HIV-AIDS – A Psychologist and Family Responds to the Challenge of Death

Len Bloom

INTRODUCTION

Since early 1992 I have been adoptive father to three young South Africa Xhosa men, once boys, but no longer. With them and their partners and children we are now a close family. I have been a psychotherapist in South Africa: helping survivors to survive (Bloom, 2003), and a father, mother and friend to the boys (Bloom, 1997).

It is well-known that AIDS-related death is, alas, very common in South Africa but I never realised that in our family we would have to cope with the traumata of two deaths within weeks of one another.

In this article, I describe the rational and irrational feelings, with which we still have to cope, and I suggest the limited extent to which my professional identity has been able to protect me from feeling as raw, sensitive and vulnerable as the rest of the family. I was often aware of my emotional weakness if I wore a psychotherapist's mask to distance myself because 'professional language robs meaning from our experience' (Symington, 2012). This paper is intimate and cannot be objective, nor should it be objective. I hope to share some insights with carers (and supervisors of carers), friends and family that may help them to understand, to accept and deal with their emotional pain.

From April 1992, barely two years since apartheid laws were abolished, I began living as a family with Xhosa teenagers in a cathedral town in the Eastern Cape of South Africa. Soon partners appeared and in 1994 the first of eight children were born. Then in April and May 2007, first Pumla, the wife of Sandi, then Zanozzi, the partner of Daniel, were diagnosed as HIV positive and within a week of writing this paper, the three-year old baby of Pumla was diagnosed as HIV positive. One tragedy ends, and another begins.

It is no platitude to insist that when a member of a family has been diagnosed as HIV+ not only the patient but all the family urgently needs sympathetic support and practical advice about the physical and emotional import of the illness.

DEATH, ANGER AND SELF

Death is overwhelming even if it is expected, but expectation is in no way an unequivocal acceptance. It is 'the uncertainties of the unknown (that) precipitate regressive experiences that make people feel helpless, and sometimes unable to use the internal and external resources available to them' (Kleimberg, 2004, 47). Carers, family and friends have to accept the known, unknown and must share another person's departing life. They may unconsciously refuse to examine intuitively the mystery, the existential agony, of another's dying by rejecting their sameness with a fellow human being in distress.

A person whom one could once reach emotionally, physically and understand, and with whom feelings could be shared, becomes less and less reachable, recognisable, even touchable, and there is nothing that we can do about it. A carer, a professional, you or me, may unconsciously suspect that the caring was never enough. So we feel helpless, then guilty and blame ourselves, consciously or unconsciously, for allowing ourselves to be helpless. Guilt is often mingled with depression and depression often leads to anger. Where can the anger go? It can rarely be repressed or completely sublimated so it is either projected towards people whom one blames, even if unfairly, or it is introspected, directed against oneself. The ability to mourn is destroyed. Melanie Klein has shown how peace of mind and making reparations are intimately linked (Klein, 1997). If we are unable to make reparations then we may be unable to cease persecuting ourselves and we fall into despair and are in danger of intractable depression.

The family was forced to do its best to contain its feelings as crisis followed crisis and there were endless conversations that avoided mentioning suffering and death, and we unconsciously shared our censored fears of the future and supported one another's fantasies of hope.

But we had another direction for our anger: the general practitioners (GPs) who, we were convinced, acted too slowly to get medication. Less angrily now, we are still convinced that the bureaucracy and professional protocol in which the GPs were enmeshed was responsible for their slow response and their seeming lack of concern. We were assured that the patients would be treated soon but 'soon' came when cell counts were so low that it was too late to save the patients.

It could be objected that a professional psychologist, like me, should be able to control his anger, even if a layman like Sandi had to allow his feelings to erupt. But how should I have controlled my anger? Why should I have tried, when the situation was both emotionally unbearable and apparently at least, partly the result of bureaucratic indifference and lethargy. It may be justified, indeed rational, to be irrational.

THE TRAUMATA OF DYING AND DEATH

I doubt if the traumata of dying and death can be faced with equanimity even if one represses disturbing, unsettling and unruly emotions. Of course, it must be admitted that every day of our lives, we repress, deny or sublimate unwelcome and unruly emotions, whether they arise now in relationships or are hangovers from earlier childhood experiences. Broken relations, shattered love, despair and disappointments are disturbing emotions that we may bury too deep for tears. Yet they may erupt from our past to revive the separation anxieties of childhood. Perhaps even a Rankian birth trauma may intensify the present separation of imminent death. Or a built sense of security, identity and the future is rarely as secure as we would wish, or expect it to be. Pumla's and Zanozzi's deaths aroused our childhood insecurities about the future lifespan – a future that we were daily seeing may never come. Our sense of loss is not only a loss of a person but a loss of oneself (Freud, 1917), as we introject another person's disappearing as no longer a real person with a future in a real world.

We were not aware that we were contributing to that disappearance by treating Pumla and Zanozzi as though each were shrinking into a baby, and ultimately into nothingness. The 'baby' was helpless and at an unconscious level, this depersonalised the loss of the identity of a woman. This, I was convinced, was introjected by Sandi who also suffered this loss of identity by being turned into a reluctant nurse. Was Pumla's resistance to being fed similar to the baby's symbolic resistance to its feelings of impotence? And Sandi's inability to get the 'non-baby' to eat made him feel 'I'm as helpless as the baby! What a naughty baby to make me feel like this.'

MOURNING

Now the deaths have happened and we have to face our loneliness and helplessness. Now even more sharply than during the period of illness, grieving and blaming ourselves overwhelms the family. If only we had then done this or that maybe Pumla and Zanozzi would have been themselves and the shrivelled ghosts would have vanished. Culture and social rituals may drown emotions in alcohol, religious words and a group's superficial and forced merriment, but the reality of death cannot be played, drunk or danced away.

Mourning is exhausting, depressing and necessary. It hits us in two ways. Firstly, we have lost forever an attachment from our past. Sandi says sadly and often: 'I don't know Sandi now. I'm empty. There is a big hole in me……' This is not a man slipping into a schizoid state, but someone who suddenly has lost a vast chunk of his identity – an identity shared with his departed wife. His psychic emptiness is transformed into his physical sense of emptiness and incompleteness.

One can, however difficult it may be (because unconscious guilt is peculiarly intractable), rebuild a loving relationship in our phantasy of the lost person. We may moreover be unconsciously confused about whom we are mourning. I only unexpectedly realised how attached I was to Pumla, but who was Pumla? Was she the sister that I never had? A daughter, close to me because of my closeness to Pumla? A mother, whose closeness I had long missed and of which I was unaware? But mourning may be impossible when the loss revives early conflicts when one did have phantasies of hurting, or even killing a loved one, the love for whom was deeply ambivalent. Ambivalent? Because the deceased has turned one's life into chaos and has aroused unwelcome feelings, perhaps the most disturbing of which is the self-blaming question: What did we do wrong to you so that we've lost you?

Freud, in his 'Mourning and Melancholia', asserted that if one could mourn or grieve then one was less likely to fall into a depression. He paradoxically said that healthy mourning includes an element of reality thinking: we lose someone and our world is poorer because of that loss. Revisiting the past in memory is a rational way to keep the lost person alive. Gradually, reality creeps in unawares: our sense of loss may lessen, we may feel less alive in the present world; to survive, strengthens. Irrational guilt can be felt as irrational and thus can be gradually discounted. One's ego need not be forever wounded, but a taint of denial may persist. I am reluctant to recall the dates of Pumla's and Zanozzi's deaths and their funerals, although they are in my diary. Sandi will not change Pumla's message on the answer-phone, the voice remains 'alive'.

LACK OF EMOTIONAL SUPPORT

The family collectively were unable to offer emotional support to Sandi, Danile and I and the young children, because all of us, adults and children alike, were shocked by the illness and death. We had no support from medical personnel although some doctors knew the family well and could hardly have failed to observe us and sense our distress. Neither the doctors nor the hospice staff invited us, much less encouraged us, to share with them our fears and anxieties. We yearned for such an invitation; at the very least we would have appreciated their efforts and sympathised with their fears and anxieties.

Why didn't we take this initiative? In South Africa as perhaps in the UK, the culture of medical authority is difficult for the laity to question, much less to challenge. When we tried, often in desperation, to consult our doctors, they were too busy or absent. We felt that we were deliberately and coldly abandoned. We were left to watch helplessly while Pumla and Zanozzi wasted away, and we had to improvise our own way to nurse them because we were never advised what more we could do to give them hope, emotional support and physical ease. We were baffled and distressed by our desperate need to show our love and to improve our caring, while Pumla and Zanozzi were unable to talk, eat, lie comfortably or respond to our care.

We were never helped emotionally to deal with our persecutory, self-blaming guilt, and this made it more difficult to create a family ethos with collective strength with which to support Pumla and Zanozzi as members of the family. There was a numbed family silence, a fear of failure, and it was more and more difficult to share our inner distress and dismay, although we are normally a talkative family. We are only now beginning to talk directly about our loss and to openly share our grief.

CONCLUSION: SILENCE IS NO SOLUTION

Silence destroys emotional health and prevents therapy. It is more than denial or even a deeply felt reaction to shock and dismay, and it is far more than a defence to shut out the world of sorrow. One of my saddest memories is baby Phumza, three years old, wandering lost in the house, asking 'where is my mother?'. Her mother was dying but unable to hold her daughter or even talk to her. Now the little girl cries no more, but has she forgotten or denied her mother's and her aunt's deaths? As she grows older will she resent their deaths, wish to avenge them, unconsciously form relationships that are symbolically similar, and to some extent satisfying? We have no answer to these depressing questions.

Silence, even denial, actively expresses unconscious guilt: 'I have survived, or, at any rate, I'm surviving – so far! Do I deserve to survive when others have died?' The repressed, hard to acknowledge guilt and anger of the survivors makes them emotional and thus, frustrates the struggle to restore the family to a 'normal life'.

What cannot be denied is that we will never come to terms with our insensitivities. How sensitively did we help little Pumla and Zanozzi to endure their suffering, decay and loneliness? How little we did to convince them that they needed to feel no guilt – they were not abandoning their families, even though they were not able to whisper a 'goodbye'.

Mitscherlich and Mitscherlich (1975) have analysed the collective inability to mourn the dead murdered by the Nazi regime. I believe that a family is no less able to mourn as a group unless it can collectively compensate for the triple failures of the group psyche.

1. The reality of death and dying is overwhelming, too painful to resist rationally and with control. But a family can, like ours, grope towards encouraging adults and children to look to the future and gather gradually the confidence that they can at least try to move forward as Pumla and Zanossi would want us to do.

2. Aggression, feelings of revenge and bitterness may be too powerful to sublimate during the early time of mourning. We as a family projected our anger on the medical profession and on one another. But, if a family can, like ours, begin to talk out its anger and hurt then destructive

feelings may lessen. The most urgent need is to talk about blame so that no one feels the family is blaming someone and by so doing rejecting him or her from the family. One loss is more than enough to grieve for.

3 Unconsciously our feelings cannot be denied, but the family's suffering can be prevented from destroying the family if it can be accepted and shared and individuals gradually become free to accept one another as free of blame.

Dying and death also dehumanises the survivors. Mourning should be the task of rehumanising the survivors.

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