Occupational Stress and Burnout in Professional Caregivers of People Living With HIV/AIDS

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ABSTRACT

As the number of HIV/AIDS cases is still increasing, so is the need for trained and professional caregivers. There are a wide range of clinical challenges that caregivers have to face with the changing face of the disease. But who looks after the caregivers? Their needs are not being addressed as seriously as they need to be. As a result, Stress and Burnout issues are common among them and this is also impacting the quality of care-giving. Burnout is actually a process and not a sudden event and so its identification at an early stage is important. It is high time that this issue should get its due importance and care of caregivers be taken up more actively and effectively. Professionals like doctors, nurses, social workers, counselors invest a lot in the process of care and support but at a lot of times end up being physically and emotionally exhausted, drained, fed up and at times also changing and quitting the job. This leads to a lot of issues and questions that need to be answered through empirical research so that help and coping programmes can be formulated for them in order for them to cope and work better in difficult situations which are common in HIV care.

Key Words: People Living with HIV/AIDS (PLHIVs); Occupational Stress and Burnout; Professional Care givers; Coping Mechanisms

INTRODUCTION

There is a large and increasing amount of literature on several aspects of HIV/AIDS, but mostly about those infected by the deadly virus. Amongst those who are affected directly by it are the caregivers who have been largely neglected. Working with a person living with HIV is in itself a

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process of discovery. Care giving can be a very fulfilling and emotional experience. But the demands that it brings with it can take a toll on the care giver, physically, psychologically and socially. And if the clients are critically and terminally ill like HIV/AIDS patients, it can be all the more exhaustive. There is immense input that a caregiver has to put together at times compromising with his or her own health, personal time, family time and this at a lot of times leads to stress and burnout. This is a fairly common phenomenon amongst professionals engaged with PLHIVs around the world. With the number of HIV/AIDS patients increasing and so is the burden on the limited number of trained caregivers. Professional caregivers include doctors, nurses, social workers, volunteers in NGOs, counselors and psychologists.

As a result of this fatigue and exhaustion some common reactions follow like changing or quitting jobs, neglecting the clients, avoiding situations, role confusion, personal problems like family discords, social discrimination etc.

Defining Stress and Burnout

Occupational Stress- ‘the psychological state that is or represents an imbalance or mismatch between people’s perceptions of the demands on them (relevant to work) and their ability to cope with those demands’ (Miller 2000). It is an individual based, affect laden experience associated with stressors that are perceived and interpreted subjectively and uniquely by everyone.

Stress in HIV/AIDS care can be caused due to a variety of factors like – client overload, demands of the care-giving activities ranging from physical and personal care of the clients to round the clock monitoring and care of the severely ill, daily domestic chores of the caregivers own household, fear and uncertainty about HIV contagion and their own health, strong feelings of guilt, anger and helplessness etc. Insufficient compensation and encouragement are also leading factors for stress.

Burnout is viewed as the exhaustion of physical or emotional strength as a result of prolonged stress or frustration, and it became a part of the mental health literature in the 1970s, and has been detected in a wide variety of health care providers. Burnout has been understood to be an individual stress experience that is embedded in a context of social relationships, and thus involves the person’s conception of both the self and the others. Several models of Stress and Burnout have been propounded. The model of Burnout that is the most widely accepted is the Three- component model of – Emotional Exhaustion, Depersonalization and Reduced personal accomplishment (Maslach & Jackson, 1981).

Emotional exhaustion- refers to the feelings of being emotionally depleted of one's emotional resources, and having no capacity to offer psychological help or support to others.

Depersonalization- refers to a negative, callous or excessively detached response to other people, who are usually the recipients of one's service or care.

Reduced sense of personal accomplishment- refers to a decline in one's feelings of competence and successful achievement in one's work.

The components mentioned above can be easily found and explained through the professional's experiences. There are clearly many diverse emotional experiences in the care giving relationship that a client and caregiver experience. These range from a mix of positive and rewarding ones like a client responding and recovering well. While on the other side of the spectrum can be the negative ones like giving "bad news" to the client and his family, dealing with patients deaths, problems with co workers, etc which can lead to emotional exhaustion. The negative experiences at times lead the caregivers to adapt some coping mechanisms like neglecting the client's needs, distancing themselves from the clients, avoiding conflicting and difficult situations, or and taking frequent offs from work. Changing and quitting jobs can also be an extreme decision that some make.

Burnout in professional caregivers of PLHIVs

Research has clearly shown that the probability of developing stress and burnout in professionals involved in the human services is high. The increased involvement with clients, their families and friends, over identification with clients, dealing with death and bereavement issues adds to the stress. Although caregivers of patients of other terminally ill diseases like cancer would also face similar issues, there are some unique characteristics of HIV and AIDS care that make the caregivers more vulnerable to stress and burnout like –

- The secondary stigmatization of working with a stigmatizing disease like HIV that has issues related to sex and sexuality which are still largely considered taboo in society
- The identification and emotional involvement with clients who may have caregivers own sexual orientation or substance use difficulties (eg. Truck drivers, CSWs, IDUs, LGBTQs)

- The absence of a cure for AIDS as a disease and a universally fatal outcome
- The intensity of the epidemic worldwide and the high numbers of those infected
- The fears of contracting HIV infection in course of occupational exposure
- Exposure to death and dying of the clients and dealing with bereavement issues with family and friends (Van Dis and Van Dongen in Miller 2000).

The health professionals at risk include doctors/physicians, nurses, social workers, dentists, care providers in oncology and AIDS-patient care personnel, emergency service staff members, mental health workers, and speech and language pathologists, among others. All the above factors make a complex web of circumstances in which the caregivers get entangled and find it difficult to cope. Along with these, lack of proper training and orientation in care-giving, absence of counseling or any other help for themselves, lack of support from family and friends may add to stress and burnout.

There are also a lot of ethical dilemmas that caregivers may face. There are behavior patterns that are associated with HIV/AIDS which are not approved by society and at times the caregivers may also not approve of them at a personal level. But as professionals they can't refuse to care for a patient. Aspects related to sex and sexuality, drug use, prostitution etc are still a taboo in Indian society especially. Overcoming these by putting one's preferences and wishes aside and maintaining a non judgmental attitude may be difficult at times. Maintaining a professional distance from all clients always is also not easy for the caregivers, because after all human tragedy strikes a cord somewhere with them. There are situations where the caregivers may also be HIV positive or share the same sexual orientation as the client and so the identification and over engagement with them.

Caregivers may also face social discrimination amongst their own families and friend circles and especially with spouses. This at times leads to lying about the work profile and hiding away from family and friends and being socially isolated. A large majority of people in our society still don't understand the disease and its implications and also that it is ok to work with a PLHIV without getting involved and infected in any manner. Spouses especially find it very difficult to handle these issues and live in constant fear. This in turn forces the caregivers to rethink about their professional commitments and at times force them to change or quit their jobs.

Why is it important to address this issue?

HIV/AIDS is a multi dimensional issue. Apart from the medical aspect, there is also a large social and psychological aspect related to it. With the increasing number of HIV/AIDS patients around the world, the number of trained caregivers is limited. A trained health service workforce is imperative to ensuring good quality services to people living with HIV. There is limited empirical research especially in India, about the challenges and constraints that these professionals face in meeting the diverse health needs of PLHIVs. There is also an urgent need to study and review information on their attitudes, motivation and level of preparedness in addressing the diverse sexual and reproductive health needs of PLHIVs in the context of the present human resources crisis and emerging prevention and treatment strategies.

There is also a great need for significant investment in improving the health infrastructure and providers' awareness levels and ability to take the prescribed universal precautions against infection in health care settings. It is equally imperative to address the training needs of the caregivers in order to build their capacity to meet the requirements and expectations of the diverse sub-populations of HIV positive people around the world. This includes not just doctors but also the nurses and midwives, who are the primary caregivers for a large number of the population in many resource-poor settings. Qualities like unconditional support and proper knowledge about the disease in them are crucial for helping HIV positive people seek and adhere to treatment, prevent sexually transmitted infections, unintended pregnancies and transmission of HIV. They should also be able to support positive living that is free from the stigma and discrimination that currently surrounds HIV/AIDS.

Some caregivers who may themselves be HIV positive, can make an important difference, because they can empathize with the patients more, especially if they are supported in their workplaces, are knowledgeable about HIV and sexual and reproductive health issues. For this having the appropriate skills to provide good quality care are also essential. All this will go a long way in care and support of PLHIVs throughout the world. Because it is hard to imagine the lives of people with HIV/AIDS without the committed force of professional caregivers. There are evidences from all around the world where patients are refused treatment and neglected in hospitals because the caregivers are not trained and are afraid to handle them for the fear of contagion. There is lack of awareness and knowledge about the modes of transmission and prevention and hence the discrimination with PLHIVs. There is little that medicine can do in HIV/AIDS care. Apart from treating the opportunistic infections and reducing the viral load the largest burden of care is on the nurses, counselors, social workers and volunteers and definitely on the family. Aspects like nutritional care, cleaning and bathing, psychological help, just being there to calm the patient and talk with them are important along with the everyday needs of the patients.

Strategies for Coping with Stress and Burnout

It is clear that care giving is a stressful activity and it has different kinds of impact on the professionals. There can be different factors that can cause stress at work. As we know that each individual is unique, so are the coping styles. And that everyone tries to ignore the situation to some extent unless it gets intrusive and starts to impact life seriously. It takes a while to actually understand the impact of the pressures. Till then different mechanisms are used to carry on with work and life.

Coping styles are important determinants of burnout. There are factors that determine these also like support from the colleagues, general work environment, social support, personal attitudes, biases and prejudices against HIV/AIDS etc. Some common coping styles used by professionals range from avoidance behavior , praying, wishful thinking, planning problem solving to situation appraisal and acceptance. Each of these also has a different impact on the quality of care and the relationships with clients.

Research done on professionals through some coping scales has shown that coping styles can be – Internal and External. Internal styles include the more positive coping mechanisms like self expressions of feelings and emotions, patience, waiting and taking time out. These seem to have a greater sense of control over the work related stressors. External styles on the other hand include more passive strategies like negative and fatalistic attitudes, religiosity, faith and prayer, and denial.

Certain factors like age, workload and years of experience are also related to burnout. Research indicates that older nurses used more of internal coping strategies like being patient and understanding with clients under stressful conditions than the younger counterparts who lost control more often and would run away from the situation. People who tend to use Internal coping mechanisms are said to report lesser burnout compared to those using the external styles.

Unfortunately there is lack of training and orientation about the coping mechanisms in the professionals. It is important to teach people about the correct methods and the reason to use it in specific stressful conditions. In India, trainings and refresher courses are limited. Professionals like doctors, nurses, social workers, counselors, psychologists and volunteers who are in constant touch with PLHIVs and are at the brink of burnout need to be addressed. Coping effectiveness trainings are more popular in the west, and they teach which technique should be used in what situation. All situations are not the same and some can be changed and others not. More such burnout prevention programmes should be designed keeping in mind the individual differences. It is also important to start the interventions early and not wait for the professionals to be burned out, so that there are better chances of preventing and handling burnout.

Commentary

In the present day context, with the increase in number of PLHIVs, occupational stress and burnout of professional caregivers merits special attention as they are serious issues if we want to address HIV/AIDS care and support holistically. It's not just important to discuss and research on PLHIVs issues but also on the caregivers issues who are at times the real heroes in the battle for prevention and treatment of HIV/AIDS. Issues like stigma and discrimination are also faced first hand by them in the work situations and at times they end up internalizing them in the absence of any help, counseling or self help programmes. So, it's like sitting on a dormant volcano of unaddressed issues that can erupt any time and lead to immense destruction of the mind and body. It is important to think of practical strategies that can provide better care and support and working conditions for the professional caregivers. It is high time that we look at their issues with the same compassion that we address the other issues related to HIV /AIDS care. After all the long battle against HIV/AIDS has to be fought with a strong army of caregivers who are self satisfied and are thus ready to provide sustained care and support.

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