

Disclosure Decisions: HIV-Positive Persons Coping With Disease-Related Stressors

Qualitative Health Research
XX(X) 1-11
© The Author(s) 2011
Reprints and permission: <http://www.sagepub.com/journalsPermissions.nav>
DOI: 10.1177/1049732311405803
<http://qhr.sagepub.com>


Lotte Rodkjaer,¹ Morten Sodemann,²
Lars Ostergaard,¹ and Kirsten Lomborg³

Abstract

The purpose of this grounded theory study was to investigate how Danish HIV-positive persons live with their disease, focusing on HIV-related stressors. Using the Glaserian method, we analyzed textual data from in-depth interviews with 16 HIV-positive persons. Decisions about disclosure appeared to be a major concern and a determining factor for HIV-related stress. Consequently, we developed a substantive theory about disclosure decisions in which three different strategies could be identified: (a) disclosing to everyone (being open); (b) restricting disclosure (being partly open); and (c) disclosing to no one (being closed). Disclosure was a continuum; none of the three strategies automatically relieved HIV-related stress. The theory describes the main determinants and consequences of each strategy. Our study demonstrates the importance of recurrent individual considerations about disclosure choices and plans, and offers a theoretical basis for interventions designed to assist persons living with HIV to make the best possible individual decisions regarding disclosure, and thereby reduce HIV-related stress.

Keywords

constant comparison; depression; disclosure; grounded theory; HIV/AIDS; research, qualitative; stress / distress

Mortality rates for those infected with human immunodeficiency virus (HIV) have decreased substantially in recent years as a result of improved medical effectiveness (Jensen-Fangel et al., 2004; Keiser et al., 2004; Mocroft et al., 2003; Van Sighem et al., 2005). Although highly active antiretroviral therapy (HAART) has transformed HIV from a terminal to a chronic disease (Lohse et al., 2007), this transformation has not changed the way the public views the disease (Joint United Nations Programme on HIV/AIDS, 2007). The fact that HIV remains a highly stigmatized disease throughout the world (Herek, Capitano, & Widaman, 2002) is also significant in Denmark (Danish AIDS Foundation, 2009). Although overt expressions of HIV-related stigma have declined during the past decade, nearly one in four Danes remain fearful of having direct contact with an HIV-positive person; every 5th HIV-positive person has told two or fewer people that they are infected; and every 3rd HIV-positive person is afraid that their HIV status will become known in their social circle (Carstensen & Dahl, 2008; Danish AIDS Foundation).

The psychosocial impact of receiving an HIV-positive diagnosis is well documented. Receiving this diagnosis is almost always a life-changing and traumatic experience (Leserman et al., 2002). Difficulties associated with discrimination and stigmatization necessarily complicate the coping process, and a need to implement holistic models

of care that address the psychosocial, spiritual, and physical dimensions of living with HIV infection has therefore been advanced (Barroso & Powell-Cope, 2000). Collectively, these stigma-related experiences might contribute to stress and adjustment difficulties among persons living with HIV (Clark, Lindner, Armistead, & Austin, 2003; Heckman et al., 2004; Lee, Kochman, & Sikkema 2002).

It is well established that persons with an HIV infection have high rates of stressful life events. In particular, HIV presents individuals with multiple challenges that might overwhelm their coping resources and impair their psychological adjustment to the ongoing demands of managing this stigmatized, chronic disease (Bouhnik et al., 2005; Ironson et al., 2005). Furthermore, because HIV-positive people might respond to stigma by concealing their disease from others, concerns about the consequences of inadvertent disease disclosure could interfere directly with self-care efforts. Researchers have begun to outline

¹Aarhus University Hospital, Aarhus, Denmark

²Odense University Hospital, Odense, Denmark

³Aarhus University, Aarhus, Denmark

Corresponding Author:

Lotte Rodkjaer, Department of Infectious Diseases, Aarhus University Hospital, DK-8200 Aarhus N, Denmark
Email: lottrod@rm.dk

the effects of stigma on adjustment and health, and conceptual models of adjustment to HIV disease increasingly recognize the importance of stigma (Heckman, 2003; Schmitz & Crystal, 2000). Psychological factors might also affect HIV disease progression, and the impact of stressful events on changes in disease markers has previously been reported (Leserman et al., 2002). The association between HIV and depression is attributed to multiple factors, including poorer cognitive and physical functioning because of HIV or treatment side effects (Clifford, 2008; Hult, Chana, Masliah, & Everall, 2008; Vance, Farr, & Struzick, 2008), health-induced anxiety and stress, HIV-related stigma, and social isolation/loneliness (Rodkjaer, Laursen, Balle, & Sodemann, 2010; Vanable, Carey, Blair, & Littlewood, 2006).

Danish researchers found that self-reported emotional strains such as guilt, shame, stress, loneliness, living a double life with HIV as a secret, and stigma had an emotional impact on the daily life of HIV-positive persons, and were significantly associated with a higher risk of depressive symptoms (Rodkjaer et al., 2010). These feelings are difficult to define, and stress, for example, can include many conditions; it can refer to the strain involved, to the physical and mental changes taking place in one's body, and to an individual's sense of inadequacy. Stress can lead to depression, and depression is documented as the second most common form of psychological distress experienced by individuals with HIV (Bing et al., 2001; Ciesla & Roberts, 2001; Leserman, 2008; Rabkin, 2008). To close the gap between meaning and measurement (Barroso & Sandelowski, 2001), the purpose of this qualitative study was to explore how HIV-positive persons in Denmark live with the disease, focusing on stressors related to HIV.

Method

We used a Glaserian grounded theory research design with concurrent interview data collection and a constant comparative analysis (Glaser, 1978; Glaser & Strauss, 1967; Lomborg & Kirkevold, 2003).

Participants

Sixteen participants were recruited from an outpatient clinic that provides care for 11% of the total HIV-positive population in Denmark. The participants had all participated in a cross-sectional, questionnaire-based study about HIV and depression in 2008 at the same outpatient clinic. The maximum variation sample consisted of 4 women and 12 men, 8 of whom were heterosexual and 8 of whom were homosexual, ranging in age from 22 to 66 years. Ten participants had previously been or were currently (at time of interview) diagnosed with depression,

and 8 were diagnosed with HIV before 1996 (when there was no access to HAART), whereas the other 8 were diagnosed after 1996.

Data Collection

Data were collected from in-depth, semistructured individual interviews with the 16 participants. All interviews were conducted by the first author (Rodkjaer) between March and August 2009, and lasted about 1.5 hours each. The interviews started with a few open-ended questions, allowing the persons to express in their own words what it was like living with HIV. Next, some predefined themes guided the interview, focusing on (a) facilitators/barriers to living with HIV, (b) strategies for coping with HIV, and (c) stress and depression. The interview guide was flexible and was developed concurrently throughout the process of data collection and analysis. Immediately after each interview, the interviewer made a general summary and the participant was invited to elaborate and/or correct any potential misunderstandings.

Analysis

Digital audio recordings of the interviews were transcribed verbatim and entered into the computer program NVivo 8 (QSR International, 2008). The systematic data handling and search functions in this program helped us to structure and manage our data (Richards & Richards, 2003). The analytic process included open, selective, and theoretical coding. In the open coding process, the transcripts were inductively analyzed line by line, and several codes were developed to assess the data. Subsequently, the open codes were clustered into categories. After an analysis of the first six interviews, the core category "making individual decisions regarding disclosure" emerged as a main concern, which was ethnographically faithful and enduring beyond the single participants. Once the core category was generated, the sampling became selective along the line of this category. Subcategories and their properties were developed using further data collection (six interviews) and a constant comparison of the data as a whole. In the theoretical phase of the analysis, the relationships between the core category and its subcategories were determined and described. The process continued until no new properties emerged and theoretical saturation was reached. In accordance with the grounded theory method (Glaser & Strauss, 1967), memos were written during the entire analytical process to record ideas about emerging categories and assumptions about their relationships. The first and last authors (Rodkjaer and Lomborg) worked together and discussed the analytical progress using the data and memos throughout the analysis.

Ethical Issues and Approval

The study was approved by the Regional Health's Human Research Ethics Committee and the Danish Data Protection Agency. Before starting an interview, the patient was introduced to the study, told that all information would remain confidential, and assured that declining to participate in the study would in no way affect their access to treatment. Furthermore, participants were informed about their right to withdraw from the interview at any time. Before beginning the interview, the participant signed a consent form that addressed the purpose of the research, explained the confidentiality issues, and explained that the interviews would be tape recorded and transcribed.

Findings

An analysis of how the HIV-positive persons incorporated the disease into their lives revealed detailed information about disease-related stressors. Their main concern was "making individual decisions regarding disclosure" to find the right balance to suit their current personal life situation. The three different strategies of disclosure imposed different dilemmas and possible stressors; the three strategies were (a) disclosure to everyone (being open); (b) restricted disclosure (being partly open); (c) disclosure to no one (being closed). None of the strategies automatically released disease-related stress. Decision making concerning disclosure was shaped by factors specific to the individual, as well as factors specific to the social environment. Sharing their HIV status could provoke anxiety and cause perceived threats to their personal well-being because HIV is still associated with stigma and prejudice. One woman expressed,

People have so many prejudices because it has to do with your sexuality, and they think you have lived a promiscuous life. I think it will take years before this attitude changes. Maybe when they develop a vaccine, so you can't transmit it to others. When you talk about diabetes or cancer, people feel sorry for you, but that is not necessarily the case if you say you have HIV.

It took a good deal of time for the participants to find—and energy to sustain—their emotional balance in life, and coming to terms with being HIV positive. Within the context of a society that stigmatizes the disease, a new personal identity as "a person living with HIV" had to be incorporated into the self. Whether the HIV-positive person wanted to or not, he or she had to "crack their individual code" on whether or not to disclose their HIV status and find some kind of balance or peace within themselves. One patient stated,

As time passes, you learn how to crack the code before things get worse, and you learn how to cope with HIV. . . make peace with it in a way . . . that is important to me, so I can get on with my life.

The participants were not only physically infected with a virus, but also "psychologically infected" because of the challenge regarding disclosure. One of the participants described it with this metaphor: "I had been hit by a hard bullet. This bullet is constantly being activated and deactivated, and it has something to do with my loneliness and living in secrecy with HIV."

Each participant coped very differently, according to his or her choice of disclosure strategy and also within that individual strategy, depending on individual resources and the individual's way of meeting life challenges in general. It appeared that a personal commitment to life, along with a sense of control and the ability to see obstacles as challenges, influenced their strategic preferences. Making an active choice by weighing the pros and cons of the consequences of disclosure seemed to be of great importance. Having a desire to disclose, the participant still contemplated potential reactions and consequences. Making individual decisions regarding whether or not to disclose influenced the participants' experiences in terms of secrecy, control, social support, and protection against stigma and prejudice, and was, therefore, a prior determinant of disease-related stress. An outline of the three disclosure strategies and their consequences in terms of secrecy, control, social support, stigma, and prejudice is presented in Table 1.

Decision making was both an acute and recurring challenge rather than a momentary phenomenon. Once the diagnosis was stated, disclosure was one of the first things that had to be considered. The decision was often characterized by having mixed emotions and questions, such as whom to tell, when to tell them, and what to tell them. The majority of participants indicated that they had adopted a way of no or limited disclosure during the early postdiagnostic phase. This strategy gave them the opportunity to come to terms with their HIV status before dealing with the reaction from others. Disclosure was an ongoing process throughout life, and not just an issue at the time of diagnosis, and turning points or transitions occurred over the years. Some persons did change their strategies. As illustrated in Figure 1, the transition could go either (a) from disclosure to no one to restricted disclosure, and sometimes even to disclosure to everyone; (b) from restricted disclosure to disclosure to everyone; or (c) from disclosure to everyone to restricted disclosure (e.g., when the HIV-positive person had a new job and/or moved to another area).

The participants' respective disclosure strategy sometimes changed over time and was related to their individual

Table I. Consequences of the Three Strategies of Disclosure

Disclosure to Everyone (Being Open)	Restricted Disclosure (Being Partly Open)	Disclosure to No One (Being Closed)
Relief from secrecy	Secrets	Secrets
Loss of control	Control	Control
Social support	Social support	Social isolation
No protection against stigma and prejudice	Protection against stigma and prejudice	Protection against stigma and prejudice

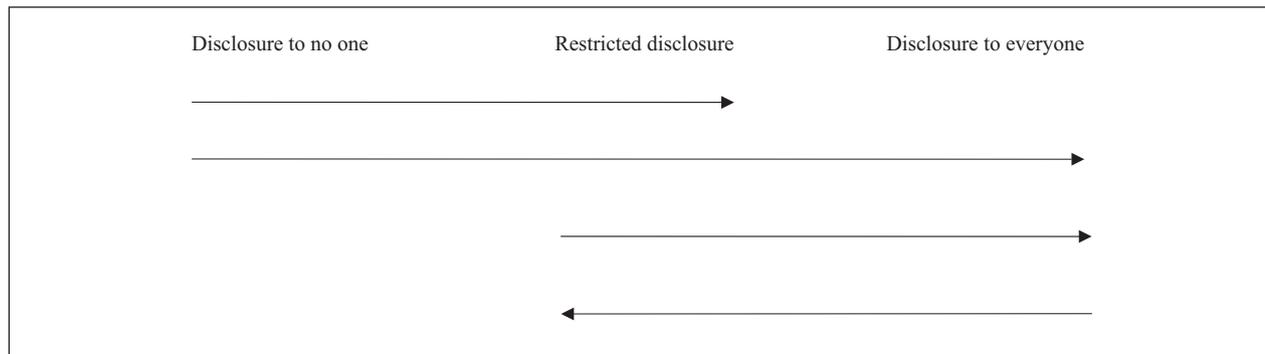


Figure I. Transitions between different disclosure strategies

development, whereas some seemed to gain openness with increasing age, alleviating their worries. Positive experiences after disclosing their HIV status motivated some toward being more open, whereas negative experiences had the opposite effect. One man said,

It overwhelmed me being interviewed by the newspaper, because I wasn't prepared for the consequences. The journalist didn't keep his promise about what to write, and he wrote things that we hadn't agreed on. . . . It took me quite some time to cope with this, and to cope with both negative and positive responses from people. . . . I will never give an interview again, or go public about my HIV status.

Some patients explained that they needed to start afresh, and changed strategy when they moved to another town or changed jobs. A woman said,

I am having treatment, and HIV does not influence my work effort so I can't see the point in telling it to my boss now that I am changing jobs. . . . I don't see myself as a sick person, and I want to focus on the healthy side of me. HIV is not an issue for me any longer, and it doesn't influence my daily life. . . . I want to start a new life where HIV is not in the front but [is] just something I live with. If people ask me I will just tell them. But I will not tell them as the first thing.

Disclosure to Everyone (Being Open)

HIV-positive persons who disclosed their HIV status to everyone in their network had the simple strategy of always disclosing their status to other people. This strategy was not synonymous with being easy; rather, it imposed on the person a variety of thoughts on how and when to communicate it to other people. Typically, the decision was made soon after the diagnosis, and the HIV-positive person's attitude was that their network must accept them as they were if they were still to be part of the person's life. This strategy relieved the participant from living with secrets and the stress associated with worries about "who have I told what to," "what if they find out," and "which story shall I tell." Not everyone in the HIV-positive persons' network accepted their status, and some of their network might therefore disappear during the disclosure process. A man expressed it in this way:

If my friends couldn't accept it then we couldn't be close friends. . . . They thought I was too hard on them, but as I said to them, I won't live a life with friends that are afraid of me, that don't want to drink from the same cup as me, or are worried that I could infect their children when I give them a hug. They had to make a decision and a lot of them dropped me. . . . It was very hard, but I know it was the right thing for me to do.

Choosing the open strategy did not mean disclosure to everyone the participants met, but if people asked them they would disclose their status. Unintentional disclosure and concerns about others finding out about their HIV in an inadvertent way was the reason for choosing this strategy. The participants who chose the open strategy wanted people to get to know them a bit before they told them about their HIV status, especially people they were or wanted to be close to. This approach was chosen so as to be seen as the person they were without interference from other people's opinions and prejudices about HIV. Once other people felt sympathetic toward them, then HIV would not be in the foreground in the relationship. One woman stated,

I like people to have a chance to know me a bit before I say anything, especially people I am close to. Then they have an opinion about me without knowing I am HIV [positive], and I think this makes a difference. . . Hopefully they will think of me as a nice person, and then HIV is just a minor thing.

Being open helped the HIV-positive persons accept their new identity by balancing their integrity with their HIV status. The HIV-positive person had to be prepared to face stigmas and prejudices, and to support the persons to whom he or she had disclosed. In fact, very often people had a lot of questions and needed a lot of information, and it required a lot of energy to tell them about their HIV status and also provide HIV information. The participants prepared themselves beforehand to be confronted in an unpleasant way, and to protect themselves if people met them in a negative way, although it often turned out positively. One man said, "My girlfriend reacted in a positive way when I told her. I don't know how I would have coped if I haven't had her support." Another participant agreed about the importance of social support:

None in my family had been condemnatory at all. They felt it as a vote of confidence that I told them about HIV . . . and they support me in a good way. It is hard to imagine if they were not there for me . . . it is nice to know that somebody cares for you.

This strategy induced loss of control about who knew about their HIV status, what others would be thinking, and who the person to whom they had disclosed their status would tell. The HIV-positive person who chose this strategy felt that the way out of stigmas and prejudices was to talk about it, and for some, this strategy served as a kind of therapy.

Restricted Disclosure (Being Partly Open)

Restricted disclosure was a mixture of the two other strategies. It was the most common choice, and also the most complex. Some of the participants managed this complexity, living a balanced life, whereas others suffered from emotional distress and depression. It was a commonly employed tactic for protecting oneself from potential stigma and rejection. It required constant decision making and problem solving about what information to share and with whom, and there was no simple way to decide who to disclose the information to. Most participants were exceedingly reluctant to disclose their HIV status to more than a chosen few, usually partners, immediate family, and close friends. Disclosure of HIV status varied depending on several factors, including the type of relationship; a wish not to worry or "burden" loved ones, particularly young children and elderly parents; wanting to avoid pity, questions, or well-meaning advice; or to avoid unpleasant situations. A woman said the following:

I haven't told my children who are 13 and 15 years of age. I don't think they have to worry about me because I feel okay. . . . To keep a secret will also be a burden to them and I don't think that is healthy for them.

There was concern about being stigmatized, rejected, and discriminated against because of a lack of knowledge about HIV. Alternatively, this concern was balanced by a need to share this information with others. There were several reasons for choosing this strategy, and it had a number of implications. Reasons for non-disclosure of HIV status included fear of being talked about behind one's back and being ostracized by others. Not focusing on HIV was facilitated by restricted disclosure, and telling as few people as possible about their diagnosis meant there were fewer occasions when they had to acknowledge the reality of the diagnosis and discuss it. The HIV-positive person did not want to be "the HIV-positive person" at his or her work place, but to be seen as "the teacher," or "the nurse," and so forth. Some described it as a dilemma when they had only disclosed their status to some of their friends or family, especially if they all were gathered together and there was always a chance that their HIV status would be disclosed inadvertently; concerns about privacy could be great. Not disclosing felt like lying and being dishonest, and it was difficult lying to loved ones when they usually told them things that were important to them and talked about issues that influenced their lives. Not disclosing HIV, not being able to be a whole person, was a constant stressor, and some felt "left out of a normal life."

Participants composed individual explanations/stories or ways of telling people who confronted them with questions, without mentioning HIV, and were psychologically prepared when meeting people unexpectedly. The story had to be very close to the truth so they could feel comfortable telling it, and not be too absurd because then people asked too many questions. A woman told this story:

I made up this story saying that I have an infection in my blood that the doctors diagnosed when I was hospitalized, after I had been travelling a lot due to my work . . . and I can't remember the Latin name, but the doctors want to control it for research purposes. . . . I have said it so many times now that I believe it myself.

There was a sense that, by confiding their secret, they would unfairly force others into secrecy too, and that was a reason for only disclosing it to a few others. Some gave the person to whom they disclosed the information the permission to share it with someone, so they had someone to discuss it with.

Overall, this strategy stressed being afraid of not being able to keep track of their own lies, and they had to live with secrets. Some described it as "being a secret agent; constantly afraid of being revealed," or "living a double life." For some, this "double life" was less dominating after they had lived with the disease for a couple of years, because they adapted the strategy and their secrets as a "normal" part of living. Most HIV-positive persons worried about others finding out about their HIV status in an inadvertent way, and found it stressful not having control over who knew and who did not know. A man expressed this dilemma:

Some of my friends know and some don't, and I have a son and a daughter and it is only my daughter who knows. It is a problem when we are, i.e., at a birthday, because sometimes the ones who don't know ask me questions because they care for me. . . . I don't always know what to say, and I don't know if the others have told them that I am HIV positive.

It was customary to take a day off from work when visiting the hospital, saying that they were, for example, going to the dentist or were on vacation. This strategy had implications for how the HIV-positive person accessed social support. They got support from the network they disclosed their status to, and described that having someone to talk to about HIV apart from the staff at the hospital supported their ability to balance their lives with HIV and minimize their worries and anxiety. Restricted disclosure was employed to gain some control over their condition by informing only close relatives, and doing so at a time

when they felt ready to deal with others' reactions. This desire for control might explain the finding that many participants had told relatively few people about their HIV status, as well as explain the fear of how people would react if they found out. Telling just one person meant having to wonder if they had told their spouse, children, friends, and acquaintances, and suddenly the individual would lose control over who and how many knew about their HIV status, which induced concerns about the ability of others to cope with the information.

Disclosing to No One (Being Closed)

Those who chose to keep their secret had a relatively simple strategy similar to that of persons who disclosed to anyone, but the strategy was the opposite: never to disclose their status. Many described HIV as being compartmentalized, something kept absolutely separate from everyday consciousness and from most aspects of life. One man said,

I never talk about my private life at work like my colleagues do, and I think they think I am a bit strange not telling anything. . . . If I did tell I would be afraid they would find out that I am gay and HIV positive.

The main reason for keeping their diagnosis a secret was similar to that of those who disclosed their status to some: protecting themselves from potential stigma and rejection. Stressors associated with this protection method, such as fear expressed by others, ostracism, and degradation, as well as stressors within the individual's family network such as denial, anger, guilt, and uncertainty, did have an impact.

The need for silence could mean loneliness, and some avoided intimate relationships so they would not have to bear the burden of disclosure to their partner, protecting themselves against rejection and not having to worry about infecting others. By not disclosing to anyone, they could not mobilize their social network for help in living with HIV, but had to maintain their own coping strategies. Some believed they could no longer maintain meaningful relationships, and did not have the social support that others did, or optimism about their future. One man said,

I was very social before I got HIV. Now I have built up my own defenses. I live alone. I work at home, and no one knows about HIV, not even my 20-year-old son. . . . I don't think that is healthy for me, but I think it is difficult to change now. . . . I would like to tell my son now that he is no longer a child, but I think it is very difficult, and I have learned to cope with my loneliness.

The ability to control knowledge of one's HIV status was very important. By maintaining silence about this issue, some expressed that they felt they were supporting the suspicion or rejection of HIV-positive persons in the society, but they did not have the courage to stand up. Living in secret with HIV was preferred, although a lot of energy was spent keeping it a secret, influencing their daily lives in a negative way. Disclosure to no one was the key to normalcy, the key that ensured that life would go on as if nothing had changed, even though everything had changed. It was a paradox, because they were affected by consequences they wanted to hide from anyway, because they isolated themselves from socialization. This strategy prevented positive effects such as increased social support and decreased stress. A man stated, "My social life is suffering. I have lost my ability to communicate with other people." The social life of HIV-positive persons who chose this strategy suffered because the strategy influenced their ability to communicate with other people.

Discussion

Our findings show that living with HIV is as much a psychological and social phenomena as a physiological and medical concern. Continuously making individual decisions to determine the best possible way to disclose their diagnosis to others was a preoccupation of HIV-positive persons. It was a complex and potentially stressful phenomenon, a lifelong challenge, and a dynamic and ongoing social and psychological process.

There are some limitations to the study. There might be some limitation because of the recruitment strategies in that HIV-positive persons who chose not to disclose might also tend not to access health care services. In Denmark we have the Danish HIV Cohort Study (DHCS). The cohort covers all HIV-infected individuals monitored by Danish HIV-treatment clinics (Obel et al., 2009). The overall estimate is that most of the HIV-positive persons in Denmark do attend the visits at the outpatient clinics. There is free access to antiretroviral treatment and free visits to the hospital. We cannot assume that our findings from using the grounded theory reflect all the details of the entire range of attitudes, experiences, and behaviors among HIV-positive persons. There might be gender and cultural differences, differences according to means of infection (i.e., homosexual, heterosexual, transsexual, drug use, or born with HIV), and differences between children, youths, and adults that we have not considered in our study of the Danish HIV-positive population. However, we do believe that our theoretical account of HIV-positive persons coping with disease-related stressors fits the overall reality of HIV-positive persons living in Denmark. Our theoretical account is relevant for HIV-positive persons and also

informal and formal health care professionals who meet with HIV-positive persons.

The substantive theory contributes to an explanation of the psychological strains of living with HIV, but might need modification once the general cultural attitude toward HIV changes. In accordance with Taylor (2001), our findings demonstrate that the stigma associated with HIV was experienced differently by each person, and changed dynamically for those who disclosed their status throughout the course of the disease. Disclosure is a complex issue that has received increasing attention (Ciccarone et al., 2003; Crepaz & Marks, 2003; Kalichman, DiMarco, Austin, Luke, & DiFonzo, 2003), and is associated with issues of accessibility and the efficacy of social support, as well as being related to individual stage of infection and state of health. Misinformation and fear also contribute to the persistence of HIV-related stigma, and this stigma might jeopardize the person's mental health (Major & O'Brien, 2005).

Although the literature highlights the potential costs of disclosure, there is a tendency to designate disclosure as being therapeutic, functional, healthy, and something that should be encouraged. Our findings indicate that disclosing one's HIV status should not be a goal in itself, but an ongoing discussion regarding disclosure toward a healthier individual strategy. We have shown that the persons who chose to disclose their status to no one suffered because they lacked social support, and had difficulties maintaining close personal relationships because of stress associated with the disease. Social avoidance or rejection can hinder people's psychological and physical health (Brashers, Neidig, & Goldsmith, 2004). Those who chose to disclose to everyone risked facing peoples' stigmas and prejudices. This strategy, which was not the most common one, seemed to necessitate the person had a high sense of self-esteem. Restricted disclosure was a mixture of the other strategies, and because of its complexity, it was a challenge to find a good balance. Our findings reveal that disclosure is not a static phenomenon, but a lifelong process. Baumgartner (2007) also found that disclosure was a component interwoven throughout a process, and found three types of disclosure: (a) telling significant others, (b) public disclosure, and (c) situational disclosure. The author argued that HIV-positive persons found a process of disclosure that correlated with the level of incorporation of the HIV identity.

Our findings underline the relevance of *The Shifting Perspectives Model of Chronic Disease*, by Paterson (2001), who indicated that living with a chronic disease is an ongoing and continually shifting process in which a "disease in the foreground" or "wellness in the foreground" perspective has specific functions in the person's world. The major paradox of living with the "wellness in the foreground" perspective of chronic disease is that, although the sickness is

distant, the management of the disease must be foremost; that is, the disease requires attention in order not to pay attention to it. The person must recognize the disease as a fact of life, while at the same time rejecting the limitations and significance of it. The model implies that researchers and clinicians should extend their focus on chronic disease from how it affects the person's well-being to a conceptualization of the person's perspective of the disease in the larger sociocultural and psychological context. In relation to HIV and disclosure, it is therefore an ongoing challenge for the health care team to support the HIV-positive person's ability to balance disclosure, and not just an issue to discuss at the time of diagnosis.

Baumgartner and David (2009) argued that it takes time from the initial emotional reaction to incorporating HIV into the self, a time of transition that bridges the period immediately after diagnosis and the present. In our study, we found that turning points occurred for those who disclosed their status and experienced the reality that coping strategies that proved to be more successful emerged during transition as they confronted the challenge of their diagnosis, and who took control of and responsibility for their lives and acted on a new awareness. Positive experiences with disclosure motivated one toward being more open.

In a review, Arnold, Rice, Flannery, and Rotheram-Borus (2008) found nearly similar strategies of disclosure. They concluded that, rather than examining HIV disclosures in the context of relationships (partner, family, friends, employers, health care providers, and so forth), it is possible to understand disclosures around personal identity. The findings in our study support this understanding, showing that (a) disclosure is an individual matter related to individual resources and ways of meeting challenges in life; i.e., resilience; and (b) disclosure is related to the situational conditions in which the person is living. HIV-positive persons with higher levels of hardiness (which is an aspect of resilience) are shown to exhibit positive mental and physical health outcomes (Farber, Schwartz, Schaper, Moonen & McDaniel, 2000). Consistent with prior research (Holt et al., 1998), our findings demonstrate that disclosing one's HIV status is both an acute and recurrent stressor, and disclosure has a dual meaning, being both a stressor and a mechanism by which individuals cope with their infection.

We found that disclosure most often occurred after carefully weighing the positive social, physical, psychological, and emotional dividends against the negative consequences of disclosure. This was also reported by Serovich (2001). We found a relationship between stigma and disclosure, and this was consistent with a previously described dilemma (Chesney & Smith, 1999). If the person chose disclosure, then they no longer had to deal with concealing a secret; in contrast, they were then exposed to stigma reactions

and stigmatization. In our study, we found that disclosing one's HIV status to others supposedly allowed people to achieve social support, which is in line with findings from other studies (Emlet, 2006; Kalichman et al., 2003; Serovich). However, it also allowed for the possibility of stigma, shame, and rejection, as also published elsewhere (Brashers et al., 2004). A conclusion of a meta-analysis was that disclosure correlates positively with social support, and stigma correlates negatively with both reported disclosure and social support (Smith, Rossetto, & Peterson, 2008).

The findings from our study show that keeping secrets was associated with personal distress and loneliness, which is consistent with the existing literature (Wiener, Battles, & Heilman, 2000). Expecting and fearing rejection because of stigma was associated with more constricted social networks, and social networks might be particularly important for successful psychological adaptation to HIV (Mavandadi, Zanjani, Ten Have, & Oslin, 2009). It is generally thought that keeping a secret might stress one's body (Pennebaker, Hughes, O'Heeron, 1987), and that disclosure to some might result in better mental and physical health (Pennebaker, Colder, & Sharp, 1990).

Fighting the stigma toward HIV, which is the main barrier to disclosure, seems to be a double-edged sword. Should the change occur from the HIV-positive persons or from their surroundings? In a meta-analysis, the authors suggested that reducing the existing stigma surrounding HIV and providing another way to discuss it without inducing stigma might, in the long term, influence how often those living with HIV disclose their status to others, allowing them the opportunity to gain support and limit further transmission (Smith et al., 2008). Our findings support this idea. Thus, on an individual level, health professionals should offer a basis for interventions designed to assist people living with HIV in reducing disclosure-related stress, making effective disclosure decisions, and learning communication skills for effective disclosure. Disclosure is integral to the incorporation process of living with HIV, and advances in HIV treatment have increased the interest in the quality of life of HIV-positive persons.

It appears from our study that people living with HIV struggle with disclosure as a lifelong stressor, and that only some found a persistent strategy for preventing stress and depression. To address disclosure on an interpersonal level, the intervention needs to be individually tailored, and the role of the health care professional becomes that of assisting people with HIV with their ability to identify and understand their perspectives about HIV, help guide the patient when turning points occur, intervene earlier, and encourage a more positive adaptation. Researchers in previous studies have concluded that overall stress-management interventions significantly improve mental health and quality of life (Scott-Sheldon, Kalichman, Carey,

& Fielder, 2008), and interventions designed to address negative self-image or personalized stigma could address a range of needs including individual counseling, cognitive behavioral therapy, social support, empowerment, and group counseling (Emlet, 2007; Galvan, Davis, Banks, & Bing, 2008; Heijnders & Van Der Meij, 2006). To our knowledge, there are no studies that have taken the different strategies described in this study into account when developing interventions, or that considered disclosure as an ongoing challenge throughout life, as described by Paterson (2001).

Taking the above-mentioned discussion and our findings into consideration, we suggest that researchers and clinicians should extend their focus on chronic disease as a continually shifting process. The infected person might benefit from a systematic and ongoing discussion of all the issues linked with disclosure to reduce the stress and depressive symptoms, focusing on what puts the person off balance rather than thinking of risk factors to adopt a more healthy disclosure strategy to stay in balance. We also suggest that future research should examine disclosure and interventions designed to increase comfort with disclosure. Interventions should focus on communication strategies adopted by HIV-positive persons to live a balanced life—with a lifelong perspective.

In this article we have demonstrated the importance of recurrent individual considerations about choices and disclosure plans, and we offer a theoretical basis for interventions designed to assist persons living with HIV to make the best possible individual decisions regarding disclosure of their HIV status, and thereby reduce HIV-related stress.

Acknowledgments

The authors are grateful to all participants, without whom this work would not have been possible.

Declaration of Conflicting Interests

The authors declared no conflicts of interest with respect to the authorship and/or publication of this article.

Funding

The authors disclosed receipt of the following financial support for the research and/or authorship of this article: Support was received from the Skejby Research Foundation, Aarhus University Hospital, the Health Insurance Foundation, the Central Denmark Region Research Foundation, and the Lundbeck Foundation.

References

- Arnold, E., Rice, E., Flannery, D., & Rotheram-Borus, M. J. (2008). HIV disclosure among adults living with HIV. *AIDS Care, 20*, 80-92. doi:10.1080/09540120701449138
- Barroso, J., & Powell-Cope, G. M. (2000). Metasynthesis of qualitative research on living with HIV infection. *Qualitative Health Research, 10*, 340-353. doi:10.1177/104973200129118480
- Barroso, J., & Sandelowski, M. (2001). In the field with the Beck Depression Inventory. *Qualitative Health Research, 11*, 491-504. doi:10.1177/104973201129119271
- Baumgartner, L. M. (2007). The incorporation of the HIV/AIDS identity into the self over time. *Qualitative Health Research, 17*, 919-931. doi:10.1177/1049732307305881
- Baumgartner, L. M., & David, K. N. (2009). Accepting being poz: The incorporation of the HIV identity into the self. *Qualitative Health Research, 19*, 1730-1743. doi:10.1177/1049732307305881
- Bing, E. G., Burnam, M. A., Longshore, D., Fleishman, J. A., Sherbourne, C. D., London, A. S. . . . , & Shapiro, M. (2001). Psychiatric disorders and drug use among human immunodeficiency virus—Infected adults in the United States. *Archives of General Psychiatry, 58*, 721-728. Retrieved from <http://www.archgenpsychiatry.com>
- Bouhnik, A. D., Préau, M., Vincent, E., Carrieri, M. P., Gallais, H., Lepeu, G. . . . , MANIF 2000 Study Group. (2005). MANIF 2000 Study Group. Depression and clinical progression in HIV-infected drug users treated with highly active antiretroviral therapy. *Antiviral Therapy, 10*, 53-61. Retrieved from <http://www.intmedpress.com/serveFile.cfm?sUID=a4fc039d-8c6f-47ff-b6ab-cc51ed847dc1>
- Brashers, D. E., Neidig, J. L., & Goldsmith, D. J. (2004). Social support and the management of uncertainty for people living with HIV or AIDS. *Journal of Health Communication, 16*, 305-331. Retrieved from <http://www.gwu.edu/~cih/journal>
- Carstensen, M., & Dahl, A. (2008). Patient association. HIV-Denmark. HIV and living conditions—A survey of living conditions and quality of life of people living with HIV in Denmark. Retrieved from <http://www.levekaar.dk>
- Chesney, M. A., & Smith, A. W. (1999). Critical delays in HIV testing and care: The potential role of stigma. *American Behavioral Scientist, 42*, 1162-1174. doi:10.1177/00027649921954822
- Cicarone, D. H., Kanouse, D. E., Collins, R. L., Miu, A., Chen, J. L., Morton, S. C., & Stall, R. (2003). Sex without disclosure of positive HIV serostatus in a US probability sample of persons receiving medical care for HIV infection. *American Journal Public Health, 93*, 949-954. Retrieved from <http://ajph.aphapublications.org/cgi/reprint/93/6/949>
- Ciesla, J. A., & Roberts, J. E. (2001). Meta-analysis of the relationship between HIV infection and risk for depressive disorders. *American Journal of Psychiatry, 158*, 725-730. Retrieved from <http://ajp.psychiatryonline.org>
- Clark, H. J., Lindner, G., Armistead, L., & Austin, B. J. (2003). Stigma, disclosure, and psychological functioning among HIV-infected and non-infected African-American women. *Women Health, 38*, 57-71.
- Clifford, D. B. (2008). HIV-associated neurocognitive disease continues in the antiretroviral era. *Topics in HIV Medicine, 16*, 94-98. Retrieved from <http://www.iasusa.org/pub>

- Crepaz, N., & Marks, G. (2003). Serostatus disclosure, sexual communication and safer sex in HIV-positive men. *AIDS Care, 15*, 379-387. Retrieved from <http://www.tandf.co.uk/journals/carfax/09540121.html>
- Danish AIDS Foundation. (2009). *Danskerens viden, holdninger og adfærd i forhold til hiv-smittede [Danes' knowledge, attitudes, and behavior in relation to the HIV-infected]*. Retrieved from <https://www.aidsfondet.dk/sw/frontend/show.asp?parent=240881&layout=0>
- Emlert, C. A. (2006). A comparison of HIV stigma and disclosure patterns between older and younger adults living with HIV/AIDS. *AIDS Patient Care STDs, 20*, 350-358. Retrieved from <http://www.liebertpub.com/products/product.aspx?pid=1>
- Emlert, C. A. (2007). Experiences of stigma in older adults living with HIV/AIDS: A mixed-methods analysis. *AIDS Patient Care STDs, 21*, 740-752. doi:10.1089/apc.2007.0010
- Farber, E. W., Schwartz, J. A., Schaper, P. E., Moonen, D. J., & McDaniel, J. S. (2000). Resilience factors associated with adaptation to HIV disease. *Psychosomatics, 41*, 140-146. Retrieved from <http://psy.psychiatryonline.org>
- Galvan, F. H., Davis, E. M., Banks, D., & Bing, E. G. (2008). HIV stigma and social support among African Americans. *AIDS Patient Care and STDs, 22*, 423-436. doi:10.1089/apc.2007.0169
- Glaser, B. G. (1978). *Advances in the methodology of grounded theory: Theoretical sensitivity*. Mill Valley, CA: Sociology Press.
- Glaser, B. G., & Strauss, A. L. (1967). *The discovery of grounded theory: Strategies for qualitative research*. Hawthorne, NY: Aldine de Gruyter.
- Heckman, T. G. (2003). The chronic disease quality of life (CIQOL) model: Explaining life satisfaction in people living with HIV disease. *Health Psychology, 22*, 140-147. doi:10.1037/0278-6133.22.2.140
- Heckman, T. G., Anderson, E. S., Sikkema, K. J., Kochman, A., Kalichman, S. C., & Anderson, T. (2004). Emotional distress in nonmetropolitan persons living with HIV disease enrolled in a telephone-delivered, coping improvement group intervention. *Health Psychology, 23*, 94-100. Retrieved from <http://www.apa.org/pubs/journals/hea>
- Heijnders, M., & Van Der Meij, S. (2006). The fight against stigma: An overview of stigma-reduction strategies and interventions. *Psychology, Health & Medicine, 11*, 353-363. doi:10.1080/13548500600595327
- Herek, G. M., Capitano, J. P., & Widaman, K. F. (2002). HIV-related stigma and knowledge in the United States: Prevalence and trends, 1991-1999. *American Journal of Public Health, 92*, 371-377. Retrieved from <http://ajph.aphapublications.org>
- Holt, R., Court, P., Vedhara, K., Nott, K. H., Holmes, J., & Snow, M. H. (1998). The role of disclosure in coping with HIV infection. *AIDS Care, 10*, 49-60. Retrieved from <http://www.tandf.co.uk/journals/carfax/09540121.html>
- Hult, B., Chana, G., Masliyah, E., & Everall, I. (2008). Neurobiology of HIV. *International Review of Psychiatry, 20*, 3-13. doi:10.1080/09540260701862086
- Ironson, G., O'Cleirigh, C., Fletcher, M. A., Laurenceau, J. P., Balbin, E., & Klimas, N. . . ., Solomon, G. (2005). Psychosocial factors predict CD4 and viral load change in men and women with human immunodeficiency virus in the era of highly active antiretroviral treatment. *Psychosomatic Medicine, 67*, 1013-1021. doi:10.1097/01.psy.0000188569.58998.c8.
- Jensen-Fangel, S., Pedersen, L., Pedersen, C., Larsen, C. S., Tauris, P., Møller, A. . . ., Obel, N. (2004). Low mortality in HIV-infected patients starting highly active antiretroviral therapy: A comparison with the general population. *AIDS, 18*, 89-97. doi:10.1097/01.aids.0000096873.36052.6d
- Joint United Nations Programme on HIV/AIDS. (2007). *Reducing HIV-stigma and discrimination: A critical part of the national AIDS programme. A resource for the national stakeholders in the HIV response*. Retrieved from http://data.unaids.org/pub/Report/2008/jc1521_stigmatisation_en.pdf
- Kalichman, S. C., DiMarco, M., Austin, J., Luke, W., & DiFonzo, K. (2003). Stress, social support, and HIV-status disclosure to family and friends among HIV-positive men and women. *Journal of Behavioral Medicine, 26*, 315-332. doi:10.1023/A:1024252926930
- Keiser, O., Taffe, P., Zwahlen, M., Battegay, M., Bernasconi, E., Weber, R. . . ., the Swiss HIV Cohort Study. (2004). All cause mortality in the Swiss HIV Cohort Study from 1990 to 2001 in comparison with the Swiss population. *AIDS, 18*, 1835-43. Retrieved from <http://journals.lww.com/aidsonline/pages/articleviewer.aspx?year=2004&issue=09030&article=00013&type=abstract>
- Lee, R. S., Kochman, A., & Sikkema, K. J. (2002). Internalized stigma among people living with HIV/AIDS. *AIDS and Behavior, 6*, 309-319. Retrieved from <http://www.springer.com/public+health/journal/10461>
- Leserman, J. (2008). Role of depression, stress, and trauma in HIV disease progression. *Psychosomatic Medicine, 70*, 539-545. doi:10.1097/PSY.0b013e3181777a5f
- Leserman, J., Petitto, J. M., Gu, H., Gaynes, B. N., Barroso, J., Golden, R. N. . . ., & Evans, D. L. (2002). Progression to AIDS, a clinical AIDS condition and mortality: Psychosocial and physiological predictors. *Psychological Medicine, 32*, 1059-1073. Retrieved from <http://journals.cambridge.org/action/displayJournal?jid=PSM>
- Lohse, N., Hansen, A. B., Pedersen, G., Kronborg, G., Gerstoft, J., Sørensen, H. T. . . ., Obel, N. (2007). Survival of persons with and without HIV infection in Denmark, 1995-2005. *Annals of Internal Medicine, 146*, 87-95.
- Lomborg, K., & Kirkevold, M. (2003). Truth and validity in grounded theory—A reconsidered realist interpretation of the criteria: Fit, work, relevance and modifiability. *Nursing Philosophy, 4*, 189-200. doi:10.1046/j.1466-769X.2003.00139.x

- Major, B., & O'Brien, L. T. (2005). The social psychology of stigma. *Annual Review of Psychology, 56*, 393-421. Retrieved from <http://www.annualreviews.org/journal/psych>
- Mavandadi, S., Zanjani, F., Ten Have, T. R., & Oslin, D. W. (2009). Psychological well-being among individuals aging with HIV: The value of social relationships. *Journal of Acquired Immune Deficiency Syndromes, 51*, 91-98. doi:10.1097/QAI.0b013e318199069b.
- Mocroft, A., Ledergerber, B., Katlama, C., Kirk, O., Reiss, P., D'Arminio, M. A. . . . , EuroSIDA Study Group. (2003). Decline in the AIDS and death rates in the EuroSIDA study: An observational study. *Lancet, 362*, 22-29. doi:10.1016/S0140-6736(03)13802-0
- Obel, N., Engsig, F. N., Rasmussen, L. D., Larsen, M. V., Omland, L. H., & Sørensen, H. T. (2009). Cohort profile: The Danish HIV Cohort Study. *International Journal of Epidemiology, 38*, 1202-1206. doi:10.1093/ije/dyn192
- Paterson, B. L. (2001). The shifting perspectives model of chronic disease. *Journal of Nursing Scholarship, 33*, 21-26. doi:10.1111/j.1547-5069.2001.00021.x
- Pennebaker, J. W., Colder, M., & Sharp, L. K. (1990). Accelerating the coping process. *Journal of Personality and Social Psychology, 58*, 528-537. Retrieved from <http://www.sciencedirect.com/science/journal/00223514>
- Pennebaker, J. W., Hughes, C. F., & O'Heeron, R. C. (1987). The psychophysiology of confession: Linking inhibitory and psychosomatic processes. *Journal of Personality and Social Psychology, 52*, 781-793. Retrieved from <http://www.sciencedirect.com/science/journal/00223514>
- QSR International. (2008). NVivo 8 [Computer software]. Melbourne, Australia: Author. Retrieved from <http://www.qsrinternational.com/>
- Rabkin, J. G. (2008). HIV and depression: Review and update. *Current HIV/AIDS Reports, 5*, 163-171.
- Richards, T., & Richards, L. (2003). The way ahead in qualitative computing. *Journal of Modern Applied Statistical Method, 1*, 16-26. doi:10.1007/s11904-008-0025-1
- Rodkjaer, L., Laursen, T., Balle, N., & Sodemann, M. (2010). Depression in patients with HIV is underdiagnosed: A cross-sectional study in Denmark. *HIV Medicine, 11*, 46-53. doi:10.1111/j.1468-1293.2009.00741.x
- Schmitz, M. F. & Crystal, S. (2000). Social relations, coping, and psychological distress among persons with HIV/AIDS. *Journal of Applied Social Psychology, 30*, 665-683. doi:10.1111/j.1559-1816.2000.tb02818.x
- Scott-Sheldon, L. A., Kalichman, S. C., Carey, M. P., & Fielder, R. L. (2008). Stress management interventions for HIV+ adults: A meta-analysis of randomized controlled trials, 1989 to 2006. *Health Psychology, 27*, 129-139. doi:10.1037/0278-6133.27.2.129.
- Serovich, J. M. (2001). A test of two HIV disclosure theories. *AIDS Education and Prevention, 13*, 355-364. Retrieved from <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1237028/>
- Smith, R., Rossetto, K., & Peterson, B. L. (2008). A meta-analysis of disclosure of one's HIV-positive status, stigma and social support. *AIDS Care, 20*, 1266-1275. doi:10.1080/09540120801926977
- Taylor, B. (2001). HIV, stigma and health: Integration of theoretical concepts and the lived experiences of individuals. *Journal of Advanced Nursing, 35*, 792-798. doi:10.1046/j.1365-2648.2001.01912.x
- Vanable, P. A., Carey, M. P., Blair, D. C., & Littlewood, R. A. (2006). Impact of HIV-related stigma on health behaviors and psychological adjustment among HIV-positive men and women. *AIDS and Behavior, 10*, 473-482. doi:10.1007/s10461-006-9099-1
- Vance, D. E., Farr, K. F., & Struzick, T. (2008). Assessing the clinical value of cognitive appraisal in adults aging with HIV. *Journal of Gerontological Nursing, 34*, 36-41.
- Van Sighem, A., Danner, S., Ghani, A. C., Gras, L., Anderson, R. M., De Wolf, F. . . . , & ATHENA National Observational Cohort Study. (2005). Mortality in patients with successful initial response to highly active antiretroviral therapy is still higher than in non-HIV-infected individuals. *Journal of Acquired Immune Deficiency Syndromes, 40*, 212-218. Retrieved from <http://journals.lww.com/jaids/pages/articleviewer.aspx?year=2005&issue=10010&article=00014&type=abstract>
- Wiener, L. S., Battles, H. B., & Heilman, N. (2000). Public disclosure of a child's HIV infection: Impact on children and families. *AIDS Patient Care and STDs, 14*, 485-497. doi:10.1089/108729100438863

Bios

Lotte Rodkjaer, MPH, RN, is a research nurse at the Department of Infectious Diseases, Aarhus University Hospital, Aarhus, Denmark.

Morten Sodemann, PhD, MD, is a professor at the Department of Infectious Diseases, Odense University Hospital, Odense, Denmark.

Lars Ostergaard, PhD, DMSc, MD, is a professor and head of the Department of Infectious Diseases, Aarhus University Hospital, Aarhus, Denmark.

Kirsten Lomborg, PhD, MScN, RN, is an associate professor and head of department at the School of Public Health, Department of Nursing Science, Aarhus University, Aarhus, Denmark.