

## Television Illness Depictions, Identity, and Social Experience: Responses to Multiple Sclerosis on *The West Wing* Among People With MS

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This project contributes to our understanding of how audiences interpret televised depictions of illness by investigating responses to the depiction of multiple sclerosis (MS) on the television drama *The West Wing* from 1999 to 2002. The study employs qualitative methods, including a focus group, individual interviews, and the collection of electronic message board posts to investigate how people with MS interpret the dramatization of the illness. Findings are analyzed in terms of respondents' perceptions of (a) the portrayal of the physical disease, (b) the portrayal of the social dimensions of MS, and (c) the impact of this portrayal for themselves and others with the disease. The study found that participants engaged in self-comparisons with the depiction of MS within the program. These comparisons resulted in a range of reactions from individuals varying in relation with their multiple physical and social experiences with the illness. Thus, illness experience adds complexity to judgments about accuracy, meaning, and outcomes related to health depictions. Participants expressed a desire to see more symptoms depicted, and they noted concern about the identities communicated to the public about people with MS and its influence on their daily, lived experience.

During its first season, viewers of *The West Wing* learn that President Josiah Bartlet has multiple sclerosis (MS). In the second season, the president reveals this diagnosis to White House staff and the public.

President: ... I have a relapsing-remitting course of MS.

Toby: I'm sorry sir?

President: I have multiple sclerosis.

Toby: What does relapsing-remitting mean?

President: It's ... I dunno ... it's the good kind of MS.

Toby: It's the good kind.

President: Yeah, as opposed to secondary progressive.

Toby: Which is the bad kind.

President: Yeah. MS is a chronic disease of the central nervous system. Symptoms can be as mild as numbness or as severe as paralysis.

Toby: And loss of vision?

President: Yeah.

Toby: And cognitive function?

President: Yup.

Toby: Is it ... I'm sorry, is it fatal?

President: No. That's the good news. The bad news is there's no cure.

(“17 People”)

Given strong evidence of entertainment media's influence as a socializing agent, Kline (2003) notes, “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).

*The West Wing's* dramatization of MS is an important depiction of chronic illness. Despite some new examples of expanded attention to illness, such as Samantha's experience with breast cancer on *Sex in the City*, long-term attention to illness on television remains rare. It is particularly rare for a main character on a prime-time television show to deal with chronic illness, or to address the interpersonal issues related to such illness (Signorielli, 1993; Turow & Coe, 1985). Typically, illness depictions on television last only a few episodes and result in full recovery (Lupton, 1994). Additionally, MS in particular is not well understood by the public (National Multiple Sclerosis Society [NMSS], 2002a), so the show's depiction may constitute an important source of social learning about the disease.

MS advocacy groups praised *The West Wing* for portraying the disease (Mink, 2000), but this praise does not tell us how people with MS view the unfolding of this storyline in their daily lives. Media scholars note that audiences play an active role in interpreting media portrayals and engage in audience research to uncover this process (Fiske, 1987; Radway, 1984). In the arena of media and illness, Sharf, Freimuth, Greenspon, and Plotnick (1996) investigated this process by studying audience reactions to the depiction of cancer on the show *thirtysomething*. Yet, as we will discuss, less is known about how people that suffer from the illness depicted perceive dramatization of disease.

The purpose of this article is to examine audience interpretations of MS on NBC's high-profile drama *The West Wing*. This research adds to the audience reception literature and research into the experience of illness by understanding the reaction of individuals who have MS. Specifically, the study investigates how people with MS interpret the depiction of the illness in terms of (a) the portrayal of the physical disease, (b) the construction of identity through the portrayal of the social dimensions of MS, and (c) the audience's perceptions of the impact of this portrayal on people with MS. The article proceeds by reviewing research on popular media and health, the role of audience responses, and relationships between media and the social experience of chronic illness. After describing the interpretive methods used to gather audience responses, we present the themes that emerged. The article ends by discussing the practical and theoretical contributions of the research.

### MEANING, MEDIA REPRESENTATIONS, AND THE EXPERIENCE OF HEALTH AND ILLNESS

A significant body of work addresses depictions of health by the media. Yet as we discuss, most of this research is concerned with the accuracy of illness portrayals or the impact of role modeling on the public's health choices (see for discussion Kline, 2003; Seale, 2002).

Initially, the study of media and health was grounded in the assumption that media portrayals can be judged in terms

of their accuracy or inaccuracy (Seale, 2002). Much of this work is positivist or postpositivist in orientation. Commonly, researchers draw from effects models, using survey or content analytic methods to criticize television for dramatizing risks that are relatively rare and downplaying or ignoring messages about more common risks. For example, deaths on television tend to be inaccurate with disproportionately high numbers of people dying violent deaths (Seale, 2002), whereas Gordon, Williamson, and Lawler (1998) found that British television tends to depict unrealistically high survival rates from CPR.

Similarly, scholars have sought to judge whether television models positive or negative health-related behavior. Gerbner, Morgan, and Signorielli's (1982) cultivation theory integrates content analysis of portrayals with audience research regarding effects. Subsequent work has examined the effects of depictions such as character nutritional choices (Signorielli, 1993) and safety behaviors (e.g., seatbelt wearing; Larson, 1991). This cultivation tradition also examines the influence of positive televised role modeling in raising awareness of potential health risks (Marcus, 2000) and promoting health behaviors such as immunization (Glik et al., 1998) and family planning (Singhal & Rogers, 1999).

The cultivation line of research can yield important insights for scholars who are interested in illness portrayals. For example, Signorielli (1993) finds that television can produce stigma, noting that televised depictions of disability tend to treat disability as "personal problems that must be overcome" (p. 28) and portray people with mental illnesses as violent and as social failures. However, 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 (Seale, 2002).

These quantitative approaches can be contrasted with interpretive perspectives. Research in the interpretive and critical tradition draws from social constructionism and symbolic interaction to investigate the role of discourse about health and its relationships with private and public meanings, identity construction, and social interaction (Charmaz, 1999b; Lupton, 1994; Radley & Billig, 1999; Sharf & Vandeford, 2003). The role of meaning is particularly important when examining the depiction of disease, given that meaning is a key issue in distinguishing between disease and illness. Disease "denotes a technical malfunction or deviation from the biological norm," and illness "refers to the social, lived experience of symptoms and suffering which is innately human" (Lupton, 1994, pp. 92–93). Drawing from Kleinman (1988), Lupton describes illness problems as "those practical difficulties caused by illness, many of which are related to socio-cultural expectations" (p. 94).

A significant body of scholarship has addressed the construction of meaning in media illness depictions. Susan Sontag (1977) famously described illness as metaphor, not-

ing how public discourse appropriates the language of disease in ways that may influence the experience of such diseases (cancer, tuberculosis), including stigmatization. People with cancer are stigmatized by descriptions of the disease as an invasion or as punishment for indulgent lifestyles and may become afraid to seek diagnosis and treatment.<sup>1</sup> Although the approach is generally critical toward media messages, rhetorical criticism allows authors to examine the multivocality of meanings that may be portrayed in the media, moving beyond accurate/inaccurate and good/bad distinctions to explore more nuanced issues of representation. For example, Treichler (1993) found mixed messages in television movies about AIDS that attempt to reduce fear and stigma yet depict people with AIDS as not fully in control of their lives. Sharf and Freimuth's (1993) rhetorical analysis of the depiction of cancer on *thirtysomething* noted both positive and negative aspects of the show's depiction. Although the show provided useful education about the disease, the character portrayed with cancer was an "unrealistic public role model" (p. 147) who had greater access to information and less concern about health insurance and job loss than most people. Such depictions are important, given that entertainment television narratives of illness act "As an unobtrusive source of health information for vast numbers of people" who may have little direct experience with the illnesses depicted<sup>2</sup> (Sharf & Freimuth, 1993, p. 141).

### Illness Depictions and Audience Research

The preceding rhetorical research is highly valuable, providing insight into layered, ideological meanings associated with illness depictions. These studies look at what gets represented; another area to examine is *how* audiences then make sense of the various depictions. Given that media texts are polysemous, the power of media messages depends partly on the way in which they are interpreted and used by the recipients (Kitzinger, 1999). Even when audiences share a common interpretation of the intended meaning of a TV program, they may differ in their reaction (Kitzinger, 1999). Thus, audience reception studies attempt to understand how readers interpret particular meanings in light of their own life context (Fiske, 1987; Radway, 1984).

Growing interest in the role of the audience is exemplified by Sharf et al.'s (1996) examination of audience responses to the depiction of cancer on *thirtysomething* based on interviews with regular viewers of the program (see also Lupton and Tulloch, 1996). Viewers described having emotional re-

sponses and discussing the show with other people. Some viewers learned about the physical and social effects of cancer, whereas others reported that the program raised unanswered questions. The research also found that as they watched the program, some rehearsed what they would do if they or someone they knew developed cancer.

Yet it is possible that the concern with media's unobtrusive influences on people with little experience with illness has led to the oversight of audiences who have the illness or disability depicted. Significant work remains to be done to understand responses to illness depictions by these viewers, given that people with illness are likely to bring a variety of unique issues to their experience of media depictions. Seale (2002) notes that people often seek out mediated information to deal with health problems, especially when an illness is newly diagnosed. In addition to information, popular media may be a significant source for self-evaluation for such people. For example, Aydin, Ball-Rokeach, and Reardon (as cited in Signorielli, 1993) found that breast cancer patients were dependent on television and radio for social comparison and self-evaluation. Viewing positive stories led to negative self-evaluation of their own health status, yet these women still preferred positive stories of overcoming disease.

This process of self-evaluation is often about establishing or reestablishing identity when dealing with illness (Seale, 2002). Individuals are confronting new discourses—categories, labels, and arguments that may lead to new perceptions of the self as healthy/unhealthy, able/disabled, normal/abnormal, and more.

The depiction of disease and its influence on social experience is particularly important for people living with chronic illness, which may mark a person as socially deviant. Radley and Billig (1999) note that chronically ill individuals speak about their health in a context of possible criticism that necessitates careful management of public interaction. The ill person requires medical care but may be unable to return to the socially expected "well role" (following Parson's model; Karp, 1999). The person may be excused from work and other expectations and must justify these entitlements (Radley & Billig, 1999).

Additional complications for social interaction may result if chronic illness leads to disability. Scholars note that communication between the disabled and able-bodied can be awkward and uncertain (Murphy, 1998; Thompson, 2000). Colvert and Smith (2000) report that unemployment rates are very high among people with disabilities and find that fear, uncertainty, and misunderstanding may pervade workplace communication between disabled and able-bodied employees. People with disabilities may be apprehensive about their work role due to stigmatization and a fear of job loss. In interviews, they are often unsure about what to reveal about their disability. At times people may choose to hide their disability, but this can lead to problematic work expectations (Colvert & Smith, 2000) and negative self-evaluations (Merrigan, 2000).

<sup>1</sup>Important for this study, Martin (1990) found that discussions of immune systems stigmatize people with "inferior" immune systems. Lupton (1994) supports this with an example of a doctor who describes lupus as "self-destruction" and treatment as "punishment" (p. 65).

<sup>2</sup>This claim is supported by research findings that images of disability are important sources of information for people with little experience with the issue and that the amount and type of television watched correlates with intolerance of mental illness.

However, people living with chronic illness or disability may define and manage their illness and their self-concept in a multitude of ways. As a result, there is no single “accurate” portrayal of disease and disability. Thus, audience research is necessary to replace the assumption that groups depicted in the media will respond similarly to that depiction. Charmaz (1999a) finds that people living with illness may respond at different times by “ignoring it, minimizing it, struggling against it, reconciling to it, and embracing it” (p. 95), and media may play a variety of roles in this experience. For example, in a study of a prostate cancer support group, Arrington (2000) notes that the illness narratives of Sipowicz’s prostate cancer on *NYPD Blue* may help build community among people living with a condition.

In sum, entertainment narratives do more than educate or misinform people about diseases. Depictions such as *The West Wing*’s play a role in the social construction of illness, and this process may influence perceptions of self and the experience of social interaction for people with chronic illnesses in a variety of complex ways. Next, we describe MS and its depiction on *The West Wing*.

## MULTIPLE SCLEROSIS

MS is a chronic, potentially disabling neurological disease that affects approximately 350,000 Americans (Stuifbergen, 1997), with worldwide prevalence estimated at more than one million cases (Kidd, 2001). Although the disease is not considered life-threatening, about 3,000 people die from complications of the illness each year within the United States alone (Kidd, 2001). MS is characterized by deterioration and scarring of the coatings of nerve cells in the brain and spinal cord (Stuifbergen, 1997).

Primary symptoms include weakness, fatigue, vertigo, numbness, impairment of memory and concentration, visual disturbances, and possible mood swings (NMSS, 2002a). MS has unpredictable physical, cognitive, and emotional effects. Thus, symptoms vary from person to person and vary over time in the same person (NMSS, 2002b). Relapsing-remitting MS means that after an episode of MS symptoms, an individual recovers and enters a period of remission (NMSS, 2002a). These episodes often leave damage. For example, if an episode causes severe dizziness, some vertigo may become a part of the person’s daily life (NMSS, 2002a).

Although there is no cure, there are several drugs that may slow the course of MS (Vancheri, 2001). Patients with MS are also told to avoid heat and stress, as higher temperatures further impair the demyelinated nerve, and some researchers speculate that stress may exacerbate the fatigue associated with the disease (NMSS, 2002b).

More than 40% of individuals who have MS hide it from family, friends, or colleagues for fear of their reaction (“‘The West Wing’ asks provocative questions,” 2001). An April 2001 Harris poll found that 36% of people with MS say that

having the disease has had a negative impact on their personal relationships (Tasker, 2001). Public misconceptions include the belief that MS is fatal, leads to the use of a wheelchair, and should prevent women from having children (NMSS, 2002b). The public often believes that people with MS are less motivated or capable than others, and many employers believe they are less efficient workers (Tasker, 2001).

## MS ON *THE WEST WING*

*The West Wing* (written by Aaron Sorkin from 1999 to 2003) is an hour-long, fictional drama depicting the behind-the-scenes events of the White House and the daily lives of President Josiah Bartlet (Martin Sheen) and First Lady Abigail Bartlet (Stockard Channing). Critics and audiences have welcomed the show; in its first season, it was nominated for 18 Emmy Awards and won 9 (Haugsted, 2000). Politicians such as Madeleine Albright have commented on the realism of the show’s political depictions (Branegan, 2000). Communication researcher Parry-Giles (Parry-Giles & Parry-Giles, 2002) found that the show has improved perceptions of the presidential office and other government employees. This public perception of realism may extend to concepts about MS.

The Southern California Chapter of the NMSS worked closely with show researchers on developing the plot (Altman, 2001).<sup>3</sup> Martin Sheen conducted research into the disease to assist his performance. Montel Williams, diagnosed with MS, has publicly praised the program for its realism (Williams, 2001). Mike Dugan, president of the NMSS said, “We want to thank *The West Wing* for helping to enhance understanding about the disease. . . . This is a first on network television” (Mink, 2000, p. 73).<sup>4</sup>

According to the storyline in 2001, President Bartlet had been diagnosed with relapsing-remitting MS for 8 years. Of the 67 episodes that aired before our interviews in 2002, 42 do not mention or allude to MS. In 15 episodes, many of which are focused on the ramifications of his hiding the illness, MS is the major storyline. In 10 episodes, passing mention is made of MS.

The viewing public learns about the MS in an episode in January, 2000 (“He Shall From Time to Time”), when the president passes out with a fever of 102 degrees, and his wife, a physician, rushes to his side, fearing for his life (although fever is not a risk for those with MS). She decides to inform

<sup>3</sup>Sorkin reports that he chose to depict MS because he wanted the president to be bedridden, watching soap operas during one episode, and he did not believe that the flu would be an adequate reason.

<sup>4</sup>He also stated “President Bartlet’s life with MS has the potential for great good or ill. If he does well, despite the challenges of the disease, the public will become more accepting of individuals with MS, and ironically, individuals with MS will become more accepting of themselves and their abilities to lead fulfilling lives.”

the chief of staff of the illness, and at this time, we learn that only 13 people know about the disease. The president's MS does not become a significant part of the storyline until April, 2001 ("17 People"), when a flashback scene shows Bartlet passed out before a national election debate. Neither of the MS episodes are detrimental to his everyday health.

In the show's third season, the president discloses his diagnosis to his staff. Much of the staff reacts angrily at not being told earlier, such as the communication director, Toby, who responds, "It will appear to many, if not most, as fraud" for failing to share the information with the public. Staff members express concern about his ability to do the job.<sup>5</sup>

When the president announces his illness to the public, his approval ratings dip. A dramatized poll shows that 74% of the public believes that MS is fatal. Impeachment charges are derailed only when the president agrees to accept censure. Following this, the staff remains concerned about public perception of physical and political weakness due to his disease. For example, his chief of staff is concerned that if the president wears a coat to meet the Russian president, photographs will show the president "wearing a coat ... to protect his MS-riddled body from the fierce climate in Finland" ("Enemies Foreign and Domestic").

Given the high profile of the show and the longevity of MS, the depiction of this illness is significant. Its implications are particularly significant for people living with MS. The disease is poorly understood by the general public, and there is stigma associated with it; thus, the depiction may play an important role in generating meaning associated with MS and thereby influence the daily social interaction of people with MS.

### RESEARCHING AUDIENCE RESPONSE AMONG PEOPLE WITH MS

To understand how people with MS interpreted this representation, we used audience response research. This research involves the use of qualitative, grounded methodology to understand audience perspective in depth (McQuail, 1994). In this case, focus groups and individual interviews were conducted with *West Wing* audiences with MS. In addition, these methods were supplemented by analyzing Web site posts about the show from people with MS in public chat rooms and message boards.

One researcher attended an informal meeting of a local support group for MS patients and their caregivers, where she

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<sup>5</sup>His wife asks him not to run for a second term because of the disease. "Do you get that your own immune system is shredding your brain, and I can't tell you why?" When he responds that he has only had two attacks, she notes that potentially he may experience "memory lapses, loss of cognitive function, failure to reason, failure to think clearly, and I can't tell you if it's going to happen." Yet the president appears flippant about the disease, calling it "his thing."

explained the research goals to potential participants (those who watched *The West Wing*) and built rapport. Participants asked questions and provided suggestions for questions. After this, a focus group was conducted with nine attendees. Additionally, six individual telephone interviews were conducted with viewers who were not able to attend the focus group. Finally, to supplement these data, the author also gathered Web posts from people with MS who discussed *The West Wing* on publicly available Web sites.

The focus group was conducted in the group's regular meeting space. Confidentiality among group members was less of a concern in this setting where members met frequently to discuss personal issues.<sup>6</sup> Participants ranged in age from 44 to 63. Seven had been diagnosed with MS, and the other two were primary caretakers for individuals with MS. The length of time since diagnosis ranged from 2 to 22 years. Questions focused on their perceptions of the depictions of disease, how people reacted to the disease on the show, how participants felt the show may affect the public and people with MS, and what they would like to see portrayed differently. The focus group interview was audiotaped and transcribed.

Second, one author conducted six telephone interviews with members of the NMSS to overcome the problem of difficulty with mobility for some people with MS. These interviews ranged from 40 to 60 min, and the same questions were asked as in the focus group.

Finally, the project includes the Web site posts of 19 individuals who identified as people with MS, drawing from transcripts of their posted interactions from February to April of 2002. The message boards were found on a Web site offering information and support to MS sufferers (*MSWorld*, n.d.), and on a Web site for television fans (*Television Without Pity*, n.d.). These areas were not protected by any security measure such as passwords or member-only status. These textual data place interviews in a broader context of reactions to the program among people with MS. Although the small number of participants is a limitation of the study, the depth of responses and similarities that emerged across these data sources increase our confidence in the insight provided by participants.

### Analysis

Responses were analyzed using grounded methodology (Charmaz, 2002). Both authors sorted responses based initially on common topics (e.g., the role of stress, absence of symptoms). We then sorted these topics into shared themes (e.g., problems with accuracy, negative influence on viewers). Drawing from the literature on illness experience described earlier, these themes then were divided into different categories: reactions to the disease, reactions to depictions of

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<sup>6</sup>Additionally, focus groups members were told that their participation was voluntary and that they could withdraw from the study at any time.

social issues surrounding the disease, and audience perceptions of the ramifications of these depictions. In the next section, we describe audience reactions to the program.

### AUDIENCE RESPONSES TO *THE WEST WING*

Here, we present the themes that emerged from the discourse in each category: depictions of physical disease, depictions of identity and social interaction, and assessments of the ramifications of these depictions, using illustrative quotes from participants as support. This section is followed by a discussion of the theoretical and practical implications.

#### Representations of the Physical Disease

Participants were concerned about the degree to which *The West Wing* accurately depicted MS and its symptoms. For the most part, audience members felt that the show failed to depict significant elements of the disease. However, because MS manifests itself differently, these judgments often differed based on the experience of the respondent.

First, participants assessed the realism of the symptoms. When asked if the depiction of MS was accurate, respondents most often said “no.” Although they began many statements by saying, “I know it affects everyone differently,” respondents added that the portrayal lacked too many important elements of the disease.

One of the primary issues for respondents was the president’s lack of apparent symptoms. One focus group participant summarized the group’s response, “What we’re saying is, he doesn’t seem to have any of the symptoms that most people have; he doesn’t seem to have any noticeable symptoms or any symptoms that they talk about except for that one time when he had to go to bed and get a shot.” The group referred to the president’s illness as “Hollywood MS.” The lack of symptoms resulted in a lack of identification between these audience members and Bartlet. “Right now I don’t feel he is one of us,” said one respondent in a wheelchair.

The symptoms of most concern for many viewers were stress and fatigue, which the participants found to be central to managing their own disease. One focus group participant said, “We’ve got a man who apparently works from the early morning and he’s always walking home in the dark at night unaffected by the day’s activities, seemingly, and that’s unbelievable.” Another stated, “One of the major issues that is dealt with is fatigue; even at the onset you think ‘why am I always tired? Why can’t I do more?’ And here’s a guy who just absolutely is going full throttle all the time, and you never see him say, ‘I’m going to sit down. I have to take a nap.’”

Second, people with MS have a different level of insight into the degree of realism depicted in managing the illness than would someone unfamiliar with the disease. For example, one group member questioned one of the show’s pre-

mis, that Bartlet’s doctor does not know about the MS, saying, “His doctor is a real dunce that he doesn’t know the prez has MS.” Many participants worried that the depiction of Betaseron use to manage the disease may overpromise the drug’s benefits. An interviewee noted, “That one time he took it, his wife showed up, with him flat on his back, and gives him a shot of Betaseron. Where are the show’s advisors? That isn’t how it is done. It doesn’t work that quickly; you can’t take one shot and that’s it; it’s all better.” Several also noted that the show failed to discuss how difficult the drug is to obtain and underplayed side effects of the drug such as dry skin, flu-like symptoms, and depression.

As participants discussed the realism of Bartlet’s symptoms and disease management, they often made judgments about the accuracy of the show by comparing the president’s symptoms with their own. For example, as they discussed symptoms, focus group members noted the president’s schedule “Would be hard. I mean I can go maybe two days with 18 hours staying awake, but after that I crash for three days.” Another added, “I work out every day and pretty much go about my business, but I still have days when my legs are numb, and my arms are numb, and I have trouble thinking ... can’t drive a car, you know, I’ve fallen a few times ... it sort of wakes you up once in a while.”

Posts that were positive about the depictions because they felt they were realistic also compared the show to their own illness experience. For example, one stated, “I love the MS portrayal on *TWW*, mostly because I have symptoms very similar to the president.”

These varying responses underscore the idea that there is no straightforward reality against which we can compare illness depictions. They also demonstrate the personal, comparative way that people with illness may engage dramatizations.

#### Representations of Illness Problems

In addition to reactions to the depiction of the physical *disease* on *The West Wing*, participants also responded to the depiction of *illness* by focusing on the social aspects of the disease portrayed on the show, or what Kleinman (1988) calls *illness problems*. Although viewers disagreed about the need for positive versus realistic portrayals, the show provided a vehicle for discussing intimate issues related to identity for people with MS.

First, unlike what many felt was an unrealistic depiction of disease symptoms, many participants found the portrayal of Bartlet’s social situation to be realistic. In particular, they identified with the president’s struggle to decide whether or not to reveal his disease. One interviewee explained,

For people with MS the same issue comes about—when is the time to tell your employer? That’s something that everybody with MS has to wrestle with. I didn’t feel that it was necessary to tell anybody until I absolutely had to; I kept it quiet for 2 to 3 years.

A Web post noted that, “The NMSS Web site encourages folks to NOT TELL because there are so many misperceptions out there about what MS is.”

Both revealing and concealing the diagnosis can be problematic, just as the president encountered in the fictional world of *The West Wing*. A focus group member described being fired after refusing to tell a boss about the diagnosis at the urging of a physician, and a Web post explained that the fictional reaction of the staff and public was realistic because his or her boss’s reaction to the diagnosis “was ‘I can’t have a cripple work for me. I need someone who can do their whole job.’” Discussing the show as if it were real, one Web post noted that for Bartlet, “The big deal [about disclosure] is that ... 74% will also believe that he is totally unable to perform and will die any minute ... many Americans are uninformed about MS and will assume things that aren’t true.” Thus, the dramatized public and political concerns about the president resonated for many viewers.

Second, despite the ability of many to identify with the president’s struggle to decide if he should reveal his diagnosis and with the realism of public reactions, some respondents were nevertheless upset by the depiction of public reactions on the show. This divergence reflects a tension between the desire for *realistic* portrayals versus *positive* portrayals. *The West Wing* portrayed reactions of disbelief and anger toward the president by friends, employees, and the public. Many real-life MS patients fear or actually receive similar responses when they reveal their illness, and they worry that depictions of negative reactions may exacerbate these responses in real life. One Web site participant with relapsing-remitting MS expressed trouble with reactions to the president’s disclosure, “It’s more of a gut reaction to the fact that the president’s disability is an issue at all ... when will our society reach the point when differences are embraced?” Another post asks, “MS is not a fatal disease. It doesn’t keep a president from fulfilling his or her duties. Since when is having MS an impeachable offence or a fraud against the American people?” A more strident post suggests that some people with MS may experience personally those dramatized messages directed toward the president.

“I think that Aaron Sorkin needs to apologize to those of us he is calling liars by proxy. You feel guilty about having an illness. You want understanding from those you love but not the overt sympathy. You just want to be treated normal, but you are aware that you can’t always be normal. Not telling is a way to preserve normal for as long as possible. Don’t make me feel guilty for wanting to be normal.”

In many of these comments, respondents explicitly linked their perception of the show’s depiction of social issues to the severity of their own illness.

A third issue that arose among participants was debate about whether or not someone with MS ever could be president of the United States. Thus, the show prompted question-

ing about their own sense of their social possibilities with MS. In contrast to the aforementioned people who felt that MS does not impair one’s abilities, some felt that the disease made one ineligible for such an important, stressful, position. One focus group participant felt that Bartlet should not be president because he makes decisions about important matters such as sending troops into battle. An interviewee stated that, “MS has an unpredictable course. A person could become blind, numb, paralyzed, and there are cases of cognitive dysfunction, which obviously would incapacitate a sitting president.” The issue also arose on the Web, where one post stated, “The president could be experiencing impaired judgment, loss of cognitive ability, etc. and a) no one else would know, even in the situation room, and b) he might not even know, which would be a worse problem.”

That these discussions of competence and appropriate occupational roles for people with MS arose in three places (Web, focus group, and interviews) illustrates how a television program can prompt groups to initiate intimate discussions, questioning their own perceptions of identity and social possibilities. Also, these statements suggest that many respondents were not inspired by the portrayal of someone with MS in such an important position, as might be expected.

These comments about the social issues depicted on the program illustrate that there is little agreement about what would constitute a positive portrayal of MS. Viewers disagree about whether negative reactions function to bring realism to the show or model problematic behavior for the viewing public. However, viewers commonly made personal comparisons to the show, and initiated personal discussion about the role of MS in their lives.

## PARTICIPANT ASSESSMENTS OF THE RAMIFICATIONS OF THIS PORTRAYAL

Participants with MS viewed depictions of the disease not only in terms of judgments about quality, but also engaged in sense-making activities around the implications of those depictions. Perceived ramifications included concerns about how the show would influence other people with MS, how depictions would influence the broader public, and how that would in turn influence their own daily interactions. In addition, participants expressed active preferences for how the program could be improved to change outcomes for people with MS. These concerns center on the issue of identity construction. Not surprisingly, given the range of illness experiences and opinions about the show, many of these positions are conflicting.

First, some participants expressed concern about the influence of the show on audiences with MS, particularly those newly diagnosed. For example, a focus group member said,

What might end up giving people the wrong impression is how good his drug is that he’s taking; people will say, well I want to take that drug that the guy on

*The West Wing* is taking because his MS is really good and I'd like my MS to be like that.

Second, respondents expressed varying levels of concern about what the general public would learn about MS from *The West Wing*. To begin, many felt that the show would fail to educate people about the disease because at that time the president did not display significant symptoms. One focus group member explained, "It might make people more comfortable with the fact that MS is out there, that it's not contagious and it's not fatal, but [the show] doesn't educate what it really is. Maybe what it's not," and another added, "They are squandering the opportunity to educate people." An interviewee stated, "The other question would be, 'Do the writers think they are doing something for the MS community?' If they do, maybe their efforts are misdirected." One Web post noted that any single representation of MS may distort public understanding because of the variability of the disease: "The hardest part about MS for all of us—and the part that makes it hard for others to 'understand'—is that there is no one path the disease takes."

On the other hand, some respondents held hope that the show's depiction would provide positive education for the MS community. One interviewee said that despite problems, she would love to see the program send the message that "a person with MS can hold any job, including president of the United States." A Web post stated, "I do hope this opens a whole avenue of discussion as to (a) the public perception of anyone with a chronic disease and (b) the rights of the chronically ill to participate fully in American life." A second posting reads, "MS might even benefit from its portrayal here. . . . Perhaps the intelligent writing in this show will help point out that the same illness can affect each sufferer in different ways." Another hoped the show would spur fundraising for MS.

Third, operating at a "meta" level, Web posts expressed concern with the influence of *The West Wing* on the public's perception of their own identity as a person with MS. For example, one post reads: "The most difficult mental aspect of this disease for me has been the perception of MS by my family, friends, and coworkers. When they see a fictional character with MS as the nation's president and a talk show host [Montel Williams] parading MS guests out to show the 'world' that MS is just a DX [diagnosis] and not a liability in life, they think I'm exaggerating my symptoms for sympathy or am just being lazy."

Thus, some people with MS who view the show believe that problematic portrayals of the disease influence how others view them. In this sense, they believe that *The West Wing* has made the experience of their disease more difficult by negatively influencing interpersonal interaction. A similar point is made in a post that angrily attributes professional problems to the depiction.

I've been thinking that a class action lawsuit may be in order. I think *The West Wing* is doing a terrible disser-

vice to those of us with MS, especially, I might add, to those of us who are high-level professionals who have MS. Now that I am officially diagnosed, I am having a tough time getting another professional job (my MS, like "Pres. Bartlett's MS" is basically "invisible"). *West Wing* is making my quest for a professional job even more difficult.

Participants whose disease was in the earlier stages, on the other hand, did not expect the show to influence their interpersonal or public interactions. For example, an interviewee stated, "The people that do know that I have it, all my family, they don't act any differently towards me because I haven't slowed down. If I did [slow down], I would feel differently, but no [the portrayal] doesn't bother me socially."

Last, whether they felt that the show was a positive or negative depiction, interview and focus group participants had suggestions for change. When asked how they would like to see the depiction of MS on *The West Wing* change, interviewees consistently said that they wanted to see more symptoms. Despite the desire for positive portrayals of MS, they wanted such portrayals to be realistic first. The following are the immediate responses to "What would you like to see in this depiction?" "The fatigue." "Make him have more symptoms." "Make him sicker." "If he just got fatigued every now and again." "Walk with a cane because he did fall at one time." A focus group member elaborated, "He doesn't even have to say I've got to take a nap because I've got MS, but he should be shown as being affected by the disease."

Yet it is interesting to note that when imagining their own desires for the show, these viewers considered their identification as people with MS but also as fans of *The West Wing*. Unlike much of the scholarly tradition that overlooks the role of entertainment in their criticisms of health depictions (see Seale, 2002, for discussion), at times, these viewers placed themselves in the perspective of fans, writers, and producers, describing tensions between education and entertainment. For example, an interviewee who wanted to see more symptoms added, "I realize that they have a good show, and they don't want to screw with it by turning it into a medical show; it is a political show." Another suggestion focused on entertainment value.

If they showed him trying to cope with even mild symptoms occasionally, it would add drama . . . I can picture all kinds of scenarios and complications. Plus, it would be great MS education! And not even just MS—so many have to hide their health problems in order for people to accept them as functional human beings.

Judgments about entertainment value also related to self-identity. For example, a Web site post stated,

I guess it's not good TV to show someone like me on a bad day or someone in the last stages of MS who is



bedridden and has had to have their tendons cut to straighten them out from the fetal position so they can be moved.

In sum, people with a depicted illness bring a variety of unique issues to their viewing. In this case, they experienced concerns about what audiences with MS will come to believe about the illness, how the general public will view and interact with people with MS, as well as hope that the show would educate the public. Respondents also balanced their identities as people with MS and as fans of *The West Wing*.

## DISCUSSION

Examining these responses to *The West Wing* provides practical and theoretical insight into how illness depictions may be interpreted and evaluated by people living with illness. In this section, we highlight some of the important issues that emerged in the research.

First, it cannot be said that there is a single “MS response” to the show. Indeed, the points of disagreement and contradiction that arose are informative. For example, there was a central tension in the responses between the desire to see realistic symptoms and social interactions and the desire for MS to be treated in more positive terms as nonproblematic for the president. Although this show received public praise from MS groups about its handling of MS, many interview participants and Web posts criticized the show for a failure to include significant symptoms of the disease. Although it is not surprising that someone with intimate knowledge of an illness would be more critical of the disease depiction than the general public, it is interesting to note that many of these viewers with MS wanted to see realism versus a portrayal of the disease in which having MS is no impediment to being president.

Second, participants linked their reactions to their own illness experience. Seemingly contradictory responses become less so when understood in terms of an individual’s personal experiences. For example, those who had pronounced symptoms wanted to see more symptoms depicted and desired to see the illness treated with both accommodation and respect, whereas those with few symptoms wanted MS to be no impediment to being president. Their varied reactions can be linked to Charmaz’s (1999a) arguments that people with chronic illness interpret their illness in a multitude of ways. These findings highlight the benefits of qualitative assessments, in that what constitutes both accuracy and good or bad representations cannot be straightforwardly assessed without reference to multiple illness experiences.

Furthermore, this active comparison with entertainment programming provided opportunity for people with MS to discuss their own experiences with the disease and their sense of self. The show’s plot led members of the MS community to discuss their own social limits and possibilities,

providing a mechanism for discussing intimate issues related to their roles, identities, and senses of self.

Third, respondents reacted to the show on a number of levels and from various subject positions. For example, participants responded as people with MS and as fans of *The West Wing*. They watched the show in terms of their own identification, but also with concern about the messages communicated to the broader public. Fiske (1987) astutely argues that the meaning of texts “shifts towards the subject position of the reader more than the reader’s subjectivity is subjected to the ideological power of the text” (p. 66). Yet this case adds another layer to that assessment. Although this study supports Fiske’s notion that social experience is a more important source of meaning than TV, people with MS are concerned about the possible impact on the perceptions of a public that has little counterbalancing experience with MS. These viewers are aware that they are subject to others’ responses.

## CONCLUSION

The grounded approach of this research project helped to uncover multiple responses to the depiction of MS on *The West Wing* by people with MS. These varied responses provide insight into the need for qualitative investigations of audience interpretations. We believe that the divergence between public praise of the depiction by MS groups, the advising given the show (Levesque, 2000; Williams, 2001), and findings in this study illustrate the need to discuss depictions with a diverse group of people living with the disease.

This research suggests that if entertainment programs endeavor to depict chronic illness, they have some responsibility to depict realistic symptoms and illness problems on an ongoing basis. No one depiction will please every audience member. However, in this case, participants felt that the addition of occasional symptoms would facilitate greater identification for people with MS, better educate the public about the disease, and add drama to the story. In addition, increasing the number of depictions of people with chronic illness would help to illustrate a variety of symptoms, coping mechanisms, and styles of social interaction. For example, if Bartlet were to encounter other people with MS, the program could demonstrate the variability of the illness. Token representations are problematic in the burden they encounter to “stand for” so many illness experiences.

The sense of responsibility to improve depictions may not arise from the television industry alone; however, research like this may become a part of the arsenal of public and academic advocacy groups (Glik et al., 1998; Montgomery, 1989) as they work with Hollywood to improve health and illness depictions on television.

In 2004, the *West Wing* began to depict the president with more symptoms of MS and continued to do so until the show ended in 2006. These episodes provide an opportunity to un-

derstand how audiences interpreted this change. These interpretations would be of interest to television producers considering illness-related storylines.

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