

CARE OF THE CAREGIVER **- SOME PRACTICAL MEASURES**

The final session of a national workshop on HIV/AIDS Management and Care, hosted by the University of Natal's School of Nursing in July 2002, dealt with "Care of the Caregiver".

Presented by Professor Donna Gallagher (Associate in Family Care, University of Massachusetts Medical Centre, USA), this session covered four general categories of caregivers, i.e. the provider, the family, friends and community. The experience of the epidemic in both US and in SA had overwhelmed hospitals' resource bases for the provision of care for terminal patients, compelling their managers to send HIV/AIDS patients home to die.

In South Africa, where the epidemic is so widespread and so few structures for home-based care are facilitated by the healthcare system, (not to speak of those within communities), this situation has wreaked havoc on neighbourhoods and families. Levels of stigma and discrimination against HIV-positive people and AIDS patients are so high that home-based care volunteers from outside the family are bearing the burden of terminal AIDS care, largely in secret.

Prof Gallagher described this burden as one that encompasses several emotional factors for all types of caregivers, be they nurses, relations, friends or community volunteers: anger, fear of transmission, rejection, bereavement, stress/worry, depression and hopelessness, decreased motivation and "compassion fatigue". All of these emotional pressures impinge on the individual while the onerous practical chores of terminal care work are being undertaken, often in crisis mode.

Nurses are, generally speaking, deeply caring people who commit themselves to their special vocation; their natural response is to become emotionally bonded with their patients and so they tend to be extremely drained following every death. They feel angry about the lack of funding and medication available for HIV/AIDS care, and the lack of recognition for the level of suffering that characterises both the illness and the care thereof. They try not to take it out on their families, but in the end, the depletion of physical and emotional energy becomes too severe and they do seek alternative employment. Those who remain in these jobs tend to become burnt-out and bitter, or toughened and emotionally cold, merely to survive psychologically, if not materially.

Prof Gallagher noted that this level of "compassion fatigue" is usually only seen in nurses who have worked for 35 to 40 years in their profession; since the AIDS epidemic began sweeping across the world, nurses with only two or three years in service are experiencing "fall-out".

In the US, there is still enough stigma prevailing around HIV/AIDS to make nurses unwilling to admit to their professions in certain circles - they will not readily introduce themselves as "AIDS nurses" at dinner parties. Post-exposure prophylaxis (PEP) does help to allay some of the fear felt by nurses about transmission of the virus while on duty - although it was not certain that PEP is available to all South African nurses.

Delegates at the workshop felt that their employers should be obligated to provide moral and psychological support, recognition and some form of education and training for their families, so that awareness of their needs could be raised. It was also noted that an information network (e.g. via e-mail list-serve) could be very helpful in this regard.

The plight of HIV-positive nurses did not go unmentioned - their needs are extensive. While in the US there exists an Association of HIV-Positive Nurses, in South Africa there is no such body, and the frustration of being limited to only symptomatic management of the disease (with only theoretical promises of drug therapy becoming available) is nothing short of cruel.

Prof Gallagher emphasised that nurses and other medical practitioners have a right to complain about these issues; they must have outlets to express their concerns, their grief and their anger, and be given relief to counter their exhaustion.

The gathering was mindful that there are many community volunteers taking over the terminal care once the AIDS patients are returned home - almost invariably for no reward or recognition at all. If the patient is lucky, their caregiver will be a family member, but the levels of stigma around HIV/AIDS in our communities are so intense that families reject the patients, and so it is the home-based care volunteers (in many cases, retired nurses and teachers) who take on these responsibilities.

If family or friends do take the patient in, they suffer a protracted and often inadequately expressed burden of guilt and grief: guilt at feelings of revulsion when confronted by the more gory symptoms of the illness in their loved one - family members will argue about roles and responsibilities in sharing the workload, and then feel ashamed at wasting time and energy on such disputes while their relative, in pain and dying, can hear or see them. This can traumatise the patient, as s/he feels helpless and dejected at being the source of such turmoil in the family.

In some communities, there are cultural frameworks - mostly gender-biased - determining which family members will do the base-level work of care, and those who do the bulk of the physical chores, i.e. women, do not have an opportunity to grieve properly. Children within the family will often "act up" and behave rebelliously as a means of responding to the tensions and emotional pain enveloping the home - which only adds to the caregiver's problems.

Friends who become caregivers experience many if not all of these pressures. Communities react with fear (of transmission, of the stigma and for the future), disbelief, a sense of "guilt by association", and a group-grief due to multiple losses. In the US, neighbourhood responses have become dismissive e.g. "You have the anti-retroviral drugs now - why do you need so much care - why are you dying at all from HIV/AIDS?". In Botswana, where communities are swamped with deaths from AIDS, it has been found that fear of contamination affects their willingness to care; in many cases, families there have more than one member in the terminal stages of AIDS.

Prof Gallagher listed the practical measures and interventions that would be required to address the needs shared by the four categories of caregivers:

Information and training guides on care procedures, gloves, medical care kits, adequate shelter and food supplies, transport services and religious/moral support. Community members need to organise themselves to provide respite to families with more than one terminal patient, so that caregivers are afforded at least a few hours of relief. Support groups should be gathered, advertised and facilitated, but with due sensitivity in targeting the various needs of age, gender and other peer-group characteristics. Levels of education, stigma and empowerment need to be carefully assessed in providing all these resources.

Telling the truth about the disease and the death also provides genuine release from the emotional trauma - e.g. "She died of AIDS" rather than "She died of TB". In South Africa, doctors do not inform families of the diagnosis because of the right to confidentiality and the stigma attached to HIV/AIDS - so how do we tell the truth and protect privacy at the same time? *(Note: Prof David McQuoid-Mason of UND's Law Faculty believes that caregivers should be fully informed but only with extensive counselling.)*

It is important that the individuals who die do not simply "disappear" from the group, and that caregivers are enabled in processing their loss, with the recognition and support of their employer, company or institution. This can be done through colleagues honouring the lives and passing of the deceased through rituals and ceremonies, displaying personal items which treasure the memory of the person, group projects like quilt-making and "walls of grief" - all of these help in healing large numbers of bereaved individuals. Lighting candles near and around photo-walls honouring deceased staff members has worked particularly well in hospitals and offices.