**Tweeting an Identity:**

**A Content Analysis of Twitter Posts by Individuals Living with HIV/AIDS**

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ABSTRACT

This study examines the twitter posts (tweets) of people living with HIV/AIDS (PLWHA) in an effort to better understand how these individuals have incorporated their HIV positive diagnosis into their lives. Newly emerging social networking sites offer PLWHA the opportunity to be both the producer and the user of their projected messages. How these individuals choose to present themselves within this public domain offers insight as to how an adjusted self-concept manifests in everyday situations and exclamations.

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The United Nations estimates that there are 42 million people living with the Human Immunodeficiency Virus (HIV) or have the Acquired Immune Deficiency Syndrome (AIDS) in the world today (United Nations 2009: UN Statistics Division). Though the United States’ infection rate is lower than the rate in some countries, there are currently 1 million Americans living with HIV/AIDS. Of the approximated 40,000 new infections acquired yearly, African-American females between the ages of 13-25 years old constitute the majority at risk. Despite numerous attempts to spread awareness and educate society about the realities of HIV/AIDS, many are still in the dark about how it is transmitted and what it means for those living with the disease. HIV/AIDS, once considered to be a death sentence, continues to trigger stigmatization, guilt, and humiliation. Unlike many life-threatening conditions, the diagnosis of being HIV positive elicits harsh societal reactions as well as moral judgments from society. These societal perceptions greatly impact the self-perceptions of those who are subject to such disapproval, and thus the identities of individuals who have received an HIV positive diagnosis must accommodate this shift.

REVIEW OF LITERATURE

Nearly three decades ago the earliest diagnoses of HIV were accompanied by great confusion about the ways in which HIV was and could be transmitted and who was most susceptible to infection. According to the Center for Disease Control (CDC), “HIV was first identified in the United States in 1981 after a number of gay men started getting sick with a rare type of cancer” (2007). People were dying quickly and in large numbers, and the general public was nervous about this unfamiliar threat to society. Though the disease was first identified in 1981, it took researchers two years to isolate the casual agent (Montagnier 2000) as the HIV virus. As the public learned that this virus does in fact spread through the exchange of bodily fluids, including blood, semen, vaginal fluids, and breast milk, moral judgments were attributed to infected individuals.

*Stigma*

Visser, Makin, and Lehobye (2006) describe the stigma surrounding the HIV/AIDS epidemic in terms of two separate categories: personal stigma and perceived community stigma. Personal stigma denotes the attitude of an individual member of society. These personally held attitudes are typically shaped by first-person experiences (2006). Perceived community stigma, on the other hand, refers to an individual’s interpretation of the reactions of his or her fellow community members (2006). Visser, Makin, and Lehobye note that, “There may be an overlap between the concepts, because perceptions regarding the attitudes of others may be coloured by one’s own attitudes. Personal attitudes are also informed by community constructions” (2006:45). An exploratory study conducted in the South African Tshwane community found that, “The respondents perceived the community’s reaction to HIV/AIDS to be far more negative than their own” (2006:50).

*Construction of an HIV Positive Self*

Roth and Nelson argue that, “personal narrative is an appropriate method for exploring the patient’s role in the production of an HIV/AIDS diagnosis and the subsequent construction of an HIV positive self” (1997:2). Looking through the lens of the perspective, “living with a chronic illness becomes part of a personal identity and social and personal frameworks” (Roth and Nelson 1997). However, Roth and Nelson emphasize the fact that the construction of a new identity is far from instantaneous. Identity construction is a continual process that calls for the participation of not only the individual who has received his or her HIV positive diagnosis, but also the supportive involvement with various mezzo and macro social entities, such as families, physicians, and the HIV positive community (Roth and Nelson 1997).

A study conducted by Cadell and Marshall (2007) makes the claim that an HIV positive individual who is also homosexual or transgendered may be faced with additional hurdles in “constructing a sense of continuity of self” if they have experienced the loss of a partner to HIV/AIDS (2007:538).

*HIV as Identity, Experience or Career*

A study funded by the Australian Research Centre sought to gain a more in-depth understanding of the “dynamic processes whereby people give meaning to the lived experience of being a person with HIV” (Bartos and McDonald 2000:299). Current research has focused mainly on whether HIV positive individuals take their medication regularly and the correspondence with practicing safe sex (if you are HIV positive), but not on the relationship of one’s HIV status to their sense of self. Bartos and McDonald interviewed 76 people living with HIV/AIDS (PLWHA) in Australia and found that PLWHA had three main modes of subjectification about their HIV status: whether HIV was viewed as identity, experience, or career. They found that members of the gay male community were more likely to view HIV as an identity, possibly because being gay in and of itself is a marginalizing event. “Coming out” as HIV positive is like one more step in disclosing one’s status as a gay male. Because the AIDS epidemic in America has so long been identified with the gay male community, it does not really disrupt their sense of self. They have come to grips with who they are and this is one more add-on to that identity. Researchers also asked participants how a cure for HIV or AIDS would change their existence. Some surprisingly answered that they would not want a cure because it would change who they are. Thus, HIV has become intertwined with their identity.

HIV is also an experience. For some, HIV is something they deal with and they address, even amongst other commitments they may have. For these individuals, HIV positive status’ influence on their life is recognized, but it is something that they have experienced, something they have gone through, but not something that internally defines them. HIV positive status is something that they, as an individual, have had to experience. Those who viewed their HIV positive status as experience, when asked about a possible cure, would openly receive it. To them it was another battle, hurdle, or roadblock in their life that they had to overcome. The idea of there being a cure was the elimination of one of the primary battles in their life.

HIV as career describes someone who has a career that has to do with AIDS activism or in some aspect of social services addressing HIV/AIDS. This category also included people who considered themselves an agent for change by either making a difference in their community (through educating or informing people about HIV/AIDS), or people that consider themselves an asset to medical science by positioning themselves to work closely with doctors to improve how others handle HIV positive individuals. Those who viewed HIV as career tend to want to strike a balance in their lives, because they are not only living with HIV/AIDS themselves, but because their work also becomes a job to them. Individuals may begin to see HIV/AIDS as a career because they are trying to have other things going on in their lives and not their let own status consume them. Those who view HIV/AIDS as career would tend to say that they would welcome a cure as well because even though it might put them out of a job, they see the medical-scientific side to it and that this is something that we can work for prevention and treatment of- making the most of medical resources at our disposal.

This article was saying that unless you fit the stereotype of what tends to be thought of as an HIV positive individual (which would stereotypically be a gay male that considers himself part of the gay community), you are not really going to see yourself as the typical HIV positive person (whether or not that is the case).

*HIV Identity*

Flowers, Davis, Hart, Rosengarten, Frankis, and Imrie (2003) interviewed 30 Black African HIV positive men living in London. These semi-structured interviews showed the critical effects of stigma on individuals living with HIV/AIDS. Whether stigma is “enacted” or “felt,” identities are disrupted. The unsturdy self-concept experienced by those interviewed influenced their decisions to spend an increased amount of time in isolation and a rise in reported feelings of depression. Those who felt more sturdy in their post-diagnosis state were more likely to have had strong support systems surrounding them. The continued enactment of love and reliability of those individuals around PLWHA greatly impacts the level of stability reported by the interviewees.

THEORY

In the Borderlands/La Frontera theory, Anzaldua examines what happens when a person never truly feels at home in their (own) identity. Individuals living in “borderlands” experience the strain of belonging to identity groups that characteristically conflict with one another. For Anzaldua, a Lesbian Chicana-American, she does not feel fully embraced by nor does she fully identify with any one of her categorical identity labels. Though Anzaldua may embrace the identity characteristics of being a woman, a homosexual, of Mexican heritage, and being an American citizen, none of these identifiers offer a home for the self.

When Anzaldua visits family members in Mexico, she is not ‘Mexican enough.’ Gender stereotypes that are embedded within the Mexican culture (such as sensuality and machismo behaviors) are not congruent with the homosexual lifestyle that Anzaldua leads. Yet, when Anzaldua is in the United States, she does not entirely fit in the identity category of being an ‘American’ due to the incorporation of her Mexican roots. Therefore, no matter where Anzaldua is, she does not ‘fit in.’

The Borderland theory can offer a lens to better understand the identity struggles of an individual who has received an HIV positive diagnosis. The general public’s stigmatized perceptions of PLWHA weigh heavily on those who see themselves differently from the way others see them. When one or more of the labels a person identifies with are incongruent with the realistic circumstances of his/her life, that person can either readjust his/her self-perception to match their situation or experience the distress of a conflicting identity. Social identity theory explains an identity conflict using the terms: actual self, ideal self, self-perception, and projected self. The actual self is who a person is in reality, based upon their everyday thoughts and actions. The ideal self can be understood as the individual a person hopes they are (or will be). Often an individual sees potential and/or hopes to become their ideal self, the person they dream to be. How a person sees themselves in reality is referred to as his/her self-perception, whereas the projected self denotes how others see that individual. When who a person sees themselves as being (self-perception) and who others see them as (projected self) do not align, the individual will feel frustrated by the stress of an imbalanced identity. As a result, the affected individual can either readjust his/her self-perception or continually experience the significant stress of feeling misunderstood.

If an individual who identifies herself as a heterosexual Christian woman of sound judgment/morals receives an HIV positive diagnosis, the general public’s stigmatized projections of PLWHA will result in her experiencing a significant rise in her stress level. If generalized stereotypes portray PLWHA as promiscuous homosexual men who have lacked the proper sense to protect themselves from contracting the virus, the HIV positive individual who does not identify with such descriptors will feel condemned. Those who do self-identify with being promiscuous homosexual males may embrace their diagnosis as a new identity unto itself. If who they see themselves as being is the same as who they now are, constructing an HIV positive identity will follow fluidly. However, those HIV positive individuals who do not identify with the stereotypes of PLWHA experience the stress of a borderland identity.

The aforementioned example of a self-identifying heterosexual Christian woman of sound judgment/morals can be used to better illustrate this point. The typical Christian church community would most likely hold negative stereotypical perceptions of PLWHA as unrighteous (in the past, religious communities have pronounced HIV/AIDS as a sign of God’s judgment on the wicked). If in reality this woman has had two sexual partners, the projection that she is an ‘easy’ woman who did not show enough self-restraint would be quite damaging to her identity.

This study will analyze the tweets posted by individuals living with HIV/AIDS to investigate whether or not PLWHA express the stress of experiencing a borderland identity.

METHODOLOGY

This study is a content analysis of tweets of individuals living with HIV/AIDS. A content analysis was chosen in order to study Twitter in an effort to uncover patterns in the tweets of PLWHA. Twitter is a social networking site that poses a simple question to its users, “What are you doing now?” Twitter account holders (twitterers) answer this question in whichever way he or she determines to do so. Twitter posts (tweets) may be in dialogue with another twitterer or stand alone as solitary individually uttered statements.

*Sample*

This sample of five individuals living with HIV/AIDS that actively use Twitter was selected through a systematic search. The term “HIV positive blog” was typed into the Google search engine looking for five subjects who met specific criteria. Potential subjects had to identify themselves as HIV positive, be at least 18 years of age, offer a “follow me on Twitter invitation,” be an individual (not a group or organization), and tweet in the English language. Within the first five pages of the Google search results the researcher came up with three individuals who fit the aforementioned criteria: Marvelyn Brown, Oriol R. Gutierrez Jr., and Jack Mackenroth. After other search terms proved to be unfruitful, the researcher went to the first person on the list, Marvelyn Brown’s, twitter site. From Marvelyn’s list of 235 followers, the researcher looked at every 10th person to see if they met the five criteria points. If not, the researcher moved to the next twitterer on Marvelyn’s list of followers. To determine whether or not a follower of Marvelyn’s met the criteria, the researcher clicked on his/her personal website link if one was provided. Three additional people were found who fit the criteria: justbthat, Just\_Trav, and DaddyDab. The original intention was to code 150 tweets, but one person had 36 total. Thus, he was dropped from the sample, leaving five tweeters. Any individual whose tweets were analyzed in this study offered a public invitation to be followed on Twitter and proof of such was printed out by the researcher and kept on file.

*Coding*

The coding for this study was designed in order to highlight which of the twitterers’ identity characteristics (if any) were being referenced or emphasized within the contents of each tweet analyzed. A copy of the coding sheet the researcher used when collecting data can be found in the Appendix.

*Strengths and Weaknesses*

This research design has several strengths. First of all, Twitter is a relatively new social networking program on which little research has been conducted. Therefore, this study explores uncharted territory by using a fresh public domain as its data source. Secondly, tweets offer a unique perspective for analyzing identity construction due to the raw nature of instantaneous utterances. The level of pre-planning and editing that goes into a tweet’s development is significantly lower than the amount of structured thought and self-editing that a person tends to apply to, for example, a blog entry. Hence, a tweet’s contents may show more unfiltered thoughts.

There are potential weaknesses in this study as well. Only a small sample of the targeted population was studied. Time constraints for this project kept the researcher from following the twitter posts of selected subjects in their entirety. Therefore, the depth of the data is not quite as thorough as desired. In addition, the fact that Twitter is a public domain may influence the manner in which twitterers present themselves. The tweets analyzed may be more guarded or pre-constructed than responses to an anonymous survey may have been. Also, this study does not include tweets of those HIV positive individuals who are not unsolicitedly sharing their status. Those PLWHA who are not comfortable exposing their diagnosis would be an important subset to learn more about.

FINDINGS

*Type of Twitter Post*

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| Username: | Tweets: | Retweets: | Replies: | Totals: |
| marvelynbrown | 47 | 2 | 101 | 150 |
| oriolgutierrez | 108 | 41 | 1 | 150 |
| justbthat | 44 | 4 | 102 | 150 |
| Just\_Trav | 28 | 3 | 119 | 150 |
| DaddyDab | 100 | 0 | 0 | 100 |
|  | 327 | 50 | 323 | N=700 |

The type of tweeting that each member of the sample took part in varied. However, each individual whose posts were coded for stuck to one type of tweeting in 75 percent or more of their contributions. Those individuals who replied much more than they tweeted (marvelynbrown, justbthat, and Just\_Trav) were engaging in conversations, using Twitter as a vehicle for speedy communication and relationship maintanence. The other two sample members (oriolgutierrez and DaddyDab) tweeted in monologue.

*Mentionings of HIV and/or AIDS in Respective Tweets*

Out of the 100 twitter posts that I analyzed of DaddyDab’s, 48 mentioned either HIV or AIDS within the limited 140-character post. Of the 48 tweets that included the words HIV and/or AIDS, 29 contained the acronyms once, 13 tweets contained them twice, and six tweets even had three mentionings of HIV and/or AIDS. In total, DaddyDab’s 100 tweets that were coded contained 72 repititions of the words HIV and/or AIDS. Whether it was a mentioning of visiting kids who were sick with HIV/AIDS at the local hospital (such as, “Heading to the hospital to visit some local kids with HIV and AIDS.”), a reminder that there was an upcoming AIDS walk (such as, “Join Dab the AIDS Bear for Walk for Life London [AIDS Walk] on June 7, 2009.”), or encouraging others to vote for legislation that would affect HIV/AIDS health coverage (such as, “Help Dab the AIDS Bear save financially challenged Americans with HIV/AIDS. Call your elected official…”), DaddyDab rarely strayed from the topic of HIV/AIDS.

The twitter user oriolgutierrez was not shy in using the words HIV and/or AIDS either. Oriolgutierrez included the aforementioned acronyms in his posts the second most frequently in this sample with a total of 60 mentionings. Of the 60 times that oriolgutierrez typed the words HIV and/or AIDS, 47 were solitary inclusions, five were double, and the acronyms even appeared three times in one tweet. In the 150 tweets of oriolgutierrez’ that were coded, 53 mentioned the words HIV and/or AIDS. Generally, this user’s references to the aforementioned acronyms were charged with political activism (such as, “Learning about using new media to fight HIV/AIDS…” and again with, “…Stigma a Barrier to HIV Care and Medication Adherence…”).

Both marvelynbrown and justbthat included the words HIV and/or AIDS in their 150 tweets each seven times. In addition, both users only exhibited sole mentionings of the acronyms within the seven specific tweets each. Marvelynbrown’s addresses including the coded term(s) tended to highlight her personal role in AIDS activism (such as, “…Marvelous work that you are doing form one AIDS Activist to another!”). It may be noteworthy to mention that justbthat did tweet directly regarding Ryan White (both his legacy and the legislation in his name) in seven posts (in addition to the seven already accounted for). For example, “Debt negotiations comments on Honoring the Legacy of Ryan White…” is a snippet from one of justbthat’s tweets.

Though the research conducted did not find a single mentioning of the words HIV and/or AIDS within the 150 tweets produced by Just\_Trav, this absence should not be taken as an indication of a lack of information. The fact that Just\_Trav did not directly include or address the topic of HIV and/or AIDS by name should be taken into careful observation.

*Mentionings of Sexuality*

Four of the individuals whose Twitter profiles were analyzed rarely mentioned sexuality (sexual behavior or orientation) in the 150 (and in one case 100) tweets that were coded. However, one sample member (justbthat) mentioned his current relationship (or conversed back and forth with his significant other) in more than 30 percent of his tweets. Several pictures of the couple together could also be viewed by posted attachments.

*HIV as Identity*

An analysis of oriolgutierrez’s 150 coded tweets indicates that HIV as identity is the mode of subjectification that he has taken in dealing with the reconstruction of his own biography post-diagnosis. Bartos and McDonald (2000) describe those individuals who have dealt with their HIV positive status by proclaiming their status readily within a single phrase of self-description. One of oriolgutierrez’s tweets declares his personal self-description, “Just added myself to the…twitter directory under: #latino#gay#hiv” (Twitter 2009). Such a tweet demonstrates that oriolgutierrez’s HIV positive status is central to his core sense of self. Oriolgutierrez has integrated HIV along with his race and sexual orientation as the immovable aspects of his self. In addition, those who have integrated their HIV positive status into their lives as an “aspect of the self” will often refer to the sharing of their HIV positive diagnosis as “coming out as HIV positive” (Bartos and McDonald 2000). Oriolgutierrez clearly exemplifies this description in this (as well as several other) forth-coming tweets, “Coming Out Again: A feature article I wrote for POZ about my coming out process, first as gay and again as HIV positive” (Twitter 2009). Furthermore, [enter safe sex references].

DaddyDab qualifies as having taken on the HIV as identity mode of subjectification as well. [enter his examples as well]

*HIV as Experience*

This sample yielded an example of Bartos and McDonald’s 2nd mode of subjectification as well (2006). The select 150 tweets of justbthat’s that were coded offered a case in point for HIV as experience. The research conducted led to this conclusion not merely because of what justbthat tweeted, but just as importantly, because of what he did not choose to tweet as well. Bartos and McDonald detail those individuals who have adapted to the news of their HIV positive diagnosis by dealing with the issues and circumstances that accompany their status as something to be “dealt with, not dwelt within” as viewing HIV as experience (2000).

The specific set of data analyzed would land Just\_Trav in the HIV as experience category as well. Of the 150 tweets that were coded, Just\_Trav did not mention HIV and/or AIDS once. Hence, attributing his view of HIV to that of being his identity or his career would not be well-founded. Just\_Trav can be viewed as modeling HIV as experience due to his apparent lack of being consumed by his HIV positive status.

*HIV as Career*

From Bartos and McDonald’s description of HIV as career, the data collected would indicate that marvelynbrown models this 3rd mode of subjectification (2000). Those individuals who have readjusted their lives (or lifestyles) and objective goals to actively meet the needs of the HIV community without dissolving the distinction between self and involvement have embraced HIV as career (Bartos and McDonald 2000). [enter example] Furthermore, marvelynbrown represents those who see HIV as career by prioritizing a balance between various areas of her life. For example, marvelynbrown obviously sees herself as being dedicated to the awareness effort with tweets including phrases such as, “from one AIDS Activist to another,” “spreading knowledge & empowerment,” and the post, “preparing 4 my skit 4 da Bonner Brothers Hair Show were I show hair stylist how 2 incorporate HIV education n2 their job n da gossip!” (Twitter 2009).

DISCUSSION

I was surprised to find that re-tweeting (the copying and pasteing from another twitterer’s profile in a tweet of a twitter user’s own submission) was not more popular. I would have thought that the high level of social activism amongst the sample members would have inspired more copying and pasting of links. Therefore, awareness was not as blatantly emphasized as I had thought it would be. However, DaddyDab did dedicate the majority of his posts to tweeting announcements of his activist pursuits (which fall under the categories of career, identity/self, and awareness). In reviewing the data, I saw DaddyDab’s profile as an example of HIV as an individual’s identity. Rather than highlighting various identifying characteristics in his life, DaddyDab consistently reiterated his involvement in the HIV community and his efforts to use his experiences and career to positively impact others. Further research could examine Twitter profiles with the intention of classifying the “modes of subjectification” that Bartos and McDonald’s 2000 study, “HIV as Identity, Career or Experience” identified.

The sample studied included a mixture as far as the level to which the individual’s HIV positive status had been incorporated into their own identity. Holding up the finding of earlier research, those who were openly homosexual did tend to mention the HIV “community” and their active participation within that environment more frequently than the heterosexual (or undisclosed) PLWHA. Marvelyn Brown illustrated the mode of subjectification of HIV as career. The young female African-American AIDS activist has taken on the crucade against the spread of HIV/AIDS as a full-time job. I did notice that she seemed to want to keep the topic at an “arms-length” when off the clock as the HIV as career mode indicates.

In hindsight I would have chosen a different methodology in regards to my means of sample selection. A larger sample would have been key in order to draw any significant conclusions. With a sample size of five people, I feel as if I am merely speculating.

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APPENDIX A

1. Name/ Username:
   1. Marvelyn Brown/ marvelynbrown b. Oriol R. Gutierrez Jr./ oriolgutierrez
2. Jonathan Perry/ justbthat d. TRAV/ Just\_\_Trav
3. Dab Garner/ DaddyDab
4. Number out of the 150 being coded for: \_\_\_\_\_\_\_\_/150
5. Date posted: \_\_\_\_\_/\_\_\_\_\_/2009
6. Time posted at: \_\_\_:\_\_\_\_\_\_ am/pm
7. Data (this specific tweet’s content):
8. Tweet or Retweet or Reply (In response to another’s tweet)
9. Topic (Genre) of message’s content:
   1. Awareness \_\_\_\_\_
   2. Political \_\_\_\_\_
   3. Medical \_\_\_\_\_
   4. Family \_\_\_\_\_
   5. Popular Culture \_\_\_\_\_
   6. Ethnicity/Race \_\_\_\_\_
   7. Gender \_\_\_\_\_
   8. Sex \_\_\_\_\_
   9. Sexuality \_\_\_\_\_
   10. Religion \_\_\_\_\_
   11. Self/ Identity (as subject of post) \_\_\_\_\_
   12. Career \_\_\_\_\_
   13. Socioeconomic Status/ Finances/ $ \_\_\_\_\_
10. Keywords (that hint to identity characteristic’s saliency in this instance):