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Older Adolescents' Self-Determined Motivations to Disclose Their HIV Status

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Abstract Disclosure of HIV status is an important topic for youth living with HIV/AIDS, yet theoretical frameworks for understanding HIV disclosure motivations have been poorly applied. Self-determination theory (SDT) proposes that people are at optimal functioning when they are engaging in activities that are interesting and enlivening. This study utilized SDT to understand young adults' motivations to disclose their HIV status. Interviews and observations were conducted with nine youth aged 17–19 and two adult staff. Results indicate that SDT is useful for understanding types of motivation (i.e., amotivation, controlled, and autonomous motivation) to disclose. Amotivation was the most common type of motivation, and came from two recursive sources: fear of stigma and previous experiences of others disclosing without their consent. Controlled motivation to disclose occurred when participants were motivated to disclose because of reasons related to other people, rather than internal or personal reasons, and included the reasons of wanting to gain a closer relationship, reciprocate a shared secret, for psychological or emotional relief, and for attention. Autonomous motivation included two themes: the life perspective that “Having HIV is just part of who I am,” and valuing educating others because education was perceived as important and beneficial to others. This study extends SDT into the domain of HIV disclosure in older adolescents. People providing guidance and support to older adolescents with

HIV/AIDS can use SDT to understand different motivations to disclose.

Keywords Youth with HIV/AIDS · Self-determination theory · Motivation · HIV disclosure · Older adolescents

Introduction

Disclosing one's positive HIV status is typically difficult and fraught with concern and fear regarding the outcomes of the disclosure, which has some bearing on the motivation to disclose. While certain psychological and social assets can buffer or ameliorate the worry, disclosure remains a salient issue for people living with HIV/AIDS. Adolescents living with HIV/AIDS are especially vulnerable to the omnipresent concern about disclosure due to changes related to their ongoing social, psychological, and cognitive development. Over the last 15 years, advances in biological and behavioral treatments of HIV infection have led to longer life spans, improved quality of life, and fewer psychiatric problems for youth with HIV (Donenberg 2005). Still, disclosure remains a topic of major concern in adolescents' lives (Hosek et al. 2000; Wiener and Battles 2006) and the people who support them.

HIV Disclosure

HIV disclosure has been examined in a number of studies, and some of these studies included influences on motivations to disclose. In a concept analysis, HIV disclosure was found to be characterized by the attributes of: experiencing an event, communicating something, timing, contextual environment, protecting someone, relationship status and improving something or being therapeutic (Eustace and

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Ilagan 2010). Eustace and Ilagan (2010) also found that the process of HIV disclosure contained antecedents and consequences. Antecedents included disease acceptance, desire to protect others and gain support, and individual, familial, community, and social factors. Consequences could be positive or negative regarding family, sexual partners, friends, and community. In a qualitative study of South African adolescents with HIV (Petersen et al. 2010), family and peer support was an important factor in participants' coping with their HIV status. Petersen et al. also found that although HIV disclosure to schools by caregivers generally resulted in greater academic support for the adolescents, disclosure through gossip and rumor had the potential to result in stigma and discrimination.

Without social support, youth with HIV can experience feelings of social isolation, anxiety, and severe loneliness (Travers and Paoletti 1999). In a meta-analysis of 21 studies with 4,104 participants conducted by Smith et al. (2008), the relationship between social support and disclosure across the studies was significant but small. Smith et al. (2008) concluded that when people living with HIV felt that HIV carried a greater stigma, they reported less social support, and this relationship was moderate. Greater HIV stigma also corresponded to fewer disclosures of one's HIV status. Although this relationship was small, it was stable between studies. Stigma is a major constraint to HIV disclosure.

Other factors influencing HIV disclosure have been examined. In a qualitative study on why 29 adolescents aged 12–20 disclosed their status, Michaud et al. (2009) found no associations between the participants' gender, age, nationality, and family composition, and the extent and target of disclosure. Michaud et al. also found that younger adolescents' disclosure was linked to that of the parents, while older adolescents tended to independently decide how and to whom to disclose. Decisions about disclosure linked mostly to adolescents' own representation and family situation, and not to their level of maturity. Michaud et al. (2009) found that there were two primary types of disclosure: passive and active. Passive disclosure related to situations (especially for younger adolescents) when parents or caregivers handled the disclosure themselves or advised the adolescents how to disclose (such as to teachers). Active disclosure related to adolescents deciding to reveal their HIV status directly, such as to friends or sexual partners. Understanding factors that facilitate or inhibit adolescents' self-determined motivation to disclose is crucial for supporting the work of people who serve youth with HIV/AIDS.

Self-Determination Theory

One theory that can be utilized to understand youths' motivations to disclose their status to others is Self-

Determination Theory (Deci and Ryan 1985; Deci and Ryan 2000). Self-determination theory (SDT) examines the psychological processes that occur within the social context and how these processes influence one's reasons or motivation to act or behave. In a HIV disclosure context, we propose that self-determination represents motivation to disclose that exists along a continuum varying along the lines of motivation that more or less comes from the self, promotes a sense of an internal locus of control, and is regulated based on personal importance, conscious valuing, and inherent satisfaction.

Six dimensions of motivation exist along the SDT continuum, as seen in Fig. 1. Several scholars have grouped the six types of motivation into three categories for ease and simplicity in examining SDT-related concepts (e.g., Boiche et al. 2008; Fortier et al. 2009; Gegenfurtner et al. 2009; Ntoumanis and Standage 2009). The three categories are amotivation, controlled motivation, and autonomous motivation. Amotivation is a state in which people do not act, act without intent, or lack the intention to act (Pelletier et al. 2001) because the related behavior or outcome is not valued. In the context of HIV disclosure, amotivation reflects a lack of purpose or plan to disclose status for any reason. Controlled motivation consists of external and introjected motivation, and occurs when one does something for an instrumental or non-internal purpose. In the context of HIV disclosure, controlled motivation reflects disclosing with approval-based pressure with the purpose of gaining something from outside the self, such as increased relationship status. Autonomous motivation consists of identified, integrated, and intrinsic motivation, and occurs when one does something because the activity is inherently satisfying, enjoyable, and in line with one's value system. In the context of HIV disclosure, autonomous motivation reflects disclosing because having HIV is part of oneself and disclosure reflects the value and goal of helping others. Autonomous and controlled motivation types are not proposed to be mutually exclusive, but are two independent types of orientations or constructs (Boiche et al. 2008). In this study, autonomous motivation reflects planning to disclose for purposes related to personal identity and values, and controlled motivation reflects planning to disclose because disclosure would be expected within the context of the relationship, not because disclosure is valued for its own sake. The third type of motivation—amotivation—reflects lack of interest in or planning to disclose.

Types of motivation have consequences for action. As Ryan and Deci (2000, p. 69) explain, "Motivation produces." In this study, the product of motivation is HIV disclosure (which could have positive or negative outcomes). In the context of HIV disclosure, autonomous motivation produces the intent to disclose for the sake of disclosure,

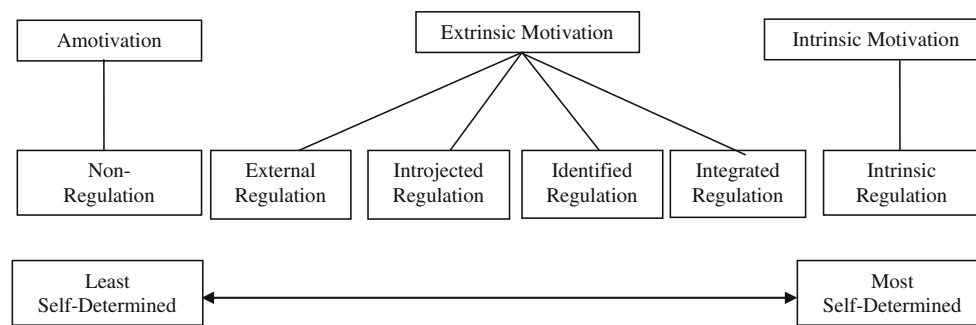


Fig. 1 The types of motivation and regulation within self-determination theory, along with their placement along the continuum of relative self-determination (Deci and Ryan 2008a)

controlled motivation produces the intent to disclose for the sake of relationship status, and amotivation produces a lack of disclosure. Regulatory processes (i.e., how outcomes are pursued; Deci and Ryan 2000) for amotivation include the experiences of feeling non-intentional, non-valuing, incompetence, and a lack of control. Controlled regulatory processes include the experiences of feeling compliance, mostly external rewards and punishments, self-control, and ego-involvement. Autonomous regulatory processes include the experiences of feeling personal importance, conscious valuing, congruence, awareness, synthesis with the self, interest, enjoyment, and inherent satisfaction.

A wealth of research has demonstrated that more autonomous motivation is linked to better outcomes in a variety of life domains (e.g., Boiche et al. 2008; Ntoumanis and Standage 2009; Smits et al. 2010; Soenens and Vansteenkiste 2005). SDT has been applied in a number of contexts such as youth recreation (Baldwin and Caldwell 2003), sports (Spray et al. 2006), education (Gegenfurtner et al. 2009), summer camp (Roark et al. 2010), psychopathology (Niemic et al. 2006), and work (Gagne and Deci 2005). However, SDT-based studies on motivation have not been applied in the area of HIV-status disclosure for youth. Applying SDT to HIV disclosure for adolescents can provide a framework for understanding this phenomenon.

Self-Determination Theory and HIV Disclosure

Individuals who regulate their behavior autonomously choose to do so because of the personal importance of the behavior for their health (Williams et al. 1998). Uysal et al. (2010) conducted a SDT-based study on self-concealment in a sample of mostly female college students. Self-concealment was defined as the “tendency to keep distressing personal information secret” (Uysal et al. 2010, p. 187), and had a direct negative association with well-being. Additionally, the researchers found that the association between self-concealment and well-being were valid regardless of personality differences. However, the connection

between Uysal et al.’s study and the present study is tenuous because Uysal et al.’s sample included mostly female college students and included measures about concealing or sharing general personal information. Disclosure of HIV status in particular is arguably more fraught than an orientation to share or conceal general problems in one’s life. While other SDT-based research has addressed the topics of HIV medication adherence (Kennedy et al. 2004; Lynam et al. 2009) and distress and well-being of gay men with HIV (Igreja et al. 2000), to our knowledge, none have addressed HIV disclosure in older adolescents.

Accordingly, this study aimed to utilize SDT to understand older adolescents’ motivations to disclose their HIV status, using qualitative methods (Patton 2002; Yin 2003). This study was grounded in previous research on the developmental outcomes of summer camp participation sponsored by an AIDS foundation in a major southern city during 2007 and 2008 (Gillard et al. 2010, 2011). Although not a focus of the previous research, the theme of HIV disclosure emerged from youth participant data as an area in need of further investigation. Qualitative approaches to SDT (i.e., Dawes and Larson 2011; Fortier and Farrell 2009; Oliver et al. 2008; Perlman and Goc Karp 2010) have been much less widely used than quantitative approaches, and qualitative approaches were appropriate in this study because of the focus on understanding motivations for HIV disclosure in older adolescents.

Method

Procedures and Participants

The Springfield College Institutional Review Board approved the study, and the AIDS foundation management staff provided permission to conduct this research with program participants. Data were collected at a program operated by the AIDS foundation that was held in June

2010 and served 41 young adults aged 16–19 who were selected through consultation with their caregivers and health care providers and who voluntarily chose to attend. Participant observations and semi-structured one-on-one interviews with nine youth participants aged 17–19, and interviews with two adult leaders were used to gather data. The first author was a mentor in the program, which entailed supervising participants throughout daily activities, driving participants to activities, and engaging in activities such as discussions and educational and motivational workshops.

Prior to the first day of the program, the AIDS foundation sent consent forms to parents and caregivers, and collected signed forms upon participant arrival. On the first night of the program, the first author explained the purpose of the study to the group and that she would be approaching several participants throughout the week to inquire about their potential participation in interviews. The program director and first author consulted about which participants to approach for interviews to ensure a representative sample of a range of attitudes about disclosure, and to ensure that only those participants under age 18 who had parental consent to participate would be approached. The attitudes ranged from non-disclosed (except to health care providers) to public disclosure. Throughout the program, the first author approached individuals for interviews, and those under age 18 provided assent if they had consent forms signed by their parents or caregivers, or signed consent forms if they were 18 or older. Nine participants agreed to participate and none refused.

Semi-structured interviews lasted 10–60 min each. Participants who were primarily amotivated to disclose their HIV status gave shorter interviews, and participants who had more of a range of motivations to disclose provided longer interviews. Interviews were typically conducted in a quiet place in sight of, but out of earshot of other participants. Examples of interview questions included: “Approximately how many people know about your

HIV status? How did they find out? What were their reactions? What influenced your decisions to talk to people about your status? What are your opinions about disclosing your status in public, such as speaking in front of a group, writing an article, or other ways?”

See Table 1 for a summary of interview participants, their demographic information, and their primary motivation types. The demographic and disclosure profiles of the interview participants reflected those of the overall program. Of the interview participants, three did not willingly disclose their status to people outside of the program, three disclosed to close friends and family, two disclosed only to close family, and one disclosed frequently and publicly.

Participant observations centered on topics immediately or tangentially connected to disclosure, such as youth-led discussion workshops about disclosure held in meeting rooms at the residence hall where the participants stayed throughout the program, and the group’s visit to a city council meeting where the AIDS foundation (but not individual participants) was publicly recognized by the council. The first author also recorded observations of unplanned and unexpected situations regarding disclosure, such as when the group attended a banquet at a restaurant with members of the public in attendance, and one participant became distraught because she believed that a guest speaker identified members of the group as having HIV. The purpose of the participant observations was to triangulate the data and reduce the likelihood of misinterpretation, clarify meaning, and bring credibility to the findings (Patton 2002). Participant observation data were compared to interview data to verify results.

Data Analysis

Data were axially and selectively coded, and categories were generated that related to the SDT concepts of amotivation, controlled motivation, and autonomous motivation. Indicators were theoretically sampled that represented

Table 1 Interview participant information

Pseudonym	Age	Gender, race/ethnicity	Perinatally or behaviorally infected?	Found out status within previous year?	Predominant type of motivation
Gordon	17	Male, African American	Behaviorally	Yes	Autonomous
Priscilla	18	Female, African American	Perinatally	No	Controlled
Maribel	18	Female, Hispanic	Perinatally	No	Controlled
Nate	18	Male, Hispanic	Perinatally	No	Autonomous
Sasha	18	Female, African American	Perinatally	No	Autonomous
Steve	18	Male, Hispanic	Unknown	No	Amotivation
Tania	19	Female, African American	Unknown	No	Amotivation
Tyrone	17	Male, African American	Perinatally	No	Controlled
Vincent	18	Male, Hispanic	Behaviorally	Yes	Amotivation

the concepts relevant to SDT, and their properties and dimensions were compared until categorical saturation was achieved (Strauss and Corbin 1998). The authors engaged in a process to establish inter-rater reliability that consisted of multiple readings of coded data and discussions to establish that the codes related to the data and appropriately represented SDT concepts. The first stage of the process resulted in approximately 85 % agreement. After consultation, the authors revised their codes to reflect 100 % agreement.

Construct validity was established in three ways to form correct operational measures of the concepts of self-determination, motivation, and disclosure: multiple sources of evidence, chains of evidence, and member checks. First, multiple sources of evidence (i.e., observations and interviews with adults and youth participants) were collected and the researchers confirmed their convergence on the same set of findings. Second, an established chain of evidence was created through links between the questions asked, data collected, and conclusions drawn to ensure a logical, sequential process that could be anticipated and reproduced by external auditors. Third, to improve the credibility of the findings, the first author conducted member checks with most of the participants from the 2010 program during focus groups held during the 2011 program. Participants confirmed that the three types of motivation related to their behaviors and attitudes about disclosure. The analytic strategy to ensure internal validity involved relying on the theoretical propositions of SDT to make sense of the findings, and employed a constant comparison approach to analysis (Strauss and Corbin 1998). Finally, this study includes a documented auditable database available upon request to provide reliability. The authors remained aware and reflexive of potential biases throughout the study by keeping a researcher journal and discussing findings with others who work with and conduct research with youth with HIV/AIDS, and on SDT.

Results

Results of the data analysis revealed that participants shared both actual past experiences or behaviors, and intentions or attitudes about disclosing. The results focus on actual past behaviors, but it is important to note that attitudes were integral to participants' explanations about their motivations to disclose.

Amotivation

Amotivation occurs when individuals experience a lack of intention and motivation to act (Deci and Ryan 2008a). Explanations of why they felt amotivated to disclose were

the most frequently discussed by all participants, even those who indicated that they were autonomously motivated to disclose. Amotivation came from two recursive sources: fear of stigma and previous experiences of others disclosing without their consent. When others disclosed without their consent, participants were less likely to disclose because they perceived a loss of control over information shared and imagined negative reactions, further reinforcing their amotivation to disclose. Results related to amotivation had a global quality, wherein the participants explained their lack of intention to disclose to people in general, not specific and known people.

Participants reported feeling amotivated when others disclosed their status for them, without their permission. Even though participants wished to keep their status private (i.e., "It's *my* business"), they often had no perceived or real control over others' actions. Peers and parents or caregivers sometimes disclosed participants' statuses without their consent, leaving the participants to handle whatever fall-out occurred and often fracturing the relationships. From observations of discussions about disclosure, it appeared that there were slightly more instances of disclosure without participant consent from parents and close family members than by friends or peers. The negative reactions to disclosure thwarted the participants' social-contextual environment that could have supported autonomous motivation.

A participant in a group discussion about disclosure described how she felt when her aunt told her that her mother told her about her status: "It's my business. For her to tell her [shakes head and sucks teeth]. You can't tell my business, especially to someone I don't like." The participant expressed bitterness about the incident that reinforced her lack of intention to disclose to others; she believed that if she told others, they might tell others without her permission as her mother had done. "Vincent" provided this experience at school as the reason for why he did not disclose his status.

I moved over here to go to high school, and my dad told my teachers, or someone in the school and it got around, and all the kids were messing with me. Like I went to school, I wasn't expecting it. I went to school one day and it was like that. They would make comments in front of me, like loud enough so I could hear, like 'be careful, I heard that guy's got a disease, be careful, don't eat at the same table because you might get what he's got.' Then little by little they started [saying] "HIV and AIDS."

Participants also discussed reasons they were amotivated to disclose because of specific examples of previous experiences in which the person to whom they disclosed reacted in negative ways. Implicit in these descriptions was

the belief that if their closest and caring family members would reject them, they could expect nothing more from people less close. For example, Vincent explained that his father used to “give me hugs, kisses, take me out. But after all this, everything stopped.” Later in the interview, Vincent described his family interactions and said, “For a while, they kind of rejected me and would keep their distance,” and did not want Vincent to touch his baby cousin. Stories were common of family rejection based on inaccurate knowledge of HIV transmission. “Sasha” expressed anger and frustration about her grandmother over the years:

The only person who didn't accept it [having HIV] was my grandma, and she's really distant from me. She just started hugging me like this year 'cause [before] she thought she would get it. I remember when we were little and we were at the pool and she wouldn't get in the pool 'cause she thought she could catch it thataway.

Hearing other people's negative stories of disclosure also promoted participants' amotivation to disclose. For example, while discussing the effects of her participation at a camp for youth with HIV/AIDS on her decisions to disclose, “Maribel” explained, “It more scared me sometimes though, all the stories that I heard [at camp]. So I was always more cautious.” Maribel did not want those negative stories and consequences to happen to her, further reinforcing her amotivation.

“Gordon” summarized the attitude of many of the program participants about why they had no intentions to disclose, “I feel like, friends, especially the school I go to, you tell one person somebody something, it go to one person and the next person and it come back. And then you never know how people gonna take it.” When asked why they did not tell people their status, Gordon replied “Rejection,” and Maribel replied, “There are judgments out there.” “Priscilla” was asked if she would ever speak in public about her HIV status, and replied, “No. Because the world is so cruel and I can only take so much. I can only take so much.” Priscilla had recently graduated high school after enduring 4 years of persistent stigma and negative interactions because of her known positive HIV status. Predominately amotivated participants believed that they had a lack of control over the transmission of knowledge about their HIV status, and over others' reactions to learning the news, so they had a lack of purpose or plan to disclose status for any reason.

Controlled Motivation

Controlled motivation “involves behaving with the experience of pressure and demand toward specific outcomes that comes from forces perceived to be external to the self”

(Deci and Ryan 2008a, p. 14). Controlled motivation consists of both external regulation in which one's behavior is controlled by external factors related to reward or punishment, and introjected regulation in which the behavior is related to avoidance of shame, approval-seeking, and conditional self-esteem (Deci and Ryan 2008b). Results indicated that controlled motivation to disclose HIV status occurred when participants were motivated to disclose because of reasons related to other people, rather than internal or personal reasons. Controlled motivation to disclose HIV status included the reasons of wanting to gain a closer relationship, reciprocate a shared secret, for psychological or emotional relief, and for attention.

Disclosing to gain a closer relationship was the most common theme in the category of controlled motivation. Priscilla explained, “When I get ready to tell someone, mainly it's because I'm in a relationship with them ... because they wanted to be intimate.” Some participants had “scripts” for disclosing, such as “Nate” who explained, “Like, before I actually become officially, they become officially my *friend* friend, I'll kinda test them out.” Maribel used a similar strategy to disclose, “I used the whole hypothetical method, like ‘What if I told you this, or what if I told you that?’ See how the person responds to that to decide if I really want to come out and tell them.”

Often, participants discussed their attitudes about disclosing to gain a closer relationship. Vincent discussed what it might be like making friends and disclosing to them in college: “If they're a good friend they have a right to know so they can be a support system or they can keep their distance from me or whatever.” Gordon explained how relationships could be tested by disclosing: “If they really love and care about you, they want to be with you. But if they leave you, you know how they really feel. If they really care, they'll stay.”

The theme of “reciprocity” emerged in several interviews and group discussions, and participants reported that they often disclosed their status to another individual because that person had first disclosed something private or sensitive to them. Participants seemed to experience some pressure to disclose to someone else, based on their perceptions of the relationship, but disclosure was still voluntary to a limited degree. Feelings leading up to the disclosure conversation were reported as containing a sense of pressure or conflict, and lack of integration or comfort with the self.

One program participant shared her criteria for disclosing her status in romantic and potentially sexual relationships: “If you're together for a month, that shows a level of commitment and you have a trust basis.” Priscilla conveyed a specific situation: “I told this one dude because he shared some personal information about being raped or

whatever, and I told him that ‘cause I guess I feel that I was obligated to tell him that for some reason.” Later Priscilla discussed what happened for her in a couple of her relationships: “You feel like he’s telling you everything about him, and you’re telling him everything too, but if you don’t tell him this it’s like a weight on your shoulders. You like, ‘I *have* to, I *have* to.’”

A few instances emerged of disclosing for psychological or emotional relief. Maribel expressed feelings of obligation to disclose her status to her friends as a way of explaining why she took medicine while on overnight trips or visits: “I didn’t want them to think I was taking drugs or anything [laughs].” Telling her friends her status relieved the burden of “sneaking around.” She explained that she told her friends because “I didn’t see the point of that when I already trusted them. So I might as well just tell them, and I did so they would know and everything.” Similarly, “Tyrone” discussed in his interview his primary reason to disclose to his best friend: “Get the weight off my shoulders, then I would know what he was gonna say.” An adult mentor explained that she observed that participants disclosed to cause “whatever questions people are asking to stop.” Gordon disclosed to his guidance counselor to relieve the pressure created as the counselor kept asking him how he felt about being sick and sharing with Gordon his own personal experiences with his father who had HIV.

Data analysis of controlled motivation to disclose resulted in some minor themes that were inherently untestable because the source of the information was second-hand. First, disclosing to receive attention included the receipt of awards and recognition for educating people about HIV, disclosing for “shock value,” and legal obligations to disclose. During an interview with Nate (who expressed primarily autonomous motivation to disclose his status), he shared that he had received several awards for his volunteer work in educating people about HIV/AIDS. He relayed in an interview and with another adult mentor that his mother suggested that getting awards and recognition was why he disclosed so publicly. However, Nate railed against that accusation and was adamant that personal recognition or awards were not his purposes in his public disclosure efforts. Additionally, one program participant was perceived by adult mentors to disclose his HIV status to “shock” others. According to one of the adult mentors who knew him for several years, this participant disclosed at assemblies at his school to gain social status, pity, and attention. The adult mentor explained that for some youth, “I think for some of them it’s reaching out. The need of love. And if they disclose, would that person feel sorry for them, and show them more love?” Finally, during workshops with facilitators, several participants raised questions about the requirement to disclose their status to sexual partners because of legal obligations, which

reflected the potential for additional aspects of controlled motivation to disclose. In sum, participants with predominantly controlled motivation disclosed because disclosure was expected within the context of the relationship, not because they valued disclosure.

Autonomous Motivation

Autonomous motivation “involves behaving with a full sense of volition and choice,” (Deci and Ryan 2008a, p. 14). Autonomous motivation consists of identified/integrated and intrinsic regulation. Identified/integrated regulation refers to behavior that, while somewhat influenced by extrinsic factors, is primarily sourced within the individual because of valuing of activities that have personal importance or because activities reflect their set of goals and values. Intrinsic regulation refers to behavior done because of the positive feelings associated with the behavior itself.

The category of autonomous motivation was the smallest of all categories of motivation in terms of participants sharing actual previous experiences. Rather, several participants speculated on what they might do in the future. Autonomous motivation included two themes: the life perspective that “Having HIV is just part of who I am,” and valuing educating others because education was perceived as important and beneficial to others. Education consisted of talking to friends or strangers about HIV/AIDS in general or in relation to participants’ personal experiences. However, although the disclosure occurred by choice, participants did not indicate enjoying or feeling comfortable with the process of disclosure (with the exception of Nate, discussed below). Rather, autonomously motivated disclosure seemed to be a hardship that was ultimately worthwhile because of its integration with the self and alignment with personal values.

A few participants discussed their attitudes regarding how living with HIV was integrated into their lives. Nate explained his approach: “It’s kind of easy for me to tell people because I’m a real person and if you don’t like me for who I am, then obviously you might miss out on a very cool person and maybe a longtime friend.” He also explained that “HIV’s not a death sentence, it’s a lifestyle ... Just because I have HIV doesn’t mean anything else ... I’m not any different from anyone else.” Two participants discussed what they thought about Nate’s approach and suggested that they wanted to adopt his attitude. For example, Gordon shared his plans for when he returned to school in the fall: “I’ll be ... saying ‘So what? I have it. I’ve been going to school with you all year, and I’m still here. I eat so much food, I’m healthy.’ That’s why I think now I can tell people.”

Some participants perceived disclosure as a necessary opportunity and responsibility to educate others on an important and potentially life-saving topic. Some interview

participants shared that they had used or planned to use the opportunity to educate others about HIV/AIDS as a springboard for disclosing their status. “Tania” explained that she wanted to tell more people about her status because she was “mad that people are clueless and ignorant.” Nate frequently wore tank tops that revealed on his shoulder a 3-inch by 1-inch red AIDS ribbon tattoo. He used the display of his tattoo as an invitation for others to ask him about it, to talk about his status and how he acquired HIV, and to answer questions. Nate frequently spoke to high school classes and community groups about HIV/AIDS. Discussing his decisions to disclose his status while teaching classes about HIV/AIDS, Nate said, “I have the choice not to tell them or to tell them. But I want to. I should tell them because they’ll get more out of it [if I tell them about my status], but I really don’t have to.”

Two participants (Sasha and Nate) discussed instances of public disclosure. Sasha discussed what happened when she allowed her picture to be published on the front page of a newspaper that mentioned her positive HIV status:

It made me feel better about myself because I don’t like keeping secrets too much. ‘Cause at times I get depressed and I keep too much inside and it just overflows and I will break down. So I just wanted to let that out, just a little bit.

Later in the interview, Sasha expressed nervousness but openness to engaging in further public speaking at the bequest of her doctor; she understood the decision to do so to be her choice.

Other participants shared that they utilized opportunities to disclose when the topic of HIV or AIDS emerged in social situations. Some participants wanted to educate others because they wanted their friends to know more about their lives and not be worried for their health. Maribel discussed the importance of education to reduce stereotypes and misinformation, “Like how it can be transmitted. And how nowadays, especially with technology and medicine, a person can live a relatively normal life, it’s not like they’re in the hospital or having a hard time.” Tyrone speculated on what would happen when he told his best friend: “[He will] probably will have the same response as everybody else, like ‘Oh, are you gonna die?’ Or [I will] have to explain to him the whole, explain that the virus attacks the immune system.”

Priscilla explained why it was so important to educate others: “So they won’t have to go through the same thing ... So, I would hate that to happen to anybody, even my worst enemy. I wouldn’t wish [HIV] on anybody.” Priscilla shared a story of educating her friend that reflected a conscious valuing of education:

I told one girl because she was really sexually active and I was like ‘You have to stop. Because I can sit

here and tell you I have HIV.’ She said ‘Huh?’ I said ‘Yeah. It don’t mean that the person you’re sexually active with will tell you.’

Sasha referred to her motivation to educate others as wanting to “Put out a warning hoping that somebody else would listen. To help save somebody else.” Sasha hoped to educate others through her poetry so that they would understand living with HIV/AIDS and “know how that is.”

The most autonomously motivated participant was Nate, as evidenced by his response to a question about what makes it easier to tell people his status:

HIV is who I am and I do value it, and it’s something I’ve been taught through my whole life since I got diagnosed and my mom educated me ever since I was diagnosed and I’ve been educated on it and it’s been drilled in my head, like for years, and I research it myself and I love doing it [educating others].

Nate demonstrated integrated motivation as he explained his approach to education: “I’ll take all the personal questions you want. It can be anything from me having sex to I want to have a kid when I’m older. I don’t mind, I will answer them with honesty.” In sum, instances of autonomous motivation to disclose HIV status reflected motivation that came from within the self, with full choice and volition, and for purposes related to personal identity and educational goals.

Discussion

This study utilized SDT to understand young adults’ motivations to disclose their HIV status. The results of this study indicate that SDT is useful for understanding types of self-determined motivation (i.e., amotivation, controlled, and autonomous motivation) to disclose. Amotivation was the most commonly reported type of motivation, and involved fear of stigma and rejection based on real or perceived instances of information shared by others without consent in personally important social contexts, and feelings of loss of control over information shared about their status. The accumulation of negative experiences over time seemed to reinforce in participants feelings of amotivation. Controlled motivation involved participants wanting to disclose to gain a closer relationship, reciprocate a shared secret, for psychological or emotional relief, and for attention. Autonomous motivation involved participants’ life perspectives that “Having HIV is just part of who I am,” and having values and goals to educate others. Given that a fundamental premise of SDT is that people are naturally inclined toward growth and well-being, opportunities to experience active or autonomous motivation are warranted, especially for adolescents.

Disclosing one's HIV status because of relationship-related external motivations reflected controlled motivation. In this study, disclosure was a means to an end for most participants, and was not done for any inherent satisfaction found in disclosure. Therefore, we conceptualized controlled motivation as a type of motivation intended to bring others closer. That is, the motivation to disclose was controlled by intentions to manage relationships with others. This particular finding extends the concept of controlled motivation in the field of SDT. The motivation to disclose to deepen a relationship, reciprocate a shared secret, to gain psychological or emotional relief, and to garner attention has strong connections to other research on social support and HIV disclosure. For example, social support in the context of HIV/AIDS can be important for health outcomes because members of an individual's social network who are aware of individuals' HIV status can provide encouragement and support for medication adherence (Roberts and Mann 2000).

Disclosing one's HIV status for inherent personal satisfaction reasons reflected autonomous motivation. In this study, disclosure was personally valuable because of its relation to personal identity and as a means to educate others about HIV/AIDS. Therefore, we conceptualized as autonomous motivation this type of motivation that was inherently personal. The helping attitude reflected in the autonomous motivation to disclose as a means for education about HIV/AIDS can promote feelings of closeness with others, which can be important for youth feeling isolated because of their HIV status. Participants' explanations of motivations to disclose as a means to educate others about HIV/AIDS relates to SDT-based research on volunteering. Thoits (1994) suggested that people with greater personal well-being tend to have more volition to volunteer, such as those with positive personality attributes (e.g., happiness, self-esteem, low depression). Additionally, people with more social resources are more likely to volunteer and this work in turn promotes further well-being (Mellor et al. 2009). Weinstein and Ryan (2010) suggested that autonomous motivation for helping provides benefits for both helper and recipient because both experience greater need satisfaction. Autonomous motives underlying adolescents' identity styles have been shown to positively relate to commitment and personal well-being, whereas controlled motives negatively relate to psychosocial adjustment outcomes (Smits et al. 2010).

In an evaluation of the impact on HIV-positive people of public disclosure of HIV status, Paxton (2002) found that decreasing stigma and stopping new infections were equally strong motivators to becoming community AIDS educators. Participants reported that public disclosure led to a diminution of discrimination, was extremely rewarding, and led to a less stressful, more productive life and

improved well-being. Paxton's findings, combined with the findings from this study, suggest a need for further research on the benefits associated with autonomous motivation in the context of public HIV disclosure. For example, Nate and Sasha (and a couple of other program participants) appeared to demonstrate indicators of well-being, such as hope for the future and desire to improve their communication skills through formal education with the purpose of educating others.

Implications

The findings from this study indicate implications for policy and practice for people who work with and care for youth living with HIV/AIDS. Specifically, practitioners can utilize these findings to gain understanding of the lived experiences of young people with HIV/AIDS that can inform counseling and programming. Through understanding the issues related to self-determined motivation to disclose status, practitioners can develop empathy and sensitivity, and can better support clients as they explore issues, develop goals, become empowered, and enact decisions based on clarified personal values.

Given that autonomous motivation closely relates to enhanced physical, emotional, and psychological well-being in domains other than HIV disclosure, practitioners should work with clients to identify potential positive social and emotional benefits of disclosure, such as by learning about others' positive experiences. Of course, it is imperative to compassionately respect the type of motivation to disclose that individuals possess; disclosure can be a life or death decision for some youth. Still, disclosure can have numerous benefits outside of the self as well, especially regarding the decrease and elimination of stigma throughout communities. More research is needed about the conditions, contexts, and situations that lead to autonomous motivation to disclose, and how to create these conditions that support growth and well-being.

When parents (and peers) tell others without permission, it breaks the security of attachment and brings into question one's sensitivity and responsiveness (LaGuardia et al. 2000). Emotional reliance (willingness to turn to others in emotionally salient situations) is associated with greater well-being and varies across different relationships, cultural groups, and gender (Ryan et al. 2005). Given this, counseling and support policies for families should make explicit the potential negative consequences of disclosing youths' status.

We urge practitioners to carefully consider the assumption that frequent and public disclosure is most beneficial for people living with HIV/AIDS. This might be true on a population-level. However, in this study,

individuals who were amotivated to disclose their status seemed likely to experience harmful outcomes of pressured disclosure such as loss of trust and self-esteem or loss of significant personal relationships, and amotivation continued in a reinforcing cycle because of these concerns. People living with HIV can have difficulty maintaining close personal relationships because of stress associated with the diseases and rejection from close ties (Brashers et al. 2004). Youth with HIV/AIDS are wise to consider the quality of the relationship before disclosing and make “educated guesses” about the potential trajectory of their relationships (Poindexter and Shippy 2010).

People within the support systems of youth with HIV/AIDS could increase their discussions of disclosure techniques and planning. Supporting youth in developing a healthy social identity could include discussions about strategies to challenge stigmatizing attributions projected onto people living with HIV/AIDS. Bakeera-Kitaka et al. (2008) found that young people with HIV in their study lacked specific behavioral skills, such as disclosure of HIV status to their sexual partners, and this closely linked to fear of rejection and stigma. Sturdevant et al. (2001) found that without disclosure, less condom use was reported, even controlling for the perception that the sexual partner was infected. Garnering positive social support can be an important life skill and create greater protective factors for youth (Lam et al. 2007).

Limitations to this study exist. This study utilized a broad distinction between three primary motivation types rather than precise distinctions between the six types of motivation in the SDT continuum. Additionally, this study is limited in generalizability because of the small sample size of nine participant interviews. However, the convergence of data from participant observations and interviews with staff members in conjunction with member checks and other means to improve reliability and validity of the qualitative adds rigor to the findings.

Future research is needed. More research should be conducted to quantitatively measure the types of motivations to assess their prevalence in the context of HIV disclosure. Longitudinal studies should be conducted to explore if and how self-determined motivation to disclose changes over time. Research should be conducted with age groups older and younger than adolescents aged 17–19 to further establish operational constructs of SDT in the context of HIV disclosure, such as experiences of autonomy, relatedness, and competence. Future research should also include variables related to length of time that participants have known their status, and the mode of transmission (i.e., perinatal or behavioral).

This study extends SDT into the domain of HIV disclosure in older adolescents. SDT proposes that people are at optimal functioning when they are engaging in activities

that are interesting and enlivening. Goffman (1963) suggested that deciding to disclose a stigmatizing condition can transform people from passive recipients of stigma into an active agents in control of their own lives. This resonates with the basic premise of SDT that “people are active organisms, with evolved tendencies toward growing, mastering ambient challenges, and integrating new experiences into a coherent sense of self,” (SDT Overview, www.psych.rochester.edu/SDT/theory.php). As Paxton (2002) noted, there is a “paradox” in coming out openly as an HIV positive person because “in facing monumental fear and stigma, one is inevitably liberated from the overwhelming burden of secrecy and shame, (p. 588). Disclosure can be ultimately beneficial to all concerned because it can enrich the disclosers’ lives and help their communities increase in compassion and care for people living with HIV/AIDS.

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