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“Because this is not the end:”
Motivation and Change in People Living with HIV/AIDS

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Motivation and Change in People Living with HIV/AIDS

“Because this is not the end.” Motivation and Change in People Living with HIV/AIDS

With great improvements in antiretroviral treatment, HIV/AIDS has become a condition people are living with throughout their lives. It is therefore important to understand how people mentally and emotionally cope with the onset of disease and create behavioral change to maintain health. Through interviews with residents living at a housing facility for people with HIV/AIDS, I found there are a variety of ways that individuals respond to illness. Behavioral change results from how people understand their identity in a personal and social context. People also vary in how they manage their disease, depending on the type of social support they receive. As individuals learn and grow from their experiences with illness, they often become advocates for their own health and view their status as an asset in helping others. This research helps to inform service providers, policymakers, and communities about how to best allocate resources and foster health change for individuals living with HIV/AIDS.

By nature, human beings are adaptive creatures (Frisancho 1993). We switch schools throughout our lives, go through puberty, explore different career paths, and the majority of people are able to successfully manage such change. However, at times, severe change can challenge one's self-identity, creating what Mezirow (2000) calls a "disorienting dilemma"—an HIV/AIDS diagnosis being a prime example. People who face such dilemmas may experience the condition that causes the disorientation as an all-powerful impediment to their ability to be effective in seeking positive change. Starting with a diagnosis, individuals often experience depression or anxiety, sometimes lose the support of family and friends, and may turn to substances such as drugs and alcohol in an attempt to relieve much of the emotional and physical hardship they experience. Through this experience, however, individuals often develop and show great efficacy to create "turning points" and subsequent change to better their situation (Seeley and Russell 2009). From this research, it is evident that such motivation not only occurs on a personal level, but is also influenced by society.

Considering that people have a difficult time coping after being diagnosed with HIV/AIDS, it is remarkable that many are ultimately able to turn negative life circumstances into positive self-improvement. While practitioners generally have set protocol for how to improve the lives of patients living with HIV/AIDS, this research aims to map how individuals become personally motivated and involved in their own health improvement. In specifically examining motivation, I investigate how people living with HIV/AIDS are personally and socially driven to promote and improve their well-being. Motivation is often described as coming

from within an individual, however in a sociological context I describe it as emerging out of social relations and interactions with others.

While there has been much improvement over the past 40 years in how people respond to HIV/AIDS, many still face great discrimination and lack necessary resources to better their health (Mill et al. 2010). In 2010, the Obama Administration made strides in releasing a five-year strategy to reduce the rate of infection and health disparities as well as increase accessibility of resources for people living with HIV/AIDS (Yahia and Frank 2011). However, for such efforts to have most positive effects, we must first understand how individuals overcome impediments to ultimately take advantage of social resources. Then, the collected information can be used to inform policy and social services and ultimately help people overcome barriers to health.

By approaching the question of motivation from a sociological perspective, I move beyond the focus of individual behavior in the context of chronic illness to better understand factors that influence one's ability to create change. In this research, I first explore how behavior within the individual is critical and variable in responding to the onset of disease. I then recognize the significance of outside factors, namely social support and social labeling, and how they affect one's ability to create change. Through this research it is evident that people respond to illness in a variety of ways, as personal behavior results from how individuals understand their identity and condition in a broader social context.

Literature Review

Behavioral change is an important topic to explore in researching how people cope with disease, as humans are extremely resilient and motivated when adapting to new situations. However, it is important to understand that at times it is extremely difficult for people to accept change and proceed normally with their lives. For many it takes profound support and motivation in order to create behavioral change. Seeley and Russell highlight “transition does not just happen with the passing of time. It is achieved by people taking action and making changes in their lives” (Seeley and Russell, 2009:44). Their research explains that individuals must come to “turning points” in their personal lives in order to create change. However, they do not discuss the possibility that people take action during specific circumstances, and perhaps motivation is not an inherent characteristic within all individuals but instead arises within specific certain contexts.

Similar research regarding health-promoting behavior within the general public also emphasizes the importance of self-efficacy in improving one’s health (Callaghan 2011). The research outlines specific behaviors such as proper nutrition, physical activity, and stress management that people must manage in order to lead healthy lives. Researchers describe, “the pursuit of health, in short, has become one of the more salient practices of contemporary life, commanding enormous social resources” (Crawford 2006:404). People living with chronic illness, however, often lack the requisite resources to facilitate change on their own, often needing additional social support from others. For example, those living with HIV/AIDS often face great barriers when attempting to return to the

work force after a leave of absence. They commonly doubt if they will be able to juggle the stress of chronic illness and a job, fear they may lose public health benefits if they take a paid position, and worry they could be denied health insurance due to their HIV/AIDS status (Razzano and Hamilton 2005).

Individuals seldom have sufficient support from others to encourage and advocate for them when returning to the workplace, which can lead to long term unemployment . Thus, people with HIV/AIDS often become isolated from society and struggle to resume activities they once participated in pre-illness because of the many obstacles they face. It is therefore important to question how to create better policy and services to assist these individuals as much as possible, to break down barriers and allow them to reach societal ideals of health and “normal” functioning.

Behavioral change is critical and variable

Little research has explored what fuels behavioral change during disease, which is crucial to know in order to help people make positive adaptations and personal-transformations. Gifford and Grossl (2002) state that people living with HIV/AIDS have to manage their medication, treatment plan, communication with health-care providers, symptoms, side effects, depressed and/or negative emotions, disclosure, and many other issues on a frequent basis; and individuals greatly vary in how they address these challenges. Some people become extremely upset and vulnerable at the onset of illness while others remain comparatively stable. Researchers have proven that “stressful events and emergencies are a part of life for clients with chronic illness,” however there is

great variation in how they respond to such stressors depending on their “life skills” and strategies in overcoming hardship (Lubkin and Larsen 2005:329). Once a crisis has taken place, such as an HIV/AIDS diagnosis, an individual can either experience personal growth or a lower level of functioning. Fisher et al. (2002) argue that such change primarily occurs on the individual level, but I question past research and propose that perhaps one’s social context plays a greater role in influencing change than previously described.

It is first important, however, to acknowledge that individuals widely vary in how they adapt to the onset and progression of illness to later understand how society plays a role in further supporting or deterring such change. For example, many people respond to the diagnosis of illness in a very negative manner, by developing depression or resorting to illicit drug use. While some continue to behave in negative ways, others report that a pessimistic outlook becomes exhausting over time. Thus, it is evident that some individuals become motivated and create change to improve their lives in hopes of carrying out a more positive lifestyle (Lubkin and Larsen 2005).

Lisa Baumgartner (2002) similarly argues that many individuals living with HIV/AIDS experience a perspective transformation over the development and progression of their illness. She reported that over time, individuals saw their HIV/AIDS status as a way to make a positive contribution to society and help others with the illness by volunteering and serving on committees (Baumgartner 2002). She further described how people living with HIV/AIDS became greatly oriented towards the future. Once a good treatment plan starts, they felt better and

more optimistic about prospective plans and changes they could make in their lives and the lives of others (Baumgartner 2002). While Baumgartner's longitudinal study focused on how individuals can positively change over the progression of their HIV/AIDS, she does not explore the difficulties people first face before reaching "turning-points," as I address in my research.

Motivation arises in specific contexts: social support

As introduced earlier, individuals often experience transitional periods after the initial diagnosis and onset of chronic illness, both positive and negative. While Fisher et al. (2002) largely associate the majority of change and agency to occur on the individual level, there are also societal factors that greatly influence change during the progression of disease. Social support, for example, has a major effect on the progression of illness. Sufficient social support and positive interpersonal relations, Thoits (2011) argues, positively affects one's physical and mental health related outcomes. Smith and Christakis (2008) further support this claim in writing that social relationships can be seen as a form of social capital; people greatly benefit and succeed from the interaction and support they offer and receive from one another. The influential nature of social support is evident in that individuals with more social ties generally experience better physical and mental health (Smith and Christakis 2008).

Although social support has the potential to positively affect health and the path of disease progression, Umberson and Montez (2011) also note that having few social ties can have an equally negative effect. Scientific research has shown that poor quality of social support negatively affects overall health status,

and more specifically can impair immune functioning, a major health concern for people living with HIV/AIDS (Umberson and Montez 2011). Exclusion from past social ties can also cause great distress among individuals and lead to isolation, poor self-care, and depressive symptoms (Fekete, Geaghan, and Druley 2009). Furthermore, harmful relationships that include harassment or discrimination can also lead to a decline in one's health and behavior (Mill et al. 2010). Thus, it is important to examine an individual's social context when aiming to understand his/her mental and physical well-being during disease progression.

Motivation arises in specific contexts: master status

Along with social support, the overpowering nature of chronic illness can also influence how people personally identify themselves and how they are labeled in society. HIV/AIDS, for example, can become the master status of individuals, wholly affecting their identity and self-concept. While a positive master status, such as defining in terms of a high-paying occupation ("I am a doctor") can have great social benefits, a master status regarding chronic illness usually leads to the denial of certain rights, fewer opportunities, and diminished support (Thompson and Hickey 2005). Due to the stigmatized nature of HIV/AIDS, people living with the illness often feel inadequate and discriminated against by others. As a result, some individuals refuse to go into public places during the day, such as going to the grocery store, to avoid harassment and feelings of inadequacy. A master status can take over one's life, making it hard for individuals who are defined in terms of their illness to break away from such thinking and advocate for themselves to create change. However, being defined

by a master status of illness can also help people recognize that they want to regain control of their health and past identity, which motivates them to work hard and re-identify in terms of more positive characteristics. While past research explores the importance of support and positive status-identification within society, my research questions how people living with chronic illness are able to cultivate such resources and social capital. This research aims to unveil how people living with HIV/AIDS are motivated to create positive behavioral change and overcome obstacles to improve their well-being.

Methods

To better understand how people living with HIV/AIDS are motivated to create change in their lives, I conducted interviews with individuals living at Our House¹. Our House is an intentional housing facility specifically designed to provide low-income housing and resources for 45 people living with HIV/AIDS. I interviewed a total of eight residents living at Our House; interviews lasted between 25 and 75 minutes. At the beginning of the study, I distributed flyers to recruit residents to participate in the research. I later switched to an in-person recruitment approach to promote better knowledge and understanding about the project. I sat at the front security/welcome desk, located in the main lobby of the building, and with the help of staff I informally explained my study and asked residents if they would be willing to participate. Spending time in the lobby of the housing facility also gave me access to observe general interactions between residents and informed my interview questions and subsequent analysis.

¹ “Our House” and all names used in this paper are pseudonyms to protect the identity of individuals who participated in this research.

People living at Our House comprise a particular population sample, as all tenants have stable housing at the facility. Stable housing is often seen as one of the major barriers to health among people living with HIV/AIDS, therefore making the informants unique from the general population and important to interview (Shubert and Bernstine 2007). Housing and low income status remained constants among all participants in my research, however, people greatly differed in other aspects of their lives. Interviewees varied in terms of age, gender, race, HIV/AIDS status, education level, and many other factors.

I conducted in-depth interviews in a conversational manner, first asking interviewees to provide some background information on their lives and then continuing with more health and motivation focused questions. While questions primarily focused on health behavior, interviewees were also asked about their social/familial relationships, life goals, current living situation, and hardships/struggles. I concluded each interview by giving participants the opportunity to openly talk about any other topics they felt were relevant. The interviews focused on the individual stories and experiences of people living with HIV/AIDS to better understand how they created change, and what motivated them to do so. Through the in-depth interviews, I was able to draw similarities and differences between narratives to understand both the role that individuals plays in health promotion as well as the greater influence of society.

Although the study was open to all residents, it is important to note that people who chose to participate may have been more willing to speak about their lives, HIV/AIDS status, and changes they have experienced than those who

choose not to participate. Compared to my observation of other individuals at Our House, informants seemed to be more outgoing, interested in my research, and willing to talk with me. Given the nature of the research, which focused on personal topics, this pattern in participation could suggest that the sample of people whom I interviewed could have come to a greater acceptance of their illness than others who did not partake in the study. While this could be seen as a limitation, it also offers a unique perspective because it highlights the experiences of individuals who overcame great hardship and ultimately made many positive changes in their lives. While the research does not express the views and behavior of all people living with HIV/AIDS, it provides an interesting perspective on how society influences personal motivation, a topic that has largely been excluded from past literature on the topic of HIV/AIDS.

Data Analysis

I just kept switching and switching my lifestyle, I just continued to try and work...but I continued to get weird sicknesses...I kept thinking I could live a normal life...and I couldn't. So it was all this depression that came onto that and I couldn't work and then I went on state disability.

Alex, quoted above, was diagnosed with HIV in 1996 and disabling AIDS in 1999, but is now living at Our House, is 46 years-old, and his health has greatly improved in recent years. Although he still struggles with depression, he has a stable home, wants to begin volunteering to help others with HIV/AIDS, and hopes to start doing creative work again in the arts or theater. Alex's transformation is a prime example of the complexity and hardship that many individuals face post HIV/AIDS diagnosis. Yet it also illustrates his ability to

overcome challenges and strive to reach greater goals. Alex's story is similar to those of many other residents; almost all interviewees expressed a great desire to create change in their lives. Although residents each took their own path in instigating change post-diagnosis, larger themes such as the role of social support and re-identification linked their experiences together.

Through my analysis it is evident that there is not one stable characteristic or direct mapping that is consistent among all individuals in responding to the diagnosis/onset of illness. Instead, behavior results from how individuals understand their identity in context. Two main factors affecting identity, namely social support and master status, were especially prominent in the analysis as they led to both potential decline in health as well as proactive health behavior. People who experienced a loss in social support after a diagnosis of HIV/AIDS often lacked the necessary outside help and resources they needed to best control their condition. Similarly, those who experienced a negative transformation of their identity, solely defining in terms of disease, found it hard to find meaning in their lives and create positive health-promoting change.

However, all of the interviewees narrated great self-efficacy in overcoming hardship and learning from their past experiences to ultimately create positive change. Through integral turning points, people were able to restructure their context to become more efficacious and take control over their lives. A change in context often occurred by physically moving locations (for example, from one state to another) or changing key behaviors (for example, becoming sober from street-drugs and alcohol). By changing their social situation, people

were able to put themselves in settings where they valued themselves more and were also valued by others. Those who lacked social networks often created their own support by focusing on helping other people. Individuals who experienced a negative master status for years often became motivated to recreate their identity to focus on achievement rather than disease.

Behavioral Change in Individuals

Through the interviews I found that participants narrated a wide variety of ways in which they initially behaved after their diagnosis of HIV/AIDS.

Analyzing how people respond to their initial diagnosis of illness is important because according to Lubkin and Larsen (2005), the way individuals respond to the onset of illness can inform how we understand later behavior in dealing with the condition. For example Dan, a 48-year-old African American male, described “I didn’t really care about anything anymore. I went on, how can I put it...a very long drug using span...that lasted for a good 10 years.” However, Mason, a 40-year-old Caucasian male recounts, “I remember first being diagnosed being very scared to even walk out in public, what if I fell down and skinned my knee? I was walking back and I was thinking I’ve gotta go back and tell my partner and he needs to get tested.” While Mason was more systematic in thinking about the immediate impact of his diagnosis, Dan was unable to process the diagnosis in a constructive manner until many years later. Finally, Mary, an African American female, responded with a very different reaction, as she reported, “after I found out I was HIV positive, nothing really changed...it was the same so I just recently started HIV meds about 3 years ago.” While Lubkin and Larsen (2005) focus on

two general trajectories that individuals follow in reacting to disease, namely positive or negative, these three excerpts show there are perhaps a variety of ways individuals come to understand their disease and subsequently behave. The above excerpts make it clear that it is less important to understand whether change occurs in a positive or negative direction, but instead how people describe their progression of change. Understanding how and why people are motivated to create turning points in their lives provides more meaningful information as to how these individuals could be best supported by others in society.

While most informants noted that they experienced great changes post diagnosis, several people expressed that they were not greatly affected when they learned about their HIV/AIDS status. Both Mary and Jerome had less extreme responses to initial diagnosis than other residents. Jerome, a 24-year-old African American male mentioned, “I thought my life was really gone...but then I went to the doctor and I heard about all these other medications that fix [HIV].” As Lubkin and Larsen (2005) researched, individuals who respond in a more positive way to their diagnosis of HIV/AIDS often continue to think in an optimistic light, not viewing HIV/AIDS as a major obstacle to success and health. This phenomenon was also seen in Jerome’s narrative when he claimed that his HIV does not prevent him from doing anything; he currently holds a steady job and has already recorded a rap CD that he aspires to release in the near future. Similarly, Mary noted that while she is unable to be as active as she once was in the past, her lifestyle has not greatly changed because of her HIV/AIDS diagnosis. She

continues to live her life as she would like and simply has to take a few more pills everyday.

Mason's story represents a more common trajectory, but it is not as widely recognized in past literature because it does not follow a strictly "positive" nor "negative" track. Instead, Mason's experience illustrates that trajectories can reverse and change direction. As noted earlier, it is not the direction of the trajectory that is as important as how the process of change occurred. Mason was initially rational about his HIV diagnosis, and practical in terms of informing others, beginning medication, and connecting with a doctor and case manager. However, the weight of the diagnosis and several other unfortunate personal life events, one being the death of his long-term partner, eventually led him to experience unemployment and homelessness. Alex narrated a similar story in that he initially continued working after being diagnosed with HIV. However, after switching jobs several times, the stress of trying to maintain a career and care for his condition eventually became too overwhelming and he ended up on state disability. The loss of his job led to depression and a downward spiral in both his mental and physical health.

Major life-changing events caused both Mason and Alex to separate themselves from their past to recognize the importance of their future. Mason ended up in the hospital, near death, before he realized the value of his life and his desire to continue living. Alex finally decided he had to leave California after 15 years, where his battle with AIDS began and developed, and moved back to his hometown to refocus his life and rekindle relationships with his family. These

analyses demonstrate there are an infinite number of ways that individuals respond to the onset of disease. It is therefore less important to know how people initially react to an HIV/AIDS diagnosis, and more pertinent to understand how people eventually come to the understanding that they must create change to improve their well-being.

Finally, Dan's narrative about going on a great drug using span may seem extreme, however other interviewees echoed similar sentiments about giving up hope and having to make very concerted efforts to reroute their lives. Originally from Jordan, Armon who is now 44 years-old was disowned by his family and friends after telling them he was HIV positive. As he recounts, "everything just tailed upside down. I was rejected because of the culture and the customs of the Middle Eastern people...so I was on the street, I had nowhere to go, no place to go, I was homeless for almost 4 years." It took both Dan and Armon many years to bounce back from negative behavior surrounding their HIV diagnoses, however both men ended up making positive changes in their lives to better their health and living situation. While Dan initially started using drugs after discovering his HIV status, after 10 years and the birth of his daughter, he decided to become sober. Lubkin and Larsen (2005) note that individuals often get to the point where they can no longer handle the stress of negative and deviant behavior, and this phenomenon is largely seen in Dan's narrative. When asked why he decided to get sober, he simply responded, "I *just* got tired of it..." showing that he hit a point when he knew he wanted to turn his life around. Similarly, after four years of living on the streets post-diagnosis, Armon moved to a different state to try and

start his life over. As seen in both of these individuals' experiences, negative behavior eventually led to new chapters in their lives, as they actively created positive change.

It is important to note that Mason, Alex, Dan, and Armon all endured unhealthy lifestyles for some time, often living on the streets and not receiving consistent medical care for their HIV/AIDS. In reflecting on their experiences, all the men knew they could not live in such conditions for an extended amount of time. They recognized that HIV/AIDS is a disease they could potentially live with for years, but it would require great lifestyle alterations. In all of their cases, they had few options other than creating change if they wanted to stay alive. They knew that because of their HIV/AIDS status, it was only a matter of time before they would become extremely sick and unable to care for themselves. They acknowledged the importance of social support and resources that they lacked while living such unstable lives, which gave them motivation to finally seek these resources and create change.

Change in the context of master status

The great weight of solely identifying (and being identified) in terms of an HIV/AIDS status majorly affected how people behaved throughout disease progression. Several interviewees remarked that after they were diagnosed, they were unable to take care of themselves because with the condition came much guilt, emotional baggage, and the illness took over their lives. Their master status of disease overwhelmed other areas of their lives that they once saw as important

or key to their identity, such as a job title or relationship. This is especially evident in Alex's case when he said:

[Recently, helping out on a friend's vineyard] has been really good because that makes me feel like I'm not just someone living with HIV/AIDS... 'cause in California I was defining myself as that... my whole life was about AIDS, I go to these agencies, I get this food, I'm having to fight for my living situation.

While Alex was once a successful artist, his identity transformation after diagnosis and progression of AIDS prevented him from being able to live his life to the fullest. He solely defined himself in terms of his AIDS, as is common among people with all different types of medical conditions, from mental illness to Alzheimer's disease (Ghaziani 2004). He no longer saw himself as a successful artist, student, or even a good friend or family member. In order to create great change, Alex knew he had to move away from California to redefine himself with his pre-HIV/AIDS identity and passions in his hometown.

Often times identifying a great shift in identity can help people recognize that they need help, support, and services to better their health status. For example, Mason lived with HIV/AIDS for a long time in great denial, unable to accept that he had contracted the disease and therefore unable to take sufficient care of himself. In his case, his initial inability to accept the reality of his diagnosis led to much distress and both mental and physical health problems, which resulted in a near-death experience. However, he now recognizes that he had much "growing up to do" in order to forgive himself, move forward, and started taking better care of his health. Once he was able to overcome self-stigmatization and accept his condition as part of his identity, he did not see any

problem in disclosing his HIV status to others and was able to make more positive changes in his life. Because he was comfortable with his HIV/AIDS status, he was able to connect with a case manager who helped him find stable housing and effective treatment. This example shows that a master status is not necessarily a negative influence in an individual's life, but instead can also help people grow and overcome great barriers.

Redefining master status

In mainly asking interviewees questions about their past and current lifestyles, I was surprised by the amount of time most individuals chose to focus on future goals and endeavors they plan to pursue. It was clear in talking to many people that they had already undergone great transformations since their initial HIV/AIDS diagnosis. However, many informants were still continuing to create change in their lives; to not be defined by the master status of HIV/AIDS, but to start new jobs, go to college for the first time, ride a bicycle again, and see nieces and nephews get married. These individuals were aiming to redefine themselves in terms of positive achievement instead of disease through self-efficacy and agency. Motivation was propelled by the fact that HIV/AIDS had disrupted long-term plans and goals that they had before their initial diagnoses. Now that they are healthier, have stable housing at Our House, and more access to resources, they want to accomplish their goals. Reaching such goals often acts as the last step in proving to themselves and/or others that they have overcome adversity to create change in their lives. For others, motivation stems from the great hardships they

faced while battling HIV/AIDS, in recognizing that they still have much to live for and they deserve more in life than defining in terms of disease.

Many individuals did not lose sight of their long-term life goals, interests, and identities after their HIV/AIDS diagnosis and aftermath, but were simply unable to continue their life as usual. After completing art school in the Midwest, Alex moved to the West Coast to go to graduate school. However, Alex never made it to graduate school as his AIDS took control of his life; he lost his job, fell into great depression and became sick and isolated. Now, over 15 years later, Alex talks about wanting to get back to more creative work and eventually get his masters degree so he can teach art at a college level. He narrated, “I need to do *something* creative...because I think otherwise I just will go back to defining myself in terms of AIDS, I think that’s the next step...” Alex’s motivation to go back to school is largely based on the fact that he has lifelong goals that have not been met. He recognized that at one point in his life, his disease controlled his behavior and ability, but he is now beyond that period and wants to reclaim part of his old identity and redefine himself in terms of the achievements he hopes to reach. He reflected that at one point, when looking at himself in the mirror, he thought, “my god, you look like this frump, and my haircut looked like anybody else...” At one point in his life he had lost sight of his creativity, however in recognizing part of his identity was lost, he is now working to reclaim it.

Mary also expressed that partially because of her HIV, but also because of a heart condition, it is hard for her to exercise and take care of herself to the full extent she would like. However, after three heart surgeries, starting on HIV

medication, and overcoming breast cancer, Mary shows great motivation in continuing to regain her health. She goes to physical therapy twice a week, takes short walks, but still aims to get even more fit. She told me, “I haven’t ridden a bike in almost 30 years, I wanna ride a bike!!...When my heart gets there, you’re gonna see me out on a bicycle, you watch!” She also recently decided to lose weight and has already dropped 20 pounds. She said she is motivated to lose weight and move around because of the way it makes her feel. She swore, “lose some weight and you’ll see how much livelier you’ll feel and how much faster you can move. It’s bearing you down!” Throughout her interview, Mary demonstrated that while her health has declined over time, her identity has remained comparatively stable. Mary’s situation highlights that it is not necessary to have a completely overwhelming master status of illness in order to desire change. Mary’s situation proves that illness does not define her life, however she still longs to return to how she used to physically function before the onset of her multiple health issues. However, Mary believes that illness is just one part of her life and identity and is therefore not as insistent as others about wanting to create great change. Instead, she sets reasonable goals that she hopes to reach over time.

Many individuals were also motivated to create change because they have lived with HIV/AIDS for many years and finally have the agency and resources to redefine themselves. Mason is a prime example of this phenomenon because he lived on the streets for many years with HIV and lacked the necessary motivation and assets to create change in his life, which ultimately landed him in the hospital. However, in a breakthrough period after he left critical care, he was able to

connect with many resources and move from a nursing home into Our House. Once he was living in stable housing, he regained control over his sickness and now hopes to regain control over his identity. When asked why he is motivated to continue improving his life, he responded: “because this is not the end, this is only the beginning for me.” Having great social support has motivated Mason to strive towards many goals in the future. He explains that he does not plan on staying at Our House for a long time, he is simply there to “catch a breath” before he moves onto other adventures. He has written a business plan and hopes to eventually stop relying on welfare checks, as he wants to independently support himself again.

Similarly Don, a 51-year-old Caucasian male, now realizes the great potential he has and wants to go to college for the first time to re-identify in terms of a new occupation. When he was younger he went to cosmetology school, cut hair, stripped at a gay bar, and worked for some time in a nursing home. However, living with HIV for 26 years and seeing many of his friends suffer, he now recognizes, “I’m very lucky...I mean I could have been one of those people who is dead.” Don did not put his health first for much of his life, and continues to struggle with alcohol abuse after going through substance-abuse treatment 10 times. However, he now feels ready and motivated to go back to school and get a more meaningful job; he hopes to do something in the healthcare field either in nursing or psychology. His motivation primarily comes from witnessing hundreds of friends die and knowing that due to his good fortune and some smart choices, there is a reason why he is still here. Don has gone through great transformations

throughout his life, and hopes to continue to redefine himself in a more positive light.

Change in the context of social support

Although not always explicitly stated, it was clear through the narratives of most interviewees that either a plethora or lack of social support played a major role in how they acted during the progression of disease. As described by Umberson and Montez (2011), social support is an integral aspect of one's life and without it individuals often experience worse mental and physical health. This phenomenon was seen in Armon's situation, when his Middle Eastern family disowned him because of his HIV/AIDS status. He described, "they think that [people with HIV/AIDS] are gay, um homosexual, bisexual, so the idea of having HIV is kind of rejected to them...and after my family turned back on me, then life became so difficult," While Armon once made significant amounts of money working for his family's business, he was later forced to redefine himself, as he was fired, separated from a woman he loved, and became homeless. He was not healthy while living on the streets and developed a blood-clotting disorder in addition to his HIV/AIDS, exhibiting that his loss of social support had major personal, social, and health-related ramifications.

Despite describing how he has made great strides in redefining himself by moving, Armon still admits that he hopes to eventually reconnect and identify with his family; he misses the social support he once had. He told me that he still calls his family and friends on holidays and special occasions, but finished by saying "all the time I get denied, rejected from everyone that I used to be friends

with. [They] don't want nothing to have to do with me, I don't force that..."

When asked if he has tried to make social connections at Our House, he told me "well actually I never met anyone yet...I see them in the elevator...I would really like to have some friends, socialize with people more but I don't also want to force myself on people too." Armon's words clearly demonstrate that he is still withdrawn and hesitant to impose on others due to the amount of rejection he experienced in the past. Armon's loss of all social support at the onset of disease illustrates the great influence that social factors had on his ability to manage his HIV and life post-diagnosis. It is evident that if his family had treated him with care, his story and situation could be very different today.

Dan also experienced a change in his social identity during the progression of his HIV, as his wife no longer let him spend significant time with their daughter and he had a falling out with many friends he once knew through doing drugs. His family also dissociated from him, as seen by his response when asked if he receives much support from them. He replied "No, I have been my own support system ever since I found out I was HIV positive." While Dan seems very frank about his social situation and not openly upset by the decisions he has made; he does longingly reminisce on some relationships he had before his HIV diagnosis. He did express that he is sad that he is not able to see his daughter more often, and misses the days when they had a closer relationship. Nonetheless, it is clear in Dan's narrative that he values his health more than social support, and does not see the two as being greatly interconnected. For example, he chose to get sober to better his health, even though he knew that doing so would terminate the

majority of his friendships and social connections. Dan was aware that without creating major turning points in his life, he would not be able to move on and better his own health. He therefore finally put himself over other people, drugs, and alcohol in order to regain his health and sense of well-being.

Reclaiming social support

During the interviews, many residents expressed that through their experience with HIV/AIDS, they became increasingly concerned with helping others. These interviewees often lacked social resources in their own lives, and as a result attempted to create a sense of support through reaching out and helping other people. Interviewees often tried to find new networks of contacts and support, where their HIV/AIDS status had less meaning and fewer negative connotations affecting their social ties. For example, Johnny (an ex-drug addict) discussed helping friends refrain from using drugs and periodically checking in on them. In reality, he is simultaneously reminding himself and creating his own social support that helps him stay sober. For these individuals, supporting others and living outside themselves can help provide them with the motivation they need to continue bettering their own lives. Essentially, they are making up for and creating the social support they personally lack due to their HIV/AIDS status.

Both Don and Dan highlighted their increase in political involvement and social activism once they were living with HIV/AIDS. Both men were diagnosed with HIV in 1985, a time when AIDS was still largely unknown and not well accepted by the general public. People did not understand how it was spread, and as a result there was great discrimination and stigma attached to the condition.

Furthermore, both men lost the social support of their own family members at the same time of diagnosis. As a result, Don started protesting at hospitals when he saw that his friends were not getting hot food delivered to their rooms, as nurses were afraid to be near patients living with AIDS. He became an educational speaker, often talking at colleges and in hospitals to dispel myths about HIV/AIDS. His enthusiasm and commitment to the issue was evident when he said:

I got arrested 3 times for protesting in the hospital, and I said, hey, whatever it takes to get attention to this. And I'm proud of that, and then my mom saw me on the news and she's like "what the hell are you doing?...did you have to be so vocal about it?" and I'm like "yeah I did...and I made a difference"

Through his work, Don helped many people gain the rights they deserved and helped support himself as well, as he knew he could just as easily be one of the individuals in the hospital room without food.

Dan also commented on a shift in his attitude to be more politically active and aware after living with HIV/AIDS, yet expressed doing so in a slightly different manner than Don. After enduring and surviving a rough period of time post diagnosis, he became very health conscious by frequently exercising and eating well. He strongly feels that fast food is unhealthy and advocates for people to be more aware of the food they put into their "precious" bodies. He brought up this point several times in the interview, emphasizing that he is worried about the direction in which our country is heading in terms of eating habits. In adamantly discussing how he holds other people to high expectations, it is clear that he is holding himself to such expectations as well, as he does not have friends or family

to keep him accountable for his actions. Past research recognizes that individuals often learn through the progression of HIV/AIDS and develop a new perspective that they “need to be of service to others” (Baumgartner 2002:51). However, past literature fails to explain what motivation drives these individuals to help others. My research posits that such motivation stems from a personal lack of social support, and that individuals therefore help others in order to also create support for themselves. People cultivate their own social support through activities such as volunteering and being politically active in order to surround themselves with the support they lost at the onset of HIV/AIDS.

Johnny, a 43-year-old African American male, further illustrates this phenomenon when he emphasized that he takes action to help others in programs and volunteer projects, which subsequently provides him with feelings of support and accomplishment. He mentions that he enjoys volunteering at an organization that provides services to people living with HIV/AIDS because he learns a lot of information that he can then pass along to other people. He states, “As I continue to better myself, I want to be able to help our kids. Cause if we don’t do it, no one else is.” Johnny recognizes that he once lacked the education, resources, and support he needed in life, which is why he is so willing to give back to the community today. He echoes similar sentiments in reflecting on his experience with drugs and now living a sober life. He said:

Being here at Our House reminds me [not to do drugs] because I know quite a few people who are in here or on the street and are still using drugs...and I have to get on them, but I also remind them that I’m not only saying it to you, I’m saying it to myself.

Because if I don't try to stick to it myself, it don't do any good for me to tell you anything

This quote demonstrates that Johnny keeps himself in check through informal social controls he has created to protect and help others. He recognizes that social support is a cycle; he helps others and as a result they help him stay motivated to create and maintain positive change in his life.

Conclusion

In addressing the question of how individuals with chronic illness create change in their lives, it is now evident that these individuals are motivated to create change because of the great hardships and barriers they faced during the progression of illness. The perspective I advance in this paper argues that we should focus on issues of social support and identity perceptions to fully understand how individuals living with HIV/AIDS react and behave post diagnosis and throughout the progression of disease. After being diagnosed and living with HIV/AIDS, many individuals are often eager to regain their true identity and self-worth, to live outside the realm of illness. While past research explores that individuals are the most influential actors in responding to disease (Fisher et al. 2002), I argue that the motivation underlying self-help arises within the context of social relations. Master status identification and social support both affect how people react to the onset of disease, as well as how they later chose to make positive transformations in their lives. While Lubkin and Larsen (2005) propose that great self-efficacy within an individual is the key to instigating personal transformation, I argue that change should be analyzed in a broader context.

The individual is never all-powerful in creating positive or negative change, but instead people are affected by outside factors. Self-efficacy emerges within individuals as they aim to redefine themselves in terms of achievement instead of disease, after being stigmatized or rejected by family, friends, or the greater society. Self-efficacy also manifests from life experience with disease, after dealing with great hardship and finally deciding to reach long-term goals that have been overshadowed by illness for years. Finally, self-efficacy materializes through helping others: being socially involved helps to cultivate support for people who lost many of their own social connections at the onset of HIV/AIDS. My findings therefore supplement past research in proposing that perhaps change is an innate characteristic in people with chronic illness, as individuals inherently want to overcome the devastating nature of disease and better their lives.

These findings hold implications for creating better policy and practice to assist people in making sure they have the necessary resources to create positive health changes in their lives. For example, understanding that negative and deviant behavior post-diagnosis often stems from a lack of social support, it would be appropriate to create an intervention in which support and resources were made more readily available for people who lose many close connections at the onset of disease. Creating more accessible support groups or mentee programs may help individuals connect with a social network when they need it most. This study further applies to health research in general, as having concrete evidence that people with HIV/AIDS can experience positive identity transformations can

help newly diagnosed individuals better cope and manage the onset of chronic disease.

This research benefited by having a sample of individuals who could reflect back on the changes that could improve health, as most interviewees had been living with HIV/AIDS for over 15 years. It is also important to note that the majority of informants for this research were diagnosed with HIV/AIDS during the 80's and early 90's, when there was less information about the illness and social perceptions surrounding the disease were different than they are today. While there are possible shortcomings of this design, such as retrospective bias or a non-representative sample, such limitations help to guide future research.

Overall these findings shed much light on HIV/AIDS research, as they go beyond past literature and explore the concept of change in conjunction with motivation on a societal level. Better understanding how people transform through the progression of chronic disease can inform policy and professionals to help reduce the barriers that individuals face while living with HIV/AIDS. Most importantly, this research illustrates how a disorienting dilemma is not the end, but is instead the beginning of a process in which individuals can change, develop, and grow in a constructive manner.

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