Living with HIV: The psychological relevance of meaning making

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Abstract

A qualitative study was carried out in Namibia to explore how people infected with HIV cope psychologically with this life-threatening virus. The study was based on the theoretical concept of meaning making as developed by Park and Folkman (1997; Review of General Psychology, 1, 115–44) within the framework of Lazarus’ stress and coping theory (e.g., Lazarus, 1993, Psychosomatic Medicine, 55, 245–54). Ten semi-structured in-depth interviews were conducted with people who were diagnosed as HIV-positive but had not yet developed AIDS. The participants had known about their status for 6 months to 8 years. None of them received antiretroviral therapy. The interviews were analysed by means of the circular deconstruction method (Jaeggi & Faas, 1991, Arbeitsmaterialien aus dem Institut für Psychologie der Technischen Universität Berlin). The findings revealed that all participants had accepted their HIV-infection and that this acceptance enabled them to reconcile with having the virus. All participants felt largely responsible for their HIV-infection and they also felt that they had deserved the contraction of the virus. Self-blame and the experience of ‘personal deservedness’ (Park & Folkman, 1997) turned out to provide individuals with a sense of control over the causes of their current situation. Almost all participants reported that since being diagnosed with HIV religion became very important to them. Religious beliefs made their HIV-status more meaningful to the participants and brought a purpose to their HIV-infection as well as hope for a good outcome of this event.

Introduction

Being told that one is HIV-positive can be an incredibly distressing, painful and traumatic experience. The confrontation with the inevitable death, sooner or later, and the stigma attached to the virus make HIV/AIDS one of the most feared of all diseases (Goldin, 1994; Chesney & Smith, 1999). There has been a tremendous growth in literature over the last decade that focuses on the nature of HIV/AIDS and its economic, developmental and social impacts (e.g., Whiteside & Sunter, 2000). However, despite all the statistics and other information available, it is still possible to underestimate the psychological impact of HIV/AIDS.

Living with HIV means having to cope with a combination of various kinds of psychological challenges caused by multiple losses, fears and anxieties, uncertainties, feelings of shame, guilt, self-blame, and social stigmatization. For example, being HIV-positive may mean the loss of health, friends, employment, financial independence, physical intimacy, and the support of one’s family members (Dansky, 1994; Friedland et al., 1996). Individuals may ruminate over symptoms and temporary illnesses, fearing that death may be imminent (Holtyb, 1999). Having an incurable disease and not knowing what to expect of one’s own health status can be very stressful. HIV-positive people usually worry that they will suffer excessive pain and that physical scars and visible skin infections could disfigure them (Van Dyk, 1992). Fears that others might find out or might know already that one is HIV-positive can be acutely traumatic and psychologically paralysing. HIV-infected individuals not only worry about their own futures, but also about that of their children and family members and ask ‘How are they going to cope once I’m gone?’ (Mellins et al., 2000; Kaleeba & Ray, 2002).

According to Evian (2000), one of the most difficult challenges in being HIV-positive is, having to live with uncertainty, e.g., the uncertainty of how long one will remain symptom-free and healthy, whom to inform about the diagnosis and when to do so, who infected them and whom they might have unknowingly infected. Nagging thoughts of uncertainty and the inability to undo the infection can lead to feelings of helplessness, depression and even suicide (Castillo, 1998; Buckingham & Van Gorp, 1999; Swindells et al., 1999).

Since sexual intercourse is the main mode of transmission of the virus, HIV/AIDS receives more social stigma than other diseases (Goldin, 1994; Whiteside & Sunter, 2000) and, thus, makes the status of being HIV-positive a very secretive issue.
Having to live one’s life with a highly stigmatized secret is not only very stressful but it also causes feelings of guilt, self-blame and shame (Tangney & Fischer, 1995; Jacoby, 1996). HIV-positive individuals may see themselves as extremely infectious and literally as outcasts of society (Givan, 2003), which again increases feelings of social isolation, rejection, and the fear of never being able again to find someone to be with.

A vicious cycle arises: having to face so many psychologically distressing challenges can actually speed up the progression of AIDS, as stress can hamper a person’s immune system (Kiecolt-Glaser, 1999). Thus, the experience of high levels of stress makes the health of those living with HIV even more vulnerable, which again can increase levels of stress (Leserman et al., 1999). However, despite the stressful experiences and the many negative emotions caused by HIV, many infected people still manage to maintain a psychological balance (Pakenham & Rinaldis, 2001). The question arises as to what coping mechanisms they utilize in order to move on in their lives.

To better understand the psychological coping processes from the perspectives of infected people, a qualitative study of explorative character (Silverman, 1995) was carried out in Namibia. Namibia is among the four most HIV/AIDS-affected countries in the world, along with Botswana, Zimbabwe and Swaziland (UNAIDS, 2002), and faces a variety of HIV/AIDS-related problems caused by poverty (LeBeau & Mufune, 2001; Otaala, 2003; Iipinge et al., 2004).

**Conceptualization of the study**

This study was entrenched within the theoretical concept of ‘meaning making’ as developed by Park and Folkman (1997) within the broader framework of Lazarus’ stress and coping theory and its main features of cognitive appraisals (e.g., Lazarus & Launier, 1978; Lazarus & Folkman, 1984; Lazarus, 1993). Park and Folkman describe ‘meaning making’ as a psychological process that explicates how people make sense of particularly stressful and potentially harmful events that happen to them. Usually when faced with traumatic and stressful events, individuals ask the question ‘Why did this happen?’ While looking for causal attributions (Heider, 1958), individuals construct meaning from the event. Park and Folkman (1997) emphasize that meaning making can be considered as part of coping but it can also be an outcome of the coping process that individuals go through while dealing with stressful events. Meaning making can change over time and differs inter-individually, depending on a person’s broad orientation towards life in general and the personal significance an event has for someone. It is through meaning making that individuals are able to cope with life-changing events. Individuals who cannot make meaning out of certain events have difficulties coping with them (Park & Folkman, 1997). The concept of meaning making helps to understand how people cope with the circumstances of living with HIV.

**Participants**

The study concentrated on people who were diagnosed as HIV-positive but had not yet developed AIDS and aimed to explore how HIV-positive individuals construct meaning from their virus infection. Since in Namibia the topic of HIV is highly stigmatized and sensitive (Iipinge et al., 2004), it was extremely difficult to find people willing to participate in the study. Finally, some members of an HIV-support centre and a few people approached through community health workers agreed to be interviewed. In total, eight women and two men, aged between 20 and 48 years, were involved in the study. They had known about their HIV-status for 6 months to 8 years. None of the participants were receiving antiretroviral therapy. All but one had children and several of those were HIV-positive also. Eight of the 10 research participants had no regular income and all of them lived under severe financial hardship.

**Methods**

Semi-structured in-depth interviews were conducted on the basis of an interview guideline that targeted the participants’ perceptions about their HIV-infection. The interview guideline was based on the theoretical framework of stress and coping (Lazarus & Folkman, 1984) and its application to meaning making (Park & Folkman, 1997). The interviews were tape-recorded and transcribed verbatim and then analysed by means of the Circular Deconstruction Method (Jaeggi & Faas, 1991). This method consists of various steps that allow analysing bulk qualitative material with regard to the theoretical framework, in such a manner that the main features of the text become apparent.

**Findings**

The interviews revealed that the various HIV-related losses, fears and anxieties, as mentioned in the introduction, were also to be found among the women and men investigated in this study. Most of them had thought about ending their lives after they learned about their HIV-diagnosis. Getting used to their new health status was part of a psychologically
painful process of re-evaluating their lives. The most common uncertainty expressed by the participants was about how long they would live, and they also worried about the future of their children. At the time of the interview, all of the participants had disclosed their HIV-status to family members and friends and some of them reported that this was received with harsh rejection from family members. The interviews revealed that all of the participants had reached a stage at which they had accepted the fact that they were HIV-positive, despite their worries and emotional, social and economic hardships having not diminished.

In this study, the participants’ acceptance of being HIV-positive was based on two main beliefs. Firstly, the participants accepted their HIV-status in their lives because they felt personally responsible for it. They believed that it was their own fault that they were infected with the virus, thus, according to their views they had to accept it. One of the participants, a 22-year-old woman and mother of a 3-year-old child who is also infected, explained her HIV-positive status as follows: ‘It’s my irresponsibility. I got infected through unprotected sexual intercourse. So, it’s irresponsibility. . . . No one deserves to get the 3 years. But when you didn’t care, . . . sometimes I say I deserve it. I knew how to protect myself, I knew it. I was a promoter, a person who promoted condom use. But it happened, I don’t know how’. All of the participants, like this woman, felt largely responsible for their HIV-infection. Instead of blaming others, for instance, the partners who infected them, the participants placed the blame on themselves and their own behaviour and concluded that they had deserved the contraction of the virus. Perhaps surprising, none of the participants gave any indication that they had grudges against those who infected them.

Secondly, the participants accepted the virus because they felt that their contracting the virus was a test or punishment from God. ‘The Lord has a will, and He tests you’, said a 48-year-old woman who knew about her status for the last 3 years, and she continued to say ‘. . . because I was actually a wild person. So it’s maybe the only way in which the Lord could have tested me, so that I can come down to earth a little bit’. A 29-year-old man who was infected when he went to a conference or somewhere, if the people were asked to pray, if they started to ask for someone to pray – I never would go with that! So maybe He needed me somehow somewhere’. These citations indicate that these two women saw a purpose in their contracting the virus. Identification of a purpose in the HIV-infection was also typical for the other participants.

Interestingly, in the same way as they did not blame the person who infected them with the virus, the participants also did not blame God for this presumably purposeful act. Quite to the contrary, eight out of the 10 participants stated that their HIV-infection had brought them closer to God. One of the participants, a 24-year-old woman who knew about her HIV-status for 4 years, reported the following: ‘I have accepted the Lord. I don’t know but if I were not [HIV-] positive, perhaps I would not have accepted the Lord. But it is being positive that makes you turn back from the world so you could also think about God’. A 22-year-old man who was infected when he was 14 years old reported a similar experience when he said, ‘This HIV-thing brought me very, very close to my God, at last I realized, society has failed me, my friends have failed me, my partners have failed me, but God can never fail me. Having that belief system within me makes me stronger every day. That gives me the willpower, that gives me the strength to go through anything I want to do’.

Discussion

It was the aim of this study to explore how people infected with HIV make meaning out of their HIV-infection in order to cope with this life-threatening virus. The interviews revealed that the acceptance of the HIV-infection turned out to be a crucial factor in the meaning making process that helped the participants to maintain a balance in their psychological well-being. Park and Folkman (1997) regard acceptance as a means of resolution in the sense of reconciling a stressful situation with one’s goals, values and beliefs. Acceptance enables the person to be somehow in charge of his/her situation as it is the person who decides to make ‘peace’ with the situation.

As illustrated, the participants blamed themselves and their own behaviour for their HIV-contraction and concluded that they deserved the virus. Such attribution of ‘personal deservedness’ (Park & Folkman, 1997) might appear to be self-diminishing, however, the interviews revealed that such attribution, together with ‘behavioural self-blame’ (Marteau, 1995), actually provided the participants with a sense of control over the causes of their current situation. Maintaining one’s sense of control, even if it is through self-blame and the attribution of personal deservedness, can be interpreted as crucial for the coping process, especially when a situation like living with HIV may result in the individual losing control over various areas in his/her life, as was described above.

In this study, self-blame and personal deservedness was combined with the participants’ belief that their HIV-contraction was also a test or punishment by God. Even though self-blame (internal causal attribution) and the attributions to God
(external causal attribution) seem to contradict each other, it was the combination of these two beliefs that helped the participants to accept the virus and to reconcile with it. Attributing their HIV-infection to God made their HIV-status more meaningful to the participants and specifically, this attribution brought a purpose to their infection but also hope. According to Maro (2001), religion can be the final device that people hold onto when they seemingly have no other hope left. Religious conversion, according to Park and Folkman (1997), represents a coping method and plays an important part in the meaning making process. King (1993) noted that few studies have been undertaken on the role that religion plays for those who are HIV-infected even though religion obviously can help one to accept one’s HIV-positive status. The belief in something greater than oneself is a means to making reality understandable and meaningful (Wayfarer, 1995; cf. also Kubler-Ross, 1969). The belief that a higher order (i.e., God) had a good reason for letting a person become HIV-infected also creates hope, hope for a good outcome of this event. Hope is an integral part of human existence; without it, life has little meaning (Plattner, 1998). Hope is important because it helps the person maintain a future orientation, which is essential in order not to give up on life. However, more research would be necessary to also determine how people who do not turn to religion maintain hope and make meaning out their HIV-infection.

Conclusion

The findings of this study are based on a small and likely to be highly selected group of participants; therefore, they do not allow conclusions to be generalized. However, within the framework of a qualitative research paradigm (e.g., Silverman, 1995), the findings of this study indicate that the process of meaning making enables people to psychologically cope with the stressful life event of HIV-infection and helps them to maintain a psychological balance. Meaning making is a complex and dynamic construct that contains many areas of overlap (cf. Park & Folkman, 1997). That which provides meaning for one person might not have the same result for another. More research would be necessary, particularly of longitudinal design to investigate inter- and intra-individual changes in the process of meaning making over time (cf. also Folkman, 1984). The findings of this study indicate that the concept of meaning making would be worthwhile to be considered as an important feature in HIV/AIDS counselling programmes to assist people in the process of meaning making and to prevent them from psychological deterioration when confronted with the virus.

References


