

JOURNAL OF HUMAN BEHAVIOUR & DEVELOPMENT ISSUES

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- COMMUNITY PSYCHOSOCIAL RESEARCH (COMPRES): A NEW RESEARCH FOCUS AREA FOR COMMUNITY RESEARCH AT THE NORTH-WEST UNIVERSITY IN SOUTH AFRICA
- THE ILLNESS PERCEPTION AND MEANING-MAKING OF PEOPLE LIVING WITH HIV/AIDS
- A RIGHTS-BASED APPROACH TO UNDERSTANDING VIOLENCE-TOLERANCE AND ITS IMPLICATIONS: A BANGLADESHI EXAMPLE
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- "THINK AND GROW RICH" - AUTHOR: NAPOLEON HILL



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VOLUME 2

No. 1

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The Illness Perception and Meaning-Making of People Living with HIV/AIDS

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K. Esther Glory C Kothapally***

Traumatic events such as serious illness can have a devastating impact on a person's life. Earlier researches on persons living with HIV (PLHIV) have found that HIV infection is a medical and existential crisis. PLHIV go through psychological trauma as well as social problems such as depression, stigma, poverty and marginalization in India and elsewhere. It is evident that when people go through stressful life experiences, such as being diagnosed with HIV, ascribing positive meaning to these experiences help them cope with it. However, the meaning based psychological growth and wellbeing among PLHIV has not been adequately explored in this country. This sets the background for an exploration of the ways in which PLHIV attribute meaning to and make sense of the experience of living with HIV. The study has adopted a qualitative, phenomenological research design to explore the meaning that the participants attribute to their experience. 19 men and 18 women, between the age of 24-54, all of them seropositive and who have known their positive status for an average of 10 years participated in the study. Through purposive sampling they were recruited from various care and support centres of PLHIV across 5 districts of Kerala. Analysis of their interviews identified 11 representations of HIV which were the ways in which HIV is perceived and lived by the participants. The findings of the study are expected to help in HIV-counseling. However, this study is a one-time report of the experiences of people living with HIV. The cross-sectional and the exploratory, phenomenological nature of the study do not equip it to draw any causal conclusions.

Keywords: HIV, meaning-making, lived-experience, coping, counselling.

Introduction

It is only natural that when confronted with life threatening events people ask questions such as "why has this happened?", "why me?" or "why now?" This process of asking questions and finding answer to one's own questions is what researchers refer to as "making sense" of the situation (Baarnhielm, 2000; Plattner & Meiring, 2006). When individuals experience setbacks in their life, they respond to it in an adaptive way that may enable them to return to their previous level of psychological functioning (Taylor, 1983). One of the important themes around which such adaptations occur is a search for meaning. Meaning-making, according to Taylor, is an individual's attempt to understand what has happened and to appraise what has been the impact of what has happened on one's own life (Taylor, 1983).

It is a basic need to seek meaning and fulfilment in life (Baumeister, 1991). Many authors have found

that people need a source of meaning to be happy (Fleer, Hoekstra, Sleijfer, Tuinman & Hoekstra-Weebers, 2006; Frankl, 1969; Taylor, 1983). Research on one's psychological adjustment to life-threatening illness, such as cancer and AIDS has increasingly placed its attention on the construct of personal meaning.

Meaning in suffering has been a subject of exploration and discussion since many years (e.g., Frankl, 1966; May, 1960; Yalom 1980). Researchers in psychology have approached the concept of meaning-making as a problem the individual must face in the context of trauma or when experiences challenge expectations especially in the wake of any crisis in life (e.g., Boals, Banks, Hathaway & Schuettler, 2011; Plattner & Meiring, 2006; Wright, Crawford, & Sebastian, 2007). Researchers have highlighted the significance of meaning in life as a cognitive strategy that influences mental well-being and helps in effective coping with difficulties in life (Bower, Kemeny, Fahey, & Taylor, 1998; Janoff-Bulman, 1992).

Personal meaning has been considered as protective factor while coping with life-threatening illness such as AIDS (Fife, 2005; Farber, Mirsalimi, Williams, & Mcdaniel, 2003; Farber, Schwartz,

Schaper, Moonen, & Mcdaniel, 2000). Meaning in life has also been found to be resulting in self-esteem (Schlegel, Hicks, Arndt & King, 2009; Waterman, Schwartz, & Conti, 2008), positive functioning (Dibb & Kamalesh, 2012; Flowers et al., 2006), coping (Jacobson, Luckhaupt, Delaney, & Tsevat, 2006; Schwarzer & Knoll, (n.d.); Sherman & Simonton 2011), life satisfaction (Compton, Smith, Cornish, & Qualls, 1996; King, Hicks, Krull, & Del-Gaiso, 2006; Ryan & Deci, 2000; Steger & Kashdan, 2006) and positive well-being (Scannell, Allen, & Burton, 2002; Wong, 1998). Mascaro and Rosen (2008) found that a sense of personal meaning was negatively related to depressive symptoms, depression and hopelessness, and positively related to meaning fulfillment, hope, and internal locus of control. Moreover, meaning in life is also thought to be resistant to change by all but major life events (Park & Folkman, 1997).

Meaning has been equated with purpose in life, life satisfaction and positively valued life goals (Jim, Purnell, Richardson, Golden-Kreutz, & Andersen, 2006). Taylor (1983) was of the opinion that the basic belief of most individuals is that their life is meaningful. This belief is found to impact their understanding of the past and the present and it determines what is important in life (Fleer et al., 2006). This has also been found contributing to their psychosocial well-being and life satisfaction (Guo, Gan, & Tong, 2013). Taylor (1983) argues: "when an individual has experienced a personally threatening event, the readjustment process focuses around three themes: a search for meaning in the experience, an attempt to regain mastery over the event in particular and over one's life more generally, and an effort to enhance one's self-esteem to feel good about oneself again despite the personal setback" (p.1161).

On the other hand research also shows that people who fail to attribute positive meaning to their experience may end up in a cycle of rumination (e.g. continuously trying to find a cause for the event), which is maladaptive (Park & Folkman, 1997). Meaninglessness is found to be associated with decreased or lack of motivation in individuals with depression (Jim et al., 2006). Some of the cognitive theories that explain the link between depression and thought patterns suggest that maladaptive cognitive patterns can result in depression (Jim et al., 2006).

Illness meanings manifest an individual's personal experiences and explanations of their conditions. Illnesses meanings are "dynamic, situated and

contingent" (Kleinman, 1988, p.9). It helps one value one's own illness (Frank, 2002). Therefore the importance of meaning-making in psychological health has long been recognized in the clinical literature, (e.g., Frankl, 1969; Kleinman, 1988; Yalom, 1980) although researchers have started the investigation of the impact of meaning as an adjustment strategy in severe adverse life events only recently (Folkman & Moskowitz, 2000; Jim & Andersen, 2007; Taylor, Kemeny, Reed, Bower, & Gruenewald, 2000). However, little attention has been given to illness meanings with regard to HIV infection around the world. Most of the literature that does exist provides descriptive comparisons of lay and biomedical ideas surrounding HIV causation, symptoms and treatment (Bear, Weller, Garcia, & Rocha, 2004), and does not include the perspective of those infected (Scott, 2009). A few research reports in the literature on HIV have suggested that positive meaning may have a beneficial effect on psychological adjustment to the disease (Park, Folkman & Bostrom, 2001) and may even be associated with health protective effects (Farber et al., 2003). Despite such findings, meaning has received little attention in the research literature on HIV-related adjustment especially in our country. Hence the current study was undertaken with the objective that exploring the lived-experiences of Persons Living with HIV (PLHIV) and studying their meaning-making would help mental health professionals to effectively contribute to the psychosocial wellbeing of PLHIV.

Method

Design of the study

The study has adopted a qualitative, phenomenological research design to explore the meaning that the participants attribute to their experience. Polkinghorne (1989) emphasises the validity of this approach to explore meaning-making styles of participants when he says: "The locus of phenomenological research is human experience, and it approaches topics of interest to psychology through their presence in conscious awareness.... Phenomenologically based inquiry ask[s] how meaning presents itself to experience...." (p.45). A semi-structured interview was used as the primary tool to elicit data from the participants with the following research questions in mind: (a) how do PLHIV perceive their illness; (b) What meaning-making themes do PLHIV arrive at based on the way they perceive their illness.

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Participants

The participants were 19 men and 18 women (N=37), between the age of 24-54, all of them positive and who have known their positive status for an average of 10 years. Purposive sampling method was used to recruit the participants. The minimum educational qualification of the participants was 10th standard (n=19) and the maximum was post graduation (n=4). Participants who met the diagnostic criteria for AIDS at the time of study, as defined by the World Health Organization (World Health Organization, 2005) were excluded from the study. All the subjects were recruited from various care and support centres of PLHIV across 5 districts of Kerala.

Procedure

Data was collected through interviews, the average duration of which was 2 hours and 13 minutes. The interviews were structured based on the research objectives. The probes of the interview included general basic information about the participants; their life stories with specific focus on the experiences of being infected initial reaction, experience of stigma, impact of the infection on psychological and physical health; their coping strategies and how the meaning-making process has had impact on their psychological well-being. The interviews occurred in the care and support centres of the PLHIV. The interviews began with a broad question: "how is it for you talk about your experiences of being infected with HIV". Participants were encouraged to respond in narrative form. Interviews were translated from the vernacular to English and transcribed by the researcher. Data were collected and analyzed simultaneously. The interviews took place between October 2013 and March 2014.

Interpretative Phenomenological Analysis (IPA) was used to analyze the data. As a research approach IPA explores "how someone makes sense of a major transition in their life" (Smith, Flowers, & Larkin, 2011; p. 3) like diagnosed with cancer or being infected with HIV. IPA engages with the meaning the experiencer attributes to his/her experience (Pietkiewicz & Smith, 2012; Smith et al., 2011). IPA has phenomenology as its philosophical approach (Smith et al., 2011). Researchers who use IPA as a data analysis method engages reflectively with the participants' accounts (e.g., Smith et al., 2011). In the current study multiple coders were employed to ensure the objectivity of

the interpretation. As per the IPA guidelines the transcripts of the current study were analyzed by the coders independently before a joint thematic framework was agreed (e.g., Michie, Smith, Senior, & Marteau, 2003). The researcher was one of the two coders who drafted the final thematic framework of this study. After having analyzed the data using the steps stipulated by IPA (e.g., Smith et al., 2011) eleven meaning-making themes were decided upon by the researcher in consultation with two other inter-raters to enhance objectivity as IPA recommends (e.g., Larkin, Watts, & Clifton, 2006; Smith, Flowers, & Larkin, 2013; Smith et al., 2011). Five of these themes appeared to be similar to the representations of HIV/AIDS identified by Schwartzberg (1993). They were also adopted to this study as the "meaning related attributions" (Schwartzberg, 1993, p. 484) of PLHIV while the other six themes emerged as inductive codes in the current study.

Results

The meaning-related attributions of HIV

The coders used inductive and a priori codes to extract meaning-making themes from the transcripts (Fereday & Muir-Cochrane, 2006; Thomas, 2006). Five themes were adopted from the study of Schwartzberg, (1993) that identified 5 specific representations of HIV/AIDS as meaning attributions: HIV as punishment, loss, isolation, catalyst for spiritual growth and HIV as contamination of one's self. Inductive coding identified another 6 meaning-making themes. The table below provides the meaning-related attributions in the descending order of frequency of its emergence along with the number of participants whose transcripts had one or more indicators of these attributions and with the total percentage of the participants who mentioned these themes in their interview.

1. HIV as a Spoilt Identity (28 of 37; 76%)

HIV as a spoilt identity was manifested through extreme fear of stigma followed by suicidal ideation. Most of the participants shared fears of being hated by everyone because of being HIV infected. Many participants reported being treated like pariah; some thought that they brought bad reputation to their family. Most of the HIV positives believed that their family thought that the positive member brought them disgrace.

Example:

Participant 19, 43 year old, female, mother of two:

"How do you think you can survive with this? You can't say this to anyone. They will push you out of the society. People will not even give you drinking water. Because people think whoever is HIV infected is immoral; they sell themselves for money and that is how they get this. So people hate HIV positives. Who wants to know if you got it because you have been immoral or your husband has been immoral. No one is interested in that; people are only keen on labelling."

2. HIV as not-the-worst (21 of 37; 57%)

Though the participants agreed that living with HIV is not easy, they were also of the view that it is not too difficult either. They perceived HIV as not the worst disease that one can be afflicted with. They think that HIV infection is certainly better than having a cancer or diabetes. They were also of the view that if the question was about HIV being incurable, then HIV infection is not the only disease in that category. One participant recalled that the fits she had in the childhood as more unmanageable than HIV itself. A participant who was also haemophilic found that more troublesome.

Example:

Participant 36, 29 year old, female, mother of two:

"I am not sure if HIV is very bad. Recently a lady who was younger than me, died in our neighbourhood. When my son heard that he said: "mum your disease is much better than what that lady had... at least you can live longer". I was shocked when my son said something like that. I thought about that for a long time."

3. HIV as Fate/Punishment of God (19 of 37; 51%)

Half of the participants were of the view that God had something to do with their HIV infection. Some of them termed it as karma which is also underpinned by Hindu religious beliefs. Some reported that HIV infection was a punishment for being promiscuous and for being too sexual. Women participants who reported being infected from their husbands thought that maybe God wanted to teach them something through this experience. One female participant with Christian religious background thought that God would reward her if she went through this without

complaining. Some also thought that it had pedagogical intention.

Example:

Participant 34, 51 year old, female, lost husband to AIDS:

"Ever since I was born I have only seen poverty. Both my parents were daily wagers. I see life as a mixture of good and bad.... comforts and troubles. I don't know if it is God's punishment. But at the same time when you have only sufferings from all corners you ask God why that is happening... maybe God willed it this way"

4. HIV as Loss (19 of 37; 51%)

The participants report of the sense of loss they have experienced due to HIV infection is divided into three categories namely, loss of relationships, loss of health and loss of identity.

4.1. Loss of relationship (12 of 37; 32%)

There has been a profound sense of loss of one's close relationships due to HIV infection. It is interesting to note that this sense of loss was stronger than the loss of health that the infected experienced. It reconfirms sociological ramifications of HIV infection.

Example:

Participant 9, 48 year old, male, who has been a successful business man:

"You know when you have everything they are there with you. If you don't have anything you have no one; you are a piece of shit. But it is not their fault also. As a matter of fact, the family should not be influenced by outside factors. If you tend to listen to other people you get poisoned. A lot of families who have HIV patients with them live together. Ok... I have a son and a daughter; I look at them like kids; I don't have any difference. The attachment has come down a lot"

4.2. Loss of health (11 of 37; 30%)

It is interesting to note that only 11 participants had any concern over HIV affecting their health. Most of the participants had a sense of control when it came to the manifestation of HIV infection on their health. However, some of those who reported HIV as having an impact on their physical health termed HIV infection as a 'paralysis' or as an agent that weakened their body.

4.3. Loss of Identity (5 of 37; 14%)

This was felt by those who had to run away from their family and society and go into 'hiding' because of HIV infection. They reported feeling that they lost their identity; one participant termed it as equal to "not having a face before the society or before the family".

5. HIV as Isolation (16 of 37; 43%)

Participants experienced HIV as isolating them from the society and even from their own family. Some of them have had the experience of family and friends going away from them, while some others isolated themselves because they regarded themselves as "outcasts".

Example:

Participant 4, 52 year old, male:

"They (my family) think that I have been living an immoral life and that's how I got this. I tried convincing them but nothing worked. I am isolated in the family. They don't share food with me. I have to cook my food myself. I have to do everything for myself. It is as though I am an alien in my own family".

6. HIV as a Drive for Spiritual Growth (15 of 37; 41%)

Though most of the participants reported having some religious affiliation and being very active or somewhat active in religiously it is interesting to observe that not many of them reported HIV being a reason for spiritual growth. However, those who made use of HIV infection as a means for spiritual invigoration reported HIV as a reason for being more active in spiritual matters.

Example:

Participant 3, 49 year old, male:

"I began thinking about and focusing on spiritual things. This gave me awareness that death is a reality. Death itself became a subject of my study especially in terms of what changes does death bring about in a person. Since I am a Christian, my religion had imparted a lot of hope in death and in life-after-death. Therefore, I had a thought that I should live a noble life till I die. This thought rejuvenated my spirit even if my body was wasting away. So I can say that this infection has been a turning point in my life."

7. HIV as Contamination of One's Self (13 of 37; 35%)

The participants weighed HIV as a burden, which they could not "keep down and relax". Some of them conceived HIV as a trap it kept them reminding that one has a serious disease in oneself that people would hate if they came to know. Some of them called themselves "ugly" because they have been infected.

Example:

Participant 17, 40 year old, female, mother of two, lost husband to AIDS:

"I know that there is a virus in my body; it will never go away from my body. I have to live with it; there is no medicine for it. If a medicine is developed we are only lucky. It is like a trap from which you have no escape. You have to live with it till your end.... That's all".

8. HIV as a Shield (9 of 37; 24%)

Some of the participants understood HIV as protecting them from engaging in self destructive behaviours or from being impulsive. They reported as being more self caring after being infected. Some of them have become more disciplined because of which they believe they will not engage in self-destructive behaviours like drug abuse, alcoholism and promiscuity.

Example:

Participant 33, 38 year old, male, father of two:

"Had I not become HIV positive I would not have taken care of my life and I would have jumped into serious issues. HIV protects me from all that"

9. HIV as a Career (8 of 37; 22%)

Viewing HIV as a career was reported by a few of the participants who work as counsellors or Out Reach Workers (ORW). They earn a living from HIV/AIDS related services. Even if HIV has obstructed their normal life by infection or by the loss of their husbands due to AIDS they find comfort in the fact that it has also provided them a venue to use their time and energy and also to raise income.

Example:

Participant 32, 33 year old, female, infected through rape:

"There are so many good things that have happened. I got a job as an ORW. That brings me a

stable income. I live a more happy life now. I am able to advise people who are HIV infected and help them lead a happy and positive life. This gives me a lot of satisfaction. So these are all some of the good things that have happened in my life".

10. HIV as a New Identity (5 of 37; 14%)

Though a vast majority of the participants viewed HIV as a spoilt identity, it is interesting to observe that a few of the participants also sensed HIV as a new and enjoyable identity (even made them a celebrity) which otherwise they could not have ever achieved. It is also interesting to note that 4 of the 5 participants who reported enjoying this identity was women, who HIV gave a chance to come out of their role as housewives and face the society in a new role.

Example:

Participant 10, 45 year old, ORW, lost husband and son to AIDS, remarried to an HIV infected:

"I had always desired to come out of the kitchen and do something for people. I had no education to do that. But after the infection I could do that. I learned everything about HIV and gave class to people, to nurses, paramedical, to social workers and so on.... (laughs). My classes were all much appreciated because I had a story to tell them during the class. That was my own story and that was a real story. Whoever I gave class to was all taken aback by my story. They used to say that I gave class like a post-graduate. I loved it... (laughs.....). I thought that's exactly what I would have done had I become a medical doctor myself. I could not become that. However, HIV gave me a chance to become what I always wanted to".

11. HIV as Deservedness (4 of 37; 11%)

It is interesting to observe that there have been a few participants who refused to believe HIV as a punishment but blamed themselves for the infection. They termed themselves as 'deserving' of what they are through. Though there were only four who thought of themselves as deserving HIV infection, all of them happened to be men. It is possible that they are adhering to the conventional belief of the Indian society that men are responsible for the spread of HIV.

Example:

Participant 20, 50 year old, widower, father of two:

"I have been living a very promiscuous life... My doctor told me that that could be the reason for my

infection. I used to also heavily drink and go to women who sold sex for money. So I deserved to get this disease. I am not someone who blames God like other people who consider that God has punished them, or it is their karma and so on.... I deserve it. I bought it by paying for it. If I have this disease then I am the reason for it.... I am to blame and no one else; my behaviour is the reason for it".

Discussion

The studies on the experience of living with HIV/AIDS and its meaning in Indian context become significant because of the strong association of the disease with stigma, isolation and discrimination (Bharat 1995, 2000). Moreover discrimination connected with HIV does not stop with the infected person alone. The families of the infected are also ostracized (Temoshok & Chandra 2000). It is in this background that how PLHIV perceive their illness and what meaning they attribute to HIV infection becomes significant. It has long been established that being infected with HIV is traumatic (Sherr, Nagra, Kulubya, Catalan, Clucas & Harding, 2011) and that it produces emotional distress in PLHIV like anguish and anxiety (Brandt, 2009; Cluver & Gardner, 2007; Cruess et al., 2000); feelings of guilt, anger and shame (Shawn, Campbell, Mnguni, Defilippi & Williams 2005; Antoni et al., 2000). Confirming these findings majority of the participants of the current study reported that they experienced stigma as more traumatizing than the disease itself. It is dealing with a spoilt identity as a result of being infected with HIV that was more problematic for some, even traumatic than the disease. Other studies from India also show that stigma has a strong impact on the mental health of PLHIV (e.g. Steward et al., 2011).

Researchers have shown that there is a new sense of self emerging from successful passage through trauma (e.g. Neimeyer, 2006) promoting the personal growth of the traumatized (McFarland & Alvaro, 2000; Updegraff & Taylor, 2000). In the case of many their understanding of self and the world is shattered as they go through experiences of trauma (Janoff-Bulman, 1992). It is not the event itself that defines the stressful experience as traumatic, but rather one's perception of one's experience (Janoff-Bulman, 2006). At this point, to survive people must "find a way to live" (Baumeister, 1991; p. 15) and this process of finding a way to live is equated with finding meaning in life. The results of the current study show that being diagnosed with HIV has been

traumatic for many of the participants which is evident from the fact that 58% of them had suicidal ideation and 43% thought death was imminent. However, as life went on they began to attribute positive meaning to their infection such as HIV is not the worst disease one could live with, HIV has been helpful for personal and spiritual growth and some even saw HIV as a shield a protection from other contaminations of life.

Meaning refers to accommodative coping (Lazarus, 1991) which includes cognitive restructuring (Brandtstädter, 1992) and benefit finding (Cordova, Cunningham, Carlson & Andrykowski, 2001). Searching for meaning has been found helping those who have been through traumatic experience like being diagnosed with cancer or HIV cope with their disease (e.g. Snyder, 1999). Meaning has also been found contributing to the psychological wellbeing of the traumatized (Pakenham, Dadds & Terry, 1995). Those, in this study, who have been able to ascribe positive meaning to being infected did also report that they have been able to cope with the disease. So too has been the case of those who were able to attribute some benefits to being infected: like who found HIV infection as career or HIV as a new identity. They reported this stance as contributing to their psychological wellbeing. At the same time it is also interesting to note that some of the participants had taken the HIV infection less seriously because even before being infected with HIV they have already been struggling with other issues. For instance, women who have had alcohol abusing husbands thought putting up with husband's drinking was much worse than the HIV infection itself.

The current study goes hand in hand with the striking themes found in the literature on finding meaning in terminal illness: that, there is a conscious effort from the part of those in terminal illness to modulate thoughts, emotions and behaviours in order to achieve desired goals (e.g., Zeidner, Boekaerts & Pintrick, 2000); that the construction of illness-meaning is influenced by one's culture (Kleinman, 1988); that search for meaning is linked to coping (Lazarus, 1991; Lazarus & Folkman, 1984). Though this study discusses the illness perception and the subsequent meaning-making process of PLHIV, excluding some of the specific representations, overall patterns of seeing a disease as punishment, isolation, loss, a new identity, a shield and as a source of spiritual and personal growth could be applied to other populations.

This study is a one-time report of the experiences of people living with HIV in terms of how they view being infected with this virus and living a life that is stigmatized. The study was undertaken as cross-sectional and the exploratory, phenomenological nature of the study does not equip it to draw any causal conclusions. A longitudinal approach would have elicited the changes that ascribed meaning goes through in the course of time. However, this study is significant in terms of its utility for psychotherapy. It is important to highlight, in the therapeutic intervention with PLHIV that HIV is not the end of the life of the infected as some might think. Psychotherapy with PLHIV has to be designed in a way that it helps the HIV infected pass from negative meaning to positively perceiving their illness.

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Table: 1 The meaning-related attributions of HIV (N=37).

	Meaning-related Attributions	n	%
1.	HIV as spoilt identity	28	76
2.	HIV as not-the-worst	21	57
3.	HIV as fate/punishment of God	19	51
4.	HIV as loss	19	51
5.	HIV as isolation	16	43
6.	HIV as a catalyst for spiritual growth	15	41
7.	HIV as contamination of one's self	13	35
8.	HIV as a shield	9	24
9.	HIV as a career	8	22
10.	HIV as a new identity	5	14
11.	HIV as deservedness	4	11

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