ISSN: 0976-3031

International Journal of Recent Scientific Research

Impact factor: 5.114

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Volume: 6 Issue: 10

THE PUBLICATION OF
INTERNATIONAL JOURNAL OF RECENT SCIENTIFIC RESEARCH
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Available Online at http://www.recentscientific.com

ISSN: 0976-3031

International Journal of Recent Scientific Research
Vol. 6, Issue, 10, pp. 6807-6811, October, 2015

International Journal of Recent Scientific Research

RESEARCH ARTICLE

+HIV/AIDS, STIGMA AND COPING STRATEGIES: A QUALITATIVE STUDY REGARDING CONTEMPORARY GREECE

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ARTICLE INFO

Article History:

Received 15thJuly, 2015
Received in revised form
21stAugust, 2015
Accepted 06th September, 2015
Published online 28st
October, 2015

Key words:

HIV/AIDS, stigma, coping strategies, qualitative research, biographical disruption.

ABSTRACT

The present study aims at examining some of the stigmatizing aspects of HIV/AIDS in contemporary Greece. Based on qualitative methodology the article casts light upon the social dynamics that significantly influence the lived experiences of the individuals infected by HIV/AIDS, as well as their partners, family, friends and social relations. Stigma, albeit a social construction, is perceived as a changing and emerging feature over the course of HIV/AIDS. The primary purpose is to conceptualize how individuals with this particular illness experience social stigmatization. Besides, it demonstrates the multiple ways they copy with the disease and its consequences over their identities, bodies and biographies. Three phases of the HIV/AIDS stigma trajectory are described: (1) ambivalent compliance: a contradictory and struggling acceptance of the HIV-related stigma, (2)_negative normalization: bodily strategies of coping, and (3) reflexive management: relativization to social stigmatization. The social procedures through which participants personalize HIV/AIDS and the strategies they employ to avoid or relativize the AIDS-related stigma, to re-negotiate interpersonal relations, to re-construct biographies and to re-conceptualize and adapt to an HIV identity are deemed through the stigma trajectory.

INTRODUCTION

In his classic study on stigma, Goffman (1963) describes a multitude of social behaviors that potentially people have, when they bear a visible or latent, physical or moral stigma (cancer patients, HIV-positive people, lepers, homeless, drug addicts, alcoholics, etc.). Goffman believed that these people are members of wider social groups. Consequently, regardless of the stigma they carry, they react with relatively similar way –with regard to its structured characteristics- with those considered as normal people, especially in their daily mixed interactions. This reaction is due to the fact that the "stigmatized" know and possibly accept into "whom" they have been transformed (Savvakis, 2008). Sometimes, individuals react against the negative social classification procedures and attempt to relativize the emerging consequences. Therefore, they turn to alternative ways of viewing themselves, their body and their biography through the adoption of stigma management strategies (Goffman, 1963; Savvakis, 2013).

The knowledge of "resistance" or "compliance" is acquired during socialization through learning of social rules, which govern daily interactions. Consequently, any form of physical or moral stigma, for example seropositivity, is eminently such a case that strongly influences behavior and reactions of people who carry it, the reactions of their social environment and the entire course of their lives. HIV/AIDS is a special case because radical changes occur in the body of patients (e. g. lipodystrophy, weight loss, distortion, etc.). This dimension allows the emergence of a more sensitive sociological view, which takes into account the embodied, lived experiences of individuals (Alexias and Dimitropoulou, 2011; Alexias *et al*., 2015).

More specifically, HIV is connected to a sense of guilt, for the infected person is often considered as "sinner" or on "high risk behavior". These symbolic dimensions of the disease strongly influence the way an individual realizes himself and interacts with the others (Varas-Díaz *et al*., 2005; Williams, 2000). The AIDS stigma has been largely connected to moral guilt and ethical shame which in turn causes depression, anxiety and despair, stress, social isolation and poor mental health (Webel *et al*., 2014). The sense of social inferiority and potential devaluation have been connected with significant impacts on psychology and quality of life as: ambivalence, low self-esteem, decreased psychosocial functioning and disruption of erotic and sexual life (Persson, 2005; Guaraldi *et al*., 2008; Cabrero *et al*. 2010; Plankey *et al*., 2013), depression, feeling of shame (Ciambrone, 2001; Simbayi *et al*., 2007; Cabrero *et al*., 2010; Kalichman *et al*., 2009; Brener *et al*., 2013), fear for

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possible identification of their seropositivity through physical manifestations (Tate and George, 2001; Cabrero *et al.*, 2010), social isolation (Ciambrone, 2001), avoidance of social activities, deterioration of health status, limited control on body due to the irreversibility of lipodystrophy (Tate and George, 2001; Kelly *et al.*, 2009), body alienation (Kelly *et al.*, 2009). AIDS is nowadays considered a chronic illness. In cases like these, like, it is detected a kind of deep cleavage in the continuity of one's biography, as it results to a plethora of drastic transformations in his/her life. This dimension is conceptualized as biographical disruption (Bury, 1982; Alexias *et al.*, 2015). An HIV diagnosis is a concrete example of biographical disruption, as long as plans for happy marriage, children, and career seem to become impossible. Several researchers suggest that a person can have three kinds of responses against the biographical disruption and the transformations brought about by stigma in their social identity. The first is a cognitive response, in which the individual experiences a feeling of weakness, having the worst possible expectations for his health condition and ambivalence towards life (ambivalent compliance). The second relates to the fact that a person does not accept that disease will affect his daily life (negative normalization). This constitutes a form of normalization, in which individuals face HIV/AIDS as a "simple flu" and do not focus on the disease, thereby continuing with their lives. Finally, the third alters in an odd way all previous people's expectations and experiences, including the following phases: experiencing a changing body, reformation philosophical frameworks and surrender to the experience of the disease (reflexive management) (Tewksbury and McGaughey, 1998; Anderson and Spencer, 2002; Halkitis, 2014).

In this context, the main research interest of the article is to explore social stigma procedures and interpretative management of stigma in people living with HIV/AIDS, as constitutive aspects of their biography. Furthermore, it examines the responses given by participants and the strategies followed, in order to preserve the coherence of their individual and social identity.

MATERIALS AND METHODS

The research sample consisted of 18 HIV-positive individuals (13 men, 5 women), who were detected in the NGO "Centre for Life" (for the support of people living with HIV/AIDS). Ages of participants ranged from 36-65 years (mean= 48), while the time from diagnosis ranged from 4 to 24 years (mean=14.9). Eleven of the participants were living with HIV/AIDS more than 15 years. All participants had experienced physical changes related to HIV or HIV treatment. Moreover, all participants were receiving medication except one man who had stopped treatment.

Eighteen in-depth interviews were conducted between March and April 2012, after official approval by the Board of NGO "Centre for Life". Sixteen interviews took place at the NGO's offices and two were conducted to the participants' home. Interviews lasted from 50 minutes to 1 hour and 40 minutes. At the beginning of the interview, participants were informed regarding confidentiality and research issues and declared their informed consensus. Participants are presented with pseudonyms in the form of name initials. Ethical approval was obtained from the Panteion University of Athens research ethics committee.

In this study triangulation, is used as an attempt to increase reliability and validity of qualitative results. The researchers involved in this study analyzed the data separately in order to ensure that the considered as crucial interview themes were in accordance with the empirical material (Savvakis, 2014).

RESULTS

From the data interpretation emerged a number of research axes, which outline, as participants thematise it, the embodiment of AIDS and frame the analysis that follows. The basic themes are the following:

From the analysis of the empirical material a significant number of research themes was detected, which emphasizes, as participants the matise it, the social stigmatization of AIDS and the strategies of coping with the disease-related problems. The fundamental topics are the following:

Ambivalence about visibility of HIV/AIDS

Analysis showed that visibility is a source of dissatisfaction and anxiety, because a body with lipodystrophy reveals the existence of HIV/AIDS. On the other side, it constitutes an integral part of one's identity, which contains elements of personal biography, which the individual does not want to erase.

P., a 52 year-old man, who lives with HIV for 23 years describes this ambivalent feelings:

Without feeling bad or hiding my seropositivity, it bothers me that the others understand what I have. I didn't want to be perceived this way, as a patient. Because most people could see and understand immediately, especially the first period when it was more intense (lipodystrophy). Now it is improved. What annoyed me the most was that other people were seeing something sick. It wasn't health! As if I was warped, I would say. As long as it happened this way, its ok, the passing of time shows what we live and what we go through. These are marks that I want to have on me, to show what I live and what I am.

A common point among the subjects was the comparison with the bodies of other HIV-positive people with visible signs of lipodystrophy. The reaction concerning this was the desire of disassociation with the others and their bodies.

O., a 49 year-old man, recorded

When it happened to me I used to say "Look, he looks much uglier than me!" I don't know if it gave me courage or not, but I used to notice that, eh, and I repeat I am not one of those who have bumps on their back or have their cheeks disappeared. If you notice other people, I always compare myself to others and

I say "Why you complain now? You see there are much worse things around you!" I have seen people and I was terrified!

It is worth noting that, in some cases, individuals took for granted that others considered them as unattractive. This hypothesis seems to be related to the internalization of stigma. The person is vulnerable to rejection, which can be real or imaginary, affecting the feeling of personal value and therefore his self-confidence.

A 40 year-old man recognized that he considered himself as unattractive, reporting:

Many times I felt I wasn't liked because of lipodystrophy, which was more in my mind than in reality.

The words of D., a 46 year-old man, reveal anger and sensitivity towards the issue of rejection:

An asshole laughed at me once, because my legs were too skinny. That bothered me too much, because he knew that I was HIV-positive. I was so upset! What isolated me the most was that the others had not the guts to tell me "I detest you". I would find it more honest than this "death", to think for a moment that the other has no problem and then disappearing. People are proved "little" and it mainly occurs in the family. There you perceive things that are never expressed. Because I was always going out with guys, they were like "you deserve this".

Lipodystrophy is associated with HIV-related stigma and mediated by the concept of visibility. As symptoms become more intense, therefore more socially visible, stigma is increasing. This raises ambivalent feelings, namely the desire for recognition of AIDS as a part of their identity as well as disassociation from other HIV-positive people.

Coping strategies

A kind of response to stigma is the attempt to conceal the nature of the illness or to justify the symptoms with false claims, such as the existence of a different disease, less frightening to society.

D. a 46 year-old woman states

I said that I had a type of cancer and lie after lie I forgot what I had said.

Likewise, A. a 50 year-old man reckons

At first, I thought that if somebody asks me I'll say it was from blood transfusion. I thought I could say this! Of course it was a lie but I would have been much happier! People would say "Oh! Poor man! Others get HIV because they are not careful, they are licentious, but he got it because he was very unlucky!"
While C. a 42 year-old woman reveals indicates how she managed her mother's suspicions, who were unaware of her daughter's seropositivity

My mother suspected it once! Those who have this disease are often slimmer, but I had the opposite (lipohypertrophy), so I told her "If I had this, I wouldn't have been so fat". And that's how I escaped!

The majority of participants opted for selective disclosure of HIV. Another common management strategy of stigmatizing conditions is the attempt to predict how others will react to the disclosure. This is reflected in the following statements.

C. a 40 year-old man, describes the situation

The person who will learn about HIV should be able to manage it. Not in the sense of compassion but like men who are equal. Like I announce him I have cancer…Too much stress! Not stress! In fact, it scares me! I'm terrified because I know it needs so much management. It's very easy to communicate with people who have the same problem. Here (in Centre for Life) feels like home, in the sense that there is full understanding.

a 50 year-old man states

In order to tell it you should have checked him out first. I mean if that man really deserves to know! He may not pay any attention; he may start telling the whole world. Something that you won't like at all!

Another man, D. 46 years old avoid stigmatizing situations by creating a social network exclusively consisted of HIV-positive people, where discrimination based on HIV/AIDS do not exist and is not likely to confront rejection:

I feel good only when I meet HIV-positive people! When I meet HIV-negative I feel uncomfortable and I drive them away!

In order to maintain their life to the level before diagnosis, people living with HIV/AIDS strive to detect strategies of avoiding or reducing the impact of stigma. Participants presented a multitude of responses, more or less adaptive, which focused mainly on the question of disclosure, including selective disclosure, concealment of the nature of illness and total concealment.

Relativization to Social Stigma

However, individuals do not seem to be passive recipients of stigma, but they opposed actively and contributed to its eradication. More specifically, they seem to understand their health condition to a large extent discharged of negative symbolisms and stereotypes. This becomes evident as they use often the phrase "it could have happened to anyone, like any other disease".

M. a 38 year-old man reports

It's a chronic disease, a flu that may have more complications from the flu or diabetes. Nothing more! There are times when I say "I don't care if one will know." It is a matter of their awareness how they treat us! It's our life and can bring different things.

Only two participants could not accept it like any other disease due to its symbolic load.

S. a 36 year-old man reckons

After one year of psychotherapy I can't get over it. I tried but I can't see it as a simple illness. It's an illness plus! *More than any other!*

Another way in which individuals face stigma is by attributing it to stereotypes and ignorance of others.

While some people responded with the intention of confuting and reversing these stereotypes, which affected their personal and social identity.

DISCUSSION

The analysis of factual data revealed that a general negative body image and biography tends to prevail among people living with HIV/AIDS. The ambivalence of participants towards HIV/AIDS took both positive and negative dimensions. On the one hand, HIV is presented as a negative fact that is source of social stigma and consequential anxiety. On the other hand, it is interpreted as an integral part of their identity and also as a need for understanding and compassion. In order to avoid stigma individuals used the strategy of selective disclosure and avoidance of those who knew about their disease, but were not supportive.

As indicated by the answers, subjects were vulnerable to rejection from others, whether it was real or was interpreted as rejecting by them. This was due to the internalization of stigma, which may lead to ineffective responses, such as guilt and shame (Phillips, 2011; Lee *et al*., 2002; Weitz, 1990). Participants reported that when they didn't want to reveal the nature of their illness, they claimed to suffer from another, less stigmatized, such as cancer. Alternatively, they used false justifications in order to explain the symptoms in cases of persistent questions in their social circles. This kind of questions was perceived as dangerous and caused fear about a possible disclosure of their health condition.

The previous types of response to stigma can be described as inefficient as they didn't promote the cohesion of the individuals. However, in other cases responses were more adaptive and seem to have contributed in maintaining the coherence of personal identity. Such answers were given, including the repeated phrase "it could have happened to anyone, like any other disease", which indicates the release of HIV/AIDS from the stereotypes of risky behavior and high risk groups. In addition, adaptive responses were considered those who implicated an association between stigma and ignorance of others, the sense of personal responsibility and the subversion of existing stereotypes.

The data analysis shows that the experience of changing body image and stigmatization differentiate the way individuals perceive themselves and their previous experience. Moreover, the answers enlighted some aspects of biographical disruption, such as thwarting of long-term life plans for life, family and professional advancement. Another important issue raised was the reduction of sexual interaction, as individuals thought that HIV/AIDS and disclosure process was an obstacle to the creation of intimate relations (Carricabubu and Pierret, 1995; Alexias *et. al*., 2015).

In any case, it is of great importance for future research to investigate the impact of different types of transmission on the management of stigma and also the effect of time from diagnosis on giving meaning to the disease. These parameters would be very crucial for a better understanding of the internalization of stigma and biographical rupture that can be caused, but also for strategies to relativize these negative social classifications.

References

Alexias, G., and Dimitropoulou, E. 2011. The body as a tool: Professional classical ballet dancers' embodiment. Research in Dance Education. 12 (2): 87-104.

Alexias, G., Tzanakis, M., and Savvakis, M. 2015. Biographic strategies of Greek women with Breast Cancer: From the "injured" to the "contributing" body. Journal of Sociology and Social Work. 3 (1): 90-97.

Anderson, E. H., and Spencer, M. 2002. Cognitive representations of AIDS: A phenomenological study. Qualitative Health Research, 12, 1338-1351.

Brener, L., Callander, D., Slavin, S., and de Wit, J. 2013. Experiences of HIV stigma: The role of visible symptoms, HIV centrality and community attachment for people living with HIV. AIDS Care. 25 (9): 1166-1173.

Bury, M. R. 1982. Chronic illness as biographical disruption. Sociology of Health and Illness. 4 (2): 167-82.

Cabrero E., Griffa, L., and Burgos, A. 2010. Prevalence and impact of body physical changes in HIV patients treated with Highly Active Antiretroviral Therapy: Results from a study on patient and physician perceptions. AIDS Patient Care and STDs. 24 (1): 5-13.

Carricabubu, D., and Pierret, J. 1995. From biographical disruption to biographical reinforcement: the case of HIV-positive men. Sociology of Health and Illness. 17 (1): 65-88.

Ciambrone, D. 2001. Illness and other assaults on self: the relative impact of HIV/AIDS on women's lives. Sociology of Health and Illness. 23 (4): 517-540.

Goffman, E. 1963. Stigma: Notes on the Management of a Spoiled Identity, London: Penguin.

Guaraldi, G., Murri, R., Orlando, G., Squillance, N., Stentarelli, C., Zona, S., Garlassi, E., and Martinez, E. 2008. Lipodystrophy and quality of Life of HIV-infected persons. AIDS. 10, 152-161.

Halkitis, P. N. 2014. The AIDS generation: Stories of survival and resilience. New York: Oxford University Press.

Judgeo, N., and Moalusi, K. P. 2014. My secret: The social meaning of HIV/AIDS stigma. SAHARA-J: *Journal of Social Aspects* of HIV/AIDS. 11 (1): 76-83.

Kalichman, S. C., Simbayi, L. C., Cloete, A., Mthembu, P. P., Mkhonta, R. N., and Ginindza T. 2009. Measuring AIDS stigmas in people living with HIV/AIDS: The internalized AIDS-related stigma scale. AIDS Care. 21 (1): 87-93.

Kelly, J. S., Langdon, D., and Serpell, L. 2009. The phenomenology of body image in men living with HIV. AIDS Care. 21 (12): 1560-1567.

Kylmä J., Vehviläinen-Julkunen, K., and Lähdevirta, J. 2001. Hope, despair and hopelessness in living with HIV/AIDS: a grounded theory study. *Journal of Advanced Nursing*. 33 (6): 764-775.

Lee, R, S., Kochman, A., and Sikkema, K. J. 2002. Internalized stigma among people living with HIV-AIDS. AIDS and Behavior. 6 (4): 309-319.

Persson, A. 2004. Incorporating pharmakon: HIV, medicine and body shape change. Body and Society. 10 (4): 45-67.

Persson, A. 2005. Facing HIV: Body Shape Change and the (in)Visibility of Illness, Medical Anthropology. 24 (3): 237-264.

Phillips, K. D. 2011. Conceptual development of an instrument to measure the internalized stigma of AIDS based on the Roy adaptation Model. Nursing Science Quarterly. 24 (4): 306-10.

Plankey, M., Bacchetti, P., Jin, C., Dass-Brailsford, P., Gustafson, D., Cohen, M H., Karim, R., Yin, M., and Tien, P. C. 2013. The association of self-perception of body fat changes and quality of life in Women's Interagency HIV Study. AIDS Care. 25 (12): 1544-1550.

Savvakis, M. 2008. The lepers of Spinalonga, (1903-1957). Medicine, incarceration and lived experiences. Athens: Plethron, (in Greek).

Savvakis, M. 2013.Microsociology and Qualitative Research: Theoretical Paradigms and Empirical Applications. Athens: Kritiki, (in Greek).

Savvakis, M. 2014. Combining quantitative and qualitative methodologies: A critical overview. Statistical Review. 8 (1-2): 53-67.

Simbayi, L. C., Strebel, A., Cloete, A., Henda, N., and Mqeketo, A. 2007. Internalized stigma, discrimination and depression among men and women living with HIV/AIDS in Cape Town, South Africa. Social Science & Medicine. 64 (9): 1823-1831.

Tate, H., and George R. 2001. The effect of weight loss on body image in HIV–positive gay men. AIDS Care. 13 (2): 163-169.

Tewksbury, R., and McGaughey, D. 1998. Identities and identity transformations among persons with HIV Disease, *Journal of Gay. Lesbian and Bisexual Identity*. 3 (3): 213-232.

Varas-Díaz, N., Serrano-García, I. and Toro-Alfonso, J. 2005. AIDS-Related Stigma and Social Interaction: Puerto Ricans Living With HIV/AIDS. Qualitative Health Research, 15 (2): 169-187.

Webel, A. R., Longenecker, C. T., Gripshover, B., Hanson, J. E., Schmotzer, B. J., and Salata, R. A. 2014. Age, stress and isolation in older adults living with HIV. AIDS Care. 26 (5): 523-531.

Weitz, R. 1990. Living with the Stigma of AIDS. Qualitative Sociology. 13 (1): 23-38.

Williams, S.J. 2000. Chronic illness as biographical disruption or biographical disruption as chronic illness? Reflections on a core concept. Sociology of Health and illness. 22 (1): 40-67.

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How to cite this article:

George Alexias., Manos Savvakis and Ifigenia Stratopoulou.2015, +HIV/AIDS, Stigma and Coping Strategies: A Qualitative Study Regarding Contemporary Greece. *Int J Recent Sci Res.* 6(10), pp. 6807-6811.

International Journal of Recent Scientific Research

ISSN 0976-3031

9 770976 303009