Family Caring in HIV/AIDS: Towards a Theory of Struggle, Commitment and Resilience

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This paper is based on my doctoral dissertation entitled: “Family Caring in HIV/AIDS: Experiences, Coping and Mental Health”. An abstract of the study is provided below as background to the paper.

Abstract

This study investigated the experiences of family caregivers of persons living with HIV/AIDS in two contexts of development – Kerala and Scotland. Although the study was primarily qualitative in nature, it incorporated some quantitative methodology in order to connect the findings to existing literature on stress, coping, and mental health.

In-depth interviews were conducted with 23 respondents in Kerala and 5 in Scotland. Interview transcripts were analyzed for major themes, using elements of grounded theory. Quantitative measures included the Ways of Coping Questionnaire (Folkman & Lazarus, 1985)[1] and the Self Report Questionnaire (Beusenberg & Orley, 1994)[2]. Results were analyzed for differences in coping style and mental health between the settings. Exploratory correlational and regression analyses were also conducted.

The results indicated that caregivers from both contexts experienced significant burdens. The major experiences of the caregivers in Kerala consisted of poverty, stigmatization, discrimination, lack of support networks and adequate healthcare facilities. While the caregivers in Scotland shared some of these experiences at a lesser degree, their dominant experiences centred on caregiving stress, limited support, role stress, difficulty finding and maintaining a job, and lack of recognition of carers’ needs. Quantitative findings indicated that carers in Scotland used a wider array of coping strategies and were more likely to rely on problem-focused coping than the Kerala respondents. Although the carers in both settings experienced significant indicators of psychological distress, the level of symptoms was higher for the carers in Kerala. Correlational and regression analyses explored relationships among setting, gender, coping, and mental health problems.

The findings were discussed in terms of the existing literature related to family-caring in HIV/AIDS, coping, and mental health. Synthesis of the findings led to the emergence of three unifying concepts of struggle, commitment and resilience. A model was proposed that explained the relationship among the three unifying concepts.

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[1] Folkman, S., & Lazarus, R. (1985). If it changes it must be a process: Study of emotion and coping during three stages of a college examination. *Journal of Personality and Social Psychology, 48*, 150-170.

[2] Beusenberg, M., & Orley, J. (1994). *A user’s guide to the Self-Reporting Questionnaire (SRQ)*. (WHO Publication No. WHO/MNH/PSF/94.8) Geneva: World Health Organization.

Context of the study

HIV/AIDS is the "most globalized epidemic in history" (Piot, 2004, p.8)[3], and is described as "univocally the most devastating disease ever faced" (Piot, 2001, p.1)[4], with no region of the world being spared (Annan, 2004)[5]. Further, Annan (2004) argues that "the global AIDS epidemic is one of the greatest challenges facing our generation ... an unprecedented threat to human development" (p.7) that poses a danger not only to an entire generation, but to an entire civilization (Annan, 2000)[6].

HIV/AIDS presents great challenges, not just to the person living with HIV/AIDS, but also to their family carers who undertake to provide their care. Family carers are the cornerstone in the support of people living with HIV/AIDS; they are the invisible heroes in this third decade of HIV/AIDS. Without their contribution, the predicament of many a person living with HIV/AIDS across the world, irrespective of the context of development they live in, would be unimaginable. Grant (2003)[7] suggests that over the centuries, families have been the "bedrock of care" (p.97), providing support for their ailing/disabled family members, and this has been a symbol of their natural love and altruism. While the sentiments remain the same, the stigma and discrimination associated with HIV/AIDS has brought a new and poignant dimension to the aspect of family caring.

In communities throughout the world, families face daily hardships associated with HIV and AIDS. These include severe illness, loss of income, stigma and discrimination, bereavement and loss of human rights. The stigmatizing nature of the illness necessitates that many carers bear their burdens alone and live in a culture of silence. The burden of

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[3] Piot, P. (2004). 2004 report on the global AIDS epidemic: 4th global report. Switzerland: UNAIDS.

[4] Piot, P. (2001, November 28). *AIDS epidemic 2001*. (Press Release). Geneva, Switzerland: Joint United Nations Program on HIV/AIDS, World Health Organisation.

[5] Annan, K. (2004). *2004 report on the global AIDS epidemic: 4th global report*. Switzerland: UNAIDS. Available from http://www.unaids.org/en/resources/publications.asp

[6] Annan, K. (2000, June 25). United Nations special session on HIV/AIDS: Global crisis— global action. Keynote speech, New York.

[7] Grant, G. (2003). Caring Families: Their Support or Empowerment? In: Stalker, K. (Ed.), *Reconceptualising work with carers: New directions for policy and practice.* London: Jessica Kingsley Publishers.

caring for loved ones living with HIV/AIDS is often overwhelming, pushing families into poverty and destitution.

Despite the importance of their contributions, the work of family carers is virtually invisible. Very little attention has been paid to the phenomenon of family care for HIV/AIDS patients, particularly in the less developed parts of the world, where it is the predominant form of care (Aggleton & Warwick, 1999[8]; World Bank, 1997[9]).

Family-based care is a critically important element of the continuum of HIV/AIDS care. It enables the delivery of humane and personalised care. In resource-scarce settings such as Kerala, where there is a paucity of community health programmes and social services, family caregiving takes on a particularly critical role. The burden of caring for loved ones living with HIV/AIDS is often overwhelming, pushing families into poverty and destitution. HIV/AIDS has and will continue to have a devastating effect in developing countries (Loewenson & Whiteside, 2001)[10] unless a concerted effort is made to stem the tide of stigma, poverty and discrimination faced by people living with HIV/AIDS and their carers.

My research focussed on the phenomenon of family caring, with the goal of increasing the knowledge about this phenomenon and developing a better understanding of the unique challenges faced by this group.

This study was intended as a beginning step towards answering some of the many questions about the experience of family care. The aim was to explore the experience of family caring as it is lived by the carers, to provide a deeper understanding of the challenges they face, the efforts they make to cope with these challenges, and the effect of the experience on their mental health.

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[8] Aggleton, P., & Warwick, I. (1999). *Household and community responses to HIV and AIDS in developing countries: Findings from multi-site studies*. Geneva: UNAIDS.

[9] World Bank. (1997). *Confronting AIDS: Public priorities in a global epidemic*. New York: Oxford University Press.

[10] Loewenson, R., & Whiteside, A. (2001, June*). HIV/AIDS: Implications for poverty reduction*. UNDP background paper for the United Nations Development Programme for the UN General Assembly, New York, NY.

Methodology

The methodology consisted of an exploratory, cross-national, qualitative and quantitative study that utilised grounded theory.

The researcher aimed to develop a qualitative study that would reflect the experience of the family carers' day to day lives, as they care for a family member living with HIV/AIDS.

A secondary goal was to explore quantitatively the effect of caring for a family member living with HIV/AIDS on the carer's ways of coping and mental health. To achieve these ends, 23 family carers in Kerala and 5 carers in Scotland were selected, partly on the basis of purposive sampling (Kerala) and partly on the basis of availability (Scotland).

Each of the carers completed an in-depth, open-ended interview, which was based on an interview guide designed for this study. The interview explored the experience of caring for a family member with HIV/AIDS from the perspective of the carers. The participants also completed the WOC (Folkman & Lazarus, 1985) as a measure of coping strategies and the SRQ (World Health Organisation, 1994)[11] as a measure of mental health problems. The interview transcripts were subjected to qualitative analysis, using elements of the grounded theory approach (Glaser & Strauss, 1967[12]; Strauss & Corbin, 1990[13]), in order to develop a set of themes that captured the meaning of the experience of the carers. The WOC and the SRQ data were analysed in relation to demographic variables and compared across the two settings, Kerala and Scotland. Further quantitative analyses were also done, on an exploratory basis.

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[11] World Health Organization. (1994). *The Self Report Questionnaire*. Geneva, Switzerland.

[12] Glaser, B., & Strauss, A. (1967). The Discovery of Grounded Theory: Strategies for Qualitative Research. New York: Aldine De Gruyter.

[13] Strauss, A., & Corbin, J. (1990). *Basics of qualitative research.* Thousand Oaks, CA: Sage.

Review of the Qualitative and Quantitative Findings

The qualitative findings encompass six themes that were discovered through the process of analysis. These themes included the many issues that accompany the advent of HIV in the carers' lives; the physical, emotional, social, and economic experiences of caring; the communication, sexual, and childrearing family dynamics that arose in caring; the unique experiences of carers who were positive themselves; the role of informal social support networks; and the contributions of formal support services.

Among the important findings included under these themes are the lack of awareness regarding HIV/AIDS of many of the carers, the problems of poverty and debt, and the many issues created by stigmatization and rejection of HIV-infected and affected persons, particularly in Kerala. Another finding highlights the carers' acceptance of the burdens of caring as part of their family duties—largely because there were no alternatives available. The carers' descriptions of their reactions to the burdens of caring indicated high levels of tiredness and exhaustion, as well as physical symptoms such as sleep difficulties, loss of appetite, and weight loss. The carers expressed many worries, feelings of loss, and a great sense of isolation, particularly in Kerala, where they often lived in fear that the HIV/AIDS status of their loved one would be revealed, resulting in social rejection and further isolation. They also expressed many economic concerns, as they tried to cope with the costs of medicines as well as the loss of income from the HIV-infected family member.

Caring engendered many changes in family relationships, both positive and negative. A number of carers spoke of communication problems, though some reported that communication improved as the family worked together to deal with the issues related to providing care. The illness of their family member brought about a number of changes in family roles, and these were often experienced as difficult and confusing for the carers. Concerns regarding sexuality and the loss of childbearing arose for many of the carers, as did concerns about the welfare of children. This concern was particularly difficult for a substantial number of carers who had children and faced the need to make arrangements for their children in the event of them becoming HIV-positive and eventually dying of AIDS.

Concerns about the availability of support were also prevalent. Many of the carers, particularly those in Kerala, felt that they had very limited access to informal social support. While the carers in Scotland reported having more informal supports available, they too found that the support they received was inadequate. The carers in Scotland did have greater access to formal support services, which were virtually nonexistent in Kerala.

The quantitative findings included some exploratory analyses that examined the coping strategies used by respondents in Kerala and Scotland as well as the mental health problems experienced by the respondents. The results indicated that the carers in Kerala and Scotland relied on decidedly different strategies when coping with the stresses related to family caring. The carers in Scotland were significantly more likely to use the strategies of problem-focused coping, positive reappraisal, seeking social support, self controlling, and distancing/detachment. The carers in Kerala were significantly more likely to use the strategy of self blame. These results suggest that the carers in Scotland had a wider array of coping strategies available to them, perhaps reflecting the greater availability of resources.

The findings for mental health problems suggest that the respondents in both settings experienced significant mental health problems, particularly symptoms suggesting depression and anxiety. The carers in Kerala reported significantly more of these problems than the carers in Scotland. Exploratory regression analyses indicated that gender, problem-focused coping, and setting were all significant predictors of mental health problems. Females, those from Kerala, and those who relied less on problem-focused coping were more likely to experience mental health problems.

Finally, when all of the findings are considered together, three synthesizing concepts emerge. These concepts—struggle, commitment and resilience—capture the essence of the experience of family caring in the two contexts and encompass the many experiences reported by the carers. The concepts also serve as key elements in the theoretical model of caring, which was presented in the previous chapter. This model attempts to depict the relationships among the concepts and to facilitate a better understanding of the complexities involved in HIV/AIDS family caring.

The present research for the first time explores the varied experiences of the carers by bringing together six themes, coping and mental health and proposing a model using the concepts of struggle, commitment and resilience all of which highlight and help to explain family caring in HIV/AIDS.

A Synthesis of the themes

The previous section presented the six themes that emerged from the interviews with carers in Kerala and Scotland, highlighting the aspects of the experience of caring that were important for the carers. These themes show the many facets of the experience of caring for a family member with HIV/AIDS, reflecting the complexity of this situation and the many difficulties encountered by the carers in their day-to-day existence.

Despite this complexity, however, a process of reflection suggests some unifying concepts that may help to capture the essence of the experience of caring. During the process of fieldwork and later during data analysis, the concepts of struggle, commitment, and resilience seemed to resonate strongly through the stories of the carers. The notion of struggle reflects the many obstacles and heartbreaks that the carers encounter in dealing with experiences such as physical exhaustion, anxiety and loss, economic crises, complex family concerns, social isolation, and rejection. Commitment reflects the unquestioning bonds of duty and affection that led the carers to undertake and continue to bear the daily burdens demanded by caring. And finally, the concept of resilience reflects the strength and resourcefulness of many of these carers, who found a way to go on when it seemed that they had lost everything.

Towards a theory of Struggle, Commitment and Resilience

The process of data collection and analysis provided me with insights into the multiple experiences family caregivers encounter. In wondering what was so unique to the experiences of these caregivers, I began to explore what was beyond the visible. A picture began to emerge in my mind—a kind of metaphor, something along the lines of a prism.

When a beam of white light passes through a prism, it gets deflected as the colours of the rainbow; similarly when the six themes of the carers' experiences were reflected upon and analysed, what I saw were three concepts that seemed to run through their experiences.

Likewise, just as the multiple colours of the rainbow come together to form white light, these themes could be unified to form the concepts of struggle, commitment, and resilience.

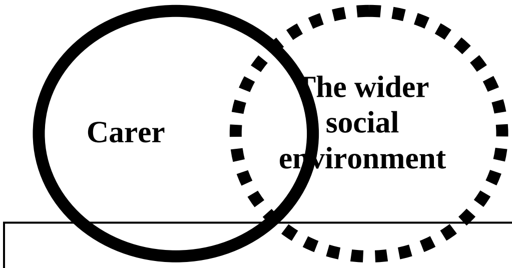
The three unifying concepts of struggle, commitment and resilience were utilised to develop a theoretical model that attempts to explain the complex process of family caring in HIV and AIDS.

An understanding of the three concepts is crucial in developing an appreciation of the model of family caring, because each concept reflects a complicated set of relationships. Each of the three unifying concepts will now be discussed, in order to provide definition and clarification of the aspects reflected in the concept.

Struggle

The concept of struggle encompasses the effort necessary to provide care and support in the context of the wider social environment, that can be viewed in terms of the pressures and conditions that impinge upon the carer and the family, as well as the supports and resources available to assist the family as they deal with the day-to-day realities of HIV/AIDS.

The pressures and resources, as well as the relationship between carer and the wider environment, are depicted in Figure 1.



Problems posed by the social environment:

- Poverty
- Ignorance
- Lack of resources
- Poor medical provision
- Poor medical care
- Inadequate social support
- Lack of recognition
- Culture of silence
- Stigma
- Discrimination

versus

Support provided by or within the wider community:

- Extended family and friends
- NGO’s
- Governmental supports

Figure 1. The relationship between the carer and the wider social environment

The process of care implies a relationship between the carer and the environment in which he or she must operate, and in the case of many of the carers in my study, that relationship was marked by many negative features and few positive ones.

Family caring is influenced by factors such as the availability of social support and the climate of stigmatisation, as well as cultural influences that help to determine the ways that people try to cope with the burdens of caring.

Because of stigmatisation and taboos, it was seen just how great a struggle it was for so many of the carers, particularly those in Kerala, who seemed to have so little going for them.

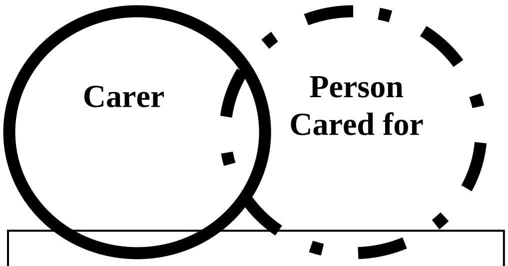
The idea of struggle seems to capture the reality of this process, and it also reflects the exhaustion, depression, anxiety, and sense of burden reported by so many of the carers.

For many of the carers, the problems and pressures were all too many, while the resources and supports were all too few, and in the case of some carers in Kerala, completely non-existent.

Commitment

The concept of commitment is drawn from the relationship between the carer and the person cared for. It reflects the sum of the forces pushing the carer and the cared-for person together, as well as the forces pushing them apart.

This relationship between the carer and the person cared for is depicted in figure 2.



Binding
- Love and dedication,
- Sense of identity
- Duty of care
- Emotional bonds
- Family obligations
- Social bonds
- Tradition

versus

Pushing apart
- Fear of Infection
- Impending Death
- Family conflicts
- Loss of employment
- Financial strain
- Emotional distress
- Physical exhaustion
- Fear of stigma

Figure 2. The relationship between the carer and the person cared for

Despite the many difficulties and pressures that the carers experience, many of them showed a remarkable level of commitment to the HIV/AIDS-affected family member. The unquestioning bonds of love, duty, and compassion that led the carers to undertake and continue to bear the daily burdens demanded by caring were illustrated repeatedly in the accounts of the carers.

Caring for a family member living with HIV/AIDS often takes enormous strength and commitment. Despite the lack of support and recognition, these family carers display remarkable commitment to meet the overwhelming demands of caring for their loved ones living with HIV/AIDS.

They have to deal with many stressful decisions and challenges and feelings that are hard to cope with. These include anger, grief, sadness and depression, as well as the very real fear that the HIV status of the loved one will be discovered and lead to social ostracism.

Caregiving in HIV/AIDS can be an emotional roller-coaster, yet even under such pressures family carers commit a great deal of their time and energy in order to be of support to their loved ones with HIV/AIDS.

For many carers, making this commitment seemed to happen as a matter of course—it was simply understood as a part of their relationship with the cared-for person. For those who made a conscious choice to provide care, the reality of their sacrifices was often minimised, as they focused instead on the needs of the HIV-affected family member.

Resilience

The third unifying concept is that of resilience. The concept of resilience reflects the strength, capacity, and resourcefulness of the carers who found a way to go on in the face of multiple adversities—a will to go on when it seemed that they had lost everything.

Figure 3 depicts the concept of resilience.

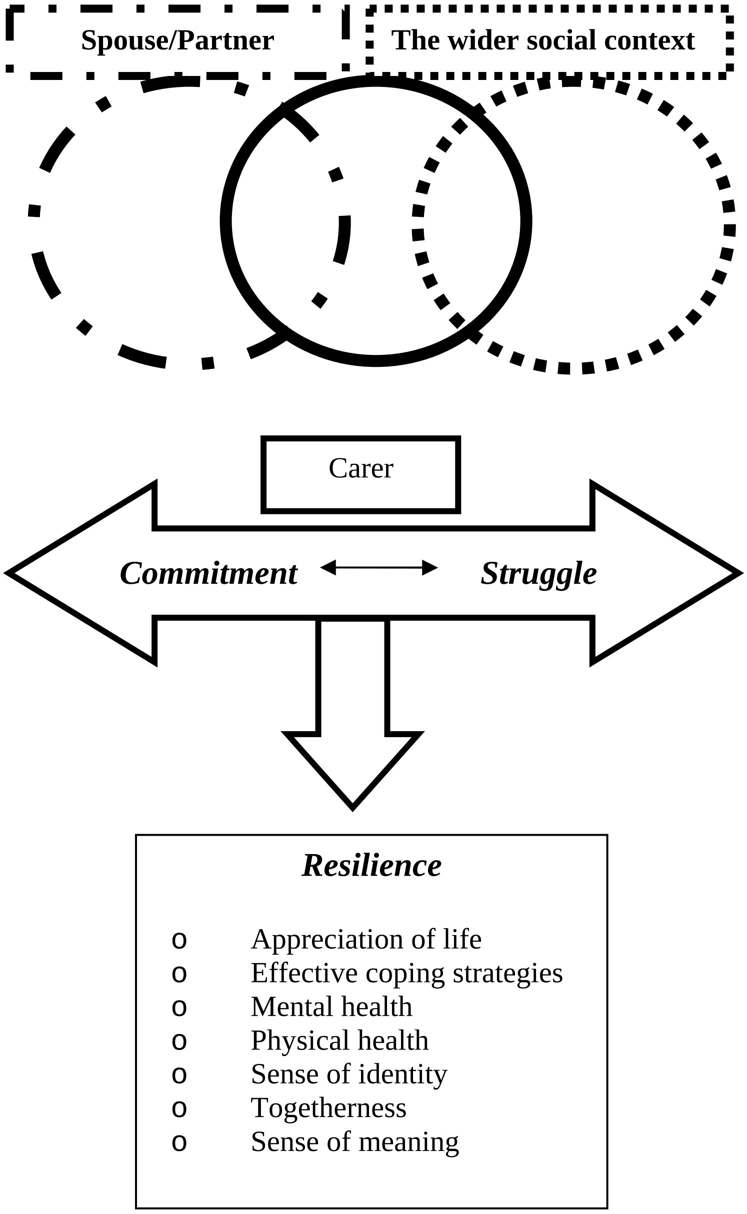


Figure 3. The concept of resilience

It is very telling that some of these carers kept on in the face of devastating obstacles, and it seemed that some of them just kept on because they had no other choice. Many of these carers simply could not afford to collapse, because then there would be no one to care for their loved-one and to see to the needs of their children.

In the context of this study, resilience is seen as the product of the interaction between struggle and commitment. As the carers strove to manage the many duties and pressures of caring and to sustain their relationships with the family member, they somehow moved to a new level of commitment and a philosophical sense about the experience.

A number of carers, particularly those in Scotland, spoke of the deeper sense of meaning that caring had brought to their lives. Some of the carers in Kerala also reflected on the new closeness that they felt toward the cared-for person, despite the hardships that they encountered.

It is important however, to acknowledge that this resilience was not experienced by all of the carers in the same manner or with the same degree of intensity or had similar conditions. Some reported that they were experiencing despair and hopelessness instead. It is apparent that some carers exhibited the quality of resilience to a much greater degree than others, who seemed to fall apart or deteriorate into despair and hopelessness.

It might be that the capacity to form resilience is a result of certain personality characteristics, or it may reflect a difference in the environment, or perhaps both.

For example, Sheena from Kerala, who had carried poison so she could kill herself if things got too bad, may not be seen as resilient as others like Gangabai who vowed to “be there” for her husband until the very end, “come what may”. This may be because some of the carers who despaired had encountered an extreme number of losses at once, or perhaps were subjected to the most extreme social environment.

Thus the three unifying concepts of struggle, commitment, and resilience are utilised to develop a model that attempts to explain family caring in HIV and AIDS.

A Theoretical Model

Through this study, the phenomenon of family caring in HIV/AIDS has emerged as a process that comprises the three key elements of struggle, commitment and resilience.

Various environmental and personal characteristics contribute to each of these elements, resulting in a complex pattern of interwoven influences. The diagrammatic model depicted in Figure 4 illustrates one way to conceptualize the pattern that emerged, to explain family caregiving in the context of HIV/AIDS. This model is offered as a tool for illustrating the complex realities faced by families involved in providing care to their family member.

Figure 4. A model of family caring in HIV/AIDS

The concepts of SCR portray the central theme of family caring in HIV/AIDS in this study. The model depicts these concepts interacting in a dynamic, iterative way, where struggle and commitment are interlinked; that is to say each feeds into the other and vice versa. They together feed into resilience, which in turn nourishes both struggle and commitment.

The model presents the context of family caring as the backdrop of the experience of family caring. The cultural, social, and economic contexts for care reflect the resources available to the carers as well as the many pressures and problems that impinge upon their daily lives, and these are depicted in the outer circle.

Family carers provide the much needed care and support to persons living with HIV/AIDS in a context of poverty, ignorance, lack of resources, lack of recognition etc, which impact on the family caring as a whole.

For many carers throughout the world, the context of care is characterized by harsh realities—limited resources, stigmatisation, and lack of recognition for their efforts.

Within the model struggle is depicted as an effort that the carers make to provide the much-needed care to their family member amidst so many adversities. The carers are prepared to struggle, because of their love, duty, dedication, compassion, and family obligations; all of which reflect their commitment. Because of their commitment, the struggle continues.

The relationship between commitment and struggle is shown by bi-directional arrows. This is shown in the middle circle, with arrows leading from struggle to commitment and backwards. The environmental and personal factors that influence each concept are listed below each concept.

Despite the challenges and limitations they encounter, family carers continue to work to provide the support needed, and this is also reflected in the middle level of the model.

Struggle and commitment are shown here in a dynamic relationship. Carers struggle to deal with the many adversities they face, and they continue to do so out of a sense of commitment.

The sense of love, duty, dedication, compassion, and obligation that the carers feel enable them to continue the struggle, and the experience of struggle in turn deepens the sense of commitment and dedication.

The next level, resilience, reflects the ability of the carers to cope and to survive the great difficulties they face, and this is depicted in the inner circle. Again, the relationship is bi-directional. The experiences of struggle and commitment contribute to the resilience of the carers, and in turn the resilience of the carers enables them to go on.

Carers who are unable to find the inner or outer resources they need to continue or to go on may fall away from the caring role, while those who are resilient are able to go on and to find new meaning in their experiences and sacrifices.

Struggle and commitment both help to mould resilience. Through the shared experiences of struggle and commitment, the carer and the cared-for person discover their own inner strengths, as well as the strength of their relationship. Resilience in turn nurtures both struggle and commitment. This is what gives the family carers the strength to go on, hence the centrality of this concept in the model.

Resilience is also placed at the centre of the model because of its importance. An understanding of the processes underlying resilience is extremely important in the ongoing worldwide effort to deal with the HIV/AIDS epidemic.

As observed earlier, family carers are vital contributors who provide much of the care for those afflicted with HIV/AIDS around the world. Thus, finding ways to discover resources and nurture the resilience of carers can be a key element in combating the devastation caused by the HIV/AIDS epidemic.

The concepts of struggle and commitment are linked to an existence that finds its basis in the past, its hope in the future, and the capacity to struggle on with commitment and resilience in the present.

The model attempts to explain the process of family caring, but also to serve as a jumping-off place for further efforts to develop our knowledge about the phenomenon of family caring in HIV/AIDS, as well as explorations of ways to provide additional support and assistance to family carers around the world.

What strikes most is the commitment the family carers in this study displayed and the tenacity with which they strove in the hope that their little contribution could somehow minimise the hardship and distress faced by their family member with HIV/AIDS. A carer’s poignant words “*I will be by his side, until the end, no matter what it does to me*” are a tribute to the remarkable contributions of caregivers who are always there until the very end.

In the struggle amidst poverty, stigma and discrimination, what springs up is a ray of hope, a sense of confidence, as one carer invoked:

> *"I hope one day I will be able to prove to the world that I was right in caring for my husband ... I hope the world will accept HIV with more compassion ... as just another illness ..."*

Implications of the Model

The very real sacrifices made by the carers in both contexts bears testimony to their struggle, commitment, and resilience in the face of many adversities. It stands out as one of the most touching facets of the phenomenon of family caring for a person living with HIV/AIDS. Without their sacrifices, many HIV-positive persons, who they were caring for would have been bereft of care and consolation. Yet, surprisingly, very little attention or recognition is given to these carers themselves, who give so much and receive so little in the way of support.

The commitment and resilience of family carers has implications for practice. Carers provide valuable services that no one else in their communities can provide, yet they get no recognition or support for their contributions.

Fostering recognition of their commitment and appreciation of their efforts could be a useful way to support their efforts and encourage them to go on when they are discouraged.

Formal or informal support groups that help carers connect to other carers might be an invaluable service in this area.

Finding ways to support family relationships and to prevent family disintegration due to stigmatisation would also be helpful.

Intervention should seek to strengthen the resilience of the carers so that they maintain the capacity to continue to care for their loved ones.

The strengths perspective and resilience literature suggest that practitioners may learn from those people who survive and in some cases flourish in the face of oppression, illness, demoralization, and abuse.

Practitioners need to know what steps these natural survivors have taken, what processes they have adopted, and what resources they have used.

If families are to be supported and empowered, then practitioners will need to be knowledgeable about what strengths families have, so that these can be recognized, learned from, and reinforced.

In conclusion the model provides a framework that enables professionals working in this field to intervene meaningfully with family carers and contribute effectively towards ameliorating the suffering that is rooted in the socio-cultural, economic, and political realities of the HIV/AIDS epidemic.