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# Talking with ALS Patients: An Exploratory Study of Patient Attitudes toward Mass Messages about ALS

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Talking with ALS Patients:  
An Exploratory Study of Patient Attitudes toward Mass Messages about ALS

by

Kamden Kuhn

A thesis submitted in partial fulfillment  
of the requirements for the degree of  
Master of Arts  
Department of Mass Communications  
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## ABSTRACT

This study examines the attitudes and opinions of ALS patients toward mass messages about their condition. Six focus groups of ALS patient support groups viewed and responded to public relations messages, charity advertisements, and a news story. Results suggest that mass messages remind participants of the need for public ALS awareness. Participants also said they shared in the narratives and identify closely with the characters in the messages they viewed, and participants expressed concern with disease depictions. These concerns included a tension between positive and realistic portrayals, identification of message inaccuracies, and a desire for more specific disease information. The ALS disease as it relates to mass communication has not yet been explored in scholarly literature. This study highlights the importance of the thoughts and opinions of ALS patients toward mass communication about their disease, and it provides a rich understanding of the participants' desires for their disease experience to be recognized and understood.

## CHAPTER 1: INTRODUCTION

Amyotrophic Lateral Sclerosis (ALS) is a progressive, fatal neurological disease that gradually robs its victims of their ability to walk, speak, eat, and eventually breathe. Named after baseball legend Lou Gehrig, the devastating nature of the disease gives its population of sufferers unique concerns, and their terminal state of living gives them a unique desire to express those concerns. The proposed study seeks to examine the thoughts and opinions of this sensitive population toward mass messages about their disease.

Health communication research related to this topic is limited to investigations of media representations of illness. A few studies have focused on patient perceptions of media messages; however, literature on mass communications and the ALS disease has not yet been developed. The present study details focus group research where ALS patients viewed and discussed several mass messages relating to their illness.

Below, background on the ALS disease and the status of the ALS community are discussed. Then, an explanation is given detailing how communication literature has neglected ALS, focused on media representations of other illnesses, and more often explored messages themselves rather than patient perceptions of those messages. Third, the focus group process used in the present study is described. Then, the findings of the focus groups are examined which revealed similar responses and themes across all six

focus groups: 1) for ALS patients who participated in this study, mass messages serve as a frustrating reminder of the need for increased public ALS awareness, 2) participants identify closely with the narratives and characters in the mass messages they view, and 3) participants express concern about disease depictions in the mass messages they view. Emergent issues are analyzed and concluding remarks include practical insight for communication practitioners.

## **Background**

ALS currently has no known cause and no known cure. The disease affects the motor neurons that carry messages from the brain to the spinal cord. When the motor neurons die, the muscles waste away. Gradually, an ALS patient becomes completely paralyzed. At the time of diagnosis, doctors give ALS patients only two to five years to live.

The disease was first described in 1869 and later made famous when New York Yankee Lou Gehrig made his well-known “Luckiest Man” speech in 1939. It is estimated that nearly 790,000 people have died of the illness since its discovery (“Who Gets ALS?,” 2011). Yet, more than 140 years later, scientists have not unlocked the mystery of ALS, and the disease has yet to be identified by the general public as an urgent social problem. While recent decades have brought a wealth of scientific information about ALS, public awareness of the fatal disease remains low. The ALS community has struggled to rise to the profile of other diseases, such as breast cancer, heart disease, and MS. And, the ALS disease is poorly understood by the general public.

Not only has the ALS disease remained low profile in history, but the ALS community has also failed to find a voice in scholarly literature, especially as it relates to

communication materials that could enhance the visibility of the disease. Researchers have focused on the ALS disease solely in a medical, clinical context; however, the topic of ALS and mass communications has not been researched. Mass communications research has looked at Multiple Sclerosis (MS) (Zoller & Worrell, 2006), although the incidence of MS is less than that of ALS. Approximately, 30,000 Americans are now living with ALS, and more are diagnosed every day (“Who Gets ALS,” 2011). This ALS community represents a significant population of people, and their voices and opinions about representations of their disease should be heard.



## CHAPTER 2: LITERATURE REVIEW

Media representations of illness have long been the subject of research, and a few studies have explored patient perceptions of messages about their illness. However, communication literature relating to the specific ALS disease is limited to studies exploring the interpersonal aspect of communication. These three branches of relevant literature, while evidencing a significant gap, also reveal several pertinent themes: 1) Attitudes and behaviors of both patients and the public are impacted by mass communications about disease, 2) level of felt involvement and message frames can influence perception of health-related messages, 3) mass communications about disease can have shortcomings in accuracy and understandability, and 4) communicating with ALS and other terminally-ill patients requires specialized strategies.

### **Patient and Public Attitudes and Behaviors toward Representations of Illness**

The first branch of literature pertinent to this study explores how peoples' attitudes and behaviors are impacted by media portrayals (Clarke, 2006; Hofstetter, Schultze & Mulvihill, 1992; Smith, 2007). This includes the attitudes and behaviors of both the public and the patient. Mass media messages rank high as a source for the public's health information (Hofstetter, Mulvihill, & Schultze, 1992). Sharf and Freimuth (1993) called television illness "an unobtrusive source of health information for vast numbers of people" (p. 141). People can learn health behaviors by watching others in

mediated contexts (Bandura, 2001). People often rely on these messages from television, radio, newspapers, magazines, books, movies, and the Internet to obtain information about health, illness, and disease even more than they rely on their healthcare providers (Hofstetter et al., 1992). These health topics are frequently covered by the media, and analyses of this content have been conducted in reference to Alzheimer's disease (Clarke, 2006), Toxic Shock Syndrome (Cheek, 1997), cancer, heart disease (Ye & Ward, 2010), AIDS (Clarke, 1992), and Fibromyalgia (Barker, 2002) among other diseases.

#### *Mass Communications' Impact on Public Attitudes and Behaviors*

Exposure to the messages referenced above has been found to be a clear factor in influencing the public's awareness, knowledge, and attitudes toward diseases (Flay, 1987; Flay & Burton, 1990). This knowledge and awareness then plays a role in the success of health promotions (Bandura, 2004). In Sharf, Freimuth, Greenspon, and Plotnick's (1996) investigation of audience responses to a television depiction of ovarian cancer, many viewers reinforced the messages' impact on their attitudes when claiming they experienced emotional responses to the depictions and even rehearsed what they would do if they were in the same situation. Mass messages also play a role in developing societal values and beliefs about disease and have been found to influence lawmakers to enact public health change (Walsh-Childers, 1994). Nelkin (1987) explains how an increase in medical and scientific coverage of disease has improved public and governmental understanding. Mediated messages have also been said to determine whether or not certain diseases are stigmatized and whether or not patients are believed to be responsible for their diseases (Smith, 2007).

In addition to the public's attitudes, mass messages have also been found to impact the public's behaviors (Snyder, Hamilton, Mitchell, & Kiwanuka-Tondo, 2004). These messages can play a role in contributing to overall public action toward the health problem (Flay, 1987), and ultimately in affecting the amount of funding for research and treatment of these conditions (Clarke, 1992). Brown and Walsh-Childers (2008) suggest that entertainment media messages may have the power to promote healthy behaviors that could prevent disease. Similarly, Snyder et al. (2004) concluded that health media campaigns have short-term measurable effects. Specifically, they found that mediated health campaigns convinced about 8% of the population to engage in a desired health behavior. However, the type of behavior change being promoted can influence a campaign's success.

#### *Mass Communications' Impact on Patient Attitudes and Behaviors*

While much literature has explored the relationship between mass messages about illness and public perception of those illnesses, fewer scholars have explored the attitudes and behaviors of the patient toward these messages. Those who have delved into this topic, however, have found that these messages can, in fact, influence the attitudes and opinions of patients suffering with various diseases (Barker, 2002; Barnett & Hammond, 1999), as well as their behaviors (Bass et al., 2006). When a person is diagnosed with an illness, he or she often seeks out mediated information for education and coping, making the content and perceptions of these messages of particular importance (Seal, 2002). Likewise, many of these patients are dependent on mass media messages for self-evaluation (Signorielli, 1993). When considering impact on patient attitudes, mass communications relating to illness can bring both meaning and legitimacy to patients and

reduce feelings of self-doubt and alienation (Barker, 2002). According to Barker's (2002) study of Fibromyalgia self-help literature, individuals use mass communications to "remake their life worlds" and "affirm the 'realness' of their experience in the face of its biomedical invisibility" (p. 284). Among cancer patients, feelings of self-confidence and an overall sense of being in control are related to the seeking of mass messages on the Internet (Bass et al., 2006). Mass communication messages produce emotional responses for viewers (Dillard & Peck, 2000; Dillard, Plotnick, Godbold, Freimuth, & Edgar, 1996). Some have even been found to have negative implications for the patient (Barnett, 1999). In fact, Barnes (1992) claims that cultural representations of disability have, at times, had negative implications for the very people those messages are intended to represent. These representations can play an important role in a patient's quality of life and should not be underestimated. However, some organizations may be tempted to allow fundraising goals to compromise the ways in which they represent a disabled population (Stockdale, 1995). Barnett (1999) concluded that representations of disability caused anger among a disabled study group. Media images have also been studied for possible consequences to both persons living with the disease and their spouses (Clarke, 1992).

In addition to attitudes, mass messages can impact patient behaviors. Mass messages on the Internet have led some patients to take a more active role in their healthcare (Bass et al., 2006). Bass et al. (2006) concluded that cancer patients' Internet information exposure is related to their propensity to ask questions, make lists, and partner with their physician. They concluded that these behaviors may be related to the Internet messages' influence on patient attitudes, namely self-efficacy: "If self efficacy can be influenced, a patient can more effectively change behavior and continue to gain

confidence in being able to adhere to the change” (Bass et al., 2006, p. 232).

Furthermore, media depictions of prostate cancer on *NYPD Blue* were found to build community among people living with prostate cancer (Arrington, 2000). While mass communications have proven to be a clear influencer of both patient and public attitudes and behaviors, the perceptions of ALS patients about mass communications of their disease have yet to be investigated, nor have their behavioral and attitudinal responses.

### **Level of Felt Involvement and Message Frames**

Second, existing literature has explored how factors such as level of felt involvement and message frames can influence perceptions of health-related messages.

#### *Level of Felt Involvement*

The Elaboration Likelihood Model sets forth a way in which communication practitioners can determine how likely an individual is to cognitively process a persuasive message (Petty & Cacioppo, 1986). Petty and Cacioppo (1986) argued that people devote significant careful cognitive thought to a message’s features and arguments when they process it through central routes. However, when someone processes a message quickly and uses simple decision making, he or she is using peripheral routes. According to this model, motivation to process and ability to process are two important factors that impact how the message will be processed and the effectiveness of a persuasive attempt. A person’s level of felt involvement in a given issue should then drive his or her motivation to process a health-related message. How relevant an issue is perceived to be to an individual will ultimately affect persuasive attempts in health-related messages since people process messages centrally under high-involvement circumstances (Petty & Cacioppo, 1986).

Furthermore, the extent to which a viewer identifies with characters in a message can impact their level of felt involvement (Messaris, 1997). Identification with message characters has been researched in relation to children (Lonial & Auken, 1986), adolescents (Shadel, Tharp-Taylor, & Fryer, 2009) and adults (Chang, 2002). When identifying with message characters, viewers look for self-congruent representations. This concept of self-congruency can play a significant role in evaluations of mass communications since it interfaces with the level of felt involvement and increases a person's likelihood to process the message (Chang, 2002). For example, Anderson and McMillion (1995) found that African-American women were more likely to be persuaded by a health message regarding breast self-exams when an African-American female delivers the message. Chang (2000) found that female viewers respond more positively to advertisements containing females than those depicting males. In this way, more self-congruent messages can result in more positive attitudes toward the message (Chang, 2000; Hong & Zinkhan, 1995). However, it should be noted that self-congruency is a less important factor in determining attitudes toward communications about already high-involving issues (Chang, 2002). When individuals are already motivated to process a message through central routes, they are less likely to rely on their senses of self as related to the message in order to evaluate it. However, under conditions where individuals are less involved and less motivated to process a message, individuals will rely on peripheral processing routes, and self-congruency becomes an accessible cue upon which to respond to the message (Chang, 2002).

When individuals are confronted with a mass message, they turn to their existing cognitive structures and self-concepts when selectively processing the information

(Markus, 1999). Individuals turn to self-knowledge more readily when their involvement is low or their ability to process is limited. In this way, self-knowledge interacts with how a person processes a persuasive message. Positive responses to a mass message are more likely when a portrayal is in line with the way the viewer sees himself or herself (Hong & Zinkhan, 1995). Furthermore, individuals may be more likely to remember at a later time mass messages that are self-congruent (Hong & Zinkhan, 1995). It has been found that brands with self-congruent images are preferred to brands with images that are incongruent to the viewer's sense of self (Sirgy, 1982). However, different self-views can affect responses to mass messages in different ways. Chang (2002) found that introverts and collectivists may respond more favorably to advertisements, in contrast to introverts and individualists (Chang, 2002). This past research exploring levels of felt involvement and self-congruency has provided a good understanding of how viewers approach mass messages in relationship to their self-concepts. However, what has been lacking in this research is a discussion regarding these issues and mass messages about disease. In the instance of this study, it may be assumed based on this research that the role of self-concept and involvement may be even more significant for disease patients viewing messages about their disease since they are so closely involved with the message topics.

### *Message Frames*

Secondly, message frames have been found to impact a person's perceptions of a mass communications message. Frames represent the context within which information is presented (Donovan & Jalleh, 1999). The topic of framing and health-related messages has received significant attention (Block & Keller, 1995), specifically as it relates to the use of positive or negative message frames. A positive frame might focus on something

to be gained, while a negative frame might emphasize loss. Martin and Marshall (1999) found that the persuasiveness of messages could be affected by the use of positive or negative message frames. While they conducted their experiment with cell phone consumers, positive or negative depictions may also play a role in the effectiveness of messages relating to more serious issues, such as disease. Positively versus negatively framed messages have been researched in relation to product attributes (Donovan & Jalleg, 1999), healthcare product advertising (Chang, 2007), and disease prevention behavior (Banks et al., 1995; Meyerowitz & Chaiken, 1987). However, research pertaining to the persuasive effects of positive and negative messages has returned varying results. For example, negative framing has been found to be somewhat more persuasive relating to mammography screening (Banks et al., 1995), breast self-examination (Meyerowitz & Chaiken, 1987), skin cancer detection (Rothman, Salovey, Antone, Keough, & Martin, 1993), and exercise (Robberson & Rogers, 1988). However, when considering parents' use of children's car-seat restraints and skin cancer prevention behavior (Rothman et al., 1993), positive message frames were found to be more persuasive. Other researchers have found that positive and negative message frames are equally as persuasive. For example, Meyerwitz and Chaiken (1987) found no framing effects for testicle self-examination. In some cases, combining a negative and positive frame into a single message may also be effective (Treiber, 1986; Wilson, Wallston, & King, 1990; Chang, 2007). Furthermore, Rothman and Salovey (1997) found that gain-framed messages are effective in disease prevention behaviors, while loss-framed messages are more effective for disease detection behaviors. Still, others have suggested that negative frames receive greater weight in the mind of the message receiver



(Kanouse, 1984). Some have suggested that the reason for this is because the greater salience of negative information contributes to more cognitive processing. In an effort to explain these contradictory findings, Maheswaran and Meyers-Levy (1990) suggested that the level of felt involvement, discussed previously, may play a role in framing effects. Again referencing the Elaboration Likelihood Model (Petty & Cacioppo, 1983), negative framing was found to be more effective under high-involvement conditions and positive framing was found to be more effective under low-involvement conditions (Maheswaran & Meyers-Levy, 1990). Other studies have suggested that even more factors may work in conjunction with message frames to affect persuasiveness (Homer & Yoon, 1992; Meyers-Levy & Maheswaran, 2004; Chang, 2007). Gender was found to be a significant factor for message framing with regard to intentions to perform skin cancer detection behavior (Rothman, Salovey, Antone, Keough, Martin, 1993). Negative frames were more effective for women, while positive frames were more effective for men. In another study, Braun, Gaeth, and Levin (1996) found that women were more likely to choose a positively-framed message, while males were not. While this existing research provides a starting point from which to understand how individuals may perceive health-related messages, the findings are clearly mixed. More importantly, research into how disease patients themselves perceive and experience these positively- or negatively-framed messages has yet to be considered.

### **Message Shortcomings in Accuracy and Understandability**

Third, pertinent literature suggests that mass messages about disease have shortcomings in accuracy and understanding.

### *Lack of Accuracy*

Research into media representations of illness have uncovered that mass messages about disease can be separated from the actual disease situation. Brown, Zavestoski, McCormick, Mandelbaum, and Luebke (2001) studied print media coverage of environmental causation of breast cancer and found significant differences between news coverage of the disease and the actual state of research on the disease. The media had given the most attention to possible dietary factors of breast cancer and avoided the possibility of environmental causation even though much scientific inquiry and social activism were occurring on the topic of environmental causation. The coverage was not found to be proportional to the actual situation in scientific and activist communities. Edwards, Grobmyer, and Walsh-Childers (2011) also studied coverage of breast cancer in consumer magazines and found that misleading information may be contributing to women's inaccurate perceptions of breast cancer risk. Women may over-estimate the role of genetics in breast cancer and misunderstand true genetic risk (Henderson & Kitzinger, 1999). Likewise, other disease messages do not always represent an accurate picture of the current scientific landscape. Instead, message content, despite possible consequences to the patient community, often remains consistent with the "disciplinary, financial, and power interests of the currently dominant medical concerns" (Clarke, 2006, p. 274). These communications can position the reader to interpret the subject in ways inconsistent with the actual condition of disease suffers or the actual status of the disease in the scientific community (Cheek, 1997).

For example, Ye and Ward's (2010) study analyzing episodes of *Grey's Anatomy* and *ER* revealed that injuries were portrayed with much more frequency than chronic

disease, despite the fact that chronic diseases account for more than 70% of deaths in the United States. Additionally, they found that viewers are likely to interpret the primetime network shows through an individual frame, while neglecting health issues as a matter of collective society. These misconceptions can transfer to the public's distorted understanding of viable health risks (Ackerson & Viswanath, 2010). In a study evaluating the public's perceptions of risk for Eastern Equine Encephalitis and cancer, Ackerson and Viswanath (2010) found that higher use of health media was related to higher odds of disproportionate risk perceptions. The two diseases received media attention that was not an accurate reflection of their public health risks. EEE, an uncommon disease that accounts for very few fatalities, received nearly as much coverage as cancer, which has exponentially greater health risk. However, accurate portrayals of health risks may be more effective in motivating individuals to take action that could reduce the health threat (Witte & Allen, 2000), and consistent communications of actual statistics are needed to cultivate those accurate representations (Schwartz, Woloshin, & Welsh, 1999). These studies of perceived risk reinforce that the media operate under a very separate set of values and prioritize the most important risks much differently than the scientific community (Kitzinger, 1999), leading to distinguishable differences between communication about disease and the actual disease situation.

In addition to overrepresentation, other previous research has shown that certain populations, diseases, and health issues can be underrepresented in media coverage, further contributing to inaccurate information. Jensen, Moriarty, Hurley, and Stryker (2010) found that male reproductive, lymphatic, and thyroid cancers were consistently underreported. Meanwhile, female reproductive cancer has remained "suspiciously absent

from news coverage” (Jensen et al., 2010, p. 148). Furthermore, media coverage focused on cancer treatment while neglecting the important issues of prevention, detection, and coping.

Communications about disease can also perpetuate misconceptions about patients living with that disease. When analyzing photographic content of cancer patients, Phillips, Della, and Sohn (2011) found that magazine images are younger, more female, and more white than actual risk statistics. Interestingly, the images also portrayed few actual signs of cancer treatment. Rather, “Most images feature healthier looking people, some actively engaged in construction work, bicycling, and yoga” (Phillips et al., 2011, p. 416). Disease patients can often identify these inaccurate portrayals and desire for their disease to be represented with realism. They feel inaccurate portrayals can influence the broader public and potentially how the public views them as patients (Zoller & Worrell, 2006). Zoller and Worrell (2006) further note that it is the responsibility of the communications outlet to ensure realistic depictions.

#### *Lack of Understandability*

In addition to accuracy, some communications about disease have been plagued by a lack of understandability. When investigating media messages about cancer screening and prevention, Mazor et al. (2010) discovered that participants could paraphrase the messages; however, they were apt to over generalize, misremember details, and express misunderstanding around specific concepts. An uneven quality of information has also pervaded some health communications, adding to difficulties in understandability. The Internet, despite its potential to be a helpful resource, contains varying qualities of health information (Freimuth, 1990; Street, 1990). Many researchers

have addressed the quality of Internet health content (Adams, 2003; Craigie, Loader, Burrows, & Muncer, 2002; Eysenbach, Powell, Kuss, & Sa, 2002). Misunderstandings of information, no matter the medium through which the information was communicated, can have negative implications, including establishing false causal relationships, discounting, and misconceptions about disease causation (Mazor et al., 2010)

While much of this research addresses the accuracy or inaccuracy of media representations of illness in quantitative terms, Zoller and Worrell (2006) noted that these approaches have inherent limitations:

These quantitative approaches are limited by the assumption that the reality of a depiction can be assessed straightforwardly, its glossing of the role of pleasure and entertainment in media, and its oversight of the role of the audience in interpreting and enacting media messages. (p. 70)

Since each viewer brings a unique perspective to the viewing experience, delving into the rich insights that reside with the patients themselves is necessary. While research into mass communications' influence on those with little knowledge or experience with a particular illness is interesting, investigating the attitudes and opinions of patients living with the depicted illness may lead to new and valuable understandings. This suggests the question this study strives to explore: How do people suffering with the ALS disease interpret and evaluate messages relating to their condition?

### **ALS-Specific Communication**

Finally, the literature suggests that communicating with ALS and other terminally-ill patients requires specialized strategies and sensitivity (Bachner & Carmel, 2009; Chio et al., 2008; Clayton et al., 2008; Parker et al., 2007). Patients suffering with terminal illnesses and their caregivers have a strong need for clear, timely information about every stage of the disease process (Parker et al., 2007). In fact, Lee and Hawkins

(2010) found that breast cancer patients purposely seek out health information on the Internet and in online support communities as a result of unmet needs for information and unmet needs for emotional support. The availability of accurate, timely, and reliable health information thus becomes very important for patients suffering with potentially deadly illnesses (Lee & Hawkins, 2010). Much of this relevant literature focuses on terminally-ill cancer patients and explains the difficulties in open communication, especially on topics of illness and death. In many cases, patients and caregivers avoid these uncomfortable topics (Bachner & Carmel, 2009; Zhang & Siminoff, 2003). ALS-specific literature about communication, on the other hand, is restricted to interpersonal communication. The topic has been explored as it relates to communication between caregivers and ALS patients or doctors and ALS patients at the time of diagnosis. Because of the specialized nature of the ALS disease, communicating with patients suffering with this illness, whether interpersonally or in mass communications, requires sensitivity. Since a large population of ALS patients and caregivers feel discouragement, communicating hope to this community can prove challenging (Chio et al., 2007). The negative nature of message content at the time of an ALS diagnosis causes patients to go to sources other than their physicians for information about ALS and ongoing ALS research (Chio et al., 2007). While this finding has important implications for healthcare professionals in diagnosis communication, it is equally important to understand more about this post-diagnosis communication that ALS patients intentionally seek out and to understand how this communication is interpreted by patients. That distinguishable gap in the research is exactly what this study strives to fill.

## Research Questions

Because studies examining patient attitudes toward mass messages are limited and studies examining ALS patient attitudes toward mass messages do not exist, research is needed to better understand the impact of these messages on the ALS patient population and the ways in which these messages may be improved. The following research develops a rich understanding of ALS patients' desires for their disease experience to be recognized and understood. By learning from these insights, communication practitioners can improve representations of the ALS disease and the frequency of those representations and thus improve ALS patients' quality of life. This study seeks to examine how ALS patients interpret and experience mass media and public relations messages about their condition and specifically to answer the following research questions.

- RQ1:           What is the initial reaction of ALS patients toward mass messages about their disease?
- RQ2:           What meaning do ALS patients find in mass messages about their disease?
- RQ3:           What concerns do ALS patients have about mass messages about their disease?

## CHAPTER 3:

### METHOD

This study employed six self-contained focus groups of people diagnosed with ALS in order to examine their experiences, attitudes, and opinions toward mass communications about their condition. Each focus group took place in the final hour of already-scheduled ALS support group meetings. The six most well-attended support groups in the state of Florida were selected as focus group locations: Tampa, Sarasota, Orlando, Jacksonville, Brevard, and Boynton Beach. The months of August through October were chosen for the focus groups as these months typically include higher support group attendance. Since many support group dates overlap and only one moderator was available to facilitate, it was necessary to conduct the focus groups in two separate rounds. The Sarasota, Tampa, and Orlando focus groups were conducted in September and October 2010, and the Jacksonville, Boynton Beach, and Brevard focus groups were conducted in August and September 2011. Patients were told the study was about “understanding how people living with ALS interpret and experience mass messages about their illness.”

The study received IRB oversight, and at each focus group, care was taken to adhere to IRB guidelines regarding voluntary participation. Patients were notified through email prior to the support group dates that focus group research would be taking place during a portion of their upcoming support group meeting. In this email



notification, patients were told that they were in no way obligated to participate in the study, and I provided an additional reminder that participation was voluntary on the actual day of the focus group. Participants were also given ample opportunity to leave prior to the start of the focus group portion of the support group meeting. In Orlando, three patients opted not to participate, and in Sarasota, three patients opted not to participate. In the remaining four locations, all attending patients voluntarily chose to participate. Each support group consisted of several friends and family members of ALS patients; however, only those living with ALS were asked to participate in the focus group. Furthermore, in each location, at least one regular support group attendee was absent due to health complications related to the disease. These considerations led to significantly smaller focus group sizes and should be noted as an apparent limitation of this study. The Sarasota and Orlando focus groups included three participants. The Tampa focus group included six participants. The Jacksonville focus group included seven participants. The Brevard focus group included five participants, and the Boynton Beach focus group included five participants. Despite the small size of each focus group, the discussions and themes that emerged in each group were consistent, and the similar, shared concerns across each group led to relevant conclusions regarding patient perception of these disease messages. In the first focus group, observing friends and caregivers began to contribute to the discussion despite instructions that only comments from patients were being evaluated. In subsequent focus groups, I asked that friends and caregivers be seated at the back of the room to discourage the interjection of their comments.

Participants ranged in age from 38 to 82. The six groups consisted of 14 white males, 14 white females, and one black female. The length of time since diagnosis ranged from two and a half months to 13 years. The lack of ethnic diversity represents another limitation of this study. Given the severe health implications imposed by the ALS disease and the difficulty of travel, it was not possible to recruit based on ethnicity.

After obtaining written consent, I conducted the focus groups using various printed and audiovisual communications from ALS charities (see appendices) as a means to evoke the patients' interpretations, experiences, and attitudes toward communications relating to their disease. Participants viewed and responded to a newsmagazine article produced by The ALS Association Florida Chapter (see appendix F), which I encountered by reviewing the local publication, and a newsmagazine article produced by The ALS Association national office (see appendix E), which I encountered during my time of employment with an ALS charity. Participants then viewed and responded to a print advertisement produced by The ALS Association Wisconsin Chapter (see appendix C) and a print advertisement produced by the ALS Society of Canada (see appendix A). I found both of these mass messages by searching for instances of ALS print advertising online. Finally, participants viewed and commented on a news story which I had seen on a local television station about a man suffering with ALS (see appendix D) and a television commercial produced by the ALS Society of Canada (appendix B) which had been discussed on several online ALS forums. Several of these communications could also be accessed on the Internet. Since this is an exploratory study, I chose a broad range of mass messages about ALS in order to evoke a wide range of response. Each message was chosen from a credible ALS charity, based on my personal experience with ALS

patients and prior understanding of the disease. Participants were handed copies of all printed collateral to read, and they reviewed the television news story and the television commercial on a projector screen. Following introductory questions (see appendix G), participants were given each message, one at a time, and asked to share their first responses, their thoughts and/or feelings, and the meanings they found in the message they had just viewed or read. I facilitated all six groups using broad, open-ended questioning and video recorded each focus group for the purpose of transcribing and better analyzing the comments and interaction of the groups. The environment of each focus group was very similar. Each took place in the meeting room of a health-related facility (nursing home, hospital, research center). Tables were arranged into a circular formation, and participants sat in chairs behind the tables or pulled their wheelchairs up to the tables. The circular formation where patients faced each other allowed for the facilitation of more natural discussion.

Following the focus groups, participant responses were analyzed using a constant comparative approach (Conrad, 1978). After transcribing and evaluating all of the responses, they were sorted initially according to common topics among the comments. As the focus groups research continued, I took the information from data collection and regularly compared it with emerging categories. The focus group research continued until no new themes were shared. Findings were then summarized to address the research questions at hand and to inform a strategic approach for mass communications to ALS patients and other victims of terminal illness.

The focus group method allowed for necessary group interaction among patients, producing valuable insights that would have been more difficult to access in an individual

interview setting (Morgan, 1997). These emerging insights allowed for exploration of this topic with richer insights and a greater depth of detail than quantitative methodologies. Furthermore, the timing and location of the focus groups (following local ALS support group meetings) allowed the research to take place among an existing homogenous community. These patients were accustomed to interacting monthly in their local support groups which provided naturalistic settings for the focus groups and enabled patients to interact in a relaxed, non-threatening familiar environment free of judgment (Casey & Krueger, 2000). The focus group method gave patients an opportunity to share and compare experiences, display observable interaction, and exhibit shared thoughts and feelings (Morgan, 1997). The travel challenges most ALS patients experience also made the focus group method preferable to others. Participating in the study required no additional travel, only the short drive required to attend a local support group meeting they, most likely, would have attended regardless of the study. Since the topic of mass communications and ALS has not been previously explored, the focus group method also allowed me to explore issues of concern that I may not have anticipated prior to the group but were brought up by patients during the discussion (Leslie, 2010).

## CHAPTER 4:

### FINDINGS

The findings of this study both confirm and add knowledge to the existing health communication literature. Despite broad, open-ended questioning, the conversations that emerged in all six focus groups were markedly similar, and each focus group revealed the same predominant themes. An overarching tone in many of the comments revealed that some participants experience emotional responses to a lack of public ALS awareness. According to participants, communications about ALS can serve as a frustrating reminder of this reality, and all six groups immediately gravitated to a discussion of the lack of awareness. Second, participants shared in the narrative of the messages they read or viewed and identified closely with the characters portrayed. Participants then experienced different emotional responses to this identification based on their individual disease perspectives. Third, participants expressed personal concern about the depictions of the ALS disease, displaying tension between a desire for realistic or positive disease portrayals, identifying some message inaccuracies, and communicating a need for more specific disease information. These three patterns pervaded the general discussion, which pivoted around improving the visibility of the ALS disease among the public.

#### **Lack of Public ALS Awareness - “Nobody Knows”**

When asked how they believe ALS is generally portrayed in mass communications, participants in all six focus groups responded with very similar

comments. For example, the following responses represent one comment from each of the six focus groups, and although these patients did not interact with each other, their responses are markedly similar.

Patient 1: I think it's generally not presented.

Patient 4: Actually, it's not. ... Say 'ALS,' nobody knows.

Patient 10: I don't see anything – any information – that appeals to the masses and gives them information to know about the disease. I see nothing like that.

Patient 18: I don't think that I've seen any information about ALS at all until I acquired the disease. ... I don't think there was anything out there.

Patient 24: I haven't seen anything. I've seen nothing.

Patient 26: I've seen nothing except what's online.

Similar observations pervaded the remainder of the focus group as participants viewed and commented on various mass communications relating to ALS, such as advertisements, public relations messages, and a news story. Some groups even tended to begin brainstorming about other advertising or public relations efforts that would get the word out about ALS. Likewise, participants tended to believe that the most important mass communications were the ones that furthered ALS awareness. After reading a story about an ALS patient's public speech during the NCAA Final Four, one participant stated, "My first impression was that it was kind of emotional. But when they started talking about how the news media covered it and how well it was covered, well, I thought that probably was worthwhile." However, some participants believed that people need to be impacted by ALS before they will pay attention to the disease problem or take action.

The communications they viewed reminded participants that they want to be heard and want their suffering to be understood. Participants commented on the prevalence of those suffering with ALS in the general population and believed this disadvantage requires more diligent efforts to build awareness of the disease, regardless of the fact that it impacts a comparably small number of people. As one participant stated, “The group is that small that it doesn’t get the attention it basically should deserve.” Another explained, “ALS is just a little piece of sand swirling around in the surf. There are too many other people out there.” Still another noted that other fatal diseases with the same number of patients receive more notoriety. Reinforcing a desire to be heard and understood, the same patient read a newsletter message from the president/CEO of The ALS Association (national office) and wanted the message to focus more on the patient community instead of the organization. “How we’ve changed... how it’s affected us. More about us! Because if not for us, then guess what, she doesn’t have this job,” he said. These emotional responses to the messages became typical of each focus group, and the participants’ desires to be recognized underpinned much of the discussion. Through tears, a female participant articulated, “The other people have to be told about ALS. The other people out there are living their lives fat, dumb, and happy, and they never know when it’s gonna strike around them.”

Furthermore, several participants wanted mass communications to “push the barriers.” After viewing a graphic advertisement picturing a son tying his father’s shoes (see Appendix B), one patient noted, “I’ve almost come to believe even more in this society we live in that the more shocking and in-your-face, the more attention it’s gonna get.” Another said that he wanted mass communication about ALS to be more

“dramatic.” When I probed further, he similarly revealed a desire for public awareness: “People would be more sympathetic and donate a little more money, or otherwise they would understand what the disease is and say, ‘Why can’t we find a cure?’”

Members of each focus group agreed that the messages they were viewing were not aired or published frequently enough. They felt that repetition of the messages they were viewing would impact public awareness about ALS. Without repetition, participants felt the messages would be ineffective, as “no one will remember the next morning.” Participants also felt that repeated mass communication about ALS would ultimately have an impact on them each personally. One participant explained:

The more the media keeps it in the public’s face, the more they hear it, the more they might understand it. So at least when you say you have ALS they’ll go ‘oh.’ Instead of ‘what’s that?’ ... The more information that’s out there helps us all, and we won’t have to keep explaining what we have. – Patient 15

Furthermore, participants articulated a desire for a public figure to act as an advocate to increase the visibility of ALS among the public. One exchange, for example, went like this:

Patient 12: If there were more figures who were high profile... people who could...

Patient 8: Be spokespersons or speak about it publicly.

Patient 9: Yeah. Advocate in some way. Just acknowledge it.

Patient 7: Like Michael J. Fox.

Patient 9: Yeah, like Parkinson’s.

Patient 8: Yeah, like Parkinson’s.

Patient 11: We have Angela Lansbury.



Patient 8: Yeah, what a great spokesperson. [sarcastically] We never saw anything she did.

Participants felt a public figure would have the ability to speak on behalf of each of them personally and give a voice to the ALS community. One participant summed it up: “What we’re hoping for... not hoping for, pray it doesn’t happen... that some big movie star or somebody like Bill Gates gets ALS... and will pour all this funding into it to find a cure.”

In critiquing the public for not paying enough attention to the ALS disease, the participants commented on the competition among diseases and charities. They expressed a desire for ALS to rise to the notoriety of diseases such as breast cancer and heart disease. One focus group member noted: “Look at all of the walks and all of the fundraising things. And I realize that there’s a hell of a lot more breast cancer out there than there ever thought of being Lou Gehrig’s disease, but still.” Varying disease names (ALS, Motor Neuron Disease, Lou Gehrig’s Disease) were believed to handicap the ALS disease in the competitive arena and aid in the awareness problem. A print advertisement that referred to the illness as Lou Gehrig’s Disease evoked the following discussion:

Patient 24: Look at the age groups. How many people know Lou Gehrig? He was out of there in the 40s.

Patient 21: Young people don’t know who Lou Gehrig is.

Patient 24: Exactly. No meaning.

Despite the familiarity of Lou Gehrig as a public figure, focus group members believed consistency in references to the disease name would aid them in their plight to establish better disease recognition among members of the general public. Discussions of disease competition led to discouragement among participants and provided further evidence that

these mass messages about ALS reminded them of a perceived need for increased ALS awareness.

Finally, all of the focus groups discussed shared frustration about a lack of ALS knowledge among healthcare professionals and a lack of ALS focus in the scientific community. The messages prompted many focus group members to share their diagnosis story in which neurologists “had no knowledge of it.” Stories of healthcare professionals who “know nothing” or “didn’t have a clue” about how to treat an ALS patient also abounded. After a comment encouraging efforts for educating high school students about ALS, one participant exclaimed, “Heck! We need to do it in the medical school.” Interestingly, at some point, the messages also prompted all of the groups to discuss a lack of progress since ALS was discovered. When commenting on a newsletter article, focus group members in Jacksonville exchanged the following comments.

Patient 13: Disappointing. To think that it’s gone over 25 years, and they have no idea what causes it or how to cure it. I think that’s a little bit frustrating, because I don’t know many other diseases that have been like that.

Patient 15: Well actually, it [article] said it has been 25 years that The ALS Association has been involved. The disease was first written about 150 years ago, which makes it 10 times worse.

Another participant stated, “The only medication they have for it is riluzole [an expensive drug that has shown little result in increasing life span].” Communications that reminded patients of this reality perplexed some, saddened others, and in one focus group, aroused anger.

That pisses me off! Seventy years of research supposedly. Why does it affect us all differently? That's what I wanna know... why? Why can I still talk, and she can't. And how is it that she can still write, but I can barely hold a pen. Give me answers to that! – Patient 9

Indeed, discussions from these particular focus groups show that mass communication about ALS reminds participants of the need for increased public ALS awareness and became the source of various negative feelings and responses.

### **Shared Narrative and Identification with Character – “There I Am”**

In every case, participants identified at some level with the characters who were portrayed in the messages they viewed, and in some sense, they saw mirror images of their lives. One participant sat next to his nine-year-old son during the focus group while the participant commented on the advertisement with an image of a young boy tying his father's shoe. “I feel sorry for the child. [Turns to his son] That's you and I,” he said. When asked how the same ad made them feel, another patient from a different focus group said, “There I am.” Others imagined what they would do if they were the main character. One participant imagined himself replacing the main character in the story of the ALS patient who gave the inspirational public speech right before a Final Four basketball game: “I can see myself doing something like this for my son's basketball team, his football team... speaking to them.” The main character in the story had encouraged others to “live in the moment.” A female participant who had lost her ability to speak, typed the following contrasting comments into her speech device.

I keep getting weaker. Now I can't walk. I don't expect to be like [patient name] or [patient name]. I don't expect to live more than a year. ... I can't live in the moment because I can't speak and paper towels in my mouth [to prevent excessive salivation, a disease side effect] make people look at me like I'm crazy.  
– Patient 21

After watching a television spot in which a recently diagnosed ALS patient begins hugging everyone he encounters, another participant commented using a computerized voice device, “Anyone if we knew this was coming would probably do things differently... and find that we hug and dance more. Although, I have done a lot of both.” Yet another said, “The hugging is good. I guess I wish there would have been somebody to hug the first time I fell.” Another participant identified very closely with the character in the television spot:

Well, it was just a heart wrencher for me, because I just had to get rid of my horse, and what they were showing right there was someone trying to hold on to the horse because they couldn't deal with the horse any other way other than to hold on to it and take him wherever. I can't even brush my horse anymore because I don't have the balance. I just fall right over. – Patient 26

Some shared personal stories similar to what they had read or viewed, recounting how they continue to live life to the fullest in spite of ALS. In each case, the communications allowed opportunity for participants to relate to the characters on a very personal level.

These narratives evoked emotional responses ranging from depression to fear to anger to inspiration based on the patient's individual context and view of the disease. Some participants responded by saying the treatment messages were “depressing,” “sad,” and made them feel “helpless,” despite the fact that the messages did “get the point across.” One participant described what he had seen by saying: “no hope... just as it states right there... it all ends with death. That's what they said. It's a hundred percent that everybody's gonna die.” Another participant began crying after reflecting on her own negative attitude about her life with the disease and through tears, she said:

Him [points to another participant]. He should be one of the standards for talking to people when you have ALS. (...) Anyone can see he's got it rough and he's not bitchin' about it, and he's happy. I'd never interview me. Not in a million years.  
– Patient 26

Tears filled another focus group after watching a news story about a young man with ALS. The communication made one woman think about “People with young children. I have a 5 year old and 7 year old [takes a deep breath].” Before she could finish another participant chimed in, “It overwhelmed me [cries].” A third participant left her seat to hug the crying patient.

Other participants tried to guard against feelings of depression, and some found inspiration when identifying with the characters in the messages. They were reminded that “there’s always hope,” that “somebody does care,” to “live for today,” to continue “fighting,” and to “do what you do while you can still do it.” After reading the same story of the patient who gave a motivational speech before the Final Four basketball game, one female patient said, “Regardless of what obstacle we are facing, we just have to do like he [character in story] said – resolve to survive and just keep moving.” Another participant echoed, “I have to have the attitude – live for today. I’m not afraid to die. That’s all I can say.” Participants were encouraged by reading about patients who had lived longer than normal with the disease, and they were motivated to make their life story similar to the inspirational communications they had viewed.

Still, other participants were met with feelings of fear or anger as a result of viewing the messages. Reflecting on one of the messages she had just viewed, one participant shared emotionally, “I’d rather have breast cancer... in both breasts. I’d rather have them tell me I’m terminal than to go through this.” Another participant responded angrily to the news story she had seen, “My feeling is... it’s bullshit. Would anyone have listened? The media moves on.” Fear of the unknown was also a common response: “I

guess it's always scary when you start looking at DVDs and see what can happen. So you kind of put it to the back of your mind and say, 'I don't want to know.'"

Regardless of the specific feelings these narratives evoked, participants in each group acknowledged that many of the messages were just a taste of reality. "There's not a cheery way to tell people about ALS. There's just not," one patient said. Another summed it up by saying "It's hard to hear, but it's true – you will never get any better than you are today." The disparity between participants who desire these realistic messages and those who desire more hopeful messages are explained in the following section. This character identification and shared narrative that participants experienced prompted the group to initiate intimate discussions about their disease experience and about their personal identities.

### **Disease Depiction Observations – “A Huge Disservice to Us”**

The final theme that emerged in all six focus groups is a concern with disease depictions. This includes a tension between positive and realistic portrayals, the identification of message inaccuracies, and a desire for more specific information.

#### *Tension: Positive vs. Realistic Portrayals*

Participants differed in their views about the need for positive portrayals of ALS as opposed to the portrayal of realistic information. This pivotal discussion centered around whether the public should be shocked with reality or if a sense of hope should be portrayed. Throughout each focus group, the opinions of participants on both sides of the spectrum emerged. The dichotomy that arose between the two perspectives is evidenced in the following exchange.

Patient 23: There is a person that had ALS and wanted to take his boat on the intercoastal, and he did this alone. ... I haven't read the book yet, but I intend to get it to read his story. ... The main thing ... is to give them some hope because we are all different in the progression. It could speed up or slow down. And to keep that hope going is what is helpful to anyone.

Patient 21: He died three months later.

Patient 23: You read the book. [group laughs]

Those who desired positive portrayals wanted mass communications about ALS to concentrate on "his abilities rather than what he lost," to portray people that are "continuing to live a productive life," or to focus on the support that is available to people living with ALS. One participant wanted to be reminded that, "It's not a death sentence today. You can still live. You can still enjoy your life." They found some of the messages they viewed to be "too dark," and one commented, "I don't like those kind of negative representations."

On the other hand, many participants possessed the opposite opinion. They desired to see realistic portrayals of ALS and identified some of the communications they had viewed as being too hopeful. Participants found the basic tenants of many of the messages to be true, for example that the disease is terminal, neurological, and devastating. However, participants in each group were somewhat skeptical of any message that communicated that a cure could be close or that awareness was increasing. They felt these messages did not communicate the reality of their disease situations and described such messages as "political fluff," "overly optimistic," organizational

“propaganda,” or “selling” hope. Two more participants made the following comments after reading a newsletter article:

Patient B: For me a bit... I would say too hopeful. ... At this very moment they don't even know where it comes from. .... They are talking you can put it in the history books. I think for me is a little bit over done.

Patient I: It's all about hope and with advances in science and technology. ... This tells me that in 25 years, The ALS Association has accomplished nothing.

Many participants felt that realistic portrayals would “demand attention” and have more depth and meaning in the ALS patient community. After viewing a print advertisement, one focus group member stated, “That’s what I like. Brutal honesty. ... Be honest about this stuff. I hate when it’s glossed over.” While these participants could appreciate the portrayal of realistic facts, discussion emerged about how the general public would perceive that type of message. The participants’ positions in the dichotomy between realistic portrayals and positive portrayals depended largely on their frame of reference, personal disease experience, and the length of time since their diagnosis. In many instances, participants linked their personal opinion to the severity of their own illness or their individual disease perspective. In many cases, participants who had been recently diagnosed with the disease were less likely to respond positively to realistic depictions. Rather, they favored more hopeful depictions. Participants who had been living with the disease longer, however, tended to react positively to more realistic depictions of the disease, and they described positive depictions as “too hopeful.” This



divergence between positive and negative disease portrayals prohibited the characterization of a typical response and evidences the personal nature of the ALS disease and the need for audience segmentation in mass communication.

#### *Identification of Message Inaccuracies*

Participants believed that inaccuracies existed in many of the messages they viewed. For example, one participant said that “specific discomforts are seldom made clear to the public.” Another stated that “they don’t portray the use of communication devices” such as are typical among ALS patients who have lost the ability to communicate. Just like the themes that evidenced a lack of awareness and shared narrative with message characters, these message inaccuracies evoked emotional responses and in many cases frustration. One patient became frustrated after reading an article about a patient who had lived 10 years with ALS, since the average life span is only two to five years. She said, “That kind of writing does a huge disservice to us because my friends will say. ‘Wow. He lived 10 years. You can be Stephen Hawking.’ No, you have to look at the mean.” They identified that some of the communications failed to represent several significant elements of the disease. For example, one participant commented, “He didn’t have any braces. He didn’t have a wheelchair. He didn’t have a walker. There was nothing that showed. Yes, he looked a little disabled, but nothing to compare with what ALS really does.” However, because of varying disease effects, there is no straightforward reality against which accuracy can be compared. These comments illustrate the personal comparative way in which many ALS patients evaluate accuracy and their increased level of insight into the realism of the depictions as opposed to someone who has no experience with the disease.

### *Desire for Specific Information*

Furthermore, participants communicated a desire to see more specific information in mass communications about ALS. In this sense, they wanted the messages to be educational in nature. Some participants expressed negative attitudes toward messages that included metaphoric portrayals, and instead wanted explicit educational information about ALS. The information of primary concern for many participants included research developments and the disease's effect on patients throughout each disease stage. Participants also wanted messages to communicate that "the mind stays healthy even if the limbs cannot work," that ALS currently has no cure, and that ALS can strike people of any age. Participants wanted the messages to be more in-depth. One said, "It sort of gives you a knowledge of the disease, but it doesn't really come out bluntly and say there is no cure yet." Another expressed, "It did not explain the disease. It said that he had it, but it did not give any details." Some participants even noted that mass communications should educate people about the specific equipment required to live with ALS like electronic speech devices and breathing machines, as well as the extensive amount of support from family and friends that is required to care for an ALS patient. One woman reflected on the movie *The Pride of the Yankees* and its failure to go into enough detail about the long-term impact of the disease. Participants expressed a desire to see details communicated that would allow the public to recognize the drastic effects of the disease. In many cases, these comments about their desire for more specific information directly linked to their desire to be heard and understood.

Overall, across all six groups, transcripts show that 1) mass messages about ALS remind participants of their desire for increased public ALS awareness, 2) participants

identify with the narratives in the messages, and 3) participants express concerns about disease depictions. These findings led me to question further the reasoning and perspectives that may have influenced the responses.

## CHAPTER 5: DISCUSSION

Examining responses to mass messages about ALS provides practical insight into how ALS patients experience mass messages about their illness and evaluate illness depictions. Some issues that emerged in the research are highlighted in this section, including participant concern for awareness, participant responses as related to personal disease experience, participant responses from multiple viewer perspectives, participant anger with the disease itself, as well as character identification and message framing. Suggested guidelines for communication practitioners, limitations of the study, as well as implications and avenues for further study are also discussed.

### **Emerging Issues**

#### *Participant Concern for Awareness*

The majority of responses revolved around the central concerns of ALS awareness and a desire to be heard. Throughout the study, this became a recurring “ALS response,” consistent among every member of every group. Participants repeatedly returned to the topic of a need for public awareness. Participants’ comments suggest that they are a public that may be vying for a voice. Comments underscore a desire to be heard and for the public to sympathize with their plight. Interestingly, at the beginning of each focus group, participants commented that they “don’t see anything... any information that appeals to the masses” and “don’t believe it’s portrayed to the masses at

all.” Yet later in the focus group, many participants referenced instances of messages that they had seen or read. When referring to news coverage of an ALS patient, one patient even noted, “I remember. I’m a basketball fan. I watched the game and saw it.” This contradiction in their comments reveals an instance of aided recall, but also suggests that the messages they have encountered in the past have not been sufficient to satisfy an apparent need to be heard and understood.

#### *Participant Responses as Related to Personal Disease Experience*

Confirming literature regarding issues of felt involvement, participants’ responses to messages were linked to their own personal illness experiences and perspectives. This helps to explain why some participants felt inspired after identifying with a certain narrative and others felt depressed, fearful, or angry. Participant evaluations of these messages were closely tied to their own self-concept (Markus, 1999) This relationship between self-concept and message evaluations may also explain the obvious dichotomy between a desire for realistic disease depictions and more hopeful disease depictions. These instances gave the participants an opportunity to discuss their experiences, personal life perspectives, and senses of self. The differing responses further confirm Charmaz’s (1999) arguments that ill people interpret their illnesses in a multitude of ways. Patient evaluation of messages cannot be understood outside of their self-concept which is in many ways tied to their personal illness experience, including current symptoms and challenges and the length of time they have suffered with the disease. One patient echoed this idea: “I’ve had ALS a lot longer than you. I admire you guys with short-term diagnoses for even being here. I couldn’t have come here after first finding out about it.” Furthermore, differing responses confirm findings that mass communications

can evoke differing emotions and further emphasize the role of emotions in consumer processing. These emotional responses then have a significant impact on the persuasion process and the effectiveness of the mass communication message (Edell & Burke, 1989). Because the evaluation of each message was tied to an individual's self-concept and disease experience, the discussions that emerged were emotional, intimate, and poignant.

#### *Participant Responses from Multiple Viewer Perspectives*

Participants responded to the messages from multiple viewer perspectives. Participants responded in terms of their own identities as patients, but also with concern for broader public understanding. Because of the expressed need for greater public understanding of ALS, participants often tried to comment from the perspective of the uninformed public. This underscores the fact that participants believe that problematic or inaccurate portrayals of the disease may influence how others think of them. To repeat the comments calling attention to the inaccuracies in one message, one patient said, "That kind of writing does a huge disservice to us because my friends will say. 'Wow. He lived 10 years. You can be Stephen Hawking.' No, you have to look at the mean." In this sense, patients believe that mass communications has the potential to make their disease experience more difficult by influencing their personal interactions. Furthermore, patients believe that mass communications could have the potential to make their illness experience easier. As one patient noted:

The more the media keeps it in the public's face, the more they hear it, the more they might understand it. So at least when you say you have ALS they'll go 'oh.' Instead of 'what's that?' ... The more information that's out there helps us all, and we won't have to keep explaining what we have. – Patient 15

Participants were aware that they are subject not just to their own responses to a mass communication message, but also to the general public's response to that same message.

#### *Participant Anger with the Disease Itself*

Participants' feelings of frustration appear to be driven, understandably, by anger with the disease itself. The messages participants viewed seem to have served as frustrating reminders of the participants' prognosis and ultimately their mortality.

Participants sometimes appeared to be blaming the organizations, such as The ALS Association, for not doing more or society as a whole for not paying enough attention.

One participant seemed to acknowledge this when he commented, "I think we're kind of railing against the disease, and we should be evaluating these advertisements." However, participants' anger may be validated when considered in context of the ALS disease.

Mass messages about the disease, then, simply serve as frustrating reminders about their disease challenges and shortened lifespan. This emotion of frustration further

underscores the importance of feelings in understanding the effects of mass communication (Edell & Burke, 1987). This feeling which was evoked by the mass messages then served as an important factor in the participants' attitudes toward the messages.

#### *Character Identification and Message Framing*

Finally, this study both adds to and confirms existing literature regarding message framing and identification with characters in mass communication messages.

First, this study adds to the research discussion concluding that level of felt involvement and self-congruency impact evaluations of mass communication messages.

Having first-hand experience with the disease, all participants had a high motivation to process these messages through central routes. According to the Elaboration Likelihood Model, their level of felt involvement gave the participants an increased motivation to process the messages since the messages related to the disease they were living with and were highly relevant to their situations. Previous research explains that self-congruency is a less important cue when evaluating messages that are high-involvement, but rather that individuals rely on self-congruency when processing messages through peripheral routes. This study provides an intriguing contradiction in the case of ALS patients. The strong theme of character identification that emerged in the focus groups suggests that participants may have relied heavily on self-congruency as a cue to evaluate the messages, regardless of the fact that they were processing the high-involvement messages through central routes. ALS patients who participated in the focus groups, having first-hand experience with the disease, already had high levels of felt involvement in the mass communication messages they viewed, and the identification they experienced with the message characters through apparent self-congruency only strengthened that sense of involvement. When the patients were confronted with a mass message, they turned to their existing knowledge and concept of self in order to process the message. In the case of disease patients, this reliance on self-congruency as a processing cue for high-involvement messages provides an apparent point of contention with existing research and warrants further study.

Furthermore, the importance of self-congruent messages to positive message evaluations may further explain patient frustration with message inaccuracies. To restate one participant's concern: "He didn't have any braces. He didn't have a wheelchair. He



didn't have a walker. There was nothing that showed. Yes, he looked a little disabled, but nothing to compare with what ALS really does." It may be assumed that this participant saw the depiction of the ALS patient on the news story she had just viewed to be incongruent with her concept of self and personal disease experience. This incongruence then contributed to her negative evaluation of the advertisement. A positive response to this message would have been more likely had the portrayal been consistent with the way this participant viewed herself.

Second, this study highlights some important implications of the use of positive and negative message frames. In this study, the message frame played a significant role in the focus group participants' responses to the messages they viewed, as evidenced by the strong tension between positive and realistic disease portrayals that emerged in each group. While this subject has been researched in relation to disease detection or prevention behaviors, patient perceptions of positive and negative message frames relating to their disease had not been considered. The tension that emerged between the patients' preferences for positive or negative message frames reveals that, in the case of disease patients, the solution is not clear cut, but rather complicated. As mentioned earlier, the Elaboration Likelihood Model posits felt involvement to be one of those important factors that influence the likelihood of an individual to process a communication, and thus the communication can become more persuasive (Petty & Cacioppo, 1986). While Maheswaran & Meyers-Levey (1990) suggest that negative framing is more effective under high-involvement conditions and positive framing is more effective under low-involvement conditions, this study suggests yet another factor may be at play when determining the effectiveness of positively- or negatively-framed

messages – personal disease experience. The participants’ message frame preference was driven understandably by their personal disease experience. All ALS patients were highly-involved in processing these messages, yet their responses to the frames still varied greatly according to their self-concept, length of time since diagnosis, current disease challenges, etc. Researchers may now turn their attention to this potential factor of personal disease experience as a possible influencing agent in the effectiveness of positive and negative message frames. This also represents a potential avenue for future communication research relating to the ALS disease.

Furthermore, the ALS disease presents a unique challenge when investigating message frames. While previous research has focused on the framing of health prevention or disease detection behaviors, it is important to note that ALS cannot be prevented and early detection is of no merit to an ALS patient, since no treatment currently exists. The emphasis of these results then center around how ALS patients perceive and are affected by positive or negative message frames, not necessarily their intention to act.

### **Suggested Guidelines**

Guidelines and suggestions derived from the findings of this study can serve as a starting point to enhance mass communications about ALS. While these findings are qualitative in nature and cannot be generalized to a larger population, the insights of these focus group members do suggest potential avenues and opportunities to enhance communication. Based on the feedback of these focus group participants, communication practitioners may consider the following.

### *Segment Audience and Tailor Message Accordingly*

The strong role of personal ALS experience in audience interpretation suggests that communication professionals should make a strong effort to segment the audience and tailor messages accordingly. Factors such as length of time since diagnosis and current disease challenges should impact the ways in which practitioners communicate, and segmenting audiences according to these factors may yield more positive results. This suggestion also translates to mass communications for non-patients, as a person with no prior connection to ALS would have less sensitivity toward the disease and may be more prone to accept positively a harsh, realistic depiction; however, this would need to be validated by further study.

### *Provide Disease Details*

Providing as many details as possible may help to clarify disease representations. While many communications may be limited in their length, providing as much disease detail as possible within the allotted time may have the potential to enhance the patient's attitude toward the message. When communicating with the general public, consider providing details about the disease's typical progression and prognosis, even though some patients may serve as exceptions to the norm. Information about research developments and the extensive amount of care required by an ALS patient are also recommended additions.

### *Create ALS Depictions that are Congruent with Patients' Senses of Self*

Since self-congruency plays a role in positive message evaluations, it is important that communications practitioners strive to depict ALS in a way that is not only accurate, but also consistent with the way in which most ALS patients view themselves. This can

prove to be a difficult task since the ALS disease does not manifest itself in the same way from person to person. The progression of the disease can often be different between individuals. However, in instances of mass communication, the most common manifestation of the ALS disease should be depicted. Depictions that achieve self-congruency with the most amount of patients will contribute to more positive attitudes toward the message.

#### *Use Consistent Disease Terminology*

Consider using ALS as a consistent primary term to reference the disease. Fluctuation between different disease terms (i.e. ALS, Motor Neuron Disease, and Lou Gehrig's Disease) may complicate efforts to promote disease awareness. If communication practitioners can establish a common nomenclature, awareness efforts can be maximized.

#### *Communicate to Increase ALS Awareness*

Communicating with the explicit goal to increase ALS awareness is valued among patients. Repetition of these types of pointed messages should be considered, as well as the use of a popular spokesperson. Furthermore, communication professionals may consider a campaign to increase knowledge of ALS among healthcare professionals. Positive patient attitudes toward communications for ALS awareness could have the potential to transfer to the organization that created the communication. This explicit concern expressed by members of the key public should also become a primary concern for communication professionals looking to enhance organizational relationships with this key public.

## **Implications and Future Research**

The grounded approach of this research uncovered several key responses of ALS patients toward mass messages relating to their illness. This study contributes to our understanding of how audiences, specifically those suffering with terminal illnesses, interpret mass messages. As Kline (2003) noted, “It is crucial to understand how values, beliefs, and norms associated with health, illness, and medicine are affected by interaction with mass-mediated messages” (p. 558). Since ALS is not well-understood by the public, mass messages about ALS may be very important to social learning about the disease. ALS patients and advocacy groups will publicly praise instances of mass communication about ALS in an effort to raise awareness; however, it is important to understand how patients interact with and experience these messages in their daily lives. By understanding the reactions of disease patients toward mass communication depictions of their illness, this study adds to audience reception literature. Furthermore, by understanding ALS patients’ desires to be heard and understood by the public, this study provides practical insight from which communication practitioners can improve ALS communications and thus improve the quality of life of an ALS patient. This research suggests that if mass communications are to depict ALS, communication practitioners have some responsibility to depict the disease in an accurate way on an ongoing basis in these messages. The rich insights provided by ALS patients in this study are crucial to that effort. This study provides us with important knowledge regarding the future development of health communication messages, underscoring the importance of discussing disease depictions with a diverse group of people living with the disease.

Further, participants' primary concern to increase ALS awareness represents a practical insight for communications practitioners looking to enhance the image of their organization. Since patients represent a key public for any ALS organization, patients' desires regarding awareness should become a key strategic goal for these organizations. According to Grunig (1992), making awareness a key objective as a result of the findings of this study should allow for the building of mutually beneficial, two-way symmetrical relationships with this key public. This relationship building can ultimately benefit the overall image of an organization. As a result of this study, communication practitioners can identify the importance of ALS awareness to their key public of ALS patients, and prioritize accordingly in order to enhance the organization's relationship with this strategic public and ultimately elevate the organization's image. Furthermore, when considering an organization's responsibility to portray accurate depictions of ALS, patients possess significant relevant insight as evidenced by this study. Their responses provide evidence for the importance of communicating accurately. The results of this study reveal that ALS patients believe that problematic portrayals of the disease can influence how other people view them, and communications practitioners should address their concerns about the accuracy of ALS disease depictions in mass communications.

Furthermore, this study presents two intriguing contradictions regarding research into felt involvement and message framing research in health communication. This study has revealed that, in high-involving messages, self-congruency may be a more important factor than researchers originally thought. Specifically, disease messages may provide a completely different venue for the exploration of the role of self-congruency. Disease patients may rely more on self-congruency as a cue for processing disease messages than

other individuals. This study has also introduced personal disease experience as another potential factor that may influence one's preference toward positive or negative message frames. One's personal disease experience seems to play a significant role in their preference toward positive or negative disease portrayals. These points of apparent contention with previous research provide interesting avenues for future research and future theory development.

This exploratory study examined participant responses to messages that were intended for both an ALS-connected public and others that were intended for the general public. For further study, researchers may consider establishing a distinction between patient responses to messages written specifically for the patient and messages intended for the general public that patients might encounter.

Finally, the strong tension that emerged between positive and realistic message portrayals should be explored further. This can be researched separately in reference to ALS patients and the general public as an audience, depending on the researcher's interest. The effectiveness of each frame should be explored as well as the factors that influence the frame's effect on an individual. Because of the exploratory nature of this study, several interesting avenues of research in varying research disciplines have presented themselves and warrant further study.

### **Limitations**

The findings of this study must be interpreted within its limitations. This study possessed a few identifiable shortcomings, including my strong personal ties to the ALS disease. I am a researcher who has been intimately involved in working with ALS patients, which may introduce an issue of bias. However, this personal connection also

served as a strength of the study as it has enabled me to identify, interpret, and contextualize discussion issues and emergent themes. To note an additional shortcoming mentioned previously, in one focus group, caregivers interjected comments, despite a request for participation from patients only. While the caregivers voiced the same concerns as the patient participants, the presence of the caregivers in this focus group may have impacted the discussion. In subsequent focus groups, I positioned the proximity of the caregivers further away in the room so that they would be less tempted to weigh in on discussions. Furthermore, the small size of each focus group and the lack of ethnic diversity limited the study. Additional participants in each focus group could have added to the discussion by introducing more themes or confirming existing themes. While the conversations that emerged in each focus group were consistent despite the small size, larger focus group sizes would have significantly strengthened the reliability of subsequent results. ALS patients of different ethnicities could have also added potentially varying perspectives to the focus group discussion and provided for a point of comparison of perspectives between races. Future studies regarding mass communications and the ALS disease could include comments from the ALS-connected public (friends and caregivers) in order to increase focus group size and the significance of the results.

## **Conclusion**

In the present study, ALS patients who participated in six focus groups were critical of mass messages about their illness. The meanings that emerge from this analysis reveal the participants' primary desire for increased ALS awareness – a desire that was often driven by frustration with charitable ALS organizations, society as a whole, or the



disease itself. I also argue that participants identified closely with the characters in the treatment messages and responded with different emotions, including inspiration, depression, fear, and anger, based on their life contexts and disease experiences. Furthermore, discussions demonstrated participants criticizing disease depictions for being too positive, too realistic, inaccurate, or not specific enough.

The study leaves us with new knowledge about disease communication that is relevant and poignant, suggesting that insights lie not only in the mass messages or media representations themselves, but the most relevant perceptions may exist in the disease's public. The underlying opinions of that public provide valuable perspectives for communicating with these niche groups and with the general public. In the case of ALS patients, these comments can give researchers and communication professionals useful insight into the participants' fundamental inclination to increase ALS awareness and a starting point from which to improve communication efforts.

The findings that emerged from this study can serve as a valuable tool for the development of message strategies when communicating with ALS patients or others suffering with illness. Identifying issues of key importance to these patients and understanding how they experience meaning in messages about their illness have provided useful guidelines that communications practitioners can use when forming mass communications for this sensitive public.

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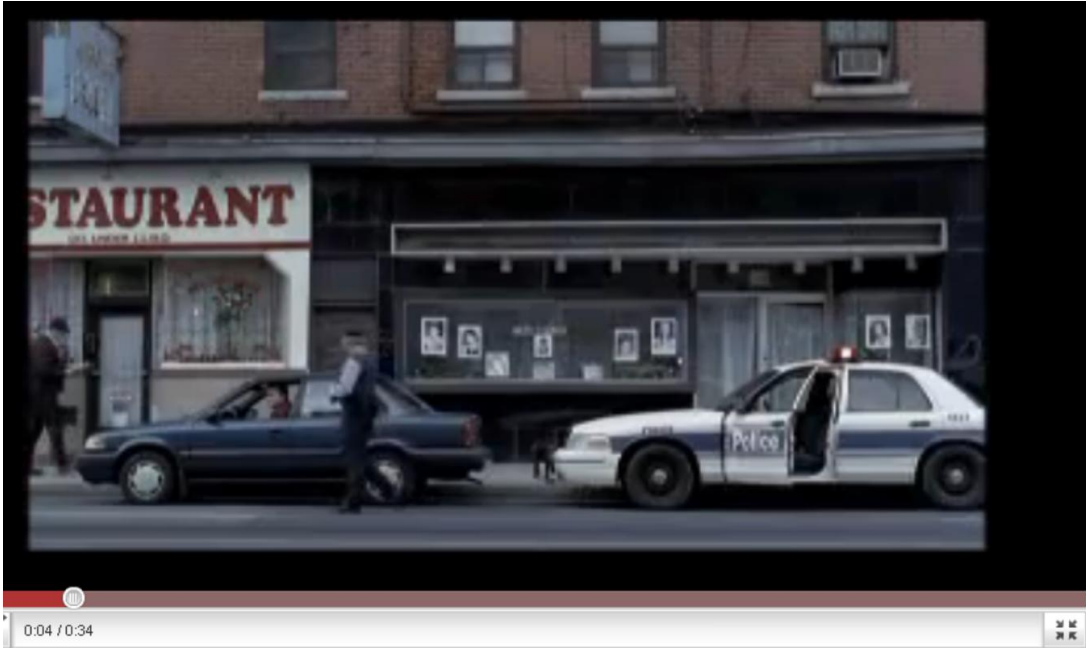
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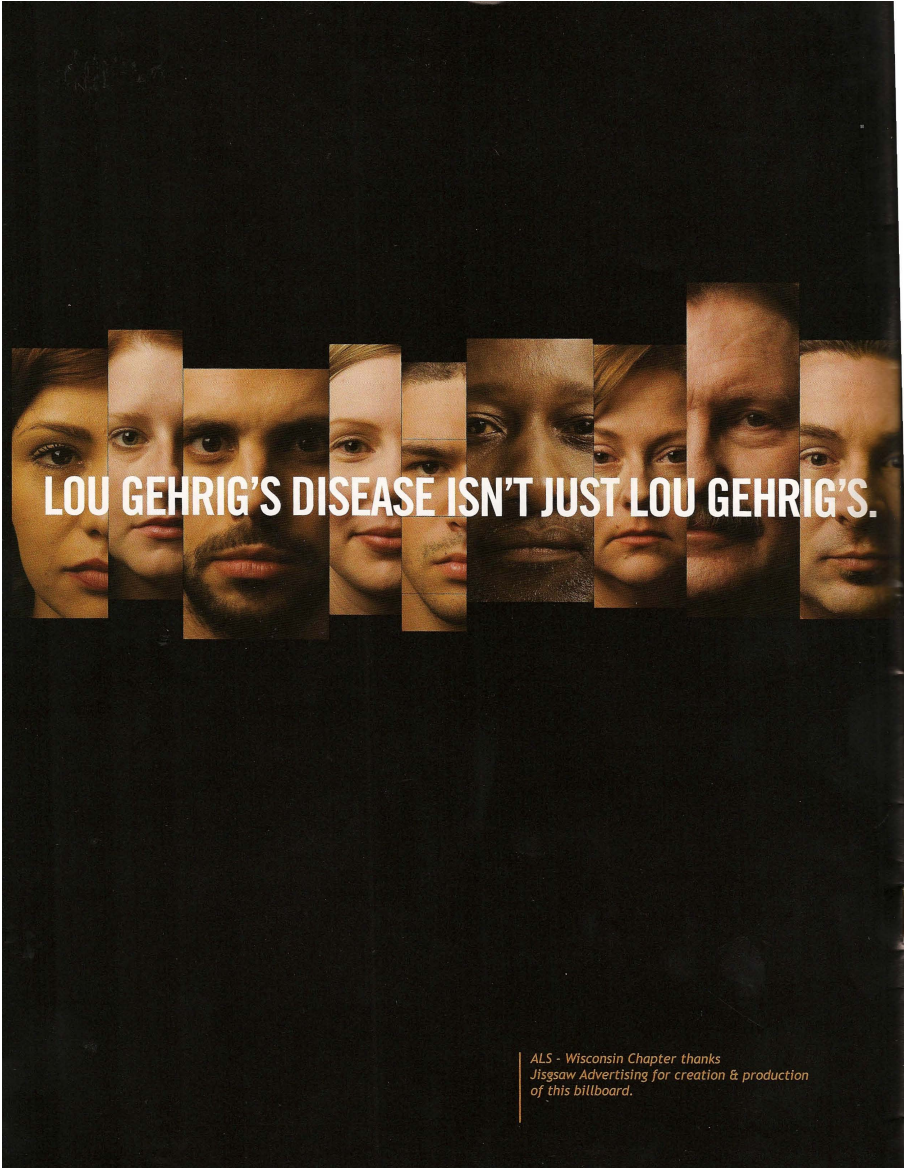
APPENDIX A: ALS SOCIETY OF CANADA PRINT ADVERTISEMENT



APPENDIX B: ALS SOCIETY OF CANADA PSA



APPENDIX C: ALS ASSOCIATION WISCONSIN CHAPTER PRINT  
ADVERTISEMENT



APPENDIX D: FOX13 NEWS STORY



# APPENDIX E: ALS ASSOCIATION (NATIONAL OFFICE) NEWSMAGAZINE

## ARTICLE



Tim and Katie Nicholson with their parents Nick, who has ALS, and Jo Nicholson with New York Yankees shortstop Derek Jeter at Yankee Stadium.

### VISION

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### Lou Gehrig Speech Continued from page 1

famous "Luckiest Man" speech at MLB and Minor League Baseball stadiums on July 4.

People living with ALS and their families have more hope that new treatments and a cure will be discovered as a result of the initiative and the awareness it has raised.

"This was one of the highest profile events in the history of fighting Lou Gehrig's Disease," said Jane H. Gilbert, president and CEO of The ALS Association. "The close to two million fans who visited ballparks during '4ALS' and the millions more who watched on television or listened on radio now know much more about this terrible disease and why their support is needed," Gilbert continued.

Even now, excitement surrounding "4ALS" and the groundswell of support for making this an annual tradition continues to grow.

"I cannot tell you the satisfaction it's given me and the clubs to participate in something like this. It is so worthwhile," said MLB Commissioner Bud Selig.

The Association's national network of chapters raised money for services and programs through The Association's "Covering All the Bases Hitting

Challenge," where fans pledged a dollar amount for each hit their favorite team made. "We were extremely pleased that the total hits of nearly half of our domestic clubs on July 4 resulted in monies being raised for ALS," said Minor League Baseball President Pat O'Conner.

Highlights from "4ALS" included the introduction of patients and spouses; live readings of Gehrig's speech by patients, celebrities and players; the playing of public service announcements by former MLB players Curt Schilling and Nolan Ryan; and auctions.

Players and coaches wore the "4ALS" patch on their chest, and the "4ALS" logo appeared on stadium scoreboards, signage and on first base. In addition, teams donated suites to chapters to host patients and families.

"On July 4th, more people received an introduction to ALS, what it is, what it does, and what it means, than on any day in the history of mankind," said Schilling, who has raised more than \$10 million through his "Curt's Pitch for ALS®" program and other events for The Association.

At Yankee Stadium, Yankees shortstop Derek Jeter and several teammates read the speech. "It was very emotional for both the players and the fans, and it truly was a goose-bumps moment," said ALS Association Greater New York Chapter president and CEO Dorine Gordon.

Larry Pouncey, who has ALS, participated in a pre-game ceremony with his wife Linda at Angels Stadium of Anaheim. "It's actually overwhelming," he said. "I find the outpouring of love humbling, and it makes me proud."

Just before his name was announced to the crowd, he spoke about his wife. "She has gone through a lot seeing me go through this, and it means a lot to her to see MLB doing something for ALS awareness," Pouncey said.

MLB's Web site promoted the initiative and featured a blog, where Jim Huff of Poplar Bluff, Mo. wrote "Dad is still fighting the good fight, and it is awesome to know that so many people are standing behind the men and women with ALS. I am sure when he saw the evening news a huge smile came to his face."

### Twenty-Five Years of Hope

A message from Jane Gilbert, President and CEO



Jane H. Gilbert

January 2010 marks the beginning of The ALS Association's 25th year in the fight against Lou Gehrig's Disease. Our vision to create a world without ALS has provided inspiration for our efforts every single day of this last quarter century.

In the few months that I've had the privilege to serve as President and CEO, I've learned that The ALS Association means many things to many people. It is the global research laboratory where scientists search for treatments and a cure. It is compassionate care that embraces and empowers the entire family through a network of chapters and certified treatment centers. It is a strong voice in government for those who have lost their voice. And, it is the

premier source for knowledge and information about this devastating disease.

Moreover, to everyone in the ALS community, The ALS Association means a reason for hope. With advances in science and technology in recent years and the continued help of donors like you, there is more reason than ever to believe that effective treatments may soon be within our grasp.

Our pledge is to leave no stone unturned in the quest to put an end to this disease, once and for all. Working together, we will relegate Lou Gehrig's Disease to its rightful place in the history books. Thank you for being a part of our quest.



## APPENDIX F: ALS ASSOCIATION FLORIDA CHAPTER NEWSMAGAZINE

### ARTICLE

# MATT WHITE SPEAKING IN SILENCE



The inspirational speech the Butler Bulldogs will never forget.

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In April, Matt White, made the journey of a lifetime – a trip that would fulfill a personal dream, captured in photos, and documented by journalists across the country.

After suffering with ALS for 10 years, the Butler University alumnus who now lives in Cape Haze, Florida traveled to Indianapolis to watch the Butler Bulldogs in the NCAA Final Four and inspire the basketball players with a speech Matt had written for the special opportunity. The trip came courtesy of an anonymous donor who paid the expenses for Matt to travel by Learjet to Indianapolis.

ALS has robbed Matt of his ability to move and speak, so he prepared the speech on his computer, using a special head mouse device which allows him to move his eyebrows and forehead to direct the cursor.

He then delivered the pre-game speech through his wife, Shartrina,

who read it for him before the Bulldogs took on the Michigan State Spartans in the Final Four.

White made a similar speech to the Butler Bulldogs in 2007, when the team versed Florida Gulf Coast University. White's motivating writing delivered just as much punch as it did in 2007, and the Bulldogs went on to defy the odds, beating Michigan State, 52 – 50. Just two days later, Matt White watched as the Butler Bulldogs took on

Duke University in the nail-biting championship game. The Bulldogs lost by just two points in the final seconds of the game.

Butler had advanced farther than many expected, and Matt White traveled home with great pride in his alma mater. Matt's courageous attitude and passion to live fearlessly grabbed the attention of the nation, raising awareness about ALS and showing the public the urgent need to fight back against such a devastating illness. Journalists from Florida, to Indianapolis, to New York followed Matt's plight, and thanks to his heroic journey and inspirational speech, millions of people now understand the devastating effects of ALS. Matt's story was featured by such news outlets as the New York Times, New York Post, ABC World News, and also during the CBS broadcast of the game, just to name a few.

While ALS has silenced Matt's voice, his influence has resonated in the hearts of millions, and he continues to persevere, living by the same words with which he inspired the Butler Bulldogs.

**“You have tremendous resolve to survive, to keep moving on, regardless of the obstacles you face,”**

**Matt wrote. “You also live in the moment. Never looking back or too far forward, you deal with, only what is in front of you and you move on.”**

Matt and Shartrina being interviewed by journalists in Venice, FL



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## APPENDIX G: FOCUS GROUP DISCUSSION GUIDE

Greeting from researcher thanking participants for agreeing to help with the focus group. Explain the importance of gaining insight into the attitudes opinions of the participants for the purpose of understanding how people with ALS experience mass communications about their disease and how they interpret cultural representations of ALS. Explain that participation is completely voluntary. Explain that the focus group will be recorded for the researcher's purposes only. The video tape will not be published but will allow the researcher to better analyze the comments and opinions of the participants.

Opening question:

- 1) Please introduce yourself and tell us how long you have been living with Lou Gehrig's Disease.

Introductory question:

- 2) How do you think that the disease you are living with is generally portrayed in mass communications?

Researcher will now tell the group that they will be asked to read two separate articles relating to ALS. Facilitator will ask the participants to not ask questions while they read the articles. "Please hold any comments until the facilitator starts to ask the focus group questions, feel free to jot down any comments or questions so we can address them as part of the focus questions."

Logistics- Participants will need to have pieces of paper and pens so they can jot down initial thoughts and comments.

Pass out copies of an ALS Association (national office) newsmagazine article and an ALS Association Florida Chapter newsmagazine article for participants to read. The facilitator will not explain the articles or answer any questions, only pass out the materials.

"We would like to get your reaction to the information that we showed you, we will be asking you to give us your opinion on both of the articles. Our goals is not to compare the articles, but to hear your feelings about each one. Please answer the questions from your own perspective not what you think someone else will think."

- 3) Can everyone please share their first response to the information you read in each article?
- 4) How does it make you feel?
- 5) For you, what is the meaning of this article?

- 6) After reading either article, what are your thoughts about the organization that published the information?
- 7) What are your suggestions for how to improve these communications?

Researcher will now tell the group that they will be asked to look at two different print advertisements about ALS. Facilitator will ask the participants to not ask questions while they look at the advertisements “Please hold any comments until the facilitator starts to ask the focus group questions, jot down any comments or questions so we can address them as part of the focus questions.”

Pass out a ALS Association Wisconsin Chapter print advertisement and an ALS Society of Canada print advertisement. The facilitator will not explain the advertisements or answer any questions, only pass out the materials.

“We would like to get your reaction to the information that we showed you, we will be asking you to give us your opinion on both of the advertisements. Our goal is not to compare the advertisements, but to hear your feelings about each one. Please answer the questions from your own perspective not what you think someone else will think.”

- 8) What is your first response to what you saw in the advertisements?
- 9) How does it make you feel?
- 10) For you, what is the meaning of each advertisement?
- 11) After seeing either advertisement, what are your thoughts about the organization that published the information?
- 12) What are your suggestions for how to improve these communications?

Researcher will now tell the group that they will be asked to watch a news story about ALS. Facilitator will ask the participants to not ask questions while they watch the story “Please hold any comments until the facilitator starts to ask the focus group questions, jot down any comments or questions so we can address them as part of the focus questions.”

Facilitator will begin to play the FOX13 news story regarding ALS. The facilitator will not explain the news story or answer any questions, only play the video.

“We would like to get your reaction to the information that we showed you, we will be asking you to give us your opinion on the news story. Please answer the questions from your own perspective not what you think someone else will think.”

- 13) What is your first response to what you saw in the story?
- 14) How does it make you feel?
- 15) For you, what is the meaning of the story?
- 16) After seeing the story, what are your thoughts about the organization that coordinated the story?
- 17) What are your suggestions for how to improve these communications?

Researcher will now tell the group that they will be asked to watch a public service announcement about ALS. Facilitator will ask the participants to not ask questions while they watch the PSA “Please hold any comments until the facilitator starts to ask the focus

group questions, jot down any comments or questions so we can address them as part of the focus questions.”

Facilitator will begin to play the PSA, produced by the ALS Society of Canada. The support group facilitator will not explain the PSA or answer any questions, only play the video.

“We would like to get your reaction to the information that we showed you, we will be asking you to give us your opinion on the PSA. Please answer the questions from your own perspective not what you think someone else will think.”

18) What is your first response to what you saw in the PSA?

19) How does it make you feel?

20) For you, what is the meaning of the PSA?

21) After seeing the PSA, what are your thoughts about the organization that produced it?

22) What are your suggestions for how to improve these communications?

Ending

23) If our purpose for this focus group is to get an idea of peoples’ attitudes and experiences of mass communication about ALS, “Is there anything that we should have talked about that we didn’t?”

24) Is there anything that you would like us to know about ALS communications that we have not addressed today?

“In closing, I thank all participants for their time and their opinions”.

## APPENDIX H: SARASOTA FOCUS GROUP TRANSCRIPT

**Moderator:** Let's start by telling us your name and what your connection is to ALS. If you're living with ALS, how long you've been living with ALS.

**Patient 1:** That's Samuel. He is one of my principal caregivers. I'm Patient 1 and I have ALS

**Patient 3:** I'm a caregiver. My wife Patient 3 has ALS. She was diagnosed in December of 09.

**Friend of Patient 2:** I'm Friend of Patient 2 and I'm a friend of Patient 2. Like you were saying I was aware of ALS. I was not aware how it does or doesn't progress. I'm here to help understand what they're going through  
I'm her lesser half and I just have to reiterate what she said.

**Patient 2:** I'm Patient 2 and I have ALS since 3 years ago.

**Wife of Patient 2:** I'm Wife of Patient 2. I'm his wife.

**Moderator:** So now I'll go ahead and I'll start directing some questions to those in the room who are living with ALS. This is very casual so feel free to interject and say what you're thinking at any point. I'll start with the question... how do you think the disease you are living with is generally portrayed in mass messages that you would read or see.

**Patient 1:** I think it's generally not presented.

**Patient 2:** It's generally not presented.

**Patient 1:** I mean I read a lot. I'm an active guy. I cared for a lot of people as a pastor for 38 years. When the doctor said ALS I had not a bit of knowledge what she was talking about.

**Wife of Patient 2:** Same with us. When he was diagnosed with ALS and the doctor told me he had ALS. I said ok what are we doing now. He saw on my face I had no idea what ALS means and he gave us information for websites to look at. Afterward your world turns upside down and really you go in a big big hole. You fall in big hole and you feel also that you are the only person with that illness.

**Patient 2:** because you don't know

**Wife of Patient 2:** You don't know yeah,. And a little bit hope is coming that after when you're climbing back up the hill then well you read a lot and you go on the website and you have people that are living 17 years with this illness so it is not so bad right. But yeah it's a struggle.

**Moderator:** Patient 3, what I'm hearing them say is that ALS is not communicated enough.

**Patient 3:** nods her head (husband says absolutely)

**Patient 2:** to a certain extent I can understand it yeah. Because there's only... let's put it this way and put it really blunt yeah. As its said... the statistics say in the US every 90 minutes someone gets ALS but it doesn't matter because every 90 minutes someone dies of ALS. So the group itself stays reasonably constant only the people change in it. But the group is that small that it don't get the attention it basically should deserve.

**Moderator:** When you have seen ALS in a mass message whether that's from a charity group or in the media, what have your thoughts been about it?

**Patient 2:** The only thing that I saw I would say March it was on TV with the guy

**Wife of Patient 2:** Jerry Lewis

**Patient 2:** Jerry Lewis yeah. When he did the marathon of the...

**Patient 1:** Labor day telethon.

**Patient 2:** Labor day telethon yeah.

**Moderator:** Patient 1 did you have any comments about that?

**Patient 1:** Well I see a variety of things. I've actually written a piece along the way. When somebody talks about the disease as being horrible, I don't like those kind of negative representations. I think bone cancer is a lot more horrible... any disease that gives you unrelenting pain. I don't have unrelenting pain. I've got lots of other things...but no pain... relatively little pain. So its not horrible it is what is. And when I hear how its gonna bankrupt you. That initially worries you because that's one of the first things I was told that it was gonna bankrupt me. Well we have figured out ways to use our resources in ways that its not bankrupting us... likely to.... But we're pretty good stewards of what we do. And live cheaply and lets do this like that. Also, things that concentrate on lifespan. I don't really care for and it's not an act of denial on my part. I've watched some wonderful people in this group whose life has been much too short. I've seen many others who've gone on for a long time. I think there is no way of telling. There is no way. My first impression when I came to this group. By god if I didn't we all have doctor's letters saying we had ALS, you wouldn't know we had the same disease. Because we've been all over the board. There's lots of variety with this. And I guess I

think things that say how people are living with it. There's a wonderful guy by the name of [insert name] who writes for the newspaper here in Sarasota. There's a column about every month. He's been like 18 years. He is in a winding down stage, but he writes well about the experience. He's an at-home dad. I've got a lot in common with him. His kids went to the school my wife teaches at and so I think it's a mixed thing of what I see in media and I would think that if I were to encourage anything it would be those things that it's not a good thing to get but the good doctors learning what caused it... and deal with that... it'd be good if stem cell research actually moved forward and we could maybe find a cure if not for us for somebody down the line. And just awareness of it. I mean my primary physician didn't have a clue. The first neurologist I went to.. didn't have a clue. I could give you a whole list of doctors I went to along the way I could say almost universal among them. We all went to a bunch of doctors before we finally found somebody who said "Here's what it is." I mean so even the medical community.

**Patient 3's Caregiver:** I'd like to comment on something we've been talking about. I think everything you read leads you to believe that people are working very hard to find some kind of cure, some kind of help. But the more we read the more we realize how little they know. They're working very hard to try to get more information but they're results are not that great. Really very truly, we don't know. We were diagnosed last December it took 9 months to diagnose it. And the only way they diagnosed it is by saying what it wasn't. And they finally decided that it was ALS. We don't know if we have a year to live or five years to live or 10 years to live. And nobody knows. The doctors don't know as much as we'd like them to know.

**Moderator:** I'd like to go ahead and pass out about a 2-paragraph article that I'd like you to read. Then let me know your thoughts on it.

**Moderator:** So I'll ask both Patient 1 ....then Patient 2 and then Patient 3 lastly so you have time to write down can share you're response to what you read.

**Patient 1:** It's very positive. She tries to be hopeful. I see the whole theme of hope in this thing. We're trying to do something. And relegate this disease someday to the history.

**Moderator:** So that message of hopefulness is something you like to see or don't like to see?

**Patient 1:** Yes very much like to see. Trying to get the awareness out there and being hopeful about doing something

**Patient 2:** For me a bit aahhh I would say too hopeful yeah

**Moderator:** Why so?

**Patient 2:** Well at this very moment yeah they don't even know where it comes from. They don't even know any cure against it. They are talking that you can put it in the history books I think for me is a little bit over done.

**Patient 1:** The point has two sides (laugh)

**Patient 2:** yeah

**Moderator:** Do you think that that was appropriate or over done Patient 1?

**Patient 1:** Well the coin has two sides. That's true. And we all look at it through our own set of eyes... our own personal frame of reference. So me being who I am, I see the hopeful side. I'm almost worried right now... you're kind of overstating that aren't you.

**Moderator:** Patient 3 did you have any comments about it that you'd like to share.

**Patient 3:** Hope and despair vascillate. It's nice to read something positive.

**Moderator:** So you think that a positive article is appropriate like Patient 1 said?

**Patient 3:** nods her head

**Moderator:** Now the question I'd like to do the same thing with is how does it make you feel?

**Patient 1:** Well these folks are out there trying to do something. That's good... cause I'm pretty powerless. There are people out there who are trying to encourage us... I think that's generally good.

**Patient 2:** In that aspect I like it because basically at least there is a group or a team of people that want to do something. Much more so than I would say in the past. Because if I look at it yeah was it you call it Lou Gehrig's Disease. That man only died in the late 30s so that was about 75 years ago and they haven't made any progress since then.

**Patient 1:** One pill- rilutek that was the only significant thing. And he didn't get that (??)

**Moderator:** Did you have any comments about it?

**Patient 3:** I feel that it's probably being worked on that there's research being done.

**Patient 3's Caregiver:** We just haven't seen many progress

**Moderator:** So now I'd like to move on to one more article to have you read. It's about a specific person living with ALS. What's your first response to this article?

**Patient 2:** I personally believe this is great article. Why I think great because the man himself has ALS and doing it this way I think brings it better over than anything else. How about when I read "millions of people now understand the devastating effects of ALS"... my answer was I wish it was true because basically I would say most probably not because for most people it is yeah like any other illness yeah if you're not confronted



with it there are so many requests to support illnesses... breast cancer and any cancer yeah... ALS is one of those yeah. So the answer is millions of people understand the devastating effects of ALS. I think of those millions yeah the majority of them forget the moment they left the stadium but that's my personal opinion.

**Moderator:** That's what we're looking for.

**Patient 1:** I pretty much agree. I remember the story. I first read it in the local newspaper who published it at the time. I read it in here. The um It's a softball but never really says what ALS is. So you read about this poor guy that's got the disease that's stripped him of so much and he's got the courage to speak out. But what is this disease? That's not really a critique it's just something. I was Samuel's age probably when I watched pride of the Yankees. I watched the movie. But when I watched ALS I had no idea what it was. And I said well that's Lou Gehrig's Disease. Well all I knew about Lou is he died.

**Moderator:** So is what I'm hearing you say is that you would like the published material about ALS to be more informative?

**Patient 1:** Yes. Even that 90 minute 90 minute kind-of thinking. There's certain boiler plate statements. What is ALS? I mean we name the disease with all its words. It's a motor neuron disease. The positive side is it says you still have something to contribute. Its very interesting living life in a wheelchair and how that diminishes you. When my wife and I go out to dinner, they always hand her the check now. You follow me? It's just...Do you have the same experience?

**Patient 2:** Yeah

**Patient 2's Wife:** Can I ask something of you?

**Patient 1:** Yeah sure

**Patient 2's Wife:** How may mane people in the meantime that you are sitting in the wheelchair ask you for example, what is your illness? Are you sick or what had happened with you? Have you ever in that time somebody come to you and ask you?

**Patient 1:** No noone asks why, but that's a hard thing for them. Because some people if you said what's wrong. People don't want to be invasive or hurtful or something. They may think it but they feel awkward about that. I don't mind saying to them up front. I use the chair because I have ALS. What I do notice... doors are a real pain... both because of the hands and because you gotta get the door around and get the chair through without either messin up the door or... but my wife describes me like a puppy. I will just simply pull in front of the door and sit. (laugh) And someone will come along and sayl, can I open that door. And I need to do that.

**Patient 2:** But what you're saying is absolutely true. We experience that both myself I was thinking about 3 or 4 months time. But I have a friend who is in a wheelchair his

whole life and he's a professional in about 3 or 4 different kind of thing. The answer is... wherever they go and there's his wife they don't do that thing. It's just a standard. It is unbelievable but its true.

**Moderator:** Patient 3 did you have any responses to the article? That you would like to share.

**Patient 3's Husband:** She thought that specific discomforts are seldom made clear to the public

**Moderator:** Specific discomforts?

**Patient 3's Husband:** Yeah I don't know if I agree with that but...

**Moderator:** the discomforts that come with ALS

**Patient 3's Husband:** yeah. And how they differ from one case to another

**Moderator:** at this time we're gonna show a news story that aired on FOX13... Based on what you could hear of that... what is your response?

**Patient 1:** that was well done you know. He came across as a guy... had something to saw with a witness to make and he made his witness. And a good guy

**Moderator:** how does it make you feel?

**Patient 1:** I just felt good about it. I mean we did it. I had Isaac throw out the ball. I haven't thrown a baseball I've not thrown a baseball in 60 years... even without Lou Gehrig's Disease. But Isaac did a nice job. And did it for us and it was a pretty awesome event and if in the stands there are 30,000 folks and a few of them got the idea that's very positive.

**Patient 2:** I think that's a very positive message. At least it gives people something to think about... maybe just for a few minutes... but at least it gives them something to think about. So I think the message itself at least I got it as positive.

**Moderator:** and how does it make you feel personally?

**Patient 2:** for me personally I think... uh... a little bit more positive maybe... yeah when I see it.

**Moderator:** and Patient 3 did you have any comments?

**Patient 3's Husband:** Patient 3 feels that she's not making the most of her time. Is there something else you want to be doing?  
(Patient 3 writes) We'll discuss it later

**Moderator:** maybe you're saying you wish you could do something like that... is that what you're saying? No?

[Patient 3 writes]

**Patient 3's Husband:** that she thinks she should be pushing the barriers a little more I don't know who's going to tell her what barriers to push.

**Patient 2's wife:** I think it is a good idea that they put it on the news... on a special program.. because a lot of people they look at the news. I think it is coming on the news and if you focus on it most people are looking at the news.

**Patient 2's wife:** So I think it is really positive and also I'm feeling as a caregiver that there is a little bit of hope because now you have the feeling that you're not alone yeah. Because in every day some days you're thinking ok I'm the only one with those problems. When you see like this then it is like hopeful and it is also when we have the meeting in here... it is like we are not alone in this.

**Moderator:** and Patient 2 do you agree?

**Patient 2:** yeah

**Moderator:** ok great... let me now show you a print advertisement that I'd like you to look at...

What's your response to this?

**Patient 2:** I like it.

**Moderator:** Why?

**Patient 2:** I think it is just an abbreviated truth of the answers that may be why I like it.

**Moderator:** Patient 1, what's your response?

**Patient 1:** too dark, too stark,

**Patient 3' Husband:** too scary?

**Patient 1:** no, too dark. I mean not color I just depression is the enemy. It stalks all of us. And so it's... his demeanor... uh... I feel sorry for the child. I mean that's you and I (directs his comments to his son)... Except we're laughin' about it.... Not about the disease but about the experience. I can get my socks on... it's horrible getting them off. Sammuell takes my socks off. He sleeps in my room and he takes my socks off some times. Don't you Sammuell? I mean he gets on the floor. I angle my chair up. He grabs a hold of it, and I back the chair up and he rolls across the floor and the socks pop off. Does that make sense.

**Moderator:** So that's the meaning that you find in this... kind of a reflection of you.

**Patient 1:** I find it a little too dark.

**Patient 2's Wife:** It screams for attention.

**Patient 1:** Yeah it does.

**Patient 2's Wife:** So maybe he asks for that yeah. What you see here is attention... maybe that is in his mind that it's ok

**Patient 3:** It's good because it covers all the specifics. It's good for the general public.

**Patient 3's Husband:** I'd like to say that when it comes to the general public... we all know that this is a fatal disease that there is no cure at this time... and we need to get that out to the general public

**Moderator:** how does it make you feel though?

**Patient 3's Husband:** Lousy

**Moderator:** Patient 3? Is lousy a good word, do you have a different word?  
[Patient 3 writes]

**Patient 3's husband:** It's acceptable to her

**Patient 2:** It makes me feel... It's just a piece of reality... yeah this is reality... so yeah. It doesn't make me feel worse or better... it's just a piece of reality.

**Patient 1:** The graphic of the neurons is [...]

**Moderator:** and why do you think that?

**Patient 1:** because its hard to picture what's going on in the disease. That part of the graphic was the best part of it with the white traces.

**Moderator:** ok let's look at this which is a similar print ad. What are your feelings about this? Anybody have an impression or an attitude about this that they'd like to share?

**Patient 1:** well it's multi-racial, multi-cultural, male-female. I mean it hits us all

**Patient 2's Wife:** what you say male and female because in the beginning when Patient 2 was diagnosed I had the idea that it was only men and a little bit woman... an din the meantime the information that we get... there is always a woman involved it is not only men.

**Moderator:** Patient 2, what's the meaning you find in it?

**Patient 2:** my first impression is maybe because I am not from the United states... but I think they should start pronouncing it as ALS and not as Lou Gehrig's disease. ALS is understood world-wide... Lou Gehrig is not. That is my first impression.

**Moderator:** does it make you feel a certain way at all?

**Patient 2:** no cuz after having read through so many articles on the internet, I know its based all over and its.... Not specific to men or women or race or whatever... but for me that doesn't make any impression on me whatsoever

**Moderator:** let's look at the last thing we're going to look at which is a commercial In the interim, is there anything that you all would like to see communicated more... any aspects of the disease that you would like to see communicated more and you think are not.

**Patient 2:** I think in general, I don't know if they have money or not to do that... but they should repeat more the thing about ALS. I say that is only through repetition you get people's attention. When you ask one of the most prominent examples is breast cancer. If you claim it enough, and if you make enough noise about it constantly, people start realizing it. If you do it accidentally which generally at this moment it is with ALS. It hits and goes by. I think if you have more repetition you get much more interest in ALS.

**Moderator:** And that's what you want.

**Patient 2:** Yeah

**Moderator:** Why so

**Patient 2:** Because I think it is a disease that you... regardless... if they should find something yeah that would prolong the disease so that you have a few years longer.. the numbers of people who have ALS would start astonishing the world. At this moment the numbers don't because they die as fast as they get it. So if somebody could find something that could prolong life with a few more years, I think the world would be astonished how many people have ALS.

**Moderator:** Let's watch this last commercial. What's your responses to that? Patient 1 would you want to start?

**Patient 1:** It's absolutely true. Parts of your body just walk away piece by piece. Your voice, ability to eat, to walk... you just loose it. And that it makes it personal to people... what would you do

**Moderator:** Does it make it personal for you?

**Patient 1:** Oh yeah.

**Moderator:** What's that meaning for you?

**Patient 1:** a lot of things that you know I call this a very hard disease because so many things that one does one cannot do anymore. I used to keep house. I retired to be the at-home dad and housekeeper. Kim went to work. This was a vocational trade that we did. And now Kim has to carry the whole bag. It's hard. It's a hard thing.

**Moderator:** Patient 2, what's your response and your feeling?

**Patient 2:** I think first of all, it's absolutely true what was said there... I personally thing yeah what the person himself was doing there was a little bit overdone but that's ok. The answer is its absolutely true.

**Moderator:** Patient 3 is writing her comments

**Patient 1:** I can't get out of the driver's seat. I can drive. I can use my right arm. I can't pull myself out of the driver's seat

**Moderator:** So to be reminded of that is it helpful to you is it hurtful to you? What's your response

**Patient 1:** it's good for the world to know

**Patient 2:** it's reality

**Patient 3:** I'm living with the wonder of what's next. It's a good reminder that I should maximize the ability I still have

**Moderator:** did that commercial have any other meaning for you?  
After seeing that, what's your thoughts about the organization that produced it?

**Patient 1:** someone is trying to publicly name it and address it. I think that's what you're trying to do... name the disease and address it. I mean I know how I feel about the organization. When Dr. Katzin said you should join the ALS society. That was on the list of about 13 or 14 things she said to do that day, and I put it at the bottom of the list. I didn't think it made much difference... and then I discovered something. It makes the world of difference, and to get their name on the top of the list, makes a difference. I believe in you guys because you've made a difference.

**Moderator:** any other impressions? So that was the last piece of material. If the purpose of this meeting was for us to understand your attitudes and opinions about mass communications about ALS. Is there anything we should have talked about that we didn't?

**Patient 2:** I only can say I strongly encourage any mass communication about ALS. The more the better. As I said before, not only because I have it but because I think at some point it starts getting an awareness that this is a bad disease... I call it an awful disease... and I think that's from my perspective... the more the better. The more mass communications you guys do the better it is... absolutely.

**Patient 1:** I would say to not lower anything you do but lift up more the active resources you provide for those of us who have ALS and our families. I don't think that story gets told enough. When I came to my first ALS meeting... I had piles of notes. But you taught me how to deal with my insurance company, you taught me what kind of wheel chair you needed... you taught me today about what kind of legal stuff. You follow me? You continually provide resources for us. My first wife died of cancer... neither of the cancer societies that relate to her disease and I'm not knocking those folks...never impacted our own personal lives a bit. You have had a huge impact on us. Maybe lift that up. You spend a fair number of your resources on providing resources for us. I don't know how your budget lays out. That's my own feeling. The Christine Brights of your world the loaner closets the networks that you have of providers and so forth.... This cpap provider does good stuff... that one... move away from them if you can. You never talk negative, you always talk positive. And you lead us to find what we need. Kim is that fair?

**Moderator:** So you want that story to be told more

**Patient 1:** Yeah what you do. Because its good stuff.

**Patient 2's Wife:** Well what you say.. I totally agree with that. I learn the last three years, almost three years, so many things. Because they are conversations like what we do in here. Information from patient to patient, emails, look at this, look at that. I almost ordered a wheelchair last month... we had information from Patient 1. A year ago.... [insert story of Advanced Life services]

**Patient 2:** It's on the side of the car – advanced life services.

**Patient 2's Wife:** I saw that in his eyes. He had no ideas what I taking about. Later on in the hospital, I said I want to say something because I'm really sad about this because you guys need to know this.

**Moderator:** and Patient 2, that was a frustration for you?

**Patient 2:** oh yeah. Although I still luckily I still can explain it.

**Moderator:** Any final comments?

## APPENDIX I: ORLANDO FOCUS GROUP TRANSCRIPT

**Moderator:** We're going to look at several different media, and I'm simply going to get your thoughts and opinions. This research is important to the entire ALS community. Let's start by introducing yourself.

**Patient 6:** My name is Patient 6. I was diagnosed in 05 – but I've been living with ALS since at least 1996 and I have hereditary ALS. So I saw my brother live with and lost I think ...

**Patient 5:** My name is Patient 5, and I was diagnosed November 4 2009, but I have been having some symptoms since about 2007, and as I think back... my right side is my weaker part. I have not any family members who have had ALS before... not to my knowledge.

**Patient 4:** I was diagnosed back in September but I think I had it probably 6 months prior to. I was losing muscle in my shoulders. That's when we first noticed it. I used to lift 50 pounds at the gym. I could only lift 40. So kept going back to the doctor and the doctor kept saying you're lifting too much, you're trying too hard. Then we went to a neurologist and got it the first day. His diagnosis was the first day, then we went through all the testing. Went through mayo clinic and that's where I'm at now. It's affected my arms right now.

**Moderator:** How do you think that the disease that you're living with is generally portraying in mass messages.

**Patient 4:** Actually it's not. Because you've got Jerry Lewis is MDA. And I don't think he mentions ALS under MDA. SO I think ALS should be a separate entity instead of being associated with the MDA. The reason why is because if we had a marathon for ALS we would probably draw more money for research. Right now you can say ALS to somebody. Then say Lou Gehrig and they'll know exactly what you're talking about. Say ALS, nobody knows

**Patient 6:** It seems like its not well known out there anyplace. Even with the healthcare industry. I was looking for a Physical therapist after I was in the hospital. We called two places. The first one we called they... my wife said are you familiar with ALS. They said oh yeah Assisted Living is what they thought it was. Of course we hung up and called the next place. I do like the fact that MDA does put out an ALS letter. But without the ALS Association, I don't think anybody would know about it.



**Moderator:** Patient 5?

**Patient 5:** With what he's saying, I have been in PT and OT, and now I'm in I guess its considered OT [...] But with the PT I just noticed myself that they are not aware when you are telling them that you are very tired and what the symptoms are. Then they'll want to give you these strenuous exercises to do. And I found out that when I would go for the rest of the day when I would be just out of it, and the next day, and on the third day I would go back again. I just stopped doing the PT and I just did some stretching on my own. {..} I just continued to do the things I've learned from her at home. Most of the doctors do not realize the things that they are doing for normal patients, [...] the neurological condition that we have is different. They just can't treat it like that, you know with the same um therapy or medication or what have you.

**Patient 4:** My neurologist when I went to see him the first time. He's been in practice 25 years, and he said I was his fifth case. So it's just not very widely known out there. Sometimes it takes a long time to diagnose.

**Moderator:** and how does that make you feel?

**Patient 5:** Helpless (laughs).

**Patient 4:** Yeah you don't wanna hear the word, and when he said ALS I kind of looked at him and he said that's Lou Gehrig's and I said oh now I know what it is.

**Patient 5:** Like with myself I had to go to two neurologists before I got a diagnosis. The first one I went to he wanted to do like they were saying in there. He wanted me to do sleep apnea and I don't have any problem with sleeping. And he wanted to do all these different tests, and he went through the MRI of the brain and the spine and the EMG but he also gave extensive.... And the first one just told me that it was a neuropathy and a nurse told me that that's what they tell you when they don't know what it is. He told me that it would just have to fix itself and that it would get better. And he explained like it's like and electrical line or a telephone lines are down and sometimes you can get totally back together and sometimes you don't. So that really didn't help me that much and then I started noticing it was worse and I went to a rheumatologist. I said I really need to see a neurologist. And he did maybe within 10 to 12 days he told me he was almost sure but he wanted to do some more. And he kept doing studies and said it was definitely ALS, also known as Lou Gehrig's Disease.

**Moderator:** Let's start out with this one. I'm going to ask you to read this and I'm going to ask you how you think and feel about it.

[Read aloud]

I'll just give you a few minutes to think about that. And then we'll talk about it.

**Patient 4:** 25 years? And the association was discovered back in 1939? Nobody paid any attention to it.

**Moderator:** so what are your thoughts about this?

**Patient 4:** Well my thought is and I just saw it on the news last night... they spent millions and millions of dollars to research how to prevent this particular cancer. And it was only diagnosed in 10,000 people a year that get this particular cancer. And they've got a cure for it now. ALS has been around 40 years 60 years and they still don't have a cure for it. And 6,000 people a year get it in the united states, and its becoming more and more common in the united states.

**Moderator:** so what are your thoughts then about this communication?

**Patient 6:** well she's got some lofty goals there that her predecessors weren't able to do either. I don't know if we're any closer to finding a cure for ALS or not. I don't see a lot being done. I hear some studies out there but I don't see.. I know lots of people with ALS and I don't see them going through any kind of testing or anything like that. I don't know why they don't use them. I think everyone with ALS should have to be tested.

**Patient 4:** or be in some type of research

**Patient 6:** yeah and you know this is... I hope she does it. But like he said they've been together for 25 years.. the disease goes back to the 1800s

**Patient 4:** but the only medication they have for it is Riluzole. 900 dollars a month.

**Patient 5:** I took it for about 4 months and I was so disorientated. I wasn't able to go out of my house without holding onto the wall and so it was making like in a vegetative state

**Moderator:** And so what are your thoughts about this communication?

**Patient 4:** This communication I think says it all.

**Patient 5:** you know that there is hope and they say that scientists and we know that there are a lot of new technologies and everything but some things that come about they just... man just can't grasp it as easily as they can with other researches. And this happens to be one of those. With my faith, I would say that only God can really help with this and we have to help ourselves because our attitude toward what we're dealing with means a whole lot and there could be more support groups like this one and people coming together and sharing which is really good but um it's a hard disease.

**Patient 5:** I know its not addressed here. You might suffer with one thing [explains how its affected her] and to me do you want us to say what they should be doing?

**Moderator:** What I'd like you to say is how you feel about this?

**Patient 4:** Well as far as this statement goes, I think she has explained it very well.

**Moderator:** And how does it make you feel?

**Patient 4:** Well it makes me feel that there might be some hope, but its not going to be anytime soon. I was kind of hoping that stem cell research in the United States would be doing something about it. But didn't the federal government just cut funding off. We have France and Germany and everybody else is so far ahead of us. Even Cuba is so far ahead of us in medical than this. It doesn't affect too many people in the United Sates – 6,000. If it was something that affected 300,000 they'd have found a cure for it because they'd have had enough patients that would pay for their research.

**Patient 5:** I was going to say in connection with what he's saying. He's right but then I say you know Mohammed doesn't come to the mountain. You go to it. Because there's a wealth of info out there where you can go and seek stem cell and whatever. The only bad part of it is that you have to pay for it out of your pocket because the insurance is not going to pay but sometimes we just have to help ourselves.

**Moderator:** Ok. I'd like to have you all read another communication. And I'd like to get your thoughts and feelings about this specific communication.  
[read article]

**Patient 5:** Amen. Well I was looking at this last part and they're saying pretty much what I said. Regardless of what obstacle we are facing, we just have to like he said, resolve to survive and to just keep moving on regardless of the obstacles. I have seen several machines that was brought to my speech pathologist. Even if you can't speak, they have machines that you can communicate. So we just have to learn how to adapt to what we are dealing with and hope and pray that a cure is found but we can still lead productive lives and what we can do we just have to do it a different way.

**Patient 6:** It's a very nice article I think. It doesn't have a whole lot to do with research or anything like that but its kind of like a feel-good story - to really put a human face on ALS rather than clinical all the time.

**Patient 4:** Cherish yesterday. Pray for tomorrow. Live for today. That's my philosophy right now.

**Moderator:** And how does this article make you feel?

**Patient 4:** Well that there are some supporters out there in this particular case. Obviously he had a lot of alumni behind him. I didn't graduate from high school so there's no big group behind me except I do have a few friends that I've known for 30 years that anything I want they'll take care of. It's an inspiring speech from somebody. What we're hoping for, not hoping for, pray it doesn't happen... that some big movie star or somebody like Bill Gates get ALS... and will pour all this funding into it to find a cure.

**Moderator:** How does it make you feel Patient 6?

**Patient 6:** Uh.

**Moderator:** Anything?

**Patient 6:** No not really. It's not warm and fuzzy or anything. It's something I would like to say in some publication only because it dwells so much on the negative all the time... it's nice to see something... somebody's come along to help this guy at least get to the games. Somebody cared enough to pay for his way there. I thought that was neat.

**Patient 5:** well, pretty much makes me feel like I do with this article and the event that we just have to keep moving on because we know that scientists and researchers are doing these, but unfortunately there's nothing that we can do to speed it up. I mean because even maybe we go bombard the white house with letters or what have you but still in the U.S. they do research on to me the things that are more prevalent than others. And maybe they just really don't know but I don't believe that they are doing that much. Like say with cancer he was saying. And I really do believe that with this type of disease there are some things that they just do not have a cure for....

But they have things that will help you to be more comfortable, motivated, and to be more productive, and continuing to live a productive life.

Like life in general... there is so much going on right now even with the economy. I mean so many people have to adapt and readjust and not give up, so we can't give up either. We have to fight this within ourselves. We are our best medicine right now because there is not a medicine out there that we can take. I hope all of us believe in God and that's a big motivation for me. And I have that feeling that there's nothing really that I can't do because I believe that we are all equipped to grip whatever we need to do to overcome whatever come along. So we just have to motivate ourselves and keep going and hopefully say and do things that can help motivate the ones...

**Moderator:** I'd like us to look at this print advertisement now. To you, what is the meaning?

**Patient 6:** Looks like its showing the disconnect from the brain to the body to the muscles

**Moderator:** Does it have any greater meaning for you individually?

**Patient 6:** Right now, no.

**Patient 4:** No hope... just as it states right there... it all ends with death. That's what they said. It's a hundred percent that everybody's going to die. This states how you get it how it affects people. Please help us find a cure. Make it a little bit bigger words.

**Moderator:** No hope is that the meaning?

**Patient 4:** Yeah it kind of says there's no hope in it. But then again, anybody diagnosed with ALS, they've only been told that... over and over. There is no hope

**Patient 5:** I believe there is hope

**Patient 4:** Some might last for 5 years. Some might go 10 years. Some might go 15 years. It might stop in your arms. This is like no hope.

**Moderator:** what are your thoughts about the organization that produced this?

**Patient 4:** this says ALS-SLA. I don't know what SLA is

**Moderator:** Based on the ad though, what kind of information do you draw about the organization that created this?

**Patient 4:** Any kind of advertisement to donate to get the money out I think is fine. But then again you've got a lot of organizations out there that you donate to that 60% of their money is sucked up by staff or expenses. 40% only goes to that. I'd rather have an organization where if I donate 100 dollars, 100 dollars actually goes to it.

**Moderator:** So based on this ad... what do you think about that organization?

**Patient 4:** I don't know what organization it is. It doesn't say it just says to visit an ALS site. It says .ca so obviously California.

**Moderator:** Anyone else have a thought?

**Patient 6:** Well I think they're showing the actual problem with ALS. That's [???} I can see them using this negative idea. I can see people giving money to help against the disease.

**Patient 4:** But are they actually giving it to an organization? It might be an organization that's yeah give me your 10 dollars and we'll keep 8 of it and we're a nonprofit organization and I'm the CEO and I make 3 and a half million dollars a year. Florida Hospital is one.

**Moderator:** at this time I'd like to show you a video news story. What's your first impression of the story.

**Patient 6:** It showed... I like the fact that its showing his kids and family and how it affects everybody.. it's not just the person that has ALS that's affected.

**Patient 5:** The first thought I had was he has this terrible disease at least he's continuing to do positive things and spend time with family and you know just continuing to live

**Patient 4:** I have a different attitude. I've been around. I'm retired from the navy, retired from the post office. I've only had two jobs in my life. I've been around the world, been married 40 years. 5 grandchildren. I have to have the attitude – live for today. I'm not afraid to die. That's all I can say.

**Moderator:** Is that what you're getting from that communication?

**Patient 4:** Oh yeah. Live for today. Enjoy today. Because tomorrow I might lose my knee. I might not be able to walk tomorrow, but I've got ALS. What we need to do is make a little bit stronger the people that don't have ALS that it could strike at any age. It got me at 66. I don't know. I didn't think why at 66, I've been going to the gym, working out, watching my diet. Planned my retirement. We were going to travel. Had a motor home

**Moderator:** If you had to use feeling words to describe that communication what would you say?

**Patient 4:** I'd say happy because that baseball organization recognizes a man with ALS, took him out there in front of a crowd. He recognized it and he enjoyed it and it was a time for it. He threw out the pitch and he made his comments to the camera.

**Patient 6:** It's a happy story.

**Moderator:** I have one more commercial to show.  
[show commercial]  
What are your feelings about that?

**Patient 6:** I think it's a good ad. My personal opinion. It puts out there what people don't know – it describes probably better describes ALS than what I've seen and I've seen a lot in the last 4 or 5 years.

**Patient 4:** If I put my arms around a waitress, I'd probably be on the floor. Either my wife or the waitress one of the two

**Patient 5:** It shows that even if he's dealing with this dreadful disease, he's very emotional and giving, to me the hug of affection, one thing that was written up there is ALS kills the body first. Well the body is flesh but we cannot allow it to kill our mind and intellect. That's what just what I saw from that particular I think well if you can keep your mind in tact and keep your emotions going and feeling food and not feeling defeated. That's what I saw in that

**Patient 4:** that was a pretty quick commercial to read it all that fast. Yeah it was all right. It gets it across that ALS kills the body but we all know that. You're asking people that we know all this information... the Internet and. Didn't give me much hope. Says its gonna lose my arms in 2 years.

**Moderator:** And would you like to have hope?

**Patient 4:** Well they're being honest.

**Patient 6:** Well I think on this... what makes you think that guy has ALS. I don't think he does.

**Patient 4:** I don't think he does either.

**Patient 6:** And I think what they're saying here. You might get it you might not. If you want to fund for it while you still can that's why he's going around hugging.

**Patient 5:** Well, I guess I could say I connected with that because I'm a hugger I love to hug I'm emotional and I just feel like there is always hope everyday. Just get through one day and just keep living. As long as you keep hope alive, you can be somebody

**Moderator:** if the purpose for this focus group is to get an idea of people's attitudes and experiences about ALS, what should have been said that wasn't

**Patient 4:** I think you can be a little bit more dramatic. Show people with ALS what the movements are. What happens. Stage 1 Stage 2 Stage 3.

**Moderator:** And why do you think that would be important?

**Patient 4:** Because I think more people would visualize it in your mind if you had an advertisement like this... here's what happens week 1, here's what happens year 2, 3, 4.

**Moderator:** And why would you like people to visualize that?

**Patient 4:** People would be more sympathetic and donate a little more money or otherwise they would understand what the disease is and say why can't we find a cure?

**Patient 4:** maybe bring it out, what's the youngest person you know that has ALS. Bring out middle age, bring out someone that is successful that caught ALS. Then you're 70 years old boom you got ALS before Alzheimer's. How does somebody actually get the disease? Why did the good Lord pick me?

**Patient 6:** If they knew how you got the disease they'd be able to find a cure for it.

**Patient 4:** Nobody knows how you get it.

## APPENDIX J: TAMPA FOCUS GROUP TRANSCRIPT

**Moderator:** We would like to find out how people who have been diagnosed with ALS think and feel about these messages. We'll look at them and I'm just going to ask for your all's feedback. There are no rules to a focus group so you can say exactly what you're thinking. And you can respond to what someone else has said that has spurred a thought within you. That's the great thing about focus group research is that it helps us to understand things that we might not figure out just in an individual interview because something that you say might spur a thought in your head. So that's the idea here. So what we'll do is we'll look at each message and we'll try to get a response from everybody. I can go to Patient 11 and Patient 10 last so you can have time to either write or type your thought and if you will read Patient 7's or Patient 11's if they have them written down.

**Moderator:** I'll just start with kind of an introductory question and you guys can tell us what you think and that is um... how do you think that ALS is generally portrayed in messages to the masses? What do you think?

**Patient 7:** They don't know what it is – I new it's name before diagnosis because of my job at the time.

**Patient 10:** I don't think ALS is portrayed very well. Occasionally you see somebody who has multiple functional problems. You know but I don't see anything any information that appeals to the masses gives them information to know about the disease. I see nothing like that.

**Patient 8:** When it is. I'll comment when I think the masses are hearing about it... I don't know that they really are and I don't know that... I personally don't feel like the masses hear enough about it.

**Patient 9:** I absolutely agree with him. I think for example Patient 11 and his wife said they have a 20-year experienced RN never even heard of it and that's somebody from the healthcare field. I mean I knew about it as a kid because of baseball and everything and Lou Gehrig. So unless you're familiar with sports and the history of baseball I mean ya know there's people now who are learning that I have it that have never heard of it. So I don't believe its portrayed to the masses at all.

**Patient 10:** It's interesting you should mention Lou Gehrig because there was some article in the newspaper that Lou Gehrig actually didn't have this disease so its not named for Lou Gehrig.



**Patient 9:** I did hear about that you never know though. That was 80 years ago.

**Patient 11:** That's a myth.

**Patient 10:** Oh it is... ok.

**Patient 12:** It was someone who was a public politician or something who just recently passed away.

**Patient 8:** The lady who was a good friend of Alex sink.

**Patient 12:** OK that's what it was.

**Patient 8:** The obit was in the paper a couple of weeks ago. That would have been an opportunity to have another public figure who was... might be something....if there were more public figures that were high profile.... People who could uh....

**Patient 8:** Be spokespersons or speak about it publicly

**Patient 9:** Yeah advocate in some way just acknowledge it.

**Patient 7:** Like a Michael J. Fox,

**Patient 9:** Yeah like a Parkinson's.

**Patient 8:** Yeah like Parkinson's.

**Patient 11:** We have Angela Lansbury.

**Patient 8:** Yeah what a great spokesperson... we never saw anything she did.

**Patient 11:** She doesn't even wear a red bracelet.

**Patient 8:** Or a pink one... my original red one.

**Patient 11:** They don't portray the use of communication devices. Can be typed in sometimes using AAC. All they see is the full speech.

**Moderator:** Anyone else...

**Patient 12:** The population is... Are there other illnesses that don't get very much attention in that population of 30 – 60 thousand that get a lot more attention than ALS?

**Patient 8:** I don't know of any.

**Patient 9:** From what I've researched there's no other fatal disease that you can be diagnosed with that doesn't get the notoriety that we do within that number of patients. I don't know of any. I've researched a good bit, and I don't know of any.

**Moderator:** There are nothing special about these. I really just arbitrarily picked some communication materials from ALS charity organizations and some from the news media themselves. We're kind of just using these as catalysts to understand your guys thoughts and feelings. I'll give you a few minutes to read this article. You may have already done so...

[show newsmagazine article]

**Moderator:** I'll ask everyone to share a reaction to what you read or a response. Anyone can start.

**Patient 8:** I remember seeing it and thinking this is good awareness, but also thinking that if his speech had been read by the computer or said by the computer rather than his wife, it would have had more affect.

**Patient 10:** I thought that this person was a gung-ho... ya know... a good example of the attitude one should have when they have this disease despite all the functional limitations he has. I think he sends a good message and I don't know how many people read this... I didn't. This is the first time I saw it.

**Patient 8.** Well it was on the... I knew about it through the ALS Association that he was going up there and I don't follow basketball and the final 4 so I wouldn't have watched it otherwise, but I did see that

**Patient 10:** I think your comment about using the voice machine...

**Patient 8:** You know he sat in his wheelchair and his wife read the speech to the players and I think it would have had more effect. it wouldn't have been as media friendly... because like Patient 11's voice computer... it doesn't put inflection in or anything.. but it says the words... I think that would have... but again it wouldn't have been media friendly.

**Patient 10:** I agree. It doesn't make a difference it shows about capable he is for expressing himself

**Patient 8:** It created quite a bit of awareness. How many of them... if you ask all the people who were watching that game... what disease did that guy have who gave the motivational speech... it would be interesting to see how many remembered?

**Patient 7:** That's my point. Who will remember at the end of the game?

**Patient 10:** I wonder why if it's beneficial when you have these articles to put down ALS/Lou Gehrig's Disease so it would bring more recognition to people.

**Patient 11:** I agree.

**Patient 8:** I think that's another obstacle we face is ... it's in this country known as ALS or Lou Gehrig's disease... To the rest of the world it's known as MND – motor neuron disease – so its all the same disease and we're going under three different names and there's only a small number of anyway so that divides us up even more.

**Moderator:** Anyone else have something to share about what they read?

**Patient 11:** Good article... gives effects of the disease and mechanisms of using a speaking machine but this publication is really speaking to the choir.

**Moderator:** How does reading something like this make you feel? Does it give you a feeling?

**Patient 8:** Uh. I can relate to what he's going through even though I'm not anywhere near as handicapped as he is right now, but I can relate to him.

**Patient 9:** I think the best thing there is that it's a whirlwind of emotions I mean... I remember I'm a basketball fan. I watched the game and saw it. At the time I was only 4 or 5 months into being diagnosed. I was still trying to find my place. It's inspirational but in the same time its kind of depressing to see where I could be 2 years from now 10 years from now whatever. To know that that's going to be me. It's a mixed bag. I mean just coming here and seeing fellow patients I mean I'm still mobile knowing that one day I'm going to be reliant on a chair or a speaking device. That's the only thing that hasn't affected me at all – my voice or anything. Knowing that I will lose that someday that's depressing. At the same time though... being able to reach out and touch somebody...and even if that inspired them or not to win the game and almost win the national championship. I can see myself doing something like this for my son's basketball team his football team... speaking to them. I coached all them growing up through now they're in high school. If I could be of some type of motivation to them then that inspires me to reach out to the youth too that I've touched along the way.

**Patient 10:** I think that I felt good – the fact that despite his handicapped to get to do what he wanted to enjoy the experience and things like that. I think that's important to people to know that he did enjoy this. And that's the way I felt about it.

**Patient 12:** Are we trying to see what ALS patients feel about this or would it work better in the general public?

**Moderator:** What you feel about it? So there are no real parameters. I'm really interested in understanding how... when you read things like this or when you see things on TV what goes through your mind?

**Patient 12:** Well at this place I feel that this is very big event this is a big victory for him and in my own personal life. It would make me feel better to see a smaller victory.

Somebody who something that you figured out how to get a lift to work better at your house or something like that or that you got your kids to come up and teach you how to use the computer.

**Patient 10:** I agree I think that's a good point.

**Patient 11:** Stress what he can do in spite of his progression. Concentrating on what he has – his abilities rather than what he lost. And that applies to each of the patients here.

**Patient 7:** Never heard of it or him before. My feeling is it's bullshit, but would anyone have listened (even on the computer). It's a bucket of anyone who can't fit anywhere else. The media moves on.

**Moderator:** Let's look at one other one. This is the last thing we're going to actually read. It's just two paragraphs.

**Patient 10:** I think that she mentions a lot of things in here. But I really would have liked to see a message from a president/CEO who has the disease itself. It becomes more credible in terms of the specific types of things that are happening. Rather than this rhetoric this thing that I read here that says we have reason to hope we have scientific research we have this we have that. I always find in diseases should be in charge where the CEO of the organization is to make the public more aware and more credible about what people go through. That's my gut reaction to this. Someone who knows what it is... who knows specific things rather than a as a researcher... that's what I think

**Patient 9:** I think this is a load of bull shit to be honest with you. You can change a couple of words here and it could be the statement for every single year. I get nothing out of reading that. It's all about hope and with advances in science and technology. I mean 25 years ago computers were coming about big. This tells me that in 25 years The ALS association has accomplished nothing.

**Patient 8:** A different picture will be there.

**Patient 9:** Basically in five years it will say the same exact thing and it will just have someone else's picture. It's done nothing.

**Patient 8:** Political fluff is what it is.

**Patient 9:** Exactly

**Patient 8:** Says all the right things and to me as a patient means very little.

**Moderator:** Anybody agree, disagree or want to share a different thought?

**Patient 7:** Blah, Blah, Blah. What has improved/changed in the past 25 years? One medication that might help for a few months. All 6 of us look and have different ALS.

**Patient 9:** Exactly. We're all affected differently.

**Patient 11:** Actually it has been 70 years of selling hope rather than stressing how technology has improved quality of life.

**Patient 12:** I'm not sure if I'm allowed to disagree. This lady is an administrator and keeping things straight and managing. This is typical. I wouldn't want to have an administrator be an adventurer going off to climb a mountain when you have ALS. I would want her to keep the administration on... The indication I get from what she said. This is better English. This is a national publication and this is a state publication. There were errors.

**Patient 11:** I want the bullshit to be highlighted in bullet points.

**Patient 9:** I look at this ...message from the President and CEO... and I think about how we are. How we're just locally trying to raise \$200,000 just for this ride. I look at this and all I see is salary. How much is she being paid? What is she really doing? She could have copied this from year one ALS Association. What does she really do? Why is there a president and CEO for this organization. A director maybe. It's not that I want to know salaries or anything. President and CEO tells me that she's making decent money. Cut out that little couple paragraphs that she wrote right there and donate some of her salary back to research. I'm not saying maybe she doesn't but I mean if she's most presidents and CEOs make 6 figures. I'm guessing. Again, I don't want to know what she makes or what you guys make for that Patient 9er. But that just tells same that big money big corporate talk and we don't need to be a corporation. This needs to be more about us. It needs to be more grassroots. More about us. Like somebody said, I'd rather see... instead of president/CEO... gave like a note from one of us patients... how we've changed how it's affected us. More about US. Because if not for us then guess what she doesn't have this job.

**Patient 10:** This is a big business model. This is how everything's set up today.

**Patient 9:** Well it shouldn't be

**Patient 10:** You're right.

**Patient 12:** The rest of this publication has more... nicer stuff.

**Patient 9:** Yeah but we're just basing it off of that one little thing.

**Patient 11:** Our chapter has one of the most effective communication practices... but mostly speaking to us and not to the masses. Piece by Piece display speaks to the public and should be nationalized.

**Moderator:** I'm going to ask you guys to look at a print advertisement.

**Patient 10:** Talk about depressing this is it. I think in some ways it's informative. It tells a real story. It's gripping in terms of the photography... showing the motor neurons. And the first is your legs. But its depressing but it's part of ALS so I don't really know why something like this shouldn't be...

**Moderator:** She says it's depressing. How does it make the rest of you feel?

**Patient 8:** I've had ALS a lot longer than you. I admire you guys with short-term diagnoses for even being here. I couldn't come here after first finding out about it. I would have found this depressing. Now I find it... ok... it's the truth and ALS... there's not cheery way to tell people about ALS. There's not... I've almost come to believe even more in this society we live in... the more um...shocking and in-your-face the more attention it's gonna get... and that is very hard on newly diagnosed people. I realize that. But it is the truth and I think it's a pretty good way of showing it. Without being more graphic... it's showing how there is disconnect. It should be in his arms and his other leg.

**Patient 10:** Well they say this is the way it starts... in your legs and then it goes to the rest of you. But I think it's a gripping picture. It demands attention.

**Patient 9:** First of all, I'll just go with the words. It pisses me off to be honest with you. Like Patient 11 said, for 70 years now, the public has somewhat known this disease, and there's no answer about why it affects it all differently to start out with. That pisses me off. 70 years of research supposedly. Why does it affect us all differently? That's what I wanna know... Why! Why can I still talk, and she can't. And How is it she can still write but I can barely hold a pen. Give me the answers to that! As far as the picture, it's depressing. Myself still having small children, a 19-year-old, a 13-year-old, and a 14-year-old...it's depressing for me for this little boy. Because I miss going out and being able to throw a baseball or the football with my son and coaching them... That's all I've done for the last 15 years is what depresses me about this. This little boy is going to miss out on all that with his dad.

**Patient 12:** It is depressing because it's getting the point across.

**Patient 8:** It is depressing. The whole disease is depressing.

**Patient 12:** Is this published or is this just a mock-up?

**Patient 10:** What is SLA?

**Moderator:** It's French. The ALS Society of Canada.

**Patient 11:** Print too small for old people. Portrays reality.

**Patient 7:** Great future. It's hard to hear, but its true – you will never get any better than you are today. FYI – my doctor's eyes told me everything – she had been crying prior to

coming back in the patient's room to tell me. I'm not allowed to be alone with my grandson in a room – there must be another person in the room.

**Patient 10:** You're not allowed to be in the room with your grandson

**Patient 7:** I've fallen.

**Patient 11:** ALS published that 500 million has been spent on research and what has it produced?

**Patient 10:** Rilutek.

**Patient 7:** Ine medication that might help for a few months.

**Patient 12:** I think we're kind of railing against the disease and we should be evaluating these advertisements.

**Moderator:** When I ask how this makes you feel, what I'm hearing is frustrated and angry.

**Patient 10:** And depressed.

**Patient 8:** And on that cheery note...

**Patient 12:** If I can add things to... could be a little bit clearly... just the graphics. It's got a lamp. It's a little bit unclear.

**Patient 8:** I can see your point with all the different lines.

**Patient 9:** They're making it to be like a puzzle. The message going from your brain to your foot, how does it get there.

**Patient 10:** And the break showing

**Patient 11:** My emotion is frustrated.

**Moderator:** Let's go to the news story and get your guys' thought about this so we don't take too much of your time.

**Moderator:** If the purpose of this focus group is to get people's attitudes and opinions about mass messages about ALS. What should we have talked about so far that we haven't?

**Patient 10:** I think we touched on this. But to go through all these years and all these publication and all these messages and things... and have accomplished so little... even to detect an absolute diagnosis of ALS... is really hard to understand.

**Moderator:** Any other thoughts on that? If the purpose of this is to understand your attitudes and opinions toward communications about ALS, what should we have talked about and brought up that we didn't. What would you want us to know?

**Patient 8:** We need more mass communication... any mass communication as far as I'm concerned.

**Patient 9:** More mass communication absolutely. I mean I don't know what the costs are to print out these handy-dandy things that we get, but it's preaching to the choir why not take out a 30-second ad during the super-bowl – where you're gonna touch a hundred million people. That will touch people. Save the money on printing these out monthly or quarterly or however often and put the money toward that. Then people might notice. That way people see. Make a commercial something about this – the kids helping his dad put shoes on. That gets the message across. Because if I was flipping through a magazine and saw this and I didn't know about the disease. I would be like oh ok. Because the print's small enough where I have no idea what that's about and I might just fly right through that. Give it some type of headline where it says ALS is a devastating disease. Something... an everyday person looking at that, flipping through a magazine wouldn't stop.

**Moderator:** Anybody else?

**Patient 10:** I'd like to see some more interviews with people who have the disease and people who act as caregivers in some of these publications. So they can actually get insight into some people's thought and attitudes and adaptabilities and things like that.

**Patient 9:** I know it's a good thing that happened with Patient 8 in Washington with the CNN and everything with the Piece by Piece display. That gets out. People watch TV people watch CNN. Even if you printed out one of these a small thing that went out to the public. I worked at the post office for 15 years... so I know what people do. They will look at this and if it didn't affect them they'll throw it right into the garbage. I've seen it. I know what people do with junk mail. It's gotta be something that's gonna catch their attention. Junk mailings is not the way to do it. It's through the media. Through television.

**Moderator:** What are your thoughts and feelings?

**Patient 9:** That's awesome. That's the type of communication that needs to be out there. That really.

**Patient 8:** but repeatedly.

**Patient 9:** repeatedly, exactly. That's the message that needs to be put out there.

**Patient 7:** a heartwarming story. No one will remember the next morning.



**Patient 9:** That's true.

**Patient 10:** The thing is if you repeat this time after time after time, people start remembering. It just can't be one isolated incident.

**Patient 9:** Exactly

**Patient 8:** The bit I did with Todd Kalas and my girls at the rays game year after that. It was on TV 30 seconds. I had more people say hey I saw you on TV. My eye doctor who I'd met the day before wrote me a note – hey I saw you on TV. That was inspirational. One of my old sales reps I hadn't seen in 5 or 10 years maybe called me up... I saw you on TV. So that type of media works. When I had more response than I've done as you know... as my agent... numerous interviews these past couple of years... by far that was the most response I got from the general public that saw.

**Moderator:** Any other comments that we want to share about that.

**Patient 11:** doesn't really explain ALS. If it portrays ALS then it's no big deal, so quit whining. In my 5 years, most communication is limited to ALS community and not public or more important to the outer healthcare fields that we depend on for life and generally appallingly ignorant. We have annual meeting in DC, but Piece by Piece was only public awareness attempt. Annual meeting cost well over 1 million and opportunity has been squandered. They had 4 transvestites in the hill and they didn't know we were in town.

**Patient 12:** If you had a radio speaker... that's media. I mean if you want to evaluate. You know they have a lot of talk shows... they have that house guy do a...

**Patient 9:** Like on an episode of grey's anatomy or house

**Patient 8:** well he's our spokesman now or possibly.

**Patient 7:** I don't know, for me I can hear and understand. People think because I can't talk, I can't hear – I've listened to people say things they would never say to my face if they knew I could hear and understand.

**Moderator:** [shows psa]

**Patient 11:** Spot on.

**Patient 12:** Much much more gripping.

**Moderator:** How does it make you feel?

**Patient 12:** I feel less depressed on that one.

**Patient 11:** It reflects reality in a very short time.

**Patient 7:** Wow, there is no cure. If there were a cure we could have an episode on house.

**Moderator:** Any more thoughts or feelings?

## APPENDIX K: JACKSONVILLE FOCUS GROUP TRANSCRIPT

**Moderator:** Tell us how long you've been living with ALS to start with.

**Patient 13:** My name's Patient 13. I've been living with it for about a year now. I first went to my neurologist because my hands were getting weak with me and I seemed like I couldn't handle things so I thought I might have carpal tunnel or something. And then he started doing all this fancy stuff where they shock you and see what your reactions are and everything. And then that's when they started saying we think you got it. So then they referred me to the Veterans. And I've been doing most of mine through the veterans' administration, primarily in Lake City.

**Patient 14:** My name is Patient 14. I've had it for about 3 and half years. It started in my feet and now it started in my hands.

**Patient 15:** I'm Patient 15. I had my first symptoms January 2010. Same thing right hand and carpal tunnel.

**Patient 16:** Patient 16, and I had my first symptoms the end of January of this year. So not too long. My diagnosis was May 5<sup>th</sup>.

**Patient 17:** I'm Patient 17 and mine started out with my feet as well just like Patient 14's and I started going to a doctor in January about it but I wasn't diagnosed until May 8<sup>th</sup> of this year.

**Patient 18:** My name's Patient 18 and I started falling late last year and then started having the test at the beginning of November, January, February, and I was finally diagnosed Friday, May 13<sup>th</sup> of this year. My left leg is a little weak and I'm severely off balance, but my hands and arms have gone first.

**Patient 19:** My name's Patient 19. My first symptoms were probably in October of 08. Started with the little muscle tremors in my right arm. I had gone to my primary care doctor. He tried some different treatment and medication. And then in March of 09 he referred me to a neurologist. He didn't feel I think at that time it was ALS. He said let's just keep an eye on you and said come back in 6 months. And then in May I fell. I went back and said something's not right. He did the nerve conduction test, blood test, MRI. The muscle spasms at that point had moved over to my left arm. He then indicated ALS was possible, but he didn't diagnose with ALS at that time. I went back in January of 2010 I said ok it's time you need to tell me. What is it? He did the second nerve conduction test and at that time he confirmed it had progressed to my back and my

muscles. And he diagnosed me so that was January 2010 with ALS. It is still predominantly in my arms. My arms are weak. I have muscle spasms in my legs, but the last visit was June. He said I see just a slight weakness in the legs, but pretty much with my legs I can get around. It's with my arms.

**Moderator:** [description of process] Have you seen mass messages about ALS? If so, What have you thought about them? The ones that are in your memory. When I say a mass message about ALS, I mean any communication that is intended for more than one person. That could be... a news story, a newspaper article, a newsletter that you got from the ALS office, a commercial, anything that's intended for a large audience. Have you seen them, what do you think about them?

**Patient 15:** I've been following the New York Times article. There's a fellow with ALS that has been writing very poignantly about the disease, very openly and frankly. I share that with a lot of people I know.

**Patient 13:** the VA has been very cooperative in this field. They furnish DVDs of things very similar to what we're doing right now with different doctors talking about different things. Plus some publications. I guess it's always scary when you start looking at DVDs and see what can happen and so kind of to the back of your mind and say I don't want to know. I'll just wait and see what happens and take it when it comes on and that's kind of the way you want to look at it. But realistically they've got plenty of information out there so it's just a matter of how much you want to get involved.

**Patient 19:** For me, I struggle between wanting to know and not wanting to know. So I like to take that mass information in bits and pieces. And not just sit in front of the computer and read and read and read all at one time. But I like to take in a little bit of information at a time myself.

**Moderator:** What do you think about the amount of information that you're seeing about ALS?

**Patient 18:** I don't think that I have seen any information about ALS at all until I acquired the disease. I don't think I ever saw an ad other than Lou Gehrig's Birthday information.

I don't think there was anything out there. Now I'm on the forum. There's all kind of information. I do want to know. I don't want to be frightened by different things that appear. But the forum is very good because it has a lot of help for people on there. The information from the ALS foundation is amazing. That's very good that they send you.

**Moderator:** What about everybody else. Do you agree? Pre-diagnosis vs. post-diagnosis? The amount of information?

**Patient 19:** I think some of that is because you don't pay attention to it until you've been diagnosed with it. I think it is probably there. I don't think there is enough coverage on it

to make the public aware. Especially people that do not have it to be aware of how prevalent it really is out there. I can say that even for when I was working I think there was a car wash here. I think Bowl's had a car wash for ALS. A friend from work mentioned it to me. I think if I hadn't have had it, I don't think Kathy would have thought anything about it. I think we are definitely more sensitive and more aware of it because we have the disease.

**Patient 18:** Well even with the Lou Gehrig ads, they never really explain the disease. Not that I had a real interest in it, but I had no idea what the disease was all about.

**Patient 15:** Well that's two different things. There's the information you go seek because you got it. Or there's the information that comes across in the mass media. In terms of mass media, you only hear about it when somebody like Lou Gehrig or Tuesday's with Morrie which is a huge benefit to educating about ALS. But even my friends who read the book when it came out... nobody remember what they read. And it was a very powerful story. Unless you have that vested interest, you don't go looking for information, you don't necessarily retain mass media messages.

**Moderator:** With that, I'm going to pass out the first two messages that I'd like you to take a look at.

[read 2 news magazine articles]

**Moderator:** What was your first reaction to reading 25 years of hope?

**Patient 13:** Disappointing. To think that it's gone over 25 years and they have no idea what causes it or how to cure it. I think that's a little bit frustrating, because I don't know many other disease that's been like that.

**Patient 15:** Well actually it said 25 years The ALS Association has been involved. The disease was first written about 150 years ago, which makes it 10 times worse.

**Patient 17:** It just took Lou Gehrig to make it famous.

**Patient 13:** I've had people say what's wrong with you. You tell them they say what is that. Then if you mention Lou Gehrig they seem to associate with it.

**Patient 18:** and it was called something else in Europe.

**Patient 15:** Motor Neuron Disease.

**Patient 18:** No it was. Yes that's how they refer to it. Yes Charcot in Europe a long time ago. Just I think that there's so few people that have it that they don't pay that much of attention to it.

**Patient 16:** I thought that I was thankful for The ALS Association and people willing to serve.

**Patient 14:** Somebody does care

**Patient 17:** When my dad had it, they didn't have The ALS Association. My mom said no one would help them with anything. No one knew anything. And so my mom is just blown away with all of the help I'm getting.

**Moderator:** What kind of feelings does this make you have, any?

**Patient 14:** Makes me feel good that somebody out there does care.

**Moderator:** Let's go over to the matt white article. What was the meaning of this article for you personally?

**Patient 14:** If you put your mind to it, you can do anything.

**Patient 16:** He's passionate about his team, and I'm passionate about mine so I can relate.

**Patient 13:** To me, just reading the story about what somebody went through, what they were able to do doesn't touch you as much as seeing pictures of them. If you actually see it on a DVD or on a movie or the news and see the expressions of the people and the reaction. To me, that touches you more than just casual reading. Not that you can't be touched a little bit with this, but it may be hard to comprehend a lot of it.

**Patient 16:** I think he had a positive outlook too. Take it one day at a time. Don't look too far ahead or back.

**Patient 18:** That's hard to do.

**Patient 15:** I'm surprised I hadn't heard about that. Of course, I don't watch TV at all.

**Moderator:** Do either of these articles make you feel a certain way about the organization that published it?

**Patient 15:** Neutral.

**Moderator:** Could either of these articles be improved in any way? And if so, how.

**Patient 15:** Definitely. I'm a journalist all my life. So don't get me started.

**Moderator:** Anybody else?

**Patient 17:** In the article about Matt White, it doesn't say anything about his struggles or what he has to deal with. Everyone has questions about it. No one understands it. It's kind of frustrating.

**Moderator:** So you would like to have more information about the struggles of everyday life.

**Patient 17:** Right because no one understands it. People are awe you poor thing. And they're like oh why can't you be here on time. That happened to my mom. They wanted to know why they couldn't get to Sunday school on time. The man said. Why don't you get up earlier, and my mom said, I'll just stay up all night then. I mean people just don't understand it and the everyday things you have to deal with. They don't see that and they don't think you have struggles.

**Patient 18:** Well and you don't know how many people had to help him on that journey.

**Patient 15:** That's my problem with both of these. They're written for the general population. Just give a snippet, which truly does nothing... nothing to really understand what it's like. The guy writing the New York times articles right now gives nitty gritty no holds bar. Very powerful writing.

**Moderator:** What does everyone else think about that approach... nitty gritty no holds barred.

**Patient 19:** I agree. I think sometimes the shock treatment works better. People are not gonna understand unless you really delve into it. Because a lot of people I know for me myself you go day to day and you push and you push and I don't open up to what your daily struggles are. If you do, sometimes I think I'll fall apart. So it's best just to keep trudging along. So if I'm not and some of you guys aren't then perhaps it needs to be written about and so people can read about it. Because I think this is more of a basketball story than what he has overcome to get there. The two sentences from his speech speak more volumes than the article itself.

**Patient 13:** One thing that kind of jumped out to me is the first line. After suffering for 10 years. All of us when we talked about ours it's been three or four years at the most. It would be interesting to know how much change he's had in his life in 10 years. Has it got extremely worse? Or maybe how he detected it at the very beginning. There's probably other places you could go to find all that out. But it's the first thing I saw. Hey 10 years. Maybe that's encouraging a little bit if he's gone 10 years and still going.

**Patient 15:** And that kind of writing does a huge disservice to us because my friends will say "Wow. He lived 10 years. You can be Stephen Hawking." No you have to look at the mean.

**Moderator:** Say that that's not average?

**All:** Agree

**Patient 15:** The mean is three years max. Be honest about this stuff. I hate it when it's glossed over.

**Moderator:** Don't sugar coat it you're saying?

**Patient 15:** Be more realistic. Say suffered for 10 years. Put a parentheses "Which is pretty unusual most people are dead in 3." It adds more weight to the story and provides information. Which is essential to good writing. You have to put it in perspective. The role in journalism is if you bring it up you have to explain it.

**Moderator:** Patient 16, were you going to say something?

**Patient 16:** I was just going to say I noticed he's had the surgery to remove his voice box and breathe through. And when you can't talk anymore they have that surgery. Nobody else would know about it unless they were an ear, nose, throat doctor.

**Moderator:** At this time, I'd like to show you a little bit of visual information.  
[Show print advertisement from ALS Society of Canada]

**Patient 14:** It's very true. Good

**Patient 15:** Powerful

**Patient 19:** Emotional

**Patient 15:** Doesn't mince words. That's what I like. Brutal honesty

**Patient 19:** Now the question would be now we like it how would the general public view it and they're probably not going to like such the cold hard facts.

**Patient 15:** I disagree. I think it makes a bigger impact and when you make a big impact so you don't go la la la and turn the page.

**Patient 18:** Yeah but I think the general public doesn't like to look at people with disabilities. I think it would be different for them and for us that understands that person.

**Moderator:** This image evokes emotion. What are those emotions?

**Patient 15:** There I am. (Laughs)

**Patient 14:** I've got an 8-year-old who could do that too.

**Patient 17:** People with young children. I have a 5 and a year old (takes a deep breath).



**Patient 16:** It overwhelmed me. (Cries) (Patient 15 hugs her)

**Moderator:** Is this something you would want to see?

**Patient 13:** Do you think that just by looking at this picture that they would really know how bad you are? He's got a little trouble tying his shoe or something. Looking at his right hand you kind of sympathize with this if you've gone through some of that. But I don't know that it would impact the public that they would realize how drastic this is.

**Patient 19:** I think the article though if you read what you just read. That's pretty devastating.

**Moderator:** After looking at the picture do you think you would read what's at the bottom?

**Patient 13:** Especially trying to figure out what's on his hand.

**Moderator:** What are your thoughts since you don't know about the organization that produced this?

**Patient 18:** They know what they're talking about.

**Patient 17:** They know the facts and they're not afraid to tell it.

**Moderator:** Do you guys respect that or do you think something like this shouldn't be out there?

**Patient 15:** I respect it.

**Patient 17:** Because it is what it is.

**Patient 14:** It is what it is.

**Moderator:** I know that some of this is tough to see but what you're telling us is very valuable because it's your opinions that matter the most.  
[Show Wisconsin Chapter print ad]

**Patient 15:** I like the play on words.

**Patient 17:** They're saying that anybody can get it. It doesn't discriminate.

**Moderator:** Is that a message you like to see?

**Patient 17:** Yes.

**Moderator:** Does it evoke any emotion at all?

**Moderator:** What would your thoughts be about the organization that produced it?

**Patient 13:** I think the one thing I see in the pictures. We usually think of Lou Gehrig's disease for old timers, but I see young faces in this. And that may be one thing that they're trying to get you to realize. You don't have to be a senior citizen to get this.

**Patient 14:** I know someone who died at the age of 45.

**Moderator:** Let's go to a news story.

**Patient 18:** It did not explain the disease. It said that he had it but it did not give any details.

**Moderator:** And that's what you want people to know.

**Patient 18:** Yes.

**Moderator:** So what I'm hearing is that you find that people have heard of the disease but don't understand the impact.

**Patient 19:** I think everybody's heard of it because of Lou Gehrig. But I think you're right even 'til I was diagnosed with it. I had seen the movie many many times, sat, and cried through it. But had no idea of truly what it was about. Because even the movie. He had the weakening of the arm and that's where it started. But even the movie from what I recall didn't go into a whole lot of the diagnosis. Long term affects. I think that's what people need to be educated on.

**Moderator:** Does this evoke any emotions?

**Patient 19:** Sure. Sympathy.

**Patient 13:** Having his children there puts a little more emotion in it too.

**Moderator:** For you, does this carry any meaning personally?

**Patient 15:** One more person. I'm happy that the media has done something to show it. The more the media keeps it in the public's face, the more they hear it, the more they might understand it. But at least when you say you have ALS, they go oh. Instead of What's that? Oh Lou Gehrig's disease. Oh what's that? So the more information that's out there helps us all then we don't have to keep explaining what we have.

**Moderator:** I heard one suggestion for improvement. More information about the disease itself any other ways it could be improved?

**Patient 17:** It didn't say how he was affected or anything. He was still walking he could still raise his arms, and it looked like there wasn't much wrong with him so people may say oh that's no big deal.

**Patient 13:** But if you look where he was standing. He wasn't but about 10 or 15 feet away from the catcher. That will let you know pretty quickly that he didn't have any strength there.

**Patient 17:** I know but still.

**Patient 15:** How many people would recognize that if they didn't have ALS.

**Patient 18:** He didn't have any braces. He didn't have a wheelchair. He didn't have a walker. There was nothing that showed. Yes he looked a little disabled. Nothing to compare with what ALS does.

**Moderator:** Do you prefer a message that is more hopeful or very shocking?

**Patient 15:** The shocking one was very powerful. I think powerful messages are always better than shallow messages. Whatever it is, especially ALS.

**Patient 17:** I think that this is better, but I think that you should say what it's all about. And also remind us that it's not a death sentence today. You can still live. You can still enjoy your life.

**Moderator:** So you're saying tell the truth of it, but portray the hope as well?

**Patient 17:** Right

**Moderator:** [show PSA]

**Patient 13:** They might think you're crazy showing the pictures that's in there. The way you grab people. I'm not sure how well that would go over with people you don't know

**Patient 15:** I think the humor is priceless. It works. It grabs you in to what's gonna happen next. And when you get there its ALS staring at you. Good very good.

**Patient 17:** It's a reminder to do what you do while you can still do it.

**Moderator:** Any emotions?

**Patient 17:** Sad

**Patient 15:** I know it's humor so...

**Patient 17:** The beginning is funny but the reality of it is yeah that's cute but it kills people.

**Moderator:** Would it compel people to donate?

**Patient 13:** I don't think it would unless you put a good explanation as to why they're doing these what I would call weird things. And go and explain why they're doing it I think with captions at the end that helps explain it a little bit why. Because you're losing your ability to use your legs and your arms. But at first to me it seemed like its out of line to react grabbing a waitress and start squeezing them would probably get the police called on you or something.

**Moderator:** Any thoughts about whoever produced this?

**Patient 13:** I think they're trying to get your attention.

**Moderator:** Does it make you think positively or negatively?

**Patient 13:** You have to see the whole thing to get a good comprehension of what it's about.

**Moderator:** That's all really valuable information. If the purpose here was to get an idea of people's attitudes and experiences of mass communications about the ALS disease. Is there anything that we didn't talk about that we should have talked about?

**Patient 15:** Well maybe set parameters in the beginning regarding mass media that comes to you versus that which you go see.

**Moderator:** is there anything you would like us to know about ALS communications that you've seen in the past or today that we should have addressed.

**Patient 13:** Have we actually told somebody if they want to get more information where they could go to get it. Have we really said now there's websites or there's different places that you could get different information. Have we really said that?

**Patient 18:** Do you think people would really want more information if they didn't already have some contact with the disease? If it was talking about cancer out there, I don't know anybody in my immediate family that has cancer so I probably wouldn't go anywhere to look any further. It would just be an ad to me.

**Patient 13:** Don't you think though if it's starting to come on and you see signs? You'd like to know where could I go if I want to keep driving. Where could I go to get a van that's wheelchair accessible? And what they can do to make it where I can maybe even drive it myself if I wanted to? How would you know all these things?

**Patient 18:** But that's what I said. If you didn't have some inkling as to what that was all about. I don't think you would follow it any further than just looking at it.

**Patient 15:** Really needs to say call now, act now, go there. Take people to action.

## APPENDIX L: BOYNTON BEACH FOCUS GROUP TRANSCRIPT

**Moderator:** Let me start out by asking a general question. How do you think ALS is generally portrayed in mass communications? And by mass communications I mean any message that has been communicated to many people at once, like a newspaper article, a TV news story, an advertisement, a newsletter article, etc.

**Patient 24:** I've haven't seen anything. I've seen nothing.

**Patient 23:** I always read the articles whether it's the New York times or other newspapers. You learn a lot like there was an article about Stephen Hawking that because he has had ALS for 44 years. He's still functioning as not a doctor as a professor at Cambridge and two years ago he got on a space ship. A Russian space ship to the moon, and he is still teaching at Cambridge. There's always hope. I also read about [doctor name] that you don't know you're going to die from ALS. There's always hope. Don't every give up. And that's what [doctor name] has said.

**Moderator:** And those messages are messages you like to see? Messages of hope?

**Patient 23:** Yes.

**Patient 21:** There's no communication that tells ALS patients about scans and treatments.

**Patient 22:** I have not seen anything on TV. Mostly see articles on research. Not much on the true impact of ALS on individuals and families?

**Moderator:** Is that something you'd like to see more of?

**Patient 22:** Yes.

**Patient 20:** There is not enough information out there. Find most on Internet.

**Moderator:** We're going to look at a variety of articles, watch some TV pieces, and the purpose is for you to tell me how you feel about it, what it makes you think, how you find meaning is.

**Patient 21:** Even doctors don't know about ALS.

**Patient 20:** Amen.

**Patient 22:** Yes.

**Patient 23:** When I went to see the doctor on Friday he asked me how long I've had ALS. I said 13 years since my diagnosis. He was blown away. He was an expert on those symptoms – never heard of someone living for more than a few years. He was an expert and he was not aware of it. What really surprised me that he didn't have that.

**Patient 24:** The neurosurgeon that operated on me in Miami, we told him I had ALS and his chin just dropped. He had no knowledge of it. So it's a big problem among doctors.

**Patient 22:** Huge awareness problem in healthcare patients can mislead.

**Patient 21:** I'm getting radiation now for excessive saliva and the oncology doctor at the center knows nothing.

**Moderator:** Let's start by taking a look at 25 years of hope. What are your first thoughts?

**Moderator:** Patient 23? Do you have any thoughts?

**Patient 23:** Not really. It's a good article. Nothing stands out.

**Moderator:** Patient 24?

**Patient 24:** I guess it's always the hope you can fix the problem. How deep are we going to fix this problem?

**Moderator:** As deep as you want?

**Patient 24:** I know nothing about ALS I have no idea how much money is going to research annually to help. Where is the hope? Where is the research being done in the best places. Things like that. I have no idea.

**Moderator:** Are you saying you would like this include some more details like that?

**Patient 24:** Yep, like MS. We know Jerry Lewis brings in 100 million dollars a year or whatever. Where are we with ALS? Where's the fullness of it. Are we just a small group like this... friends? Where is the major push?

**Moderator:** So you're looking for some specific information?

**Patient 24:** Would be nice to know.

**Patient 21:** Parkinson's and dementia haven't been solved. The brain is very complicated, and it will be hundreds of years until they find a cure, if ever.

**Moderator:** So are you saying this is too hopeful for you?

**Patient 21:** (shakes her head, yes)

**Patient 22:** Overly optimistic. Association propaganda.

**Patient 20:** Amen.

**Moderator:** So the ladies' think overly optimistic. Patient 23 would you agree or disagree?

**Patient 23:** I would agree but what's interesting. I was first diagnosed in 1998. Patient 23 Shands was then affiliated with ALS. [Name] was the role of where our care coordinator is now came over to my house to visit. Brought some videos. My wife and I watched that tape and were devastated. They tried to give us a fundraising tape they tried to what would happen in a matter of time they tried to raise money for the ALS Association. We were very depressed for days, and what you need to show indicate everything to have hope like [doctor name] said. Don't kill yourself. This person that had ALS and wanted to take his boat on the inter-coastal, and he did this alone, and he had a way to communicate with the outside world, I haven't read the book yet, but I intend to get it to read his story. So I think the main thing with people when they are first diagnosed is to give them some hope because we are all different the progression. It could speed up or slow down. And to keep that hope going is what is helpful to anyone first diagnosed with ALS.

**Patient 21:** He died 3 months later.

**Patient 23:** You read the book.

[Everyone laughs]

**Patient 24:** I think you want to show that people that are still working with ALS. They're doing something that's taking away them thinking about the ALS. They need to be able to concentrate on something even if it's two hours a day it's going to be a big help.

**Patient 22:** I do not think we need to take hope away, but in reality, research is far from a cure. Association does wonderful things that we should be focused on.

**Moderator:** So you like a hopeful message, yet a realistic message?

**Patient 22:** Exactly

**Patient 21:** It's not going to be in our lifetime.

**Moderator:** And you don't like people saying that it will be?



**Patient 21:** Shakes her head no.

**Patient 23:** I don't think there will be a cure, but I believe in our lifetime it is possible to discover a drug that could slow the progression.

**Moderator:** [Reads Florida Chapter Newsmagazine Article] What are your first thoughts or feelings?

**Patient 24:** I think the first thing that I think of is. I have ALS I accept ALS, now what am I gonna do. Move forward try to do things. You never want to accept something like that, but either way it's reality and there's no way around it. You're setting your mind to think of something else. This article is very interesting. I'm kept alive by my graduate kids that send me Facebook and emails telephone. These are kids that came from absolutely no money. We have a foundation to educate kids, get them a good job. These kids are absolutely incredible and they keep in touch with me. We built a school for kids that came from dirt floors, no water, no electricity. In Honduras. Smart as hell, no opportunity. We've put over a thousand kids. They have good jobs today.

**Patient 23:** I know about this story, and I brought it to support group meeting the article We did discuss it. I think it is important that it indicate that to keep going you need to keep your mind occupied. I am still practicing law as a New York lawyer. I do that in order to keep my mind away from thinking about my illness to thinking about my law practice to keep my mind off of it. I think it is important to have something. Like [patient name] was building these miniature ships, and he works on the computer. And that is important with ALS to keep your mind going and keep yourself occupied as best you can.

**Moderator:** So you really identify with that last wrote with he said?

**Patient 23:** yes

**Patient 20:** Acceptance is the hard part as it seems to come out of the blue. I had never known anyone with this disease.

**Patient 22:** Inspirational. Reality-based. Great example that mind stays healthy even if limbs cannot work.

**Moderator:** So that was more of the message that you like? It was reality based but it had some good facts in it?

**Patient 22:** Yes. I think it's a better way to educate people.

**Patient 21:** I keep getting weaker. Now I can't walk. I don't expect to be like Patient 23 or [patient name]. I don't expect to live more than a year because bulbar onset goes faster than muscular ALS. I can't live in the moment because I can't speak and paper towels in my mouth make people look at me like I'm crazy.

**Moderator:** You said you can or you can't live in the moment.

**Patient 21:** Cannot.

**Moderator:** Any other comments on that article?

[Show a Wisconsin Chapter print advertisement]

**Moderator:** Does this make you think or feel anything specific?

**Patient 24:** It's Lou Gehrig. His famous last words as a Yankee and that was back in the 50s. I was diagnosed with ALS in 2010, and I had never heard the name again. I never heard of ALS again until 2010. Lou Gehrig's Disease.

**Moderator:** So you're saying you don't think people would look at that and know what it is?

**Patient 24:** A lot of them. Look at the age groups. How many young people know Lou Gehrig. He was out of there in the 40s.

**Patient 21:** Young people don't know who Lou Gehrig again.

**Patient 24:** Exactly, no meaning.

**Patient 22:** It catches interest, but then goes nowhere. So easy to forget. I agree with Patient 24.

**Moderator:** I can tell Patient 22 you like more specific information?

**Patient 20:** It has been a long time since Lou Gehrig passed from him. I don't understand why there has not been much progress.

**Moderator:** Patient 21 agrees with Patient 22's comment earlier. Patient 23 did you have anything that came to mind?

**Patient 23:** Just one comment. In my fundraising which I've done now for 10 years if I don't mention Lou Gehrig many people will not know what ALS is. Kind of like Multiple Sclerosis, they don't know what that is, so I make mention of Lou Gehrig in the beginning so everyone knows.

Most people I know who Lou Gehrig is and know about Lou Gehrig's disease. They don't know about ALS. So I think it's important that you tell them what ALS is by mentioning Lou Gehrig. In fundraising.

**Patient 22:** I think we need to educate people to get their support.

**Patient 24:** I work internationally raising money around the world for this foundation, and when I mention ALS nobody has any idea. Germany, Asia, other parts of the world. It's strictly North America? Where does it evolve to? Among business people, not one of them knew ALS?

**Patient 23:** Outside of the US they call it Motor Neuron Disease. And that's in England and in Europe. They don't know about Lou Gehrig's Disease.

**Patient 22:** You are correct.

**Moderator:** Show ALS Society of Canada Print Ad. What's your feeling about that?

**Patient 24:** You can probably read a lot of articles like that. Which one are you going to donate to? You're going to pick the one you're most associated with. There's hospice there's the cancer society. Whether it's united way. Not enough people know about ALS, Motor Neuron Disease, to contribute. We get phone calls through our store everyday asking for money from different organizations. How do you find what that is.

**Moderator:** So you're speaking to the competition amongst charities?

**Patient 24:** That's correct. It's very competitive out there. It's getting tougher as the economy gets worse.

**Patient 21:** It's an orphan disease. People will donate to breast cancer before this disease.

**Patient 22:** I like that. It is eye-catching and gives a lot of information in a few words.

**Patient 20:** Yes.

**Moderator:** So you guys like that shocking message, would you agree?

**Patient 20:** Right to the point.

**Patient 22:** It grabs attention.

**Patient 23:** I agree.

**Moderator:** How does this ad make you feel?

**Patient 23:** If it's a fundraising tool, so it's not meant for someone who has ALS, so it may be a little bit depressing.

**Moderator:** But since it's a mass message you may still encounter it, and in that situation it would make you feel a little bit depressed?

**Patient 23:** Yes.

**Patient 20:** Right.

**Patient 24:** I don't mean to be smart, but I don't know what disease isn't depressing.

**Patient 22:** I do not have an issue with it.

**Moderator:** Show Local News Story

**Patient 24:** Interesting. My first thought would be Yankee stadium. I would go back and I could see the Steinbrenner's, and say you have an icon. It's Lou Gehrig's. How can we make this even stronger? He's a New York Yankee and see if they would stand behind and be the leaders. They carry a very powerful guy. If you had somebody like that. Yankee stadium holds 65,000 people. Could we get it started in a different manner. A very well thought-out program.

**Patient 23:** It was very inspirational. He has a very good attitude about his illness.

**Patient 23:** Was it inspiring to you too Patient 24?

**Patient 24:** My support is here my brother comes in every three months. So it's living for the moment going forward.

**Moderator:** Good so you can identify.

**Patient 21:** Stephen Hawking is not supportive of fundraising for us. If he did it would spread the word more.

**Moderator:** So this reminds you of a need for more awareness.

**Patient 22:** Message is educational and personal at the same time. I like his attitude.

**Patient 20:** That one has it all inspirational yet getting the word out about ALS.

**Patient 24:** I think the other thing you're gonna see they just analyzed I think it was 47 NFL players that probably have ALS, and now they're going back and doing more research. So there's ways out there to get the message out in a bigger way.

**Moderator:** I hear that this reminds you of a need for more awareness, but you also find it to be inspirational and you like an inspirational message?

**Patient 20:** Yes.

**Moderator:** How does ALS Society of Canada PSA make you feel?

**Patient 20:** Sad.

**Patient 23:** I didn't get it because I couldn't read the titles.

**Moderator:** [reads copy]

**Patient 23:** I just didn't get the ad. I didn't get it. I was unimpressed.

**Patient 24:** I had trouble with the ad.

**Patient 21:** I think it is too invasive.

**Moderator:** Does it make you feel a certain way?

**Patient 20:** Sad.

**Moderator:** Do you agree?

**Patient 22:** It did not grab me. Looked like inappropriate behavior.

**Moderator:** [show PSA again]

**Patient 21:** I agree with Patient 22.

**Patient 22:** I found the behavior distracted from the message.

**Patient 20:** Anyone if we knew this was coming would probably do things differently. And find that we hug and dance more. Although I have done a lot of both.

**Patient 24:** I look at it a little bit differently. The hugging is good. I guess I wish there would have been somebody to hug the first time I fell. And then I'm lying there waiting for two police man to come and pick me up off the ground. I think everybody probably gets a different thought.

**Patient 22:** I am currently losing hands so I would have expected the message to be upsetting but it was not.

**Moderator:** if the purpose of this focus group was to understand your attitudes and opinions about mass messages of ALS. What should we have talked about that we haven't?

**Patient 23:** I would like to say something on the last message. There are people who lose their arms and walk or in an auto accident. And I think this ad where someone can use their arms. Why don't you say in the text it's related to it. Because of ALS that they lost their arms. But I was unimpressed with the ad itself as to the relationship with ALS causing these types of symptoms.

**Moderator:** You like a message with more clarity.

**Patient 23:** Yea. For me that could have been a person that has no arms or one arms. But that doesn't necessarily mean its from ALS. Unless you just say it is. But I wouldn't know that.

**Moderator:** That message was kind of metaphoric, but what I'm hearing you say is that you like to see a direct relationship.

**Patient 23:** Yeah. For an ad.

**Patient 24:** In corporations, is there one corporation that's a leader and standing behind ALS? Corporations have access to some of the best PR companies, ad companies, that could work with us to put out at no cost.

**Patient 21:** I think the message should take people through the degeneration of muscles with dates until they die. I think it should say fatal disease.

## APPENDIX M: BREVARD FOCUS GROUP TRANSCRIPT

**Moderator:** What are your perceptions of mass communications about ALS? And when I say mass communications, I mean any message that goes out to more than one person. Could be a commercial or something you read in a newspaper, or book or newsletter. These types of mass messages about ALS. What do you think about them? Have you sent hem? And if so what have been your thoughts about them?

**Patient 28:** First of all, the paucity of such things. I don't see very many.

**Moderator:** Do you guys agree?

**Patient 25:** I agree.

**Patient 27:** I've only seen one.

**Moderator:** What was that?

**Patient 27:** And that was at CVS. They actually have like a movie or a ... I forget what it was. They were talking about as far as letting people be aware of what ALS is. And they are like one of the main contributors to ALS too. They do a lot to raise money for ALS actually. And they had like a movie going on and people were actually listen to it. You couldn't see more or less the speaker it was information telling about the disease and that was actually the first thing I've ever seen out in public that anyone notices.

**Moderator:** What about you guys? Patient 29?

**Patient 29:** I've seen an article in Pittsburg. You're sister sent it (points at wife). But not here.

**Moderator:** Nothing here, only in Pittsburg.

**Patient 26:** I've seen nothing except what's online

**Moderator:** So maybe information that you searched out yourself after being diagnosed?

**Patient 26:** Yes. I've seen nothing.

**Patient 25:** I see what the Florida Chapter sends out which I think is pretty good and uh this support group. We have a Facebook page where we do post things that would be of interest to everybody. But that's about it.

**Moderator:** So these types of messages that we're talking about. Is it something that you'd like to see more of?

**Patient 27:** In the public way, I think it would. Get it out in the public like that. That makes people more aware. More than even newsletters when you get those from the Association. I'd like to see things like that in public for people to be aware. To me, CVS was one of the most amazing ones I've seen.

**Patient 28:** I picked up a copy of a magazine in the neurologist's office. Neurology now? Is that it? Or Neurology Today? I forget what it is. Very seldom is there anything in that magazine about ALS. Lots of things about MS and some other things, but I never see much. I go for 2 or 3 months before I see an article about ALS in that magazine. Lou Gehrig died 70 some years ago and I'm always surprised that we really don't know a great deal more now than we did then. And I don't know what information you're talking about. Where does the information come from?

**Moderator:** So you're saying you'd like to see more of it.

**Patient 28:** Well, I'd like to see more useful information, yeah. Sure

**Moderator:** Well on that, now we're gonna take a look at several communication and like I said get your feedback on these items. We're gonna start off with 2 different newsletter articles I'm going to ask you to read, and then we will discuss them.

[read national newsletter article aloud]

**Moderator:** Let's just start out with. What's your first reaction to that?

**Patient 28:** Wonderful sentiments.

**Patient 25:** Yep. Yep. What I would call a puff piece. Give me facts lady I want facts. Cold hard facts. Not sentiment, as Patient 28 said.

**Patient 27:** I would say it makes me thankful that someone's out there for my voice too.

**Moderator:** Patient 29, did you have any first impressions?

**Patient 29:** She seems kind of optimistic.

**Moderator:** Does this article instigate any feelings? For you, it made you feel thankful. Does cause any feelings for anyone else?



[Participants shake heads]

**Moderator:** How could it be improved? Patient 25 and Patient 28 said it could be improved by having more facts. What does everyone else say?

**Patient 27:** Definitely facts. To know what is being done. What kind of research are they looking at? What like you said facts? More to the facts.

**Moderator:** Did you have any thoughts Patient 26?

**Patient 26:** It just made me sad.

**Moderator:** Did it?

**Patient 26:** Yeah.

**Moderator:** Why so?

**Patient 26:** Because I'm new to this and I'm not sure what's going to happen.

**Moderator:** Definitely, each of our own individual experiences with the disease color how we see these things, for sure. Absolutely. Does this article make you feel one way or another about the national ALS association, who produced it. Any thoughts or opinions toward that? I heard you say that you were glad they were there. Did Patient 29 have something?

**Patient 29's Caregiver:** what are some of the results from the research they're doing.

**Patient 27:** that's true too. What are the results? I mean. That's where the facts are.

**Moderator:** Cold hard facts again. All right, well I'm going to transition over to the second one now. And we're going to completely change tones. We're going to look at a broad spectrum of things today. And that's so that we can have a little piece of everything to get your guys feedback on. This is more of a feature.

[Read local newsmagazine article]

**Moderator:** First impressions?

**Patient 25:** My first impression was it was kind of emotional. But when they started talking about how the news media covered it. How well it was covered. Well I thought that probably was worth-while.

**Moderator:** what else? First impressions or thoughts? Does it make you feel one way or another?

**Patient 27:** It makes me feel like fighting and wanting the same thing.

**Moderator:** So it kind of makes you identify with the patient here.

**Patient 27:** Uh huh.

**Patient 26:** I think it makes you identify plus, the other people have to be told about ALS. The other people out there that are living their lives, fat, dumb, and happy, and they never know when it's gonna strike around them.

**Moderator:** So it reminds you of a need for more awareness?

**Patient 26:** Yes.

**Patient 27:** And it gives you hope and inspiration.

**Moderator:** Is there information that wasn't included in here that you would like to see included or a different way that you think it could be improved? Or maybe you like it the way it is?

**Patient 27:** Well it got personal with him, because he liked the team and it gave him the opportunity to do something that really was inspirational to himself, and it makes you want to get out and do the same things. It's not just him that can do these things. We can get out here and do these things even in the positions that we're in.

**Moderator:** and is that type of inspirational message a message that you like to see?

**Patient 27:** A lot more of them.

**Moderator:** Do you guys agree with her? Disagree?

**Participants:** [some shake heads to agree]

**Patient 28:** You know it's an inspirational story and I've seen a lot of similar inspirational stories. Our own Ken Patterson... and that's fine but as Patient 25 said the idea that it may have broadcast on the different major TV stations and maybe some newspapers is important to get the message out. Like I say it's an inspirational story and there's plenty of them around. Particularly, when you get to people like Matt and Patient 25 who have been with it for 10 years like this fellow has.

**Patient 27:** It would be nice to see a local thing though. A local person.

**Moderator:** And when you say local you mean right here in Brevard?

**Patient 27:** Yeah. Somebody that people would know. Like this person I would never know him because he lives so far away. If it were somebody locally too in each area, and

it doesn't. Just to go say go watch the manatees when we were talking about the manatees. To show different things that people are out there doing instead of just sitting at home sad or depressed. It would be nice to see these inspirational things out in the open like that.

**Moderator:** Do you guys agree more local communications?

**Patient 29:** Here's an article in the paper.

**Moderator:** Now we're going to switch gears. These were articles that were intended for an ALS connected public. Now we're going to look at some things that were intended for the general public. The first one I'm going to show you is a print advertisement.

[show Wisconsin chapter print ad]

**Moderator:** This is an image that was a print advertisement. Initial impressions of this?

**Patient 27:** I think it looks dark and gloomy

**Moderator:** And you like a more positive message?

**Patient 27:** Yes.

**Patient 29:** It's a good headline. Where's the meat?

**Moderator:** Want some more? The facts? You like the facts?

**Patient 29:** Well you know. What does it say?

**Patient 25:** If that were in the doctor's office, that'd be great. Eye-catching make people pick it up and open the page. It's kind of like the pieces project. Similar to that I think. It does attract attention.

**Patient 26:** It will have a whole rush of people running into the doctor's office "I got Lou Gehrig's I got Lou Gehrig's. Maybe then some of the neurologist will figure out what Lou Gehrig's is.

**Patient 29:** My neurologist didn't know what it was.

**Moderator:** And that was frustrating for you?

**Patient 29:** They were surprised at Mayo that we waited so long. It was obvious to them.

**Patient 25:** There are so few of us. It seems to me that it's almost impossible to expect the public to know a heck of a lot about ALS. You know they read something once a year twice a year. They might see a mention of it twice a year on TV. They might hear of

some distant relative's son was diagnosed with it. But there's just so few of us. It's really difficult to imagine that any huge amount of spending or attention trying to raise public opinion in the United States about ALS is going to accomplish anything. That's my opinion.

**Moderator:** Do you guys agree?

**Patient 26:** No. I disagree. I mean look what they've done with breast cancer. Look at all of the walks and all of the fundraising thing and everything. And I realize that there's a hell of a lot more breast cancer out there than there ever thought of being Lou Gerhig's but still. This disease is... I'd rather have breast cancer in both breast. I'd rather have them tell me I'm terminal than to go through this. (cries)

**Patient 25:** Patient 26, You're not terminal. This isn't a terminal disease in my opinion. This is a tough disease to live with, but you're not gonna die of it. That's my opinion.

**Patient 29:** My sister said the same thing, and she had breast cancer.

**Patient 25:** I was diagnosed with prostate cancer at the same time I was diagnosed with ALS. Which was the same time my wife had her first brain operation. And cancer was easy.

**Patient 26:** I've already had cancer, and I'd say that's a hell of a lot easier.

**Patient 25:** Yeah. I agree. I'd rather have cancer.

**Patient 27:** How long have you had ALS?

**Patient 25:** 10 years. I was diagnosed 8 years ago.

**Moderator:** I'm interested to hear everyone else's opinion. Patient 25 thinks that public awareness won't increase the profile of the disease. Patient 26 thinks that it would. What about everyone else?

**Patient 27:** I would think that it would, also. The more you put out there for people to see. Eventually, it would come back to you. It would be more wide spread. More I would think.

**Moderator:** Any other opinions?

**Patient 29's Caregiver:** I think um if Patient 29 had had to go to the emergency room (I don't want to mention the hospital). I don't think they're quite knowledgeable about ALS. They'd give him oxygen and there's been times I thought he's choking... should I call the ER or 911 and just tell them. Another thing. They should all have identification bracelets saying they have ALS.

**Patient 25:** Well at Parish ER they know about ALS

**Patient 29:** Nobody They did not.

**Patient 25:** Well they took care of me about 3 times, and my daughter is an ER nurse at Parish, and I know all the doctors at the ER at Parish and they know about the disease pretty good.

**Moderator:** What about Patient 28?

**Patient 28:** The problem is the rarity of the disease. The first doctor that I went to that even had a hint of what it was. He had been in practice for 20 some years and I asked him how many cases have you seen. He said 3. So this lady here in the first article says this is the 25<sup>th</sup> anniversary of our association and you made the point Patient 26 that there's many many more cases of breast cancer than there are ALS. It's just a rare disease! When I tell people I have ALS, they say "What's that?"

**Moderator:** And you think that is a problem with rarity not with public awareness?

**Patient 28:** Well it's both. But the rarity contributes to the public awareness.

**Patient 25:** What do you want the public to be aware of? Why?

**Moderator:** Well that's my question for you guys. Do you want the public to be aware? And if so what do you want them to be aware of? And how can we do a better job at that.

**Patient 25:** I don't know that there's any benefit that comes from public awareness. If you all had 100 million dollars to spend in the next few years, I don't think you should spend any more than a tiny fraction of it trying to raise public awareness. I think there are many other things... much better recipients of our money and your time and efforts than trying to raise public awareness.

**Moderator:** Well that's good that we have varying opinions here. Patient 25 thinks one way others think a different way and that's fine we're trying to get a broad spectrum of opinions here. I'm going to pass out another print ad here.

[show ALS society of Canada print ad]

**Patient 25:** That's a nice picture

**Moderator:** Reads text. What's your first reaction to that ad?

**Patient 25:** Well, I'm curious did they raise any money with that ad. If it raised money than God bless them. My suspicion is that it didn't raise more than a tiny bit.

**Patient 28:** I agree.

**Moderator:** Why do you agree with that Patient 28?

**Patient 28:** Well I agree with Patient 25 that this is fine and it's a heart-wrenching picture. But again, what is the purpose in our last discussion about gaining public awareness? As far as I can see from all of this, we want to raise money. That's what we want to do is raise money. And I don't have a clue about Patient 25's opinion on how much this might have raised, but probably not much.

**Patient 26:** I sort of agree with him. I'm not of the opinion that ads everywhere are gonna do it. If there's more attention paid to people like Matt white. If there's more attention paid to ALS walks.

**Moderator:** The more positive messages?

**Patient 26:** Yes. The ones that say ya know come and help. Rather than ya know...

**Patient 28:** The problem is...

**Patient 26:** No that was it.

**Patient 28:** The problem is you're competing with a hundred other diseases that those people think are the most important as well, and again there's so few of us compared to the total population that I don't know ya know what you're gonna do to get this message across.

**Patient 25:** I tell you. I think that The ALS Association has been remarkably successful with the advocacy days which I've never been able to attend. They have produced good things on behalf of everyone with ALS. I think it's remarkable some of the things that the ALS Association and their advocacy days have produced. I participated I think at 4 walks or 5 walks. And I think the walks raised a lot of money for our local chapter, and God bless the Florida Chapter of The ALS Association. My hat's off to them. Big time. I guess I don't know where to go beyond that.

**Moderator:** Patient 29, what were your thoughts about this ad?

**Patient 29:** Well it's sympathetic for ALS, but for raising money, that's a different story.

**Patient 27:** I think this ad was better than the other ad because this one sort of shows the hands on effect. I think it's better to show the hands on effect for the public to see than just something with faces or something like that. At least they can see what it is.

**Moderator:** How does this ad make you feel?

**Patient 27:** Well it's sad of course because you don't want to end up like this. But also seeing that hey they know what's going on. Maybe they can see what's happening to me.

**Moderator:** And by they you mean whoever created this?

**Patient 27:** or even the public.

**Moderator:** How do you guys think this could be improved?

**Patient 28:** Well it's fine the way it is, but I'm not wise enough to know about the effectiveness of something like this. You know every evening NBC for the last couple of weeks has been showing the little kids over there in Kenya and Somalia with the flies crawling on them and the bloated bellies. You're in competition with them, and everybody's trying to raise money to do good things. We all want to see a cure. As far as this particular ad, I don't know. Does anyone know how much money they raised with this?

**Moderator:** now let's look at two videos and I'm anxious to get your feedback on these to videos.

**Patient 29:** Many people are not aware there's no cure. My friends ask me how's your therapy going? How's your drug? There isn't any.

**Moderator:** And is that something you want people to know?

**Patient 29:** Yeah. There is no treatment.

**Moderator:** Patient 27?

**Patient 27:** That is true. They don't actually come out and say there is no cure found so far. It sort of gives you a knowledge of the disease but it's not really come out bluntly and said there is no cure found yet.

**Moderator:** Now we're going to look at a news story.

[show news story]

**Patient 28:** More of the same.

**Patient 29:** How long at he had ALS?

**Moderator:** I don't know. Is that an important fact that you would have wanted included?

**Patient 29:** Yeah.

**Patient 26:** I think they did say.

**Patient 28:** I thought they did. A year and half. In any case, that points out one of the problems – the wide diversity of symptoms and problems with individual people. We have the English physicist who's lived for 40 years we had a friend not long ago who died after a few months. So it's difficult to compartmentalize or categorize ALS because it's so different with all the individuals.

**Patient 28:** These things are fine they're all inspiration, and I'm still trying to come to grips with what it is you want to do and I think you want to raise money is what you want to do. Why else would we have public awareness? We don't want people to be aware just for the fact of being aware. We want them to do something.

**Moderator:** This focus group is about the general status of the disease. It's not about raising money for one organization or another. We want to know how we can communicate the message of ALS more effectively and we believe that people living with ALS understand that and have the most valuable insights to offer when it comes to how to effectively communicate the disease that you're living with.

**Patient 28:** To what purpose? You want to communicate but to what purpose? I'm suggesting that public awareness only really has one purpose. What do you want the public to do?

**Moderator:** Now we've heard from both of you that you think awareness won't help. And we've heard from the other three that they think that it would do some good. So regardless of the motive we're looking at how you experience these communication and how you think they can be better.

**Patient 28:** I don't want to have it misinterpreted. I don't mean that communications won't help I'm just asking how is that gonna happen?

**Moderator:** So maybe I should move to ask – does this communication that you just watched cause a feeling one way or another?

**Patient 25:** saw that the guy has ALS.

**Patient 28:** yeah he's a nice guy. Made a good pitch right over the plate

**Moderator:** Patient 26. For you?

**Patient 26:** Well it does show the degeneration he's going through. To a certain extent. The talk afterwards was more of a setup for it than he was. I have to say there's probably hundreds of other ALS patients that could do more awareness. [Points to Patient 25]

**Patient 25:** I'm sorry if I've made you angry then I apologize. It's the last thing in the world I'd try to do.



**Patient 26:** No, no, no. You're positive is what I mean. Him he should be one of the standards for talking to people with ALS. At least he can still talk too. Anyone can see he's got it rough and he's not bitchin' about it, and he's happy. I'd never interview me. Never in a million years (cries)

**Moderator:** it's all in the perspective.

**Patient 25:** I think I started out by saying I like the communications within the ALS community. I like the newsletters within the Florida chapter very well. I read them carefully. The communications from national – I look at them. But all of the other stuff in the public arena... ALS is just a little piece of sand swirling around in the surf. One pebble of sand in the surf. There's too many other people out there. I think it's kind of meaningless and not particularly valuable. I hate to say that because I think a lot of people believe that we can make a big dent in the public psyche. I don't think we can. I don't even think we can raise a lot of money by having public awareness, but we have done very well using advocacy days. Going to Washington D.C. Calling on our senators and our representatives and advocating for certain things to help us. I think that is very productive.

**Moderator:** Does this message make you feel one way or another?

**Patient 27:** No it made me feel aware of what he was going through. It made me feel his pain, but it was good to see that he was able to do something in public for people to see in person like that. I can also say as far as well I lost my train of thought.

**Moderator:** I'll hop to Patient 29 then we'll come back to you to see if you remember where you were going. Patient 29, does this make you feel one way or another like it could be improved in any way.

**Patient 29:** With his disability he was still fairly young with his family. Many of us are older. Many young people get it.

**Moderator:** So you think that's powerful?

**Patient 29:** People with families and kids.

**Patient 25:** Yeah I agree with Patient 29. That is moving. That will choke you up. These people with young kids. Or the young kids with daddies. Poor daddy is he's 44 now. He was 40 when he started coming. He's 44. Poor daddy. Just a young boy.

**Moderator:** Well we'll move on to the very last piece that I want to show you today.

[show ALS Society of Canada PSA]

**Moderator:** First reaction?

**Patient 25:** Pretty poor. I didn't like it.

**Moderator:** What about everyone else? First reaction?

**Patient 28:** Well, it's pretty interesting. It starts with humor. Looks like it was made in Britain I don't know. It's interesting. Again.

**Moderator:** For you, this is something that if you saw this on TV you wouldn't care one way or another?

**Patient 28:** It's not a question of care. Maybe I misunderstand our purpose here today. I thought we were looking at communications, and I'm. It's fine it communicates an idea, but again my question is why?

**Moderator:** We can discuss that a little bit more after the focus group. The end goal of this data. But for now, let's just get the data and that is what you think about this. What is your feedback? Patient 26 were you gonna say something?

[Patient 26 cries]

**Moderator:** We can come back. Patient 29?

**Patient 29:** I'm not sure. It says it kills the body first. What's that mean?

**Moderator:** So not a clear enough message for you?

**Patient 29:** When the body's gone, you're gone. So what's that mean kills the body first?

**Moderator:** So you like a more clear message?

**Patient 29:** Uh huh.

**Patient 27:** I think what Patient 26 said too what quite on the mark. It was a little confusing at first. Wondering what he disease he had because of his arms.

**Patient 25:** You know a big problem we've got. You tell somebody you have ALS. They say what's that? You say Loy Gehrig's disease. Oh yeah I've heard of that one. Ya know we're walking around half of the people think we've got... Ya know what I mean. The message is split.

**Moderator:** And is that frustrating to you?

**Patient 25:** Yeah It is. It is. Because half of the people have an inkling what ALS is and the other half have an inkling what Lou Gehrig's is. But they don't know about the other. We've divided our punch by not uniting into one thing. If we're gonna try to start getting the public on our side, we should first try to get them to understand the same thing. Lou

Gehrig's disease is ALS. ALS is Lou Gehrig's disease. Those people that don't know what ALS is but they know what Lou Gehrig's disease is. Those ads are lost on them.

**Patient 27:** I have to agree there too because a lot of people like you said don't know what ALS is and they do know Lou Gehrig's. A lot of people think even MS is like ALS. I mean there are certain symptoms in different diseases that are similar, but we're not separated from MS or other disease like that. It's not just focused it seems like more on MS than it is on ALS.

**Moderator:** And so you'd like more focus on ALS?

**Patient 27:** Yes.

**Moderator:** Do you guys agree? Patient 26 did you have something you wanted to share?

**Patient 26:** Well, it was just a heart wrencher for me, because I just had to get rid of my horse. And what they were showing right there was someone trying to hold on to the horse because they couldn't deal with the horse any other way other than to hold on to it and take him wherever. I can't even brush my horse anymore because I don't have the balance. I just fall right over. So that just...

**Moderator:** You can identify with that?

**Patient 26:** Yes.

**Patient 27:** The thing you identify though is not hugging someone. Not having the ability to just reach up and hug someone like that.

**Moderator:** What do you think the general public would think about that? I know Patient 29 said he thinks it would be confusing, what does everyone else think?

**Patient 28:** It's clear enough. It said right at the bottom. You lose your arms sometimes. But again, I have to ask. The public would look at that and say that's fine. So what? What do you want me to do.

**Moderator:** So I think you're saying there needs to be a clear call to action?

**Patient 28:** Well when you communicate anything, what's your purpose?

**Moderator:** And you're saying that the purpose should be clearly spelled out in the communication itself.

**Patient 28:** I don't know that I'm not an expert in these types of things.

**Moderator:** Anyone else want to share something on this spot here? If not, I'm just going to wrap it up by asking if the goal is for the research community to understand how people living with ALS perceive and understand messages relating to the disease. Is there anything we should have talked about you would like to say that we didn't get to talk about

**Patient 25:** Say that again.

**Moderator:** If the goal is to understand how people living with ALS understand and experience communications relating to the disease is there anything that we should have talked about or that you would like to bring up that we haven't spoken about yet.

**Patient 26:** We need to have a Jerry Lewis junior pick up the ALS movement.

**Moderator:** A big star?

**Patient 26:** Yeah. Without that...

**Patient 25:** Jerry Lewis. Is that what you said?

**Patient 26:** Yeah if we had our own Jerry Lewis

**Moderator:** A big star. That's what she's saying.

**Patient 25:** Well we've been Jerry's kids for a long time. Laughs. That was a good thing for ALS. Jerry Lewis told a lot of people. Probably more than anyone else in the world about ALS. I didn't mind being one of Jerry's Kids

**Patient 27:** But didn't he start as MS also.

**Moderator:** What do you guys think about that? The idea that we need a big star to promote the ALS disease?

**Patient 29:** It would help.

**Patient 27:** We need a star that has the disease as a spokesman.

**Patient 28:** But Jerry Lewis's purpose was absolutely clear. He wanted to raise money for research or whatever.

**Patient 27:** Well also to help with the equipment needed for these kids to live a half-way decent life so that they're not stuck in the bed or whatever. They could do the same thing for us. For those of us that aren't VA equipped or have no insurance or whatever. It allows us to have some sort of life even though we have this disease.

**Moderator:** Anything that anyone else would like to bring up that hasn't been said yet.

**Patient 27:** I think how young the disease can strike. Someone like close to my age, but even people younger, like your age and stuff to focus also.

**Moderator:** Focus on the broad spectrum?

**Patient 27:** Yes.

**Patient 29's Caregiver:** How about teaching it in our educational schools? The high schools and even the elementary.

**Patient 26:** Heck, we need to do it in the medical school.

**Patient 29:** I know.