HIV/AIDS Stories on the World Wide Web 
and Transformation Perspective

SHAHEED N. MOHAMMED AND AVINASH THOMBRE

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HIV/AIDS Stories on the World Wide Web and Transformation Perspective

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Survivor stories have been an important part of therapy and social support for persons living with human immunodeficiency virus (HIV) / acquired immunodeficiency syndrome AIDS (PLWHAs), and the World Wide Web has made these stories accessible to a vast audience. These stories are examined in the light of the concept of “transformation perspective” defined as a self-communicative experience that changes an individual’s life so that priorities and self-identity are refocused. The trigger event that alters the individual’s life might be a diagnosis with cancer, HIV, diabetes, or some other serious illness; divorce; financial tragedy; unemployment; or retirement. The “disorienting dilemma,” according to Mezirow, leads to self-examination, and thus to changes in the individual’s frame of reference. The present study found that PLWHA’s stories with more details were more likely to reflect transformation perspective.

Stories are weapons against disease.


I have lived with this disease [HIV] for about 2 months now, and don’t know how to deal with it. I’ve affected a few people with this disease and am sorry for that. I am married and continually cheated on my wife without her knowledge (we were separated at the time). I feel badly for what I did, but at the same time, things happen for a reason. I acquired this disease through unprotected sex. I hope none of you make the same mistake I have made. You can’t run from this disease. When you do that, you become like I have.

Craig¹ (HIV positive), San Diego

The authors acknowledge the critical insights and encouragement offered by Dr. Everett M. Rogers and Dr. Karen A. Foss, University of New Mexico. Authors also express gratitude to the editor and to anonymous reviewers for their kind and helpful comments.

An earlier version of this article was presented at the National Communication Association Conference, Miami, Florida, 2003.

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¹We use exact names here, as quoted from the personal stories on web pages. They may be either real or created by the individual writing the story.
The rapid increase in Internet connectivity in recent years led to a growth in the volume and variety of information available to the public. Internet usage is estimated at 115 million in the United States, some two-thirds of the adult population (*USA Today*, 2001). Health information is prominently featured on the World Wide Web; the Internet has become an important source of health information for millions of users (Berland et al., 2001; Edgar, Greenberg, & Remmer, 2002).

Web content analysis is a developing area of communication research that is particularly important in public health due to concerns about the quality, content, and use of health-related web sites. Increased web use for health information and social support prompted investigations of the content and quality of this material (Berland et al., 2001; Eysenbach, Powell, Kuss, & Sa, 2002; Wolfe, Sharp, & Lipsky, 2002). The Internet is a highly decentralized system with little or no gatekeeping function constraining publication of material on the web. Partly for this reason, health information contained in various web sites varies widely in authority and credibility. For example, one popular web site sold shark cartilage as a cancer cure (Keoun, 1996).

The study of narratives in health care is a growing area of research. The use of personal stories for health care and therapy is documented in a wide range of contexts (Bishop, 1998; Borkan, Reis, & Medalie, 2001; Hahn, 1987; Schmid, 2001; Wynne, 1987). Heiney (1995) suggested that storytelling produces therapeutic effects in the cognitive, affective, interpersonal, and personal domains of both the teller and the listener. Kirkpatrick, Ford and Castellone (1997) and Lindesmith and McWeeny (1994) noted the increasing importance of the role of storytelling in nursing and therapy. Frank (1998) pointed to the importance of stories of people “getting sick, suffering, being treated, and through treatment, being restored to health” (p. 200).

The role of storytelling in cancer treatment and support, for example, has been of particular interest to scholars (e.g., Breaden, 1997; Van der Molen, 2000). In a study of cancer patients and their family members, Chelf, Deshler, Hillman, and Durazo-Arvizu (2000) found that 97% of respondents agreed that storytelling was helpful in their coping with cancer, while some 85% of the respondents reported that hearing other people’s stories of surviving cancer gave them more hope. Krietemeyer and Heiney (1992) reported the use of storytelling as a therapeutic technique among school-aged cancer patients. Narratives are particularly useful in “transporting” an individual to identify with another’s situation and thus to facilitate deeper understanding of a condition (Green & Brock, 2000).

Likewise, studies relating to self-disclosure on the World Wide Web found that the web is an important site for self-expression (Dominick, 1999). The World Wide Web is thought to offer a level of protection, insulating the person presenting herself or himself from the usual threat of rebuff or ridicule that may occur in face-to-face interactions, particularly when sensitive information is revealed. Cheung (2001) called the web “emancipatory” because it facilitates a well-managed and crafted self-presentation while reducing or eliminating the risks of face-to-face interactions.

The World Wide Web also has been a site for self-presentation by persons living with HIV/AIDS who describe their lives, their challenges, and their experiences with the disease. These self-presentations have not been analyzed by scholars. The objective of this paper is to quantify the content of HIV/AIDS-related stories told by PLWHAs on the World Wide Web in order to examine evidence of the transformation perspective present in such stories. The authors attempted to quantify certain dimensions of the content of these personal stories.
Transportation

The conceptualization of “transportation” as a distinct aspect of narrative was originally outlined by Gerrig (1993). His extensive analysis of narrative worlds led him to the conclusion that “a narrative serves to transport an experiencer away from the here and now” (p. 3). Examples of such transportation are the feeling of being lost in a novel or story (Nell, 1988), moviegoers being surprised when the lights come back up, television viewers being engrossed about the fate of soap opera characters, and museum visitors feeling captivated by the stories encoded in daubs of paint.

The theory of narrative as “transportation” suggests that the extent to which individuals are absorbed in a story or transported into a narrative world may lead to effects of the story on their real-world beliefs and actions. Gerrig (1993) stated, “Someone [the traveler] is transported, by some means of transportation, as a result of performing certain actions. The traveler goes some distance from his or her world of origin, which makes some aspects of the world of origin inaccessible. The traveler returns to the world of origin, somewhat changed by the journey” (pp. 10–11).

Green and Brock (2000) demonstrated experimentally the immense power of narratives. They conceived of transportation as a “convergent process where all mental systems and capacities become focused on events occurring in a narrative.” As a consequence of transportation, a reader loses access to some real-world facts in favor of accepting the narrative world that an author has created.

Gerrig (1993) explained that the transported readers may experience strong emotions and motivations even when they know the events in a story are not real. Individuals are likely to engage in anomalous replotting, which he termed a process of actively thinking about what could have happened to change an outcome. Individuals return from being transported somewhat changed by the experience.

Rogers (2003) believes that narratives can transport (or involve) audience members in a story, so that health behavior change is facilitated. “A narrative can transport an individual to another time and place by moving him/her into an imagined situation. Narratives are stories that raise unanswered questions, present unresolved conflicts, and depict not yet completed activity” (p. 285). Hence, a narrative approach to health behavior change is highly involving of audience individuals (Green & Brock, 2000).

Transformation Perspective

Narrative transportation can be extended into a process of transformation that is defined as personal change brought about by an individual’s own personal experiences (personal stories or life experiences). It typically happens after an individual is transported by his or her personal stories to a different world, starting a process of personal transformation by drawing lessons from that experience. The transformative experiences qualify the change as a self-communicative experience.

Transformation is defined here as an experience that changes an individual’s life so that priorities and self-identity are refocused. The trigger event that alters an individual’s life might be diagnosis with cancer, HIV, or some other serious illness; divorce; financial tragedy; unemployment; or retirement. This disorienting dilemma leads to self-examination and thus to changes in the individual’s frame of reference (Mezirow, 2000). A transformative experience creates an immediate need for information about new alternatives. For example, cancer survivors and their family
members typically make extensive searches of web sites in an attempt to learn more about the cancer, and these individuals join both on-line and in-person support groups with others who have experienced the same cancer.

The concept of a transformational experience, also called a transformation perspective, was first studied by scholars of adult education who investigated the circumstances leading adults to return to school. The pioneering study dealt with the transformative experiences that encouraged adult women to enroll in a community college (Mezirow, 1978). In recent years, scholars, mainly in adult education, extended the study of transformative experiences to individuals diagnosed with HIV (Baumgartner, 2000; Courtenay, Merriam, & Reeves, 1998) and transformational dialogue (Foss & Foss, 2001).

Past research on the transformation perspective indicates that an individual does not return to a previous perspective once a transformation has occurred (Mezirow and Associates, 2000). Transformative experience lasts over time. For example, Baumgartner (2000) reinterviewed 11 respondents in 1995, 1998, and 1999; their transformation perspective, initiated by diagnosis of HIV positive, remained stable over this time period.

The present study investigates the transformation perspective, an approach applied to PLWHAs by Courtenay, Merriam, Reeves, and Baumgartner (2000). We extend this theory to HIV/AIDS stories on the World Wide Web. Based on Mezirow’s (1991) transformational learning theory, the transformation perspective approach suggests six components in the process of integrating HIV/AIDS into the identity of a person living with HIV/AIDS. Baumgartner (2000) found that for a particular group of PLWHAs, the common components of the integration process were the following: (1) diagnosis; (2) a postdiagnosis turning point or catalytic experience (this is the transformation); (3) immersion; (4) a postimmersion turning point; (5) integration; and (6) disclosure to others (Table 1).

The evidence of a transformation perspective has not been established on a large-scale basis (Courtenay et al., 2000; Williams, 1986). Studies of the transformation perspective framework (Courtenay, et al., 2000; Baumgartner, 2000) generally garnered evidence from semistructured face-to-face interviews with a small sample of PLWHAs. Here we examine a much larger number of personal stories by PLWHAs, as told on the World Wide Web. If the transformation perspective typifies PLWHAs, then their stories on the World Wide Web should demonstrate elements of the transformation perspective progression. The present study, therefore, attempts to explore transformation perspective in a broader range of behavior (PLWA’s stories) as expressed in a unique communication medium, the World Wide Web.

**Research Questions**

The present investigation explored the content of HIV/AIDS-related personal stories told by PLWHAs on the World Wide Web. The authors attempted to quantify certain dimensions of the content of these personal stories. Transformation perspective has not been tested previously with a large sample.

RQ 1: What are the primary themes of HIV/AIDS survivor stories on the World Wide Web?

RQ 2: To what extent is transformation perspective reflected in HIV/AIDS survivor stories on the World Wide Web?
Prior research on web content indicated that social factors such as age and gender influence the content of personal expressions on the World Wide Web (Dominick, 1999).

RQ 3: How does evidence of transformation perspective vary with the age, gender, and stage of disease of PLWHAs in their web stories?

Methods

Sampling World Wide Web content presents numerous problems. Web page content is often transitory, listings and directories of web content are incomplete, and processing new additions to such listings has become slower in recent years. This combination of dynamic content and slow indexing creates difficulty in obtaining estimates of web content. Sampling of web sites is a case of sampling from an unknown population size. In this study, the investigators attempted to gather as complete a listing as possible of personal HIV/AIDS stories on the World Wide Web. This investigation attempts to analyze the total number of those stories found in order to accurately represent the stories that exist on the web.

Traditional sampling approaches for media content tend to have limitations when applied to the World Wide Web. Recent attempts at sampling the web focused on controlled lists of search engines and search terms, reflecting traditional modalities of sampling media. With increasing sophistication, web users employ a wider range of strategies to obtain web information. These strategies may include different search engines, a range of search terms, following web rings (systems of links among sites with common interests), or following related links. Traditional linear sampling methods fail to capture the richness of these dynamic strategies.

The authors conducted web searches independently of each other, using a list of relevant terms (HIV, AIDS, HIV/AIDS, ‘living with, surviving, success stories, narratives, and survivor’) on three popular search facilities: Google, AltaVista, and Yahoo. We then made searched personal homepage listings on three popular services: Yahoo, AOL, and Tripod. Our third strategy was to follow links from individual pages and to identify so-called ‘web rings’ in which similar pages link to each other.

We retained web pages for coding if they contained stories of HIV-positive individuals that were told in the first person. We considered each story one case, even

<table>
<thead>
<tr>
<th>Table 1. Components of the transformation perspective process</th>
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<tbody>
<tr>
<td><strong>Components</strong></td>
</tr>
<tr>
<td>1. Diagnosis</td>
</tr>
<tr>
<td>2. Catalytic experience/ transformation</td>
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<tr>
<td>3. Immersion</td>
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<tr>
<td>4. Turning point</td>
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<tr>
<td>5. Integration</td>
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<td>6. Disclosure</td>
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if multiple stories appeared on the same page. After elimination of duplicates, 164 stories were identified. Both authors coded all stories. Initially each author independently coded a sample of 10 stories each and results were compared. We modified the coding sheet after differences in coding were analyzed and agreed upon. The rest of the sample stories were coded and Holsti’s intercoder reliability was negotiated to 100% on all variables.

We coded stories inter alia for evidence of transformation perspective markers by carefully reading each story to locate a change in narrative pattern. We also coded the stories for geographical location, nature of the web site on which the story was found, the gender of the subject, and age of the subject. The two coders also recorded the search terms used and the search engines consulted for each story. Data were analyzed using the Statistical Package for the Social Sciences (SPSS).

Findings

The predominant type of web site in the present sample was a support group web site, with 30.5% \((n = 50)\) of the stories in this classification. Personal web sites were the next most frequent source of stories with 28.7% \((n = 47)\) of the total (see Table 2). Males accounted for 49.4% \((n = 81)\) of the stories coded, while females accounted for 42.1% \((n = 69;\) gender could not be determined for 8.5% \([n = 14]\) of the stories). The majority of stories were told by persons in the 20-to-35 age group (36.6%, \(n = 60)\). Persons in the 36-to-50 age group accounted for 11.6% \((n = 19)\) stories.

Research Question 1 asked, What are the primary themes of HIV/AIDS survivor stories on the World Wide Web? The thematic content of the 164 stories was coded under two general headings: (1) material and (2) emotional concerns. Unlimited multiple coding was allowed on both dimensions for each story. Under the material heading, some 34.1% \((n = 56)\) of the stories contained general information and education about HIV/AIDS, 30.5% \((n = 50)\) dealt with social and political ideas related to HIV/AIDS including stigmatization, 25.6% \((n = 42)\) of the stories contained information about anti-HIV drugs and therapies, while 23.2% \((n = 38)\) of the stories dealt with disease transmission issues. Information on the HIV-positive community and its activities was evident in 19.5% \((n = 32)\) of coded stories; 18.2% \((n = 30)\) of stories dealt with issues of finance and costs, 12.8% \((n = 21)\) mentioned information on mobilization and activism, while 8.5% \((n = 14)\) dealt with clinics and hospitals.

Under the heading of emotional content, 73.2% \((n = 120)\) of the stories described the teller’s feelings and emotional transformations, 50% \((n = 82)\) of the stories

<table>
<thead>
<tr>
<th>Nature of websites</th>
<th>Number of stories</th>
<th>Percentage of stories</th>
</tr>
</thead>
<tbody>
<tr>
<td>Support group websites</td>
<td>50</td>
<td>30.5</td>
</tr>
<tr>
<td>Personal websites</td>
<td>47</td>
<td>28.7</td>
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<tr>
<td>General commercial sites</td>
<td>35</td>
<td>21.3</td>
</tr>
<tr>
<td>HIV/AIDS information sites</td>
<td>30</td>
<td>18.3</td>
</tr>
<tr>
<td>Drug company</td>
<td>2</td>
<td>1.2</td>
</tr>
<tr>
<td>Total</td>
<td>164</td>
<td>100</td>
</tr>
</tbody>
</table>
stories detailed the teller’s changes in views, and 49.4% \((n = 81)\) of stories focused on romantic relationships. Some 45.7% \((n = 75)\) of the stories contained inspirational messages, 39% \((n = 64)\) contained expressions of gratitude, 31.1% \((n = 51)\) of the stories contained expressions of support or solidarity, 26.8% offered advice on coping, 22% \((n = 36)\) spoke about counseling while 13.4% \((n = 22)\) dealt with religion or philosophy (Table 3).

<table>
<thead>
<tr>
<th>Table 3. Thematic content of 164 on-line HIV-Positive stories</th>
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<tbody>
<tr>
<td>Thematic content</td>
</tr>
<tr>
<td>I. Material concerns</td>
</tr>
<tr>
<td>General information on education about HIV/AIDS</td>
</tr>
<tr>
<td>Social/political ideas about HIV/AIDS/stigmatization</td>
</tr>
<tr>
<td>Information about anti-HIV drugs and therapies</td>
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<tr>
<td>Disease transmission issues</td>
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<tr>
<td>Information on HIV-positive community and its activities</td>
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<tr>
<td>Finance and cost</td>
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<tr>
<td>Information on mobilization and activism</td>
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<tr>
<td>Information on clinic and hospitals</td>
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<tr>
<td>II. Emotional content</td>
</tr>
<tr>
<td>Feelings and emotional transformations</td>
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<tr>
<td>Narrator’s change in views</td>
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<tr>
<td>Romantic relationships</td>
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<tr>
<td>Inspirational messages</td>
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<tr>
<td>Expressions of gratitude</td>
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<tr>
<td>Expressions of support and solidarity</td>
</tr>
<tr>
<td>Offer coping advice</td>
</tr>
<tr>
<td>Counseling advice</td>
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<tr>
<td>Dealt with religion and philosophy</td>
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</tbody>
</table>

Evidence of a Transformation Perspective HIV/AIDS in Stories

Research Question 2 asked, To what extent is a transformation perspective reflected in HIV/AIDS survivor stories on the World Wide Web? The coding process measured two major dimensions of the transformation perspective, derived from Baumgartner (2000). Stories were coded (1) for evidence of the six phases of transformation perspective (which we termed “transformation perspective phase markers”), and (2) for evidence of the outlook changes predicted by a transformation perspective (which we termed “transformation perspective outlook markers”).

The concept of transformation perspective outlines four typical reactions by an individual to an HIV positive diagnosis: (1) shock, (2) fear, (3) denial, and (4) relief (Baumgartner, 2000). In the present study, 60% \((n = 98)\) of the stories coded demonstrated at least one of these predicted diagnosis reactions. Liza, for example demonstrated the shock reaction:

I’m 30 years old and I learned I was HIV + almost a year ago & my life has changed forever. I am no longer the happy, joking person I used to
be. Instead I often stay home alone & cry about the things I can’t change. I’ve blamed GOD for dealing me such a terrible hand in life.

Rokingma narrated her initial fears:

I am a 56 year old woman, a daughter, a mother and also a grandmother. I was diagnosed in July 20 1994. I’m also a USN vet. When I got my news my family looked like deer caught in the headlights of a car! You could smell and taste the fear. The physical, mental and emotional roller coaster of constant health changes, the myriad of symptoms you experience, daily nausea, vomiting, depression, loss of appetite, etc.

Twelve percent of the stories from PLWHAs mentioned a diagnosis reaction other than those envisioned in the transformation perspective framework. These other reactions included sadness, anger, and the perception that death was close and inevitable. For example Sarah was sad:

Myself was infected via oral sex in 1990. The virus was latent for 10 years, appearing in the form of PCP in May, 2000. I am doing well on the medications. I am also taking vitamins, along with other medications for cholesterol, allergies, and heart problems. My emotions are relatively stable, with one major flaw...I wish I hadn’t acquired this disease.

The transformation perspective framework also suggests the existence of a catalytic experience or postdiagnosis turning point that marks a change from the initial reaction to being diagnosed as HIV positive. This turning point was evident in 48% of the 164 stories coded in this study. Transformation perspective suggests that immersion follows the postdiagnosis turning point, marked by immersion in the HIV/AIDS community, educating others, and the centrality of an individual’s identity as someone living with HIV/AIDS.

Sarah, who posted her story on the web, demonstrated a transformation perspective:

I am at this time pursuing a master’s degree in the hopes that I can bring complementary therapies (i.e., art, movement, music, meditation, and prayer) into the mainstream areas of medicine connected with special populations, such as HIV/AIDS, cancer, the physically disabled, along with their support groups. I’d like to research the possibilities of using these therapies, with Western and possibly Eastern medicine to take a holistic approach to a circulatory way of addressing diseases ... especially those that change lives radically. I know what they have done for me, and I’d like to help others also ... with God’s grace, mercy, and help.

Kay wrote about her personal experience, which demonstrates transformation perspective:

I found out that I had HIV on 11/06/01, one week after I found out that I was pregnant. Within a two week period, I lost my mate, I lost my job, I lost my apartment. With a five-year-old, I lived in my car for a week.
Then I stayed with a friend for a month. Finally I got employment, and my own apartment. Life is hard, I have no parents, I do have two brothers, one in jail, one happily married in Florida. They don’t know. God is GOOD ALL THE TIME. Some people say that GOD dealt them a bad hand. I don’t feel that way. God is using me to tell others that it can happen to them too. I never did drugs, slept around, I was not afraid when I got tested because I said it could never happen to me. Boy was I wrong.

Marci related her feelings:

When I found out that I was HIV Positive, I felt like God gave me a sword and told me, “Marci you can do 2 things with this sword, you can stab yourself with it and end it all or you can pick it up everyday and fight this virus” and that is just what I do. Today I am an AIDS educator, an activist, a mother and a productive member of society. Today I pick up that sword and live a very good life. Remember we must FEAR THE VIRUS - BUT EMBRACE THE PEOPLE.

Q10 Immersion was evident in 51% (n = 31) of the 164 stories coded. Mention of a clear postimmersion turning point, as suggested in the transformation perspective framework, was evident in only 7% (n = 12) of the personal stories coded, although 50% (n = 82) of the stories indicated some level of “integration” that followed the turning point in the framework.

The concept of transformational perspective envisions two phases of outlook changes in HIV-positive adults. Phase one is an exploration and experimentation stage. Stories coded in this study demonstrated some evidence of the markers for this stage: (1) taking stock (48%, n = 29), (2) adjustment in perspective (49%, n = 30), and (3) adjustment of activities (42%, n = 26). In phase two of the outlook change, the framework calls for a consolidation of new meanings. Stories in this study demonstrated evidence of this second phase: (1) making a meaningful contribution (30%, n = 19), (2) heightened sensitivity to life (48%, n = 29), and (3) service to others (37%, n = 23). See Table 4.

Leslie describes making a meaningful contribution:

I now have become active in trying to get my story out to as many teens and adults that I possibly can. There are still so many people that think

<table>
<thead>
<tr>
<th>Table 4. Outlook change phases in HIV-Positive stories</th>
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<tbody>
<tr>
<td>Phase</td>
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<tr>
<td>-------</td>
</tr>
<tr>
<td>I. Exploration and experimentation stage</td>
</tr>
<tr>
<td>Taking stock</td>
</tr>
<tr>
<td>Adjustment in perspective</td>
</tr>
<tr>
<td>Adjustment of activities</td>
</tr>
<tr>
<td>II. Consolidation of new meaning</td>
</tr>
<tr>
<td>Making a meaningful contribution</td>
</tr>
<tr>
<td>Heightened sensitivity to life</td>
</tr>
<tr>
<td>Service to others</td>
</tr>
</tbody>
</table>
IT CANNOT HAPPEN TO ME. Thanks for listening. The hardest part for me is knowing that my 2 children are not here because of me.

Jamie displayed heightened sensitivity to life and a desire to be of service to others:

I am 36 and from NY, and I have been living with “HIV” for probably 15 years now, but I’ve only been diagnosed for five years. Since I found out I have HIV my life has changed incredibly! I have my family back and have a wonderful housing program. I was in strict therapy for the first 3 years after I was diagnosed. I was an active Heroin addict for 10 years, and that’s how I can “assume” I contracted HIV. At any rate I stopped using and decided to “live” when I found out I was HIV positive. I pray every-night to God that he will give me as many years as I can have. I don’t use drugs anymore and will never again (like I said I want to “live”). Thank you for listening, I have a lot to be grateful for today! And I hope all people are smart and use condoms and young people “think” about this horrible disease before they “jump” into having sex.

Another participant, Tequilla, had outlook markers:

I met people who knew about HIV and I was thinking they can teach me some things about HIV. They told me do not stop taking your medicine because the virus would find a way to start making you immune to your meds. I started to play around and run away and not take my meds with me and I got sick, so they had to stop those meds. They gave me more and I took them and I got better. Stay safe and protect yourself against HIV.

Ralina provided another example of outlook markers:

I am a 24 year old female youth. At the young age of 10 years old, I was being babysat by my best-friend’s cousin and ended up getting brutally raped several times that evening. Two years after the rape we were finally able to prosecute the guy and get him incarcerated for a short term of only 3 years. Within 3 months of the start of his incarceration, my mom got a visit from the local health department saying that the guy who raped me tested + for the HIV virus; and that it would be a good idea for me to find out. Well a couple weeks went by and I got the bomb-shell dropped on me. My test also came back + when I was 12 years old. Because of the lack of knowledge about the virus, I ended up getting forced out of high school, because they didn’t want it in their community. I have since got my GED and Bookkeeping degree and I was able to pick up and prove everyone wrong. I am a proud mom of a 6 year old NEGATIVE child. Good luck to all!!!!

Indications of transformation perspective may be gauged from (1) the levels of phase markers, and (2) the outlook markers in each story coded. The more phase and outlook markers in each story, the greater the evidence for transformation perspective. Further, evidence of the phase markers are expected to be accompanied by
evidence of the outlook markers if, as the framework suggests, the outlook changes occur with passing phases of the framework. It was therefore necessary to investigate the relationship between these two sets of markers.

We summed the phase markers and outlook markers for each story to yield phase scores and outlook scores. The two scores for transformation perspective phases and transformation perspective outlook were positive and significantly correlated ($r = .825$, $p < .001$). This finding suggests that the storytellers experienced greater outlook changes as they experienced further phase changes, exactly as proposed by the transformation perspective framework.

How was transformation perspective in the coded web stories by PLWHAs related to the level of detail in each story? Level of detail was measured by summing all content measures for coded stories. Stories that were coded across a larger number of content categories received higher transformation perspective scores. A positive, significant correlation was found (1) between story detail and transformation perspective phase evidence ($r = .768$, $p < .01$), and (2) between story detail and transformation perspective outlook evidence ($r = .738$, $p < .01$). Thus, stories that were more detailed provided more evidence of the transformation perspective framework.

**Transformation Perspective by Age, Gender and Stage of Disease**

Research Question 3 asked, How does evidence of transformation perspective vary with the age, gender, and stage of disease of PLWHAs in their web stories? Analysis showed negative, significant correlations (1) between age and transformation perspective phase markers ($r = -.371$, $p < .01$), and (2) between age and transformation perspective outlook markers ($r = -.509$, $p < .01$). Younger persons were more likely to experience a transformation perspective. Males and females did not differ significantly in their transformation perspective in their web stories. Stage of disease was extremely problematic to code and eventually was reduced to a dichotomous variable separating those stories that self-reported the teller as having AIDS versus those that self-reported the teller as being HIV positive. Persons who self-reported having AIDS did not differ significantly on either of the transformation perspective measures from those who reported being HIV positive.

**Discussion**

The content of the on-line stories analyzed in this study suggests that web discourses by PLWHAs about HIV/AIDS present evidence of the concept of transformation perspective themes (RQ 1). Our search of literature suggests that this study may be the first by communication scholars of transformation experience. Different methodologies (mostly personal interviews) were employed in the foundational studies of the transformation perspective in adult education (Courtenay, et al., 1998, Q3 Baumgartner, 2000). None of the earlier researchers analyzed self-reported stories on the web. The earlier studies need further analysis to determine if they demonstrate various phases of a transformation perspective.

We found evidence for the transformation perspective in our analysis of the 164 web pages with personal stories by PLWHAs. The markers for the phases of transformation perspective and the markers for the individuals’ outlook changes were strongly correlated (RQ 2). We found that greater disclosure or detail in the 164 stories provided stronger evidence for the transformation perspective, suggesting that it
may be a concept that is not very obvious from casual information. Perhaps it is 420 related to the degree of introspection by individuals. Younger persons are more likely to report a transformation perspective or at least be more fully aware of this perspective (RQ 3). We found no difference between male and female storytellers in exhibiting a transformation perspective in their web stories, contrary to Dominick’s (1999) earlier findings about gender differences in self-disclosure and expression on the web.

Application of Transformation Perspective in Future Health Communication Studies

How is the concept of transformation perspective important and beneficial to health communication study? Our research suggests the value of a transformation perspective in motivating an individual’s information search on a health topic (HIV/AIDS in this case). The initial message that an individual is HIV positive starts a process of substantial changes in self-communication within an individual. The individual undergoes a process of gradual realization and orients to a position in which he or she feels a need to move toward positive behavior change. The importance of diagnosis with HIV as a crucial life change does not seem to be fully recognized in past research (Singhal & Rogers, 2003).

Transformation perspective as evidenced in the on-line self-reports of PLWHAs in this study predicts important trends within a lasting behavior change process. An individual’s self-communication regarding the HIV/AIDS diagnosis message and its consequences sparks contemplation, leading to taking self-control of personal health behavior and, often, the individual communicating his or her experiences so that others do not undergo similar negative health experiences. (Altruistic goals are greatly strengthened for most HIV-positive people.) We suggest that, with these general trends in mind, a transformation perspective needs to be taken into account in designing health communication campaigns.

Future Directions

This study could not verify the absolute truth of the 164 on-line stories. The present data are self-reports. Kenyon and Randall (2001) noted that the Internet-based exchange of stories may pose particular problems of validity:

Can participants remain anonymous and freely compose any stories they like? If so, are both the storyteller and the story listeners dealing with real lives and real facticity or only arbitrary, ephemeral, or virtual selves? In other words, are crucial differences and work when we cannot feel each other’s presence and look into each other’s eyes? (p. 14)

Are drug companies or other commercial health care organizations behind certain of the HIV/AIDS personal stories posted on the web? We do not know. This sample was obtained from all domain names (.org and .com), which typically include different ownership of web pages and web sites. Most of the stories (96%) were obtained from the .org domain; the location and the exact ownership of these web stories (and in turn the intentions of the collectors and hosts of the stories) cannot be known.
Another limitation of this study concerns the unclear demarcation between the transformation perspective phase markers and the transformation perspective outlook markers. The present authors were the coders of the on-line stories. It would have been ideal to have independent coders for these self-reports. One benefit of serving as the coders, however, is that the authors appreciated the difficulty in coding the different stages, a problem to be dealt with in future study.

This study investigated and coded only stories presented in English. This was partly a function of the predominance of English on the World Wide Web at present and also attributable to the difficulty of introducing a second or third language and their attendant cultures into the present nascent empirical analysis of the transformation perspective. There are, indeed, several self-reports and stories hosted by non-English-speaking people living with HIV/AIDS on the World Wide Web, which need to be addressed in future scholarship.

As the web continues to grow in importance as a source of information for the American public and as a source of health information in particular, research like ours needs to be extended to the end user. How do users of posted web messages use this information? Future research might include a more detailed web-based survey of the HIV/AIDS-positive web community. This survey could solicit web stories and self-disclosures in a more structured manner, perhaps facilitating more direct analysis of the expected elements of the transformation perspective.

References


