



EXPERIENCE, CONTRADICTION,
NARRATIVE & IMAGINATION:

Selected papers
of
David Epston & Michael White
1989-1991

Dulwich Centre Publications
South Australia

CHAPTER II

a conversation about AIDS AND DYING

with

Michael White & David Epston

*Previously published in
Dulwich Centre Newsletter
1991, No.2.*

About two years ago, while sitting in a garden on a fine day in spring, Cheryl White interviewed David Epston and me about our ideas in relation to working with persons who were dying. She requested that we focus particularly on gay persons who had contracted HIV, and who had developed AIDS. Cheryl asked that we endeavour to reproduce this discussion for this issue of the Newsletter. Rather than interview us again, it was her preference that David and I engage each other in a discussion of the ideas that we exchanged in that earlier interview. What follows is a transcript of that more recent discussion. We would like to thank Cheryl for encouraging us to do this. If it had not been for her searching questions, in the first place, around what we believed were heartening ways of working with persons who are dying, we would not have thought through the practices discussed here at all well, and certainly would not have articulated them in this way.

Michael White

Michael: *David, in response to the questions that Cheryl originally posed for us, I recall that you talked about some of the work that you had been doing around talking with people about how they would like to live on in the memories of their relatives, friends and acquaintances. Obviously you have found this notion of the continuity of one's life to be a fairly significant issue for persons who are dying.*

David: *Yes, I have.*

Michael: *Could you talk some about that?*

David: *The importance of this idea came to me partly through my experience of working with persons who were dying, and partly through my reading about mortuary rituals - in fact cross-cultural studies of mortuary rituals. I was doing this reading in response to your work on the "saying hullo" metaphor and the "reincorporation of the lost relationship" (White 1988). One feature of these mortuary rituals that is very apparent is the distinction drawn around the death of the body and the survival of the personhood of the deceased.*

Michael: *This is a very interesting distinction, perhaps one that suggests considerable awareness of the extent to which a person's "self" is social, of the extent to which one's sense of personhood is negotiated and distributed within a community of persons. Would you give me an example of the actual practices associated with this distinction?*

David: *Well, the distinction is usually drawn across time. At a particular point in time after the ritualized goodbye to the dead body, the relatives of the bereaved assemble again, this time to take on the virtues of the deceased, or, if you like, the spirit of the deceased. Perhaps we could say that, at this time, the spirit of the deceased is regained.*

Michael: *Would you give me an account of one of these rituals?*

David: *Right. Let's take voodoo. From this reading I became aware of the extent to which certain forms of voodoo have been misrepresented in popular culture. For example, one practice of voodoo is for the family and friends of the deceased to gather and to conceive of themselves in the image of the horse, and to imagine themselves to be mounted by the virtues of the deceased. Thus, from there on, to an extent at least, these relatives and friends experience their lives to be ridden by these virtues. This really reinforced my interest in rethinking the "therapy" of those who are dying.*

Michael: *Okay, let's talk about some of the actual practices of therapy that would interact with these ideas.*

David: *Let me begin by talking about working with the bereaved. I started asking bereaved persons questions like: "Of all the virtues of your dead sister Rosemary, which of these would you like to carry forward in your own life?", and "Do you think, by doing this, that you will be able to keep her memory alive?" So, I was thinking about how therapy might contribute to keeping memories alive. And from there I went on to the idea of asking the dying person about how they would like their "legacy" to live on.*

Michael: *This really fits with my experience of meeting with dying persons. I often find that persons have been reflecting, in one way or another, on what piece, if any, of their life will survive physical death. And so often this*

question is posed in terms of "contribution". For example: "Did I make any enduring contribution?"; "What did my life amount to?"; "What has been my significance to the lives of other persons?"

David: *It is not a question that is very often taken up by others or addressed all that well.*

Michael: *No, it isn't. And perhaps this relates to our culture's emphasis on material existence.*

David: *I think the word "legacy" is a good word for us to think more about. In fact this word was offered by Cheryl during our previous discussion of this issue. I like to think that the person's personhood is the legacy of the person.*

Michael: *And we know that this personhood is a deeply significant legacy to those who have experienced loss, deeply significant to their sense of well-being.*

David: *Yes. I recall being consulted by a woman whose best friend had died. This woman was feeling very confused and was clearly aggrieved - and had been so for quite some time. On remembering her friend, she said that she felt she "had lost her right hand". I asked her some of the "saying hullo" questions, and later, when she returned, she described her friend as "my right arm". In a manner of speaking, she redescribed her friend as embodied in her. She had taken the personhood of this friend into her body, and was no longer experiencing the confusion and the grief.*

Michael: *I would refer to this as a reincorporation, because I suspect that the woman's experience of her friend's experience was a vital part of the woman's life when her friend was alive.*

David: *Yes, it is through these questions that the lost other is re-internalized.*

Michael: *So, we know that a person's personhood is not extinguished by physical death. We know that this personhood can and does live on in the lives of those who were significant to them - lives on as it always did in the same community of persons in which it was negotiated in the first place. And*

we know that this personhood can be very enriching of the lives of others in that community. How could this understanding influence the work done with persons who are dying?

David: *Your question leads me to a consideration of testamentary practices - for example those that relate to the writing of a will. A will usually has to do with the dispersal of property. Now, on drawing a distinction around material property and personal virtues, or, as some might prefer, spiritual property, the will becomes a cultural prototype for the dispersal of personhood. What do you think of that?*

Michael: *Great! This other will would authorize the existence of personhood beyond physical existence.*

David: *Some of my reading suggests this could be particularly relevant, because many AIDS sufferers are dying "too young". And there isn't a precedent for this in modern western culture. I think that the idea of the dying person as a benefactor and of inviting certain persons to be the beneficiaries goes some way towards addressing this issue.*

Michael: *I believe that once persons have been assisted to identify their contribution to other people's lives, the formalization of this in the way of a will, as you suggest, would be a very significant ritual.*

David: *I was working with a woman who was terminally ill. Shortly before her death she made me the agent of her will and testament. As part of my duties as agent, it was my responsibility to distribute, to appropriate persons, copies of a very important document. This document included a testimony to the sexual abuse that she had experienced as a young person, some thoughts about how others might free themselves from the long term effects of such abuse, and a message of hope.*

Michael: *Now you are talking about the person's contribution to the lives of others in another way. You are talking about how persons might be engaged in passing on their special knowledges to others, or, if you like, some of their accumulated wisdom. So that these special knowledges might be circulated. These special knowledges could include alternative knowledges about ways of*

being in certain communities, like in the gay community - alternative knowledges about life and about relationships, about solving problems, about the resolution of certain dilemmas, and so on.

David: *And about courage and about dying.*

Michael: *And about alternative knowledges of self.*

David: *In what sense do you mean "alternative knowledges of self"?*

Michael: *When Cheryl interviewed us, she asked what we thought were special issues for dying persons who had been marginalized. This had me thinking about some of the dying persons who had consulted me. Those of this group who had experienced marginalization in their families, social groups, places of work or culture, had responded very positively to questions that invited them to review and/or revision the meaning of their lives. And even many of those who had not been so marginalized have been interested in reviewing the meaning of their lives at this time.*

David: *When you refer to meaning, do you mean purpose?*

Michael: *Yes, purpose. But not "purpose" in a philosophical sense like "what was it all for?". I am talking more about the purposes or intentions or motives that persons ascribe to their actions in the course of their own lives, and I am talking about the review or revision of these historical meanings.*

David: *Go ahead ...*

Michael: *Well, let's take persons who have been marginalized. It is not at all unusual for such persons to have a private story about being unworthy, about failing to measure-up in some way or another. Although at times these private stories are masked by bravado, they are often experienced as total. However, despite this, the very marginalized position of such persons is a fact that can provide a gateway to an alternative story of who they might be. For example, gay persons can be encouraged to give an account of the turning points in their lives - turning points at which they made decisions that they knew they would be derided for, or for which they would be discriminated*

against. Such decisions include those that relate to the nature of their sexual desire and, more generally, to their sexual identity and preferred lifestyle. These decisions inevitably constitute a protest, a point of resistance to accepted ways of being in this world, and mark the entry into relatively uncharted territories.

David: *Okay, I'm clear about how the development of such an account serves the purpose of challenging these highly negative and totalizing stories. Would you care to say a little more about how this relates to the revision of meaning?*

Michael: *Sure. Once these alternative accounts have been sufficiently articulated, it becomes possible to pose questions that invite a review or a revision of purpose. This is a review, in the light of the alternative account, of what the person was trying for in his or her life. To respond to these questions is to think about life as a project or a commitment, one shaped by certain desires and beliefs - by desires and beliefs of a nature that suffering could not overwhelm. By the way, this revision of purpose is not to be mistaken for a palliative. It is not based on a specious account of the person's history. As I have stated, it is based on an alternative account, and an alternative account is just that - an alternative account.*

David: *So what questions would you be asking?*

Michael: *For example I might ask the person to reflect on the alternative account by asking questions like: "What do you think this says about what you were trying to do with your life?"; or "What does this reflect about what you intended for your life?"; or "What does this suggest about what you believed your life should be?"; and so on.*

David: *I can see how responding to such questions could be a powerful and refreshing experience for persons with what our culture constructs as "spoiled identities".*

Michael: *Yes, like gay persons with AIDS. There has been so much moralizing around the issue of AIDS. For example, those victims who are not gay or intravenous drug users are commonly referred to as the "innocent" victims.*

David: *The history of the discovery of AIDS supports what you are saying about this moralizing. It was considered to be a gay issue, and for a considerable time more money was poured into the research on Legionnaires Disease when there had been something like 129 victims.*

Michael: *Let's get back to our discussion of some of the practices that relate to the revision of meaning.*

David: *Okay.*

Michael: *A community of persons can be invited to join in this activity. For example, any sympathetic relatives, friends and acquaintances can be encouraged to contribute to the alternative account, and to reflect on what this says about the plans that the dying persons had for their life - about what they desired for their lives, about what they were committed to, or, perhaps, what it says about their life as a "work". And the experience of others who cannot be physically present, but who might be considered significant, can be evoked as well. Here the "saying hullo" questions are very helpful.*

David: *Do you mean in terms of engaging the "personhood" of others now deceased - of others who may have been significant to the dying person, or who, on reflection, might be historically significant to the dying person?*

Michael: *Exactly. I was thinking of the extent to which those dying persons who are interested in the review and/or revision of meaning in their lives can be encouraged to identify certain historical figures who might be significant to them - significant to them because they also challenged accepted ways of being in life, and also entered some uncharted territory. Maybe a figure who took risks to make a life of their own with little if any support, and who was prepared to pay the price for this, in terms of suffering and so on. Or maybe a figure who did something entirely different.*

David: *Give me an example.*

Michael: *I know a gay person with AIDS whose parents migrated from Europe at enormous risk and who, with little, if any, support, endured great hardship in their project of re-establishing their lives.*

David: *Are you thinking only of relatives or forebears?*

Michael: *No. It may be a figure that the person has some historical association with, or a figure with whom the person experiences a particular affinity. Once identified, the "personhood" of these figures can be evoked through "saying hullo" questions or "experience of experience questions", and this can play a significant part in revisions of meaning, or purpose. The dying person can be invited to enter an experience of the historical figure's experience of them, through remembering, imagining and speculation. An example of the sort of question that would encourage this is: "Tell me, if you were reviewing this account of your life through this person's eyes right now, what conclusions would you come to about your intentions for your life, intentions that this person could have appreciated?"*

David: *As you have been talking, I've been thinking of the sort of questions that could be asked that might assist in the identification of such figures. I came up with: "If you looked back over the history of your life, who else did you know who may have pioneered a geographical, intellectual, emotional or social territory?" This figure would not necessarily have to be one who would exactly agree with the decisions that the dying person had made about their life, but someone who might appreciate the spirit of these decisions.*

Michael: *Yes. This discussion takes us back to the subject of the legacy. Perhaps these practices that relate to the revision of purpose lend some clarity to the nature of the legacy itself. Perhaps it is time to wrap up this discussion with some final comments, and then get back to Cheryl to ask her whether she thinks we have captured the essence of the earlier interview.*

David: *Okay. A last comment. I think we could all go a lot further in terms of exploring the distinctions that have been drawn in mortuary rituals, and to encourage persons to think about personhood as a legacy. If what we are defining as personhood lives on in the lives of others as we know it does, then we could be a lot more interested in establishing the sort of conditions around the dying person that would enable them to have a lot more to say about how this legacy will be distributed or dispersed. I am sure that all of those who decided to participate in establishing such conditions would find it "enlivening".*

Michael: *And I would just like to say that for many persons who are dying, and particularly for those who have been marginalized by our culture through the ascription of "spoiled identities", that this time can provide them with an opportunity to become more active in, or to have a more major say in, the authorship of their own lives - perhaps to take over the authorship of their own lives - and to discover, in the process, that they are persons to be treasured. This time also can provide an opportunity for these persons to have the experience of a particular sense of presence in a community of persons, and perhaps even a community of "spirits" - of a unique sense of place in the world and of a unique sense of connectedness.*

REFERENCE

White, M. 1988:

Saying hullo again: The reincorporation of the lost relationship in the resolution of grief. *Dulwich Centre Newsletter*, Spring, pp.7-11. (Reprinted in White, M. 1989, *Selected Papers*. Adelaide; Dulwich Centre Publications.)