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## The Coping Context of Anticipatory Grief for HIV Case Managers

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### Abstract

*In the early phase of HIV/AIDS the exorbitant rate of death impeded the case managers' ability to effectively engage the client in preparing for an impending death outcome. In the post-HAART era, case managers are charged with assessing and coordinating a circle of care related to a chronic illness. This article examines the context of anticipatory grief as a framework for addressing HIV as a chronic illness. A spectrum of strategies are provided for coping with anticipatory grief and multiple losses related to providing services to those HIV/AIDS infected.*

**Key Words:** HIV/AIDS, grief, bereavement, case managers

### 1. Introduction

In the early phase of HIV/AIDS the exorbitant rate of death impeded the case managers' ability to effectively engage the client in preparing for an impending death outcome. In the post-HAART era, case managers are charged with assessing and coordinating a circle of care related to a chronic illness. Poor adherence has led to a sequence of viral resistance, clinical decline and ultimately death for some (Karasz, Dyche & Selwyn, 2003). This trajectory of chronic illness to terminal illness is one that case managers must continue to manage while attempting to effectively navigate their own grieving process in managing clients who have a chronic illness. The literature (Fulton, et.al, 1996; Walker, et. al, 1996; Holley & Mast, 2009) identifies anticipatory grief as an adaptive response to impending loss because it provides the individual an opportunity to work through changes that typically accompany loss, thereby mitigating the trauma associated with the loss. HIV case managers experience anticipatory grief with clients based on Rondo's (1983) operationalized definition, behaviors such as discussing with your client the possibility of death, and having their client think about the future of loved ones if they were gone. An effective process of grief allows for case managers allows them to help their clients to address their own grief and coping related to physical needs, psychological needs, social needs and spiritual needs, which are part of the coping process (Corr, 1991b). A spectrum of methods is utilized by HIV case managers to cope with anticipatory grief related to the chronic aspect of the HIV disease process (Cho & Cassidy, 1994; Walker, 1996; Karasz, Dyche & Selwyn, 2003).

In the field of HIV/AIDS, it is known that case managers are the first line of help for HIV positive individuals needing to navigate internal and external systems to meet their psychosocial needs. Responsibilities typically address psychosocial issues as well as helping clients cope with their own grief of further loss of functioning, health and ultimately life itself. The expectation is that human service professionals will contain their own emotions related to the changes that may be observed in the trajectory of a chronic illness (Kraraz, Dyche, & Selwyn 2003). The purpose of this review article is to explore grief and coping mechanisms utilized by HIV case managers when working with clients who are addressing the chronic aspects of the HIV disease process. Anticipatory grief is used as a conceptual framework to understand the grieving process as well as highlight coping techniques utilized by case managers to continue effectively providing services to clients.

### 2. HIV and Case Management

According to the literature, over the last three decades AIDS has emerged as a major public health crisis affecting humanity. The World Health Organization indicates that more than 1.8 million people have died from AIDS-related diseases worldwide in 2009. Currently there are 33.3 million people living with HIV, and it is expected that many are likely to die over the next decade (UNAIDS, 2009). Current statistics indicate that at the end of 2008 an estimated 1,178,350 persons were living with HIV/AIDS in the United States (HIV/AIDS Surveillance Report, 2009, CDC). Every projection indicates that the number of patients with HIV/AIDS will continue to increase in all areas of the United States, as well as in the rest of the world (Valimaki, Suominen & Peate, 1998).

A diagnosis of HIV/AIDS can have a significant effect on one's life. It can affect mental functioning, and physical, financial and emotional well-being. Case management has steadily become a much-needed resource for these individuals. Case managers are usually on the front line assisting individuals in the navigation of a multiplicity of health and social service systems. The case manager works to decrease barriers and increase access to utilization of services that enhance client participation in service delivery and system integration as guiding principles. It is important that professionals have an excellent understanding of the biopsychosocial and environmental needs of the client. Entitlements and legal services should be identified immediately as a priority need if warranted. HIV/AIDS case managers are responsible for coordinating the social services and primary health care needs of the client. Their responsibility is to ensure that clients and their families have access to medical, health, social service, education and resources needed to enhance their quality of life. An important aspect of their work is to deal with the very real issue of stigmatization that set up barriers to services. This level of work with people living with HIV/AIDS (PWLHA) is intense and involves the case manager knowing their clients intricately. It is this intricate work relationship that can lead to the case managers experiencing their own level of anticipatory grief.

### **3. Anticipatory Grief**

Anticipatory grief has been defined in the literature as a phenomenon, explained by a process of grieving prior to the actual loss (Al-Gamal & Tony, 2010; Cheng, et. al., 2010; Walker, et. al., 1996). When working with clients who are perceived as being at risk of losing life the anticipatory grief can be generated via the discussion of death and it's impact on others close to that client (Rondo, 1983, Walter, et. al, 1996).

Anticipatory grief has been studied mostly in the area of cancer and from the perspective of relatives or caregivers. A limited number of studies have explored the subjective view of grief or bereavement or loss from the perspective of the HIV case managers. Cho & Cassidy (1994) explored the perspective of chronic bereavement for the worker in the field of HIV/AIDS. They viewed bereavement as the total response pattern, psychological and physiological, displayed by an individual following the loss of a significant object, usually a loved one and in this case families the case manager had worked with for years. This could create a never-ending cycle of perpetual grieving for individuals affected by HIV/AIDS and the professionals who work in this field. Cho & Cassidy agreed with Rondo (1983) and devised an extended definition of chronic bereavement that includes a concept that they refer to as multiple loss syndrome. This syndrome includes the effects of chronic anticipatory grief and unresolved grief as well as the compounding effects of experiencing several episodes of grief concurrently, having to manage ones emotions for more than one person at a time (Cho & Cassidy, 1994).

Advances in medical treatment have greatly improved the survival rates of those infected with HIV/AIDS. HIV is now viewed as a long-term incurable chronic illness with multiple treatment options. This means that individuals infected may have to live with the threat of medical relapse or viral resistance. A diagnosis of HIV is a major life stressors, as it provokes thoughts of life changes and even death well into the third decade of this epidemic. The diagnosis not only affects the person infected but all of those involved in the individual's life.

Several factors combine to contribute to the serious nature of being HIV positive. It continues to pose a major threat to life if medication regimes are not followed properly. The social stigma attached to the illness may continue to cause a level of secrecy around being tested, disclosing one's HIV status and receiving treatment. Some clients can experience a level of grief related to maintaining the life style changes that are required as part of being emotionally and physically healthy. The difficult treatment regimes that is required for many can possibly feel like a grueling task and evoke feelings of depression, anxiety and global distress (anticipatory grief reactions) for the client (Al-Gamal & Long, 2010). These aspects in combination can lead to the anticipated grief related to being HIV positive for the clients and the case managers as well. The case manager plays a critical role in helping the client develop long-term strategies to staying healthy and addressing the emotional distress that can accompany this task. In this process the case manager often times will work with the client through medical highs and lows. The multiple loss syndrome espoused by Cho & Cassidy can become more eminent when working with a large caseload of clients infected with HIV/AIDS. Multiple losses refer to having more than one client concurrently coping with aspects of their HIV/AIDS status. This consecutively leads to coping within the context of multiple loss syndrome, putting off one grief reaction after another can becomes more and more difficult as time goes on. This places workers in jeopardy of having to perform the much more arduous task of trying to work through several loss responses at the same time (Cho & Cassidy, 1994).

Invariably emotional numbing and burnout are the result of workers becoming overwhelmed by their work. This type of loss is unique, one that cannot be understood within the framework of existing traditional theories of bereavement, which describes a series of stages or phases one has to undergo, or tasks that need to be accomplished before some kind of resolution is attained (Papadatou, 2002). Papadatou (2002) identified six areas of loss that can be experienced: (1) loss of close relationship with a particular patient; (2) loss due to professional's identification with the pain of the client; (3) loss of one's unmet goals and expectations and one's professional self image and role in helping the client; (4) losses related to one's personal system of beliefs and assumptions about life; (5) past unresolved losses or anticipated future losses; (6) the anticipated death of self. For case managers each case may be experienced as a loss on one or more of the above levels of investment.

The literature speaks to the professionals need to be able to create meaning and transcend the idea of death and invest in life and living. Any form of meaning provides the case manager with a sense of mastery, and helps them overcome any state of confusion of doubt or meaninglessness (Papadatou, 2002). There is an acknowledgement that to move beyond the idea of death, the case manager needs to transcend the multiple loss experience through a series of behaviors, thought and emotions which facilitate a process of re-centering and re-connecting with oneself, and helping the client investing in life and living. This can be achieved through utilizing self-preservation strategies.

#### ***4. The Emotional Aspects and Coping Strategies***

There is a consensus in the literature that working with the terminally ill will evoke emotional feelings of grief, burnout and stress. The vicarious aspect of the working with individuals HIV/AIDS infected can make the case manager more susceptible for experiencing grief or bereavement. This was especially true in the earlier years of the epidemic before the introduction of protease inhibitors. People were not living long and most of the work was related to preparing AIDS infected individuals and their families for and impending death. From this strategies were developed within the helping profession to mitigate the emotional aspects of working with those HIV/AIDS infected.

One strategy is self-care by Figley (2002) he point out how there is a cost for caring for individuals who have a chronic illness and HIV/AIDS is no exception. The cost is connected to the realization there is no cure and the client will not fully recover. In working with clients, case managers give a level of compassion and empathy that exacts an emotional connection. This constant exposure to the client's grief in turn can manifest grief within the worker. As with Strug and Podell the case managers utilized self-care to address issues of bereavement related to the psychological trauma of repeated loss issues with clients. They found that emotional fatigue, demoralization and burnout are common symptomatic responses among HIV/AIDS case managers and social workers, resulting from interactions with HIV/AIDS infected individuals. Their work reflects a similar concept to Cho & Cassidy (1994) relating to multiple death issues. Strug and Podell's notion of anticipatory grief grew out of going from one case to another. Unresolved grief as expounded by Cho and Cassidy is an incompleteness of the grieving process for any variety of reasons. Scholars in the field all agree that professionals working with the terminally ill, experience some form of unresolved grief. The worker has chosen to focus all of his concentration on his workload and does not permit him/herself the opportunity to think about the client's situation until he can respond, without additional pressure of externally imposed deadlines or other demands on his time and energies (Cho & Cassidy, 1994). This in turn can cause the worker to delay the grief process.

The perspective of chronic bereavement (Cho & Cassidy, 1994) for the worker in the field of HIV/AIDS points to the parallel process for workers and their clients in the bereaving process resulting from HIV. It was viewed from the perspective of types of grief one experiences. They theorized that being traumatized by and through others repeatedly can leave the worker feeling emotionally disconnected. They viewed this as secondary or vicarious traumatization, resulting in psychological avoidance, desensitization and hyperarousal. As a coping mechanism to grief, the worker in turn can burnout, leading to a high rate of absenteeism, stress, sickness and job turnover. Such a commitment to the work with vulnerable populations can produce emotional exhaustion and a need for effective staff support systems. Clinical observations and research findings indicate that health professionals confronted with repeated issues of death of patients acknowledge that they grieve and describe a wide variety of grief reactions prior to or after the death of a patient (Papadatou, 2002). The literature (Figley, 2002) indicates that case managers felt the need to help the clients during all aspects of their disease cycle. There is a desire to make oneself available in anyway, which we can perceive is part of coping with the anticipatory grief.

As Figley notes, this process of availability helps the case manager in ignoring their feelings and focusing on needs of the client. Therefore, strategies on recognizing ones feelings and maintaining self is very important when helping clients cope. A second strategy identified by Strug and Podell (2002) was that of support groups. They demonstrated empirically the importance of a bereavement oriented support group. The study showed how the context of group helps case managers to cope psychologically in their emotionally work with individuals infected with HIV/AIDS. The study illustrated how a self psychologically-oriented bereavement support group provided an empathic milieu which case managers gave each other emotional strength by mirroring or validating their mutual feelings (Strug & Podell, 2002). The premise is that this type of group fosters empathy, emphasizing listening and understanding from the group member's view. It provided a subjective perspective for each case manager and the opportunity to seek support from co-workers. They acknowledged that peer support or supervision groups have been utilized in HIV/AIDS to address issues within the context of work. It was felt bereavement oriented support groups address the case managers' experience of chronic self-object loss, strengthen their self-esteem, and restoring and maintaining their psychological integrity when working with HIV/AIDS.

Self-help support groups or peer supervision were also recognized as a coping mechanism for the worker. These peer lead groups with out supervisors present allowed case managers to speak feeling about their experience with the client and the work environment at large. Although there is not an emphasize on bereavement in the peer lead groups, it does allow individuals to seek help from their peers. Cho and Cassidy viewed peer supervision as having both the aspects of supporting individuals as a griever and enhancing interventions practices for professionals. A final strategy is the use of supervision as a tool for communicating and processing feelings. Regular weekly supervision allows for the case manager to address challenges related to their caseload. Supervision should go beyond sharing information, and staff development; the supervisor should be playing a role in desensitizing the worker to traumatic stressors (Figley, 2002). Support can come in the form of listening, creative problem solving and recognizing and acknowledging when the case manager needs time to regroup (Rothman & Sager, 1998).

Supervisors provide a crucial coordinating function by monitoring the case manager and recognizing when support is needed both externally (with the client) and internally (organizational). A support network is a significant aspect in helping the case manager manage anticipatory grief. The literature reviewed concur that health professionals utilize collective sharing as a means of coping with grieving. Supervision is important in validating the case managers' feelings based on encountering situations and trusting that others would understand.

## **5. Summary**

It is clear there is a spectrum of strategies that can be utilizes by case managers when managing multiple losses. For professionals who choose to care for those who grieve changes in their lives, the opportunity and privilege of working in the presence of grief is often considered a great gift (Becvar, 2003). This review paper identified a number of strategies (self-care, support groups, supervision) that are significant in work with grief. It is vital that individuals continue working in the field of HIV/AIDS. Understanding anticipatory grief and chronic bereavement will help case managers better services individuals who are fearful of their outcome.

Bereavement training will help case managers address the challenges of dealing with their own emotions, but also provide tools in helping the client prepare and cope with the grief they experience around life changes. Multiple losses are not unique to working with HIV/AIDS; cancer survivors address many of the same issues. Bereavement training specific to multiple losses is unique; in that case managers often times are not given adequate time or space to process their losses in helping their clients. Supervision is the arena for many of these techniques to be assessed, based on what the supervisor is observing. Early detection of not managing the grief experience in the work can be detrimental to the worker and the client.

More research is required in the area of anticipatory grief and multiple losses related to HIV/AIDS. There is room do more exploration regarding training specific to addressing multiple losses and outcomes of effectiveness in work with those HIV/AIDS infected. Other possible research ideas that have evolved as a result of this review are 1) the exploration of more appropriate interventions to address coping mechanisms for HIV/AIDS patients who are living longer; 2) Comparative analysis of anticipatory grief reaction and attrition for case managers; 3) Intervention study to validate the efficacy of anticipatory grief specific to worker in the areas of HIV/AIDS.

Disciplines within healthcare must understand the implications of grief when working in the field of HIV/AIDS, as well as the importance of case management in the interdisciplinary model of treatment when caring for individuals who have HIV/AIDS. The self-help concept and knowledge of the disease as well as attitudes toward oneself and others is vital to effectively working with the population. With improved medication regimes and more treatment options the challenge is not living longer helping clients stay alive. The challenge then becomes addressing the emotions related to your clients living longer with an incurable chronic disease.

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