacobs, 1991). This has been pervasive in the literature and supports family systems theory which documents that the family undergoes change as it adapts to the illness (L.L. Northouse, 1984). Role renegotiation and family adaptation to illness is seminal because these physical and behavioral changes are inclined to impact the quality or the quantity of family communication.

One way the family may deal with illness uncertainty is through information disclosure (Jacobs, 1991), where the family learns about the illness, treatments, and prognosis. This can be especially difficult for children with illnesses because they may be protected from information because of their age or perceived inability to understand and emotionally deal with their illness (Adams-Greenly, 1986; Gibbons, 1993). Spinetta (1984) describes communication between a parent and their child with an illness as a "tangled web" (p. 2332) because it encompasses parents own views and comprehension of cancer, what it is they decide to tell their child, and what siblings know and understand (Easson, 1977; Waechter, 1987; Lewis & Armstrong, 1977-78). For adults, communication may be difficult as they grapple with informing (as
well as the amount of information to tell) other family members such as children, about a particular illness.

Another issue pertinent to communication and the family relationship is in dealing with the illness itself. As Jacobs (1991) notes, the illness may restrict communication within the family as each tiptoes around not wanting to upset the person with the illness nor wanting to fight with other family members. The repressed communication within this interaction can potentially lead to negative (or perhaps patronizing) communication resulting from the communicative tiptoeing each family member engages in. Non supportive communication is likely to occur when family members begin fighting and anger and other emotions surface as a result of the illness.

**Patronizing and Non Patronizing Communication**

Discussions of patronizing communication can be found in intergenerational and interability literature. This research finds that people in society who are perceived as being different are more likely to be spoken to through third party talk, as if they can not speak (Fox, 1995); depersonalized talk, where the person is seen as an object instead of an individual (Fox, 1995); or spoken to disrespectfully, including through baby-talk (Coleman & DePaulo, 1987; Fox, 1995; Giles & Coupland, 1991). Potentially the only difference between PWI, people with disabilities, elderly people, and other societal members is the attributes they are assumed to possess because of their group membership. Based on these research findings, patronizing speech is a demeaning and negative way of communicating with someone based on an awareness of their difference. This may be applicable to the illness context insofar as suggesting that PWI are stereotyped and communicated with differently because of their health status (Hayden, 1993), in the same way others are stereotyped and communicated with differently because of their age or physical ability.
Intergenerational (Ryan et al., 1995; Harwood, Giles, Fox, Ryan, & Williams, 1993) and interability (Coleman & DePaulo, 1987; Grove & Werkman, 1991; Fox, 1995; Emery & Wiseman, 1987; Braithwaite, 1991) research substantiates that communication towards people fitting the above descriptions is affected by these identifications. In fact, it is from these bodies of research that a definition of patronizing communication as condescending, devaluing (Coleman & DePaulo, 1987), or disempowering (Giles & Coupland, 1991; Fox, 1995) emerges. Further, this research show that society tends to psychologically stigmatize and thus communicatively patronize people belonging to these groups because of ignorance in not knowing what to say or how to speak with someone perceived as different from themselves.

There has been no specific examination of the communication PWI perceive as helpful or unhelpful. Intergenerational and interability research may lead to communicative consequences including patronizing communication. These may help in forming predictions of the effects of patronizing speech towards PWI.

**Potential Effects of Negative Communication**

It is useful to speculate on the possible effects of negative (including patronizing) and non supportive communication in situations between PWI and PWOI. Intergenerational and interability literature has explored the effects of patronizing speech and this can inform context where illnesses are present. Giles and Coupland (1991) found that nurse-speak to institutionalized elderly could be characterized as monosyllabic and simple language, which the elderly found distasteful or a nurturant. In the latter application, the elderly may internalize how and what is being said to them, leading to a self-fulfilling prophecy that they communicate, act, and dress reflective of their decremental age. Ryan et al. (1995) found that in the elderly, patronizing
communication exacerbates feelings of “declining capabilities, loss of control and helplessness” (p. 148). This is similar to how people with disabilities perceive patronizing speech. For them, it causes sadness, hurt feelings, or makes them feel belittled (Fox, 1995). Knowing what PWI perceive as patronizing communication may be important because it could enhance their communication interactions with PWOI by creating more satisfaction, possibly leading to greater self-esteem (Ward et al., 1991), and overall life satisfaction.

Hypotheses and Research Questions

The foregoing discussion of helpful and unhelpful behaviors, stigmas given to PWI, and communicative aspects of illness-related interactions such as patronizing talk, exemplifies the need to determine the types of communicative changes that PWI and PWOI may experience when an illness becomes known. The theoretical explanations of social identity theory, communication accommodation theory, uncertainty reduction theory, and predicted outcome value also help drive the following hypotheses and research questions.

Hypothesis One: People with illnesses will perceive communication interactions as having changed once they have disclosed their illness to people without illnesses.

Hypothesis Two: People with illnesses will perceive a difference in communication across contexts once they have disclosed their illness to people without illnesses.

Research Question One: What types of changes to people with illnesses perceive to have occurred since the diagnosis of their illness?

Research Question Two: What are the types of communication that people with illnesses perceive as positive?
Research Question Three: What are the types of communication that people with illnesses perceive as positive?

Research Question Four: Are the communications which people with illnesses perceive as negative similar in structure to the patronizing speech other groups experience?

Summary

These questions are important because they can serve to elucidate the intergroup and interpersonal effects of communication between PWI and PWOI caused by the illness, an area not yet explored in the literature. More importantly however, answers to these questions can serve as a starting point for diminishing negative communication that may occur since PWI and PWOI may not be educated in how to deal with cancer, HIV, or AIDS illnesses. Understanding the perceptions PWI have, the types of communication they perceive within varying contexts, and what communication is perceived as positive and negative may enlighten PWI and PWOI on how to deal with these illnesses. In turn, these findings may help augment the growing body of patronizing communication in intergenerational and interability domains and initiate a body of research on communication in illness contexts.
CHAPTER II

METHODOLOGY

This chapter explains the ways in which research was conducted to test the hypotheses and research questions presented in Chapter I. It does so by discussing the main components of the study: research design and procedures. The research design section highlights the participants, independent variables, and dependent variables. Then, the procedures section describes the organization and implementation of the data collection and coding procedures. A discussion of intercoder reliability procedures and percentages of agreement regarding the coding of the open-ended data concludes the chapter.

Research Design

The research design for this study was a 10-item survey questionnaire which was distributed on the Internet (December, 1996) to cancer and AIDS-based newsgroups and a listserv (see Appendix A for Human Subjects Institutional Review Board Approval Letter). (Observation of newsgroups and the listserv revealed that people with HIV were members of AIDS groups.) Given the Internet context, the structure of the research instrumentation was purposely kept succinct to maximize the likelihood of survey participation. Further, the questionnaire was developed so it could be responded to on-line versus uploading to respond, based on the assumption that if the questionnaire needed to be uploaded, it might discourage some people from participating. The survey questions (see Appendix B) were designed to elicit demographic data, data on whether communication has changed, and how
communication change may have occurred across contexts following PWI disclosure to PWOI.

Participants

Participants in this study were 24 adults with cancer (38%), HIV (50%), and AIDS (29%) illnesses who have access to the Internet. (Some participants had more than one illness.) Internet access is defined as PWI who belong to, know someone who belongs to, or lurk (observes but does not participate in) sci.med.aids and sci.med.diseases.cancer newsgroups and the hem-onc@sjuvms.stjohns.edu listserv. Participation in this study was voluntary, where the participants were solicited via a user group and responded if they were interested. Therefore, this was a non probability convenience sample self-selected through participation in returning the questionnaire. Self-selection was a key component in this study, especially noted in PWI who requested but did not remit the questionnaire to the researcher. PWI's denial about their illness may have caused limited participation insofar as the questionnaire directly asked how communication had changed and the ways in which it had changed. Such questions could make participants think about their illness, something PWI in the denial stage may not be prepared or want to do.

Independent Variable

An independent variable in this research was the context of the communication between PWI and PWOI. The three different contexts included family, health professional (doctors, nurses, or other health care professionals), and PWI own communication. It was hypothesized that PWI's communication with each of these groups was likely to change because of the illness.
Dependent Variable

The dependent variables in this research are the nature and types of communication which change in different communication situations as the result of the illness diagnosis. Knowledge of the illness is believed to be the causal agent in changing the communication between PWI and PWOI.

Procedures

Data Collection

Data collection began by finding newsgroups and listservs that were cancer, HIV, or AIDS-based. Some newsgroups and listservs were eliminated from the list of groups due to problems of accessibility. Others were eliminated by discovering that few people belonging to the newsgroup or listserv met the criteria of having cancer, HIV, or AIDS. The three groups used herein, two cancer-based and one AIDS group, were chosen following lurking of these groups. Lurking involves observing and learning about the nature of the groups and their members by reading messages that were posted to the groups. Following lurking, there was some interaction with group participants. Permission to post was then requested of the newsgroups. After posting approval was granted, a brief (35 line) email requesting participation and explaining the nature of the study was posted to the sci.med.aids and sci.med.diseases.cancer newsgroups. People who were interested in participating and who met the criteria were asked to send the researcher an electronic mail message to receive the questionnaire. Consent for the study was indicated by remitting the completed questionnaire to the researcher. Tacit permission was used to post an introduction, the University human subjects protocol (for which approval had been granted), and the questionnaire to the hem-onc@sjuvm.stjohns.edu listserv. Potential survey respondents from this group
were also asked to remit the completed survey via email, which acted as their consent for survey participation.

Data Analysis

Unitizing Messages

Given that five of the questions were open-ended, the qualitative data was systematically coded. Units of analysis for the qualitative data were each sentence a participant said, maximizing coding of their responses. Also, this allowed for greater ease of coding the data into categories due to the length and detail of many of the responses.

Category Development

Sentences were initially coded into social support categories (Cobb, 1976; Cobb & Erbe, 1978). However, low intercoder agreement found that social support categories were not appropriate for this data. A second coding schema was then tried. The data were applied to helpful and unhelpful categories Dakof and Taylor (1990) found when examining victimization hypothesis to look at behaviors cancer patients perceived as such from different members of their social network. With the exception of one unhelpful category (rude and inappropriate), this coding schema failed to achieve intercoder reliability.

Failure to achieve any intercoder reliability led to using a grounded theory approach (Glaser & Strauss, 1967) for coding the data. Grounded theory employs an opposite technique than the first two coding attempts. This process allows for themes to evolve from the data instead of trying to impose the data into pre-defined categories.
which may or may not be applicable. While the concept of this approach was taken, the
following rigorous category development process was employed:

In general terms "analytic induction" involves subjective sensemaking of
the data by the researcher through formulating categories for a given
datum, "testing" these tentative categories in additional cases, revising
the categories to fit these additional cases, "testing" the revised analytic
categories on additional data cases and so forth until successive
revisions produce a category set which captures the data as a whole
(Baxter, 1984, pp. 32-33).

The categories elaborated below not only established acceptable intercoder
reliability agreement, but also showed similarity across contexts and in specific types of
communication changes:

*Communication Change with Family*
Open and Improved/Enhanced Communication, Illness Talk, Emotionalism,
Confining/Restrictive, Minimal Change

*Communication Change with Doctor, Nurse or Other Health Care Professional*
Open and Improved/Enhanced Communication, Illness Talk, Emotionalism,
Informational Self-Empowerment, Fear of Discrimination, Minimal Change,
Miscellaneous

*Own Communication Change*
Open and Improved/Enhanced Communication, Illness Talk, Emotionalism,
Fear of Discrimination, Personal/Personality Introspection, Miscellaneous

*Positive Communication*
Positive Information Seeking, Person First, Genuineness/Sincerity, Emotion-
Sharing, Venting, Inspirit, Alternative Support Mechanisms

*Negative Communication*
Negative Information Seeking, Illness First, Cheerleading, Dispirit, Attribution

After the categories had been established, the researcher analyzed them for any
similarity. What resulted were categories that were shared across contexts as well as
categories that were opposite for positive and negative communication. As a result,
broad, umbrella-type categories were developed which characterized the similar
categories within the various contexts. Subcategories also emerged within some of the
categories. The same procedure was followed for the categories that emerged from
positive and negative communication questions.
Intercode Reliability

Intercode reliability in this research study was calculated for the categories that emerged from the data. To test the categories that emerged, a second coder coded the data set. The coder was provided with a description of each subcategory and the categories that emerged, definitions of the categories, and given extensive instruction in the coding process. He coded each sentence into the most appropriate subcategory or category based on the pervasive theme inherent in the sentence. If there seemed to be two ideas, the most dominant idea was coded. Intercode reliability was then calculated as percentage agreement between the two coders in each category for context, positive communication, and negative communication from the survey. Simple agreement (Braithwaite, Waldron, & Finn, in press) across all of the categories was 91%. (See Table 1 for a Summary of the Agreements.) Employing the same technique for the positive question led to 83% agreement and 79% for the negative question. Context percentage of agreement was achieved only after separating the “improved/enhanced communication category” from its subcategories of “illness talk” and “emotionalism.” This was undertaken because the description of the category lent itself more independently to the units of analysis than only being able to code into the subcategories. In addition, the coders felt that the description of “improved/enhanced” did not adequately reflect “illness talk” and “emotionalism” subcategories, indicating that the latter should be autonomous categories versus subcategories. Since there was subsequent discrepancy between “open communication” and “improved/enhanced communication” categories, they were combined.
Table 1

Summary of Agreements

<table>
<thead>
<tr>
<th>Categories</th>
<th>Percentage Agreement</th>
</tr>
</thead>
<tbody>
<tr>
<td>Open and Improved/Enhanced Communication</td>
<td>82%</td>
</tr>
<tr>
<td>Illness Talk</td>
<td>100%</td>
</tr>
<tr>
<td>Emotionalism</td>
<td>91%</td>
</tr>
<tr>
<td>Confining/Restrictive</td>
<td>86%</td>
</tr>
<tr>
<td>Informational Self-Empowerment</td>
<td>90%</td>
</tr>
<tr>
<td>Fear of Discrimination</td>
<td>100%</td>
</tr>
<tr>
<td>Personal/Personality Introspection</td>
<td>100%</td>
</tr>
<tr>
<td>Miscellaneous</td>
<td>97%</td>
</tr>
<tr>
<td>Minimal Change</td>
<td>93%</td>
</tr>
</tbody>
</table>

Summary

The focus of this chapter was on presenting a description of the research methodology. It was achieved by describing each facet of the study design, including participant demography and recruitment as well as independent and dependent variables. Procedural policies presented in section two further described how the data was gathered and how it was coded. This sets the stage for examining (in Chapter III) then analyzing (in Chapter IV) results that emerged from implementing this data study.
CHAPTER III

RESULTS

This chapter highlights the findings that emerged from the study described in Chapter II. Then, it examines the results of each hypothesis and research question. Finally, it provides a summation of the results of this study before segueing into the implications and discussion of this research that are presented in Chapter IV.

Demographics

The sample consisted of 24 participants who have had their illness from less than a month to 26 years. The average length of time with an illness was five to nine years. Participants range in age was 20 to 72 years, with the average 40 to 49 years. The gender composition was five females and 19 males.

Hypothesis One

Hypothesis One stated that PWI will perceive communication interactions as having changed once they have disclosed their illness to PWOI. To measure this, participants were asked a “Yes” or “No” question inquiring into whether they felt their communication had changed. Forty-six (65%) PWI perceived their communication changed while 25 (35%) PWI felt their communication to PWOI had not changed following illness disclosure. (No statistical test of Hypothesis One was calculated because of the difficulty in computing expectancy value for a chi-square analysis on this categorical data.) Although this question was asked across contexts, context was
relevant for this hypothesis only in tallying the total number of “Yes” and “No” responses.

Hypothesis Two

Hypothesis Two predicted that PWI will perceive a difference in communication across context once they have disclosed their illness to PWOI. This hypothesis was tested by performing a chi-square analysis on the “Yes” and “No” responses against the context categories. The chi-square value of 1.68 was not statistically significant (p<.50), finding no statistical support for the hypothesis (see Table 2). As such, it cannot be supported that PWI perceive a significant communication change within each context.

Table 2

Perception of Communication Changes Across Context Following Illness Disclosure

<table>
<thead>
<tr>
<th>Has communication changed since you were diagnosed with an illness?</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>Family</td>
<td>16</td>
<td>8</td>
</tr>
<tr>
<td>Doctor, Nurse or other Health Care Professional</td>
<td>13</td>
<td>11</td>
</tr>
<tr>
<td>Own</td>
<td>17</td>
<td>6</td>
</tr>
<tr>
<td>N=46</td>
<td></td>
<td>N=25</td>
</tr>
</tbody>
</table>

df=2, p<.50, chi-square value=1.68
Research Question One

Research Question One asked what type of communicative changes PWI perceive. The categories that emerged from the types of change were coded separately in the manner described in Chapter II and then were compared across contexts. Several of the same themes, such as open/improved communication, illness talk, emotionalism, and minimal change emanated across all contexts. Fear of discrimination and miscellaneous categories evolved for doctor, nurse, or other health care professional as well as within PWI's own communication contexts. Confining/restrictive was a category exclusive of family communication whereas personal/personality introspection was exclusive of own communication changes.

Open and Improved/Enhanced Communication

Open communication is defined as an increase in the depth and breadth of communication between PWI and PWOI. This means that the communication between people in these groups is perceived as having greater quality, such as becoming more fulfilling. It may be characterized by more honesty and frankness (Chesler & Barbarin, 1984; Binger et al., 1969) about the illness or other personal issues. Regarding her own communication for example, one participant said: “I find it has given me the ability to make it easier to talk to my children about anything they question, including my cancer.” Another participant echoed a similar sentiment: “I have an increasing tendency to be more honest and say openly what’s on my mind, instead of ‘being polite.’”

Communication may also be more sincere following the diagnosis than it was prior to it. This combines with the quantity of communication indicating that the PWI and PWOI engage in more meaningful and longer conversations. For one respondent
communication with family members became more definitive following illness disclosure: “We speak more clearly, listen with more open ears and are more patient and accepting of each other.” Open and improved/enhanced communication across all contexts may also reflect a level of comfort in being able to communicate with each other or about the illness. One man with cancer described how feeling comfortable with his doctor enabled both of them to communicate more openly:

My doctor now identifies with my sense of humor and tells jokes to me. We get so caught up in it that we both forget about the tests they are running and the examination he is supposed to be conducting. He is quite relaxed with me now because he knows that nothing he tells me will upset me.

Overall, this category reflects any improvement in communication PWI perceive in their own communication or with their family, doctor, nurse, or other health care professional since illness diagnosis.

**Illness Talk**

Illness talk is defined as discussion specifically about the illness. In this instance, more discussion can include an increase in quantity and/or quality of communication about the illness. Additionally, this type of communication may be initiated by either PWI or PWOI. This category also includes a change in support for PWI as a result of the illness or any reference to people with HIV or AIDS coming out about their sexuality. Although this category was apparent across all three contexts, it was most frequently described within family contexts, as noted in this participant’s comment: “With time and experience, we now have little problem discussing HIV, my general health, etc.”
Emotionalism

Emotionalism is representative of more expressions of love, moral support (Gotcher, 1992), and concern, such as in this participant’s example of communication with his doctor: “Both my longstanding doctor (and best friend) who cried when he told me, and my new infectious disease doc have been much closer, the whole staff there are as warm and as friendly as can be.” These expressions are also included in the family context, where each person more frequently tells one another that they are loved. This category may also include PWI or PWOI showing more concern or consideration verbally or non verbally for one another such as through more frequent visits. One participant experienced significant emotionalism as a result of her cancer:

I have a particularly supportive and close family. My children are adult and do not live nearby but they keep in constant contact with my husband and me. This contact, which has always been frequent, has increased a lot since I was diagnosed with cancer. There have been more expressions of love for me and for each other.

Confining/Restrictive

The confining/restrictive category is negative communication PWI perceive in attempting to communicate to family PWOI. Confining/restrictive communication may be unfulfilling for PWI, leading them to be cautious or restrained in what they say to their family because of how they anticipate or have experienced reactions to communication. One participant commented that the illness changed his communication with his mother:

Yes, but I’m afraid that, while I expected communication to become more substantial and attentive (with my mother, who has always been to self-absorbed to listen to anyone carefully), it has instead become more tedious and more repetitive, more soaked in generalities and more of a waste of time than previously.
Because of this communication, PWI may not have received the support they need. It may also have prevented them from having the opportunity to vent; therefore, they may feel alone or abandoned in dealing with their illness. This is depicted by the comment of a participant with breast cancer: “I cry alone.”

Informational Self-Empowerment

Informational self-empowerment arises in PWI communicative experiences with their doctor, nurse, or other health care professional. It is defined as PWI assuming responsibility for learning about their illness. Self-education about the illness and medical vernacular are also a part of the informational self-empowerment process. In this category, PWI assume a proactive approach about their own health care and may make it a point to be as well-informed as possible, even to the point of discussing, questioning treatments, or questioning the prognosis of their illness, as this participant indicated: “I’ve become a well-informed patient capable of asking questions which will shape the course of treatment.”

Fear of Discrimination

Characterizing this category are fears PWI have of being treated differently or being rejected because of their illness if they were to disclose it to others, including family, co-workers, or professionals (J.A. Kelly et al., 1987). This is particularly predominate for people with HIV or people with AIDS but may also occur to people with cancer (Keith, 1991). One participant was reluctant to disclose his HIV positive status to avert what he perceived would lead to discriminatory communication by his health care provider:

Though I have no regular health care providers (just moved), I do not disclose my HIV+ status as long as I am sure they are taking necessary precautions for themselves. This is due to my decision to have any
symptoms treated as if in the general population who gets “AIDS” indicator diseases, and to maintain a nondiscriminatory level of care.

As a result, PWI may be reserved or fearful in their own communication by not revealing their illness, or at least not doing so fully. Although PWI may want to share their “secret,” they are hesitant to do so because of the perceived ramifications of being treated differently (Keith, 1991). Thus, PWI are fearful of illness disclosure in their own communication because doing so could alter their interpersonal relationships from person-centered to illness-centered. For example, a person with HIV said: “I would like to tell my coworkers but again, I don’t want them to feel sorry for me.”

**Personal/Personality Introspection**

This category reflects a change within PWI as a result of their illness, leading to differences in metacommunication. Following their illness diagnosis or acceptance, they may have become more (or less): accepting of others, self-centered, more sensitive, or more caring, all of which may be manifest communicatively. In other words, PWI may have become more genuine in their actions, deeds, or communication with others, whether other PWI or PWOC: “I have become more short-tempered and self-centered in conversations, plus a bit more impatient.”

The above participant’s example reflects one of the very few ways described as actual communication changes that were said to have occurred since illness diagnosis. Participants typically described behavioral ways that their life changed then described how their communication changed as a result of becoming a person with cancer, HIV, or AIDS, as in this participant’s example: “[I] think I am much more tolerant and caring of other people, much more relaxed and accepting.”
Minimal to No Change

Since many participants believed that little or no change had occurred, this was seen as an important category to include. This category indicates that communication by and between PWI and PWOI exhibits very slight to no change due to an illness being introduced into the interpersonal relationship. Little to no change can be either positive or negative. That is, the state, quantity, and quality of communication prior to and following the diagnosis remained primarily unchanged, regardless of its original valence. As one participant said: “It’s always been marginal.” However, for another participant, communication remained the opposite: “All is well on this front, and always has been well.”

Miscellaneous

The miscellaneous category includes various sentences which were not codable into pre-existing categories. This “other” category emerged in communication changes with doctor, nurse, health care professional, and own communication. One participant indicated that: “I am deaf so that is a problem all to itself.” The comments from this participant were tangent to answering how his own communication had changed: “Gee. Makes me sound like a heel and a cad pre HIV. I assure you that wasn’t the case!” Regarding how her communication had changed with doctor, nurse, or other health care professional, this participant said: “Every little tick is now major analyzed.”

Summary

Given the findings of Research Question One, it was determined that there were significant changes in communication following diagnosis of an illness. This is demonstrated by the categories that emerged from the research: open communication,
more discussion of health and illness, more restrictions on some types of topics, more information seeking, greater fear in communicating given the illness, more emotional talk, and more metacommunication. Although these categories indicate the types of communication PWI perceived, there is no positive or negative valence to these changes. Do people view more communication about emotions as positive or negative? Is more open communication perceived as positive? Research Questions Two and Three sought to determine what was viewed as positive and negative communication between PWI and PWI.

Research Questions Two and Three

Research Question Two queried the types of communication that PWI perceived as positive while Research Question Three asked the types of communication PWI perceived as negative. These two questions were coded separately into categories that emerged from their respective data. The categories in questions two and three showed remarkable commonality, (e.g., positive information seeking versus negative information seeking), differing only in the alternative support mechanism (positive) and attribution categories (negative). Consequently, the categories from questions two and three were collapsed to emphasize the similarity in the themes that evolved from the coding. Table 3 shows the themes of information seeking, communication caring, illness predominance, affirmation, and other that emerged.
Table 3
Positive and Negative Communication Categories

<table>
<thead>
<tr>
<th>Category</th>
<th>Positive</th>
<th>Negative</th>
</tr>
</thead>
<tbody>
<tr>
<td>Information Seeking</td>
<td>Positive</td>
<td>Negative</td>
</tr>
<tr>
<td>Illness Predominance</td>
<td>Person First</td>
<td>Illness First</td>
</tr>
<tr>
<td>Communicated Caring</td>
<td>Genuineness/Sincerity</td>
<td>Cheerleading</td>
</tr>
<tr>
<td></td>
<td>Emotion-Sharing</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Venting</td>
<td></td>
</tr>
<tr>
<td>Affirmation</td>
<td>Inspirit</td>
<td>Dispirit</td>
</tr>
<tr>
<td>Other</td>
<td>Alternative Support</td>
<td>*Unsolicited Support</td>
</tr>
<tr>
<td></td>
<td>Mechanisms</td>
<td></td>
</tr>
<tr>
<td></td>
<td>*External/Other</td>
<td>Attributions</td>
</tr>
<tr>
<td></td>
<td>Needed Attributions</td>
<td></td>
</tr>
</tbody>
</table>

* = Not found in this study but speculated to occur.

Information Seeking

Positive

Positive information seeking is demonstrated through self-education, either on the part of PWI or PWOI. For PWI, it may include such things as reading about the illness, collecting information about the illness, or speaking with others who may have (or had) the illness (Dunkel-Schetter & Wortman, 1982). The first example shows how one participant sought information from her doctor: “I have an excellent oncologist - the tops - who is prepared to explain again and again and even photocopy medical journal articles he thinks may help put me in the picture.” Another participant reflected on the information he received from another PWI: “The knowledge base of
other HIV+ persons, good reference source for treatment options, side effects, pitfalls, etc."

POWI may positively pursue information by asking similar others (POWI) about the illness, asking sincere questions of PWI, or simply knowing some information about the illness to know what questions are appropriate to ask PWI. As one participant said: “Pretty much everybody who knows me now should be able to ask me what my CD4/t-cell count is.”

**Negative**

Negative information seeking emerges in regards to what PWI find patronizing, unhelpful, or disempowering. Negative information may be perceived as POWI asking questions about the illness or about death in a nosy, intruding, inappropriate, or rude manner. For one participant, it was not inappropriate or nosy questions she found patronizing, unhelpful, or disempowering but the lack of information she received: “Followed by doctors that tell you little or nothing. I even had a doctor tell me it wasn’t even cancer.” PWI may also resent people who volunteer negative stories about their own or another person’s illness experiences, as did this person with cancer: “When I was anticipating chemotherapy and radiation, it bothered me when people told me negative stories about other people taking these treatments.” For this participant with HIV, it was the source and type of information he found negative:

I am very, very well-informed about HIV, yet many relatives or HIV-negative friends insist on calling me every time they see some watered-down news story about it and are hurt when I don’t share their breathless enthusiasm.
Illness Predominance

Person First

The person first category indicates that PWI are thought of, communicated with, and treated no differently post illness awareness than prior to their illness. In other words, they are first and foremost a person and their illness is secondary to who they are. According to one participant: "I get the most benefit when I am treated like another human being and not like some loathsome creature or poor ‘inspiring’ crisp."

Illness First

Illness first is distinguished by an emphasis purely on the illness versus the person. Specifically, it is when the illness dominates or controls how PWI are thought of and communicated with. One participant commented that communication is: "Rarely a problem other than the occasional voiced ‘presumption of fatality’ of being HIV+.” Illness first may also be indicative of how PWI are treated because of their illness. This participant tells how the illness often comes first for him: “The most negative things are when I’m not treated like everyone else. I don’t want special treatment and hate getting it.”

Illness first then, reflects a way of communicating with PWI that makes them feel demoralized and inhuman, possibly lowering their self-esteem. Also, illness first means PWI may be treated and communicated with as if they are incapacitated because of their illness, resulting in others being overly nurturing or mothering towards them (Kubler-Ross, 1970).
Communicated Caring

Genuineness/Sincerity

Genuineness/sincerity is a way of caring that PWI do not perceive as superficial. The key component of this category is sincerity earmarked by demonstrating understanding and compassion about the illness and related issues. For one participant, understanding is indicative of PWOI’s questions: “People are very supportive of me in all ways (asking how things are going, being interested in treatments, etc.) which is always helpful to me.”

Emotion-Sharing

Emotion-sharing is defined as one-way or reciprocal communication expressing emotions, such as love, tears, or hurt. In other words, emotion-sharing is revealing to PWI or PWOI the feelings that are elicited by hearing about or reacting to the illness. On participant related his wife’s response to his illness: “She says she loves me anyway.”

Venting

Venting is a one-way form of communication whereby PWI can “unload” the stress of their illness on another person. As one participant with cancer said: “They gave me the chance to have a very necessary moan about it too: ‘Don’t you ever get just fed up with the unfairness of it all?’ which gave me the chance to let it all out.”

In the venting process, PWOI assume an active listener role, offering cathartic support to PWI, enabling them to talk freely and as needed about their illness, especially any uncertainty (Albrecht & Adelman, 1987; Dunkel-Schetter & Wortman, 1982) or fears they have about it, as the participant above demonstrated. Researchers
have previously identified venting as a coping mechanism that involves and benefits the cancer patient (Wortman, 1984). “By acting as a ‘sounding board’ for the patient, relatives, friends, or health care personnel can help the patient to interpret and manage his or her experiences” (Wortman & Dunkel-Schetter, 1979, p. 127). Validity of these results are reinforced through existing research on venting. In addition, the present research study contributes to and expands upon the coping process by generalizing into HIV and AIDS illnesses.

Cheerleading

The main cheerleading component is lack of acknowledgment about the seriousness of the illness. PWI may offer sincere communication as a way of helping PWI cope with their illness. These attempts, however well-intended, may be perceived as unsuccessful and insincere, as this participant’s example illustrated: “Lack of understanding of the draining nature of cancer and its treatment, ‘why don’t you do some walking in the mountains?’” Yet another participant indicated: “When people are really being ‘pollyanna-ish’ I can feel that they are only trying to be kind and I am just undisturbed by it.” Cheerleading may also include what PWI perceive to be sarcastic humoring, as one participant identified: “Cheerleading (‘oh, don’t worry, you’re gonna make it!’) is especially harmful because it tells me I’m being humored.”

Affirmation

Inspirit

Inspirit communication is encouraging and validational messages which are perceived as positive. Communication in this category may include telling PWI how they are an inspiration, that they are a role model, or how good they look given their
illness. One person expressed sentiments similar to other participants: “People say that I look good. That makes me feel good. They also say that I am an inspiration to others with cancer because of my positive attitude.”

Dispirit

Some PWI perceive communication about their appearance, inspiration, or role modelship as unencouraging and burdensome. This participant negatively perceived comments about his appearance: “I’m not as sure about what I find empowering as what I find power-sucking; those would be things like ‘Sorry,’ ‘It must be (hard, scary, terrible, frightening -- whatever fear that person has goes here).’” PWI may also perceive PWOI as expressing too much concern or imposing their own fears on PWI. As one PWI related: “Sometimes the remarks about still looking good seem offensive to me. I sometimes respond ‘That goes to show you shouldn’t judge a book by its cover.”

Other

Alternative Support Mechanisms

These types of communication, perceived as positive, may be exemplified by a belief in non medical sources for support, whether physical, metaphysical, or religious. They are communications PWI use to emotionally support themselves and to assume control over or sustain themselves throughout the course of the illness. Specific examples may include a change in lifestyle, exercise, religiousness, or hypnotism. Alternative support mechanisms from external sources (e.g., PWOI) may also assist PWI in getting through their illness. Again, this may include offering invocations, spiritual guidance, or being an exercise partner. As one participant said: “People
frequently say 'they are praying for me.' People have told me 'God is on his Throne' - I found this empowering."

Attribution

Attribution is a category whereby PWI try to determine and possibly understand why and how they came to acquire their illness. Oftentimes negatively perceived, it is communicated through PWIOI to PWI, where the latter begins believing they deserved their illness and that it is their fault, as if they could have somehow controlled getting their illness. One participant identified that others want him to have the responsibility for his own illness: "Of course it won't [be alright] and this puts a guilt trip on me, my fault for dying."

The portion of the above participant’s comment showing blame for the illness is rationalized by just world hypothesis (Lerner & Simmons, 1966; Lerner & Matthews, 1967), which is based on the premise that people get what they deserve. Believing that good things happen to good people and bad things happen to bad people may enable PWIOI to feel protected and insulated from acquiring the illness. Thus, they feel that they control their own destiny in not getting an illness inasmuch as the PWI controlled their own destiny via their lifestyle or behaviors in procuring their illness. Consequently, PWIOI may label PWI as having caused their own illness. PWI may sincerely believe the label PWIOI apply to them and in turn adapt a just world mentality. Attribution arises as a mutually exclusive communication category PWI find patronizing, negative, and disempowering.

Summary

Research Questions Two and Three were collapsed because the categories of information that PWI found positive and negative appeared opposite. Themes
incorporating these opposing categories emerged and included: information seeking, illness predominance, communicated caring, affirmation, and other. The positive changes in these themes (positive information seeking, person first, genuineness/sincerity, emotion-sharing, venting, inspirit, and alternative support mechanisms) implied PWI's satisfaction with the communication, moreso than was exhibited through negative communication changes (negative information seeking, illness first, cheerleading, dispirit, and unsolicited alternative support). The negative communication categories that emerged may help elucidate what may be construed as patronizing speech.

Research Question Four

This research question attempted to examine negative communication PWI may have perceived as being similar in structure to patronizing speech other groups experienced. Research Question Three provided the responses for answering Research Question Four. For example, some communication participants perceived as being negative was similar to that found in intergenerational and interability research. Some of this study's responses may be construed as patronizing speech, such as the cheerleading and illness talk categories in Research Question Three. Most predominate in these two categories seemingly is emphasis in not treating PWI differently (labeled 'depersonalization' in the interability literature, Fox, 1995) and not being mothering. One participant identified this as: “Cousin wrote to me ‘You have a tough year ahead of you.’ I don’t think so.” One participant demonstrated how he is treated differently because of his illness: “References that I ‘deserve’ it, lecture me about how to take care of myself, coddling like I can’t take care of myself.” Other comments participants made which may also be indicative of patronizing speech included:
Negative or dis-empowering words: Things like "I wish there was something I could do to help you" from another gay man who suddenly loses interest when he finds out you're positive. Personal ads with words like "...seeking disease-free partner..." Etc. or "...HIV-, seeking same..." only...

'Oh, poor you...' and other such phrases. 'Don't do that/worry about that...I can do it for you...' 'I know you're sick, so I won't expect as much from you...(work setting). Being denied or not considered for work assignments because of perceived disabilities.

Although the following comment transpired in an illness context, it is similar to patronizing communication older people experience from younger people: "The most negative things are when I'm not treated like everyone else. I don't want special treatment and hate getting it." These feelings are similar to those of older people, for whom age is made salient in the communication interaction. In such an instance, the older person experiences patronizing talk, which may mean the rate, pitch, verbosity, and context are simplified to accommodate what a younger person may perceive to be reduced hearing and cognitive abilities (Ryan, 1991; Fox & Giles, 1993). The effects of patronization for the older person may result in their premature perception of aging, where they may start to dress, speak, and act congruent with how others perceive them to be. Ultimately, they may be sacrificing their own health and hinder their own living process as they become more dependent on others to care for them (Fox & Giles, 1993; Ryan et al., 1995). Likewise, comments such as those above that were made to PWI may lead them to act and communicate in accordance with PWOI perceptions of a person with cancer, HIV, or AIDS based on the stereotypes that surround these illnesses. The potential effects of patronization for PWI, much like an older person, may result in premature perceptions of themselves with the illness, where they develop and believe the mindset that the illness determines--and dictates--who they are as well as their actions, behaviors, and communication. In both cases, it is speculated that the health and quality of life of the older person and PWI may diminish.
Summary

Research Question Four demonstrated communication PWI perceived as negative which may be construed as patronizing. Cheerleading and illness first are communication categories which may be classified as patronizing for PWI. Participant examples demonstrate how PWI are communicated with and treated differently because of their illness. This is indicative of experiences elderly and people with disabilities have because younger people or people without disabilities are uncertain of how to communicate with them. From this research, it may be concluded that the stereotypes PWI experience as a result of having cancer, HIV, or AIDS leads to patronizing communication similar in structure to what the elderly and people with disabilities experience. The similarity may result from PWI, elderly people, and people with disabilities all being stigmatized groups.

Summary

This chapter presented an analysis of each hypothesis and each research question described in Chapter I. The results from Hypotheses One and Two indicated that PWI perceive their communication to change following illness disclosure though this change does not occur across family, doctor, nurse, other health care professional, or own contexts. Research Question One found that communication changes PWI experienced from illness disclosure may be defined as open/improved communication, illness talk, emotionalism, and minimal change. These categories were found in all contexts, while fear of discrimination and miscellaneous evolved for doctor, nurse, or other health care professional communication. Confining/restrictive was exclusive of family communication and personal/personality introspection was reflective of PWI own communication changes. Research Questions Two and Three found information
seeking, illness predominance, communicated caring, affirmation, and other themes elucidated the positive and negative communication PWI experienced. The negative category in these themes demonstrated patronizing speech that PWI may experience. Condescending speech and mothering were attributes that PWI may perceive as patronizing which have also been identified in intergenerational and interability research. Chapter IV examines the implications of the research results presented in this chapter.
CHAPTER IV

DISCUSSION

This chapter links prior chapters by discussing the implications from the results presented in Chapter III. To achieve this, it analyzes the findings from the hypotheses and research questions. Through extensive theoretical application, the chapter then focuses on extending research findings in an applied or "real world" context. After discussing inherent limitations within the study, the chapter proposes avenues for future research. All of these areas are coalesced into the conclusion, which reiterates the purpose, findings, and implications from this research study.

Analysis of Results

Hypotheses One and Two

These hypotheses cumulatively predicted that communication would change following PWI's disclosure to PWOI. Hypothesis One speculated that change would occur while Hypothesis Two speculated on the contexts in which PWI were likely to experience communication change following illness disclosure. Knowing that PWI perceived communication to change enables researchers to advance another step in determining ways in which this may occur, which is addressed in the research questions.

The data from Hypothesis One indicated that PWI perceived their communication to change proceeding illness diagnosis. This is a significant finding because it showed that the illness is a variable that can lead to intergroup and interpersonal changes. Change in communication following illness disclosure leads to
speculation that change would also be noted in family, doctor, nurse, other health care professionals, or PWI own communication contexts. Yet, this latter premise was not statistically supported, indicating that communication changes are not context specific. Communication with family, medical professionals, and metacommunication among people with cancer are three areas which have been cited as being important regarding illness and communication (P.G. Northouse & L.L. Northouse, 1992, 1987). Perhaps communication across these contexts would be significant given a larger sample size. Given that the predominate gender in this research study was male, not female [contradictory to other research on cancer (Dunkel-Schetter, 1984)] this finding may represent gender differences in PWI's communication. Also, it may be that there is a relationship between the gender category and those who answered “no regular health care professional.” Of the 19 males in the study, five indicated that they had no health care professional. No females indicated they had not seen a health care professional prior to illness diagnosis.

A final consideration towards Hypothesis Two is that PWI may be emotionally closer with friends, co-workers, or others than family members. This was not taken into consideration, primarily because of the difficulty in operationalizing the level of intimacy in non family members. However, PWI may perceive there to be more support with members of these groups. Therefore, they could disclose their illness and communicate differently to people in these contexts than were revealed through this study. One study participant described how open communication about his illness with friends changed their relationship:

I was very closeted and gay, have no family but a close set of friends and since I told them that I was both gay and positive, they have been overwhelmingly supportive, have taken over getting me to doctors, shopping, done everything I need.
If a category of intimate friends was added to the study and compared to family, doctor, nurse or health care professional categories, it is possible PWI may perceive a communication change across contexts, altering the outcome of this hypothesis.

**Research Question One**

This research question queried the types of communication changes PWI perceived as a result of their illness. What resulted were several categories from within the research explaining how and why communication may have changed.

**Open and Improved/Enhanced Communication**

Briefly, this category was described as fostering greater quality, honesty, and sincerity within the communication interaction. What was noted in the examples that participants gave was that they perceived there to be greater depth to the communication. PWI's comments within this category indicated that they seemed to be perceiving open and improved communication in a positive manner, regardless of the context in which it occurred. Further, PWI perceived the illness as improving or otherwise creating open communication, suggesting that they may not have perceived open and improved/enhanced as occurring prior to the illness. If it was existent, PWI may have perceived communication as becoming even more open, improved, or enhanced following illness disclosure. Acceptance of the illness may be one rationale for this based on the premise that people more accepting of their situation (such as people with terminal illness acknowledging their impending death, S.L. Kelly & Patterson, 1995) are more inclined to communicate about it. By the same token, communication is a reciprocal process; therefore, the open and improved/enhanced communication found in this study implies that PWI and PWOI both had knowledge of the illness and both are focused on communicating with one another. Specific
comments from participants using “we” comments evidence this finding. In the illness and communication context, this finding and ensuing discussion demonstrates the fact that openness makes the communication situation stronger in the PWI/PWOI relationship, potentially leading to greater quantity and quality of emotional support for the PWI.

Do PWI suspect their illness before the diagnosis is confirmed? Have PWI voiced these concerns to PWOI? If so, the affirmation of the illness may have somewhat already been accepted and talked about, facilitating greater or more open communication. McCann (1992) found that HIV positive males receiving their diagnosis experienced negative reactions to hearing the diagnosis regardless of whether they suspected the news.

**Illness Talk**

This category is defined as that which focuses on the illness. It included coming out about the illness for people with HIV or AIDS because they perceived that to be a salient communication change for them. The results from this study indicated that coming out was an important benchmark with regard to communication changing (Bennett, 1990). Various participants reiterated that there is more talk of the illness and specifically its affect or relationship to them. For example, PWI perceived and identified communication as “we talk about illnesses more”, reflecting intergroup and even interpersonal communication processes through enabling PWI more opportunities to talk with PWOI. An additional variable is that coming out about the illness seems to be perceived as salient to communication change for people with HIV and AIDS but not for people with cancer.

One rationale for the communication change people with HIV or AIDS may have experienced may be caused by the nature of these illnesses. Research documents
that it is the impact of the illness on the person with HIV or AIDS that may determine whether they talk about their illness with PWI (McCann, 1992; Cline & Boyd, 1993; Bennett, 1990). Secondly, and perhaps more importantly, is the question of whether the person with an illness and their family were together when the initial illness diagnosis was made. Sharing the event or illness experience together has been found to raise PWI self-esteem (Ward et al., 1991) which may influence their perception of the communication. From that instant, communication may be perceived as more comfortable, satisfying, and open because there is someone with whom PWI can talk, not only about the illness but about more personal issues as well.

**Emotionalism**

In this category, PWI perceived there to be more communication about feelings because of the illness, especially those relating to communicating love, concern, and moral support. The participants’ sentences in this category indicated PWI were accepted as a person first, with their illness secondary. PWI may have reacted to the illness with concern but recognized and communicated to PWI that they still cared about them even though, and possibly regardless of the fact they have an illness. Because of the illness, its effects, or the stages of it (especially if terminal, as with one study participant), PWI and PWI may reciprocate more communication of feelings. Sharing of feelings between PWI and PWI may occur because it can lead to more support and perhaps inner tranquillity or calmness for both PWI and PWI, variables that may contradict the uncertainty and unpredictability of the illness.

**Fear of Discrimination**

Fear of discrimination emerged as a communication change because PWI perceived that PWI may treat them differently, such as by rejecting them (Bennett,
1990; J.A. Kelly et al., 1993) because of their illness. An unacknowledged or perhaps acknowledged fear of PWI in this category may be what others might say or PWI's own fear of losing their social support when they disclose their illness to PWOI. The latter is a particularly strong argument in light of research showing that greater social support is needed at this time (Cline, 1989). The fear of discrimination category can substantiate the research on stigmas, given that they are a part of Western culture. There is a pervasive theme and fear PWI have in being segregated because of their illness. People with HIV and AIDS, as found in this and other research (Bennett, 1990), are inclined to not disclose their illness if they perceive doing so will have negative ramifications such as stigmatizing and labeling. One woman diagnosed with cancer as a child said she did not want to tell her classmates because she did not want to be treated differently (Keith, 1990). HIV, AIDS (Bennett, 1990; Cline, 1989) and cancer stigmas have been documented in the research and as found here, can restrict, hinder, or otherwise impede communication between PWI and PWOI. Thus, PWI's fear of discrimination is validated by societal stigmas that surround cancer, HIV, and AIDS illnesses.

Confining/Restrictive

The family context in which the confining/restrictive category arose demonstrated that PWI may be emotionally abandoned and isolated (Adelman & Frey, 1994) because of their illness. It could be that PWOI do not want to face the illness. Having no one to communicate with about their experiences, PWI are left alone. This could lead to health, psychological, or emotional stress because of lack of needed support.
**Minimal Change**

Although there was illness disclosure, this category demonstrates that for some PWI, illness disclosure caused only a slight change to no communication change. Communication that was good or bad before illness disclosure remained in this same state following illness disclosure. From this category, it can be concluded that for some PWI the illness did not effect communication. One rationale is that PWI or PWOI may use denial to avoid confronting or dealing with illness, leading to their perception that there was little communication change. Connor (1992) describes denial as a coping mechanism that may be used “to preserve important interpersonal relationships” (p. 2). An effect of the minimal change category can serve to maintain the current state of communication as either satisfactory or unsatisfactory, or to maintain an illusion of invulnerability against the illness by denying its existence.

**Personal/Personality Introspection**

This category showed how PWI and PWOI communication was influenced by personal behavioral characteristic changes as a result of the illness. PWI seemed to incur personal changes because of the illness as they coped and adapted to the changes it may have caused in their life. Redefinition of the family role (L.L. Northouse, 1984; Jacobs, 1991; Cobb & Erbe, 1978) is one way the change may have occurred. It could also cause PWI personality changes such as becoming more caring and active or more impatient and self-centered. Are PWI perceiving these changes because they may have actually occurred or are they using the illness, as with the latter personality changes, as an excuse to be a certain way? Also, are PWI’s perceptions of personal/personality changes due to introspection, or is it a means of coping with their illness where they may be dealing with or going through stages similar to those in the death and dying
paradigm (Kubler-Ross, 1970)? The effects of personal/personality introspection are that it may lead PWI to communicate more freely verbally but moreso non verbally, where the latter often communicates emotions or positive behaviors.

Summary

This section highlighted the rationale for the categories that emerged from studying types of communication change. Each category explored what effect the findings had on communication for PWI. Through this, it can be concluded that PWI perceive some categories as advancing or impeding communication. Furthermore, PWI may have latent effects, speculated to be caused by denial or other coping mechanisms in confronting or avoiding the illness, the stigmas related to it, and personal identity.

Research Questions Two, Three, and Four

Collapsing Research Questions Two and Three was possible because of the parallel categories in the research. What evolved were positive and negative communication themes which showed similarity in categories of information seeking, communicated caring, illness predominance, affirmation, and other. The general effects of these categories provides the impetus for determining what PWI may construe as patronizing communication. The findings from Research Questions Four can also inform patronizing research by extending the types of communication PWI, elderly people, people with disabilities, and other groups see as non patronizing. The comments that are presented by participants in this study provide a foundation from which additional studies on patronizing communication in the illness context may be explored. Simultaneously, it extends and creates a spiral affect utilizing research on intergenerational and interability research which has previously studied patronizing communication.
The significant findings are those presented in the categories which show that different PWI may perceive the same type of communication with positive or negative intonations. Another interpretation of the results is understanding that PWI may also have common ideas about communication that are perceived to be positive or negative. These contradictory results were found because of the variability among PWI, giving credence to the statement that the interpretation is “in the ear of the beholder.” Some participants tangently commented that they were glad to partake in a study that could benefit other PWI as well as PWOI. The effects of this study were foretold by the participants, who anticipated the research to elucidate how and what PWOI can say to help or hinder PWI in coping with their illness.

Information Seeking

One of the primary foci of helping and hindering communication was seen through information seeking. The positive aspect of information, particularly seeking information from other (or former) PWI is congruent with research that similar others (PWI) can be a valuable information resource. Wortman and Dunkel-Schetter (1979) and Dunkel-Schetter and Wortman (1982) define information seeking as the cancer patient’s clarification about their illness through fact-based information, others similar experience, and open communication. Negative information seeking, described as the absence of information or provision of inadequate information, was equally important to PWI. Not only does this category substantiate the importance of information in the cancer context (Maguire & Sellwood, 1988), but it provides the impetus for extending research to people with HIV and AIDS. Cancer, HIV, or AIDS illnesses show the effect that positive and negative communication can have in affecting communication.
Illness Predominance

Person first and illness first are two categories in this theme describing PWI's communication results in disclosing their illness to others. Participants comments defined person first as being beneficial communicatively as well as helpful and supportive by letting them know they are important. In other words, its effect is that the communication is not the defining characteristic of PWI being. The effect of illness first represents communication changes that are clearly negative for PWI. These effects include communication which may be more demeaning and centers around the control the illness has over PWI lives. This may make PWI feel demoralized and potentially lower their self-esteem.

Communicated Caring

The types of communicated caring were manifest as positive through genuineness/sincerity, emotion-sharing, and venting while cheerleading defined the negative category. Cheerleading seems to be a very definitive category for PWI, where they are more certain of what they perceive to be negative. A paradox to this finding is that the definition and examples PWI gave represented the idea that they perceive PWOI's communication attempts as insincere while PWOI may be attempting to be sincere. How would PWI know that PWOI are attempting to offer sincere communication which is being perceived oppositely? One conclusion is that “friends, family members, and health care professionals are likely to voice reassurance on the surface, but manifest negative nonverbal behaviors as well as inconsistencies in behavior over time” (Wortman & Dunkel-Schetter, 1979, p. 141). Wortman & Dunkel-Schetter further add that this communication can leave the patient (person with
cancer) feeling isolated because of hurt feelings, which can lead to substantially decreasing social support not to mention declining self-esteem.

Affirmation

The communication and its effects in this category present opposing features for PWI. This category examines the survivorship messages PWOI communicate to PWI. For example, PWOI messages about how well PWI look (despite the illness) may make PWI feel emotionally good. Contrastly, these messages may also be perceived as negative and as burdensome, keeping PWI from feeling good about their situation. The overall communicative conclusion from these categories is that they may facilitate greater coping and PWI willingness to speak with other PWI or PWOI about their illness (Cline & Boyd, 1993).

Other

The attribution category is well-documented in the literature, as PWI lose social support, self-esteem, and begin to question their self-worth because of the illness (see for example Wortman & Dunkel-Schetter, 1979). As PWI's social support, self-esteem, and self-worth decreases, it is likely that this will have an effect, albeit not a very good one, on PWI's outlook and coping abilities with regard to their illness. Overall, they may not be able to cope well with their illness which could have detrimental effects on their health and potentially diminish their quality of life.

Summary

Research Questions Two, Three, and Four respectively focused on the positive, negative, and potential effects of patronizing communication that PWI perceived. Intergenerational and interability patronizing communication shows marked similarity to
the communication PWI find negative. This conclusion provides the impetus for additional research to validate the actual versus perceived communication changes to define and develop negative illness communication as necessarily patronizing.

Theoretical Application

Social Identity Theory and Communication Accommodation Theory

Social identity and communication accommodation intergroup theories help to define and clarify the communicative relationship between PWI and PWOI that results because of the illness. Emerging from these results is the notion that intergroup communication is less satisfying for PWI based on the fact they perceived communication in this context as negative. Hypothesis One found that PWI believed communication to change upon disclosure. The specific changes are emphasized with categories reflecting fear of communicating due to perceived discrimination, confining/restrictive, and the need for self-empowerment to regain control, not only over the illness but in communication with health care professionals. This conclusion is founded in the results that when the PWOI make the illness salient, the illness is what identified PWI, creating an intergroup situation and thwarting positive interpersonal communication. The dominance PWOI may exert through language (communication) to distinguish themselves from PWI supports social identity theory's premises (Tajfel & Turner, 1979).

Communication accommodation theory (Giles et al., 1987), through the concepts of convergence and divergence, characterizes the communication between the illness intergroups, as demonstrated in many of the illness first types of categories. Does the situation remain intergroup when PWI converge with the medical professionals through informational self-empowerment and information seeking? Does
this lead to greater convergence? Finally, the communication accommodation theory concepts of linguistic divergence with psychological convergence justifies the cheerleading category and findings from other research studies (Wortman & Dunkel-Schetter, 1979) where PWOI may simultaneously exhibit incongruent verbal and non-verbal communication (Erickson & Hyerstay, 1974). Because PWOI may be well-meaning in their communication though PWI may be perceiving it as insincere, linguistic convergence and physiological divergence may also occur.

Uncertainty Reduction Theory and Predicted Outcome Value

Interpersonal theories and their premises are demonstrated through positive communication PWI perceived to be more helpful, supportive, and satisfying. For example, open communication, where other PWI or medical professionals provide information about the illness may enable PWI to feel more at ease with their illness. Communication in emotionalism, person first, genuineness/sincerity, and inspirit categories may help PWI to validate the illness as a secondary facet of them as well as within their relationships. PWI's relationship with family, doctor, nurse, or other health care professional is not defined in terms of the illness but as PWI as a person, with their illness a secondary aspect of them. More satisfying communication is likely, resulting in greater positive value of the communication, particularly for providing moral and social support. Greater PWI's certainty within interpersonal relationships as well as about the illness can lead to positive outcomes, such as in having someone to whom they can vent about the illness or issues related to it.

Conversely, PWI may experience negative outcomes from PWOI who may have initially (following disclosure of the illness) provided certainty, help, and support for PWI but then withdrew. An explanation for this is that PWI and/or PWOI may be confronting the issue of putting time and energy into a relationship that could end. PWI
or PWOI may not want to deal with the uncertainty of death, such as when precisely it will come or face the stages of the illness that my lead to death. In general, they may not want to or be able to face death. Research on terminal illness and death has revealed that fear and anxiety about the concept of death often frightens PWOI (which may be family or parents of children with cancer) and impedes their ability to listen to, face, or talk about death (S.L. Kelly & Patterson, 1995; Witte, 1985). Koocher (1984) found that children’s fear about death is in leaving behind family or loved ones.

Maintaining a facade about the illness so as to protect PWOI is another type of communication which could create a negative outcome value (Dunkel-Schetter & Wortman, 1982). PWI may do this because they do not want to put PWOI through the uncertainty of the illness or because PWI perceive that PWOI may not be able to cope with the illness. Another reason PWI may let relationships disintegrate is because of the perceived negative value in maintaining the relationship. Following illness disclosure, PWI may find that uncertainty increases in relationships as PWOI may not know what to say to them. PWOI also may be expressing negative communication or thoughts to PWI at a time when they desire or need more positive or helpful communication. Negative outcomes may result because of the stress PWI face without having others with whom they may freely communicate about the illness. Thus, the illness trajectory may lead to uncertainty reduction, in turn leading to more positive outcome values manifest in such ways as information seeking or venting. However, it can also promote uncertainty earmarked by PWI’s or PWOI’s fear of death or protecting others, resulting in negative outcome values.

**Summary**

The relationship of social identity theory, communication accommodation theory, uncertainty reduction theory, and predicted outcome value reveals that all the
theories are relevant in the communication and illness context. Social identity theory and communication accommodation theory are applicable to the negative communication changes in cases where the illness was made salient over the person. In this context, communication changes are often more repressed. Uncertainty reduction theory and predicted outcome value however, highlight the communication changes occurring because of the illness, where communication is more sincere and satisfying for PWI. Taken together, all four theories provide the framework for how cancer, HIV, or AIDS illnesses may affect communication changes for PWI and PWOI.

Limitations

Sample Concerns

Within this study, small sample size is problematic and may be attributable to a number of factors. One of these was the forum in which the research was conducted. It is possible that the newsgroups and listserv chosen for the study were not the most conducive for such research, based on the membership of the groups. Perhaps members of these groups do not like to share their illness experience with others. Or, perhaps the number of people meeting the criteria as having an illness who belong to the groups is minimal. With regard to the hem-one listserv, the original posting asking for participants who were “terminally ill” was viewed by most members of the listserv as inappropriate. Many listserv members vehemently responded to the researcher about this labeling and consequently refused to answer the questionnaire. Following an apology posted to the group, two group members remitted their completed questionnaire to the researcher. Personal communication with one of the listserv owners (B. Lackritz, personal communication, December 22, 1995) indicated that people who belong to or participate in this listserv may be in denial about their illness.
As a result, use of the word terminal was perceived as especially derogatory. Also, tacit permission to post on this listserv inflamed some participants contributing to their decision to not complete the survey.

Another restriction to sample size may have occurred because of the questionnaire itself. Though the survey was short (10 questions), it still may have failed to be short enough with regard to total number of lines in the email. The message posted to the hem-onc listserv included an introduction, request for participation, human subjects institutional review board protocol, and the questionnaire. When the researcher received a copy of the posted message, it was eight screens long. One member of the hem-onc group indicated they do not read long messages because of time constraints. In posting to sci.med.aids and sci.med.diseases.cancer, the initial request for participation was 35 lines long. The email sending a brief note and the questionnaire to those who requested it totaled 110 or 111 lines long. Although there was significantly greater participation from the newsgroups (48% more), questionnaire length may still have affected sample size.

Also, members or observers of sci.med.aids and sci.med.diseases.cancer newsgroups fitting the study criterion replied to the posting for study participants, expressing an interest in completing the questionnaire. However, more questionnaires were sent out than returned indicating that perhaps they did not feel the nature of the questionnaire was applicable to their situation. A comment from one potential participant suggests this may have occurred. The participant asked the researcher via an email message whether the survey questions were “set in stone” because they were difficult to answer. This participant did not remit the questionnaire back to the researcher. Self-selected participation may have been a factor in this study. An additional consideration is that PWI who choose not to remit the questionnaire may feel that it intruded on or questioned their own communication. They may have felt that
their own type of communication, whether positive or negative, is satisfactory for them. Thus, PWI may not have wanted to answer a questionnaire that asked them to think about their own or others communication to them because it may have meant giving thought to how they communicate, something they may not want to do or acknowledge in relationship to their illness.

Two additional limitations pertain to the fact that the study is based on PWI's perceptions. First, the study is based on PWI perception of how communication changed upon illness disclosure. Since the majority of participants had been diagnosed with their illness five to nine years ago, there is some question to the accuracy of recall if they disclosed their illness to PWOI at that time. There was no participant indication nor question within the survey asking respondents when and if they had disclosed their illness to PWOI. Second, PWI's perception of communication change may be influenced by their feeling that people are going to communicate or treat them differently because of their illness. Because of this, PWI may be more inclined to report communication as changing when in fact no communication may have occurred. Further, it is more likely that PWI would report communication as negatively as opposed to positively changing. Another limitation is the assumption that positive communication is beneficial for PWI. Some PWI may be satisfied with communication they may perceive as negative.

The preponderance of males over females combined with computer literacy and financial status may not provide accurate generalizability of the sample findings. People using a computer newsgroup or listserv have accessibility to and at least limited knowledge of computers. A comprehensive Internet demographics study described the Internet user as “an extremely attractive target (educated, professional, and upscale”, CommerceNet/Nielsen, 1995, p. 2). also, the study revealed that men more so than women utilize the Internet, where they “comprise 66% of users of the Internet” and
“tend to use the Internet with greater frequency and duration than females” (CommerceNet/Nielsen, 1995, p. 11). Social science research conducted using this forum may need to control for this variable although, male domination in this study aids the advancement of the literature because cancer illness studies tend to have a female bias. While this research may seem male-biased, it serves to expand and enhance the generalizability of existing research.

Procedure

Using the Internet as a social science research forum may be a limitation with this study. Procedurally, perhaps a more quantitative or qualitative methodology would have been a more appropriate study for Internet research and would mirror the success of other researchers undertaking Internet research (Braithwaite et al., in press; L. Lawton, personal communication, November 29, 1995). Perhaps a greater cross sampling of groups, including those from Internet services such as Prodigy, CompuServe or America OnLine is necessary to enhance generalizability and representiveness of the Internet in general. Nevertheless, it may be a strength that this study was done on the Internet. It builds upon Internet studies in other contexts and disciplines to contribute and expand the literature in the illness context. For example, Fullmer & Walls (1994) found that bulletin boards and computers provide people with disabilities with an information tool about disabilities, resources, and a social hub. More than that, the researchers point out physiological and health changes the bulletin boards may create. “One means of enhancing the quality of life for persons with disabilities is to utilize computers and computer networks to transfer disability-related information” (Fullmer & Walls, 1994, p. 25). Braithwaite et al., (in press) also found that a computer-mediated network provides people with physical disabilities with esteem, emotional, and informational support. Similarly, Garramone, Harris, 

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Anderson (1986) found that personal identity is linked to participation in political bulletin boards where participation can make a person feel more involved by increasing their sense of political efficacy. Not only do these studies reflect the diversity of research conducted on bulletin boards and the Internet, but also stress the importance of (Nickerson, 1994) interpersonal and intergroup interactions resulting from computer-based interactions.

**Culture**

The questionnaire results from posting to newsgroups and a listserv provided no indication that the group was multicultural nor that the study participants were culturally diverse. Observations of the listserv revealed that it was culturally diverse, with participants spanning the globe. Unfortunately, the sample was not reflective of this diversity. With one exception from the entire sample (an Australian woman), there was no indication of the cultural heritage of the participants. Because PWI in other cultures may perceive illness differently, it is important to understand how they may perceive communication to change. For example, in Japan and India, a person with cancer is likely to perceive communication changes non verbally through avoidance, withdrawal, isolation, or mannerisms (Takahashi, 1990; Khanna & Singh, 1988; Gautam & Nijawan, 1987). The rationale for this is based in doctors personal or ethical beliefs in disclosing the illness. It may also be due to their anxiety with regard to death as in the Japanese culture, where the doctor’s goal is to “not disrupt the patient’s ego and emotions” (Takahashi, 1990, p. 88). Specifically, the doctor is more inclined to disclose the cancer diagnosis to family to maintain the person with an illness’ quality of life (Takahashi, 1990; Kai et al., 1993). Mtalane, Uys, and Preston-Whyte (1993) found that people with terminal cancer in the Zulu-speaking South
African culture will receive their diagnosis and prognosis from a doctor and will communicate this to their family. After this though, the illness is not discussed.

From the antecedent, research needs to take into account culture in terms of perceptions and beliefs about illness and communication. Given the world wide span of the Internet, additional Internet research could be done to explore the various functions listservs and newsgroups provide for people of different cultures.

Summary

Sample composition, perception, the Internet forum, and lack of cultural diversity are all limitations affecting the generalizability of this study. By the same token, the benefits of this research supersede its limitations, as in expanding interability Internet research into the illness context. Thus, the area of research in this study serves to broaden the current literature and provide directions for future research.

Future Research

Positive and Negative Communication

A seminal focus of future research could be to find out particular communications which are perceived as helpful and non helpful for PWI. Although this research examined positive and negative communication, the assumption is not made that negative is necessarily unhelpful. More examples or personal experiences from PWI may be insightful for coalescing a “communicative guide” for PWOI on what they can say that may be perceived as positive (helpful) or negative (non helpful) to PWI. Providing specific examples of what is perceived as positive and negative communication and why it is perceived as such from various groups of PWOI could help both PWI and PWOI in communicating with one another. What may be more
important is to move beyond the notion of positive and negative communication to analyze communication PWI perceive as satisfactory to them. By letting PWI define and perhaps provide examples of satisfactory, a more accurate description of positive and negative communication could result because subjective interpretations of the research are not being made.

Other research questions also exist: What are personal communication experiences PWI perceive as patronizing? What do PWI perceive as patronizing speech across different contexts, such as friends, doctors, and family? Is the same communication perceived as patronizing across all contexts or does it vary by context? Within the family, is patronizing speech perceived differently from spouse than from children or extended family members? Examining patronizing communication via these questions extends actions or behaviors PWI perceive as helpful or unhelpful (Dunkel-Schetter, 1984; Dakof & Taylor, 1990) into a communication context. The scope of the present study could be expanded from positive and negative communication to patronizing speech. This may potentially refine or advance new areas of patronizing speech beyond those found in intergenerational and interability research.

Expanding the scope of the study beyond cancer, HIV, and AIDS into other illnesses may be beneficial for PWI, their caregivers, and society in general. According to the National Institute on Aging, there are approximately four million people in the United States affected with Alzheimer’s (Health ResponseAbility Systems, 1993), although it is estimated that many more people have it and are unaware of it because Alzheimer’s can be a misdiagnosed illness (Query, 1990). Communication with people with Alzheimer’s is one context that may be useful to study because the mental degeneration associated with it lasts five to ten years, leaving the person with Alzheimer’s unable to communicate (Query & Flint, 1996). Because of the increased difficulty in communicating with a person with Alzheimer’s, would PWOI be more
likely to use patronizing speech given the nature of care giving for someone with Alzheimer’s? Might the positive (helpful) or negative (non helpful) communication be affected by the stage of the illness, PWI physical abilities, or their acceptance/denial of the illness? These are all areas which could extend current research studies and benefit not only PWI but their family, friends, caregivers, medical professionals, and society in general through awareness of variables that may enhance or impede the type and quality of communication interactions.

**Mass Media**

Given the prevalence of mass media in the lives of Americans, questions arise concerning its influences: How does mass media representation perpetuate social stigmas of illnesses? Why does mass media representation perpetuate social stigmas of illnesses? Do broadcast or print media realistically depict the experiences of people with various forms of cancers, HIV, AIDS, or other illnesses like Multiple Sclerosis or Alzheimer’s? A final overriding question with regard to illnesses and the media is: What are the immediate and long-term effects of stigmas, stereotypes, and labeling on positive and negative communication?

**Illness Progression and Communication**

This research study has only minimally explored the issue of PWI’s control and its possible relationship to uncertainty. Within the illness construct, is control perpetuated by uncertainty reduction in interactions with positive outcome values? Information seeking or self-empowerment arose as thematic categories in one question in this survey. Is there a relationship between having information about the illness whether from other PWI, doctors, journals, or other sources that aid in helping PWI maintain control over their illness? The possible relationship of control to information
seeking is one future research may want to explore. Is the level of control with the illness commensurate with information PWI has or does not have about it? If so, how does it affect communication? Would communication tend to be more negative in the absence of or with lower control and information seeking than in the greater control and information seeking instances? How do different contexts affect the communication and fluctuation of control and information for PWI?

Kubler-Ross (1970) advanced what have become well-known stages of coping with death and dying: denial, anger, bargaining, depression, and acceptance. Although she frames these as stages of death and dying, they may be appropriate to anyone facing a major personal crisis such as an illness. Research could benefit by looking at how Kubler-Ross’ stages manifest from PWI and PWOI intergroup communication perspectives.

**Applied Contexts**

The many gradations of chronic, serious, life-threatening, terminal, disease, and illness labels that are applied to PWI would be an area for future research which could serve to unify dispersed interdisciplinary research. A comparative study surveying PWI regarding the labels they prefer and PWOI with the labels they apply to PWI may benefit the communication process through examining any parallel or discrepant labeling that exists. In addition, such a research study may help to reduce illness stigmatization through language changes.

Future research could validate the categorical findings with regard to positive and negative communication. This could be further validated by having people belonging to in-person cancer, HIV, or AIDS support groups code the research responses in this study. Intragroup versus intergroup coding may yield different thematic categories from the research because PWI may perceive the illness sentiments...
differently based on their shared experiences as having (or having had) the illness. Having PWI code this information may provide different interpretations of the data that PWOI may not perceive. The implication of this research may provide more robust findings as it relates to communicating with PWI in what they generally perceive as positive and negative communication.

Integrating social identity theory or uncertainty reduction theory to examine the changes in intragroup and intergroup communication contexts may be a fruitful area of research in which to engage given the validational and empathic role of support groups (see for example Spiegel & Yalom, 1978; Bluebond-Langner, Perkel & Goertzel, 1991; Corder & Anders, 1974). The following research questions advance the present study asking participants whether they are involved in an on-line or in-person support group: What are the affects of Internet support groups for PWI and PWOI versus in-person support groups? Do they provide the same communicative support (or lack of) for the PWI and PWOI in their intergroup interactions?

It was not in the scope of this research to examine the health effects that communication changes have for PWI. The study was also not organized to examine PWI health effects caused by different types of communication changes. Even so, such effects have been speculated and are seemingly affected by the context and type of communication change. Some sample research questions include: Does positive communication have an affect on PWI's health? What affect does positive communication have on PWI's health? Does negative communication have an affect on PWI health? What affect does negative communication have on PWI health?

Conclusion

The purpose of this study was to examine whether PWI perceived their communication to change once they disclosed their illness to family, doctor, nurse, or
other medical professional. Another purpose of this study was to explore how PWI's communication changed once they disclosed their illness in the above contexts. An additional goal of this research was to determine what PWI perceived as positive and negative communication, with focus towards ascertaining if there was similarity between perceived negative illness communication and intergenerational or interability patronizing communication.

This study enables researchers to gain significant insight into PWI communication experiences, which is of necessity based on the increasing numbers of people in the United States who are diagnosed with illnesses such as HIV and AIDS. Of even greater necessity is knowing how PWOI communicate to PWI in a manner they latter group will find satisfactory, personally fulfilling, and vice versa. Fear, control, apprehension, and uncertainty can impede or inhibit the communication process between these intergroups as well as between the patient-family-doctor triad, where the illness defines and determines the communication. Social identity and communication accommodation intergroup theories and uncertainty reduction and predicted outcome interpersonal theories elucidate the ways in which this occurs by helping explain interactions between the different groups and in the interpersonal context. PWI, PWOI, and society in general will benefit from the immediate and long term implications of this research by knowing how to communicate with each other in ways that are effective and supportive for all concerned.
Appendix A

Human Subjects Institutional Review
Board Approval Letter
Date: November 13, 1995

To: Kimberly Sniderman

From: Richard Wright, Chair

Re: HSIRB Project Number 95-11-22

This letter will serve as confirmation that your research project entitled "Terminal illness as a social illness: the intergroup and interpersonal experiences of people with terminal illnesses" has been approved under the exempt category of review by the Human Subjects Institutional Review Board. The conditions and duration of this approval are specified in the Policies of Western Michigan University. You may now begin to implement the research as described in the application.

Please note that you must seek specific approval for any changes in this design. You must also seek reapproval if the project extends beyond the termination date. In addition if there are any unanticipated adverse reactions or unanticipated events associated with the conduct of this research, you should immediately suspend the project and contact the Chair of the HSIRB for consultation.

The Board wishes you success in the pursuit of your research goals.

Approval Termination: November 13, 1996

cc: Susan Fox, COM
Appendix B

Communication Questionnaire
COMMUNICATION QUESTIONNAIRE

Please answer the following questions by putting an X in the blank that best matches your illness experiences. If you put an X in an "other" category, please tell us what you mean by "other". You may elaborate as much as necessary in answering the free response questions.

1. a) Female_____ b) Male_____ 

2. How old are you?
   a) 10-19_____ b) 20-29_____ c) 30-39_____ d) 40-49_____ 
   e) 50-59_____ f) 60+_____

3. What type of illness do you have?

4. When were you first diagnosed with this illness?
   a) 0-5 months ago_____ b) 6 months to 1 year ago_____ c) 2 to 4 years ago_____ 
   d) 5-9 years ago_____ e) other____________________________

5. Are you involved in an on-line and/or in-person support group?
   a) Yes_____ b) No_____ 

6. What are some of the things which you find positive, empowering, or helpful that people say to you (regarding your illness) because they know of your illness? Please relate any specific examples.
7. What are some of the things which you find negative, patronizing, disempowering or condescending that people say to you (regarding your illness) because they know of your illness? Please relate any specific examples.

8. Has communication with your family changed since you were diagnosed and they were informed of your illness? If so, how?
   a) Yes____  b) No____

9. Has communication with your doctor, nurse, or other health care professional changed since you were diagnosed with your illness? If so, how?
   a) Yes____  b) No____

10. Has knowing you have an illness affected how you talk to people? If so, how?
    a) Yes____  b) No____

THANK YOU FOR COMPLETING THIS QUESTIONNAIRE. PLEASE FORWARD IT TO:

95sniderman2@wmich.edu
BIBLIOGRAPHY


