Appendix E

Telling stories, telling lies?

> A fact is like a sack which won't stand up when it's empty. In order that it may stand up, one has to put into it the reason and sentiment which have caused it to exist (Pirandello, 1921/1952: 230).

What's another word for stories? Fiction. And some critics of autoethnography argue that stories fictionalise life by giving it a structure it does not have (Shotter, 1987; Mink, 1969), and that they are always stories about the past and not the present and so are limited in their usefulness. But Ellis and Bochner argue that stories are both about the past *and* the potential future because the narrative seeks to 'keep the past alive in the present. Stories show us that the 'meanings and significance of the past are incomplete, tentative, and revisable according to the contingencies of our present circumstances, the present from which we narrate'. For we rearrange, revise, invent and omit stories or themes in the telling, stories are not neutral, do not simply mirror the facts and don't seek to recover 'already constituted meanings' but the 'meaning of prenarrative experience is constituted in its narrative expression. Life and narrative are inextricably connected', as Pirandello explains, one has to put both reason and sentiment into the sack. 'Life both anticipates telling and draws meaning from it. Narrative is both about living and part of it' (Ellis and Bochner, 2000:745-746)

Drawing on my experience of working with visioning techniques and Future Search conferences, I am convinced that in forming their past into stories to share with others people are reworking a still malleable material which takes a particular form depending on the circumstances and company in which it is told (purpose, audience etc), and that this does not compromise the story and its usefulness but brings it alive to author and listener. Part of this usefulness is that the wider political is evoked by the telling of more personal history. In my experience *writing* the story, as in autoethnography, brings the same benefits.

Some social scientists find it hard to accept telling stories as valid research; Atkinson pulls no punches when he accuses personal narrative of reflecting a

> Romantic construction of the self ... unworthy of being classified as part of social science (1997:335-339).

He argues that if as a researcher you are a story teller rather than an analyst of stories then your goal is necessarily *therapeutic* rather than analytic, and that a text which acts as an agent of self-discovery or self creation cannot be considered an academic text, and dismisses any work that does not 'use narrative to achieve serious social analysis'.

So does also having a therapeutic value mean that a narrative cannot have value as social research as Atkinson asserts? Is the only value that of advancing theory within a social science discipline? Bochner suggests that this depends on what one believes it means to be an academic, and accuses such critics of:

> Engaging surreptitiously in what feminist critic Jane Tompkins (1989:138) calls 'the trashing of emotion'; a war waged ceaselessly by academic intellectuals 'against feeling, against women, against what is personal' (Ellis and Bochner, 2000:746).

Bochner contends only a social science 'without a moral centre and a heart' would find a text which functions as an agent of self discovery or self creation threatening and asks:

> Why should caring and empathy be secondary to controlling and knowing? Why must academics be conditioned to believe that a text is important only to the extent it moves beyond the merely personal? (2000:746)

In his defence Bochner could be interpreted as focusing on the individual benefit (self discovery), however these autoethnographic texts offer more than individual benefit as they translate personal experience into political insight as the political is evoked through stories of individual lives. We use stories in order to try to make sense, to figure out how to lead our lives meaningfully, in this way they are most obviously a valid tool for first person inquiry[333], but also for second and third person inquiry through co-constructing narratives e.g. within Appreciative Inquiries and Future Search conferences. The story is not just a rendition of the past but is a medium for constructing, or co-constructing, a future, as Ellis and Bochner point out:

> The crucial issues are what narratives do, what consequences they have, to what uses they can be put. The consequences often precede rather than follow the story because they are enmeshed in the act of telling.

In my practice I have observed striking similarities between the benefits participants have gained from having a space (inquiry group) in which to gain confidence to value their everyday lived experience and to tell stories from it to the group, to make sense for themselves and with others of those stories and to explore and create new stories of themselves and their experiences. In this way they are supported to go through processes of consciousness raising, analysis and interpretation, and having made choices, the process of restorying their lives.

Listening to and gathering the stories (life histories) of research participants (e.g. DUG project) enables me to examine the scripts and

[333] See also discussion of using writing as a tool for first person inquiry in *My Approaches to Inquiry* chapter.

devices that the speaker uses to make sense of their own life experiences (as patients, nurses, consultants, NHS managers). Crucially through this process the researcher and her reader may be enabled to reflect on their own lives, gain understanding of one another and of the multiple realities involved in the creation of meaning for them (Gelya Frank, 1995. in Tierney, 2000).

Personal narrative is moral work and ethical practice, asserts Bochner, when the text is used as an agent of self understanding and ethical discussion. I am particularly interested in work when the ethical discussion includes a wider co-creating group and challenges the status quo about whose stories get told , and by whom and for what ends (and in this thesis I am asserting my right to tell my stories with the stories of my research participants). In this way the struggle to have autoethnography and the wider body of personal narrative accepted in the academy is similar to the struggles of feminist researchers to have a focus on everyday experience recognised.

Creating dialogues

I am interested in how, as a researcher I can shift the power in the inquiry relationship (and as a student shift the relationship with my examiners and colleagues), asking along with Mary and Ken Gergen 'how does our form of inscription shape the trajectory of our relationships together?' (M and K Gergen, 2002:12). This section looks at the different relationships which can be developed between writer and reader, researcher and researched with if we can view both the written text and the act of reading as performance.

Looking for a different sort of reader

This type of text (autoethnography) is looking for a different sort of reader – or more accurately to be read differently. It is a demanding text, what Wilson calls a 'writerly' text, demanding that the reader bring something of herself to the reading. Wilson (Wilson, 1998) distinguishes between readerly and writerly texts:

> [R]eaderly texts lead the reader logically, predictably, and usually in a linear fashion, through the research process. Little space is available for readers to make their own textual connections between the stories and images presented. In contrast the writerly text is less predictable. It calls on the reader to engage with the text to more deliberately bring to the reading his or her experience as a way of filling the gaps in the text (Wilson V, 1998: 173 quoted in Ellis and Bochner, 2000).

If we can view the act of reading (as well as the act of writing) as performance the reader then makes meaning as she reads, adding

something of herself to the original text (Barone, 1995[334]; Tsang, 2000; Ellis, 1997), which has inside it hooks for the reader to become caught upon, or gaps (Wilson, 1998) or blanks (Sparkes, 2002) for the active reader to fill in themselves. Carolyn Ellis explains this as she writes about an example of her own writing form:

> My open text consciously permitted readers to move back and forth between being in my story and being in theirs, where they could fill in or compare their experiences and provide their own sensitivities about what was going on. I attempted to write in a way that allows readers to feel the specificity of my situation, yet sense the unity of human experience as well, in which they can connect to what happened to me, remember what happened to them, or anticipate what might happen in the future. I wanted readers to feel that in describing my experience I had penetrated their heads and hearts. I hoped they would grapple with the ways they were different from and similar to me. (Ellis, 1997: 131).

This interactivity, created by the form of the text and the way it's read (the performance) creates relationship and connection, with the potential for what Sparkes (1994, 1997, 2002) calls

> emancipatory moments in which powerful insights into the lived experiences of others are generated. This kind of writing can inform and disturb readers by illustrating their involvement in social processes about which they may not have been consciously aware (Sparkes, 2002: 221).

The same interactivity creates the potential for the individual and collective restorying that result.

Writing about this interactive performance McLeod (1997) notes that a story exists in the space between listener and the teller, and that each story is created in relation to an audience. 'So it is as if to some extent the recipient(s) of the story draw it out of the teller ... even a story written alone ... has an implied audience' (McLeod, 1997:38).

So there is an injunction on the reader to engage mindfully with these texts, they require an active reader. Frank (1995: 23) helpfully distinguishes between thinking and feeling *with* the story, rather than being told *about* it:

> To think *about* a story is to reduce it to content and then analyze that content. Thinking *with* stories takes the story as already complete; there is no going beyond it. To think with the story is to experience it affecting one's own life and to find in that affect a certain truth of one's life! (Frank, 1997:23)

[334] Barone T (1990). Using the narrative text as an occasion for conspiracy. In *Qualitative Inquiry in Education*, ed. E Eisner and A Peshkin (pp. 305-26) New York: Teachers College Press.

Brett Smith (1999: 275), writing about his work on the experience of mental ill health, writes of the reader–as–bricoleur whom he invites to breakthrough the traditional scientific ways of knowing, and to 'feel, hear, taste, smell, touch, and morally embrace the world of depressions', now that really does sound like thinking *with* the story!

How, as researcher, I present research material to my reader seems critical to fostering reading with.

> The way we represent the world to our colleagues and related audiences contributes to our ongoing relationships within these life worlds (Shotter, 1997). Our words constitute forms of action that invite others into certain forms of relationship, as opposed to others. (Gergen, 2002:13).

There is the potential that in our writing about our inquiries we may come to distance the reader from the writer and from the researched-with[335] as more traditional formal academic and managerial reporting does. We need to be mindful and to ask ourselves: Do we create and write from an all-knowing-writer stance that gets in-between the reader and the researched? Do we believe, or act as if we believe that the reader has nothing to contribute at this point, or can the new forms of writing also open up new forms of relationship, which can extend the new relationship between researched and researcher *and* include a relationship with the reader of the text too? In this way the text becomes performance (Gergen) because it can engage the reader, it can stimulate curiosity and a sense of involvement, it can evoke the interactive reading with described by Frank and Sparkes. I have come to think about it as akin to the experience of theatre.

In my experience theatre (when it works well) is not a passive experience. The content of the play and more importantly the performance, engage the audience – dissolving away the surroundings of the performance space; the proscenium arch, the 2D scenery, the costumes, props and makeup, and instead enabling performer and audience to be in-relationship, to connect– the feeling is so close and so connected. The performer creates the fantasy world that the audience actively enters into; they believe the story, they know the character intimately, they feel the character's pain and joy and go away from the performance questioning things about their own lives.

Ken and Mary Gergen describe autoethnography's potential to enable the reader to feel that they can have an intimate understanding of the writer without the usual power differentials in the reader/writer relationship.

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[335] Those who, in more traditional forms of research would be described as researched-upon.

> We feel that we are in-dwelling – roaming about the author's mental interior and sharing the contents with her. The hierarchy implicit in traditional writing is removed … Like traditional writers, she offers illumination, but not to an audience of the ignorant; rather she invites others to hear her story through their own frames. (Gergen and Gergen, 2002:15).

There is no all-knowing writer in the relationship they describe, instead there is an invitation to come in close and listen, feel and take part in a dialogue, an injunction to understand that relationships are 'the fundamental matrix from which human meaning is born' (Gergen and Gergen, 2002: 27). As social constructionists the Gergens, drawing on Bahktin, understand that any performance is emotionally embedded, and that emotions are 'cultural performances that only make sense within the constructed world of a given culture at a particular point in history, and in an interdependent relationship with the actions of others' (Gergen and Gergen, 2002: 29).

Researcher/researched

Action research needs to be transparent and this applies to both the process and forms we use to present the knowledge created. The ethics of action research, and of qualitative writing forms such as autoethnography, require us to re-examine the relationship between researcher and the 'researched-with'. As a researcher we enter the lives of those 'under-study' and this initiates a relationship, and this relationship will itself be affected by the way we as researchers revealed the material that comes from the research – both what effect it has (did anything happen as a result) and the nature of the revealing/ sharing (how was it done? What were the feelings revealed? Whose feelings were revealed?).

It's important to get participant's voices heard and through autoethnography and similar ways of writing we can also reveal the voice and feelings of the researcher, and so level the ground by making and exposing the relationship. In this way we are challenging the traditional neutral dispassionate researcher role and looking for roles more congruent with our action research aims of participation, collaboration and equity; more relational and humane ways of operating as researcher. This can give birth to a new range of collaborative, polyvocal, and self reflexive methodologies (Denzin and Lincoln, 2000).

Making a difference

For me the point of writing in this way (and inquiring in this way) is to produce 'useful' work, by which I mean writing which will change something, will move someone to action rather than just sit on the shelf.

Ellis and Bochner writing of autoethnographic texts say that these narratives:

> (L)ong to be used rather than analysed; to be told rather than theorized and settled; to offer lessons for further conversation rather than undebateable conclusions; and to substitute the companionship of intimate detail for the loneliness of abstract facts (2000:744).

I have enjoyed the radical nature of many of the autoethnographic texts I have read, and in my own writing value the autoethnographic form as one through which I can work for change – including in my own (first person) practice, in my readers (second person) and, where relevant, wider cultural and social change (third person). I find myself disagreeing with the observation William Tierney made about autoethnographic texts when he wrote that autoethnographies are 'more concerned with literary structures than with changing oppressive structures' and that 'in autoethnography there is not the same 'moral and social imperative for the protagonist to tell his or her story' (2000:540-541). He was comparing them with testimento, writing in which the testifier's life story is directly linked to social movements for change, testimento constitute 'resistance literature' (Harlow, 1987). This may be a reasonable criticism of the 'literary autoethnography' but not of the wider genre of autoethnographies, which include forms such as reflexive ethnographies which emphasise how the personal illuminates the wider culture.

I have written elsewhere in this thesis about my role as an activist, I hope that these texts which tell everyday stories will contain that dynamic; a call to feel, talk and act, particularly to act. A call to go down into the streets, as Pablo Neruda puts it when he writes of his impatience with books about books[336].

> I don't come out
> of collected works,
> my poems
> have not eaten poems –
> they devour
> exciting happenings,
> feed on rough weather,
> and dig their food
> out of earth and men.
> I'm on my way
> with dust in my shoes
> free of mythology;
> send books back to their shelves,
> I'm going down into the streets.
>
> From *Ode to the book*
> Pablo Neruda. [1954]1970.

[336] I note with pleasure that he wrote this poem the year I was born.

How much to say?

Autoethnographic writing poses a number of risks to the writer(s) including the sense of vulnerability that comes from revealing oneself rather than hiding behind the data. Hertz appears to agree with Ellis and Bochner when she writes of the risk of revealing oneself through autoethnographic writing only to be accused of self indulgence:

> Revealing one's self is not easy. For example, how much of ourselves do we want to commit to print? How do we set the boundary between providing the audience with sufficient information about the self without being accused of self-indulgence (Hertz, 1997: xvi).

Sparkes, reacting to the (implied) criticism of one of his student's texts as self indulgent, asks how we keep autoethnographic writing self-knowing, self-respectful, self-sacrificing, and self-luminous rather than allowing the writing to become self-indulgent (Sparkes, 2002), and writes of the new ways in which we need to examine the qualities of this new way of writing (Sparkes, 1998[337]) in order to be able to distinguish between the self knowing in-service of self and others, and the simply self indulgent text.

Sparkes offers the following criteria for judging autoethnographies (Sparkes, 2002: 211), which are notably similar to those offered by Richardson (2000):

- What substantive contribution to our understanding of social life does it make?
- What are its aesthetic merit, impact, and ability to express complex realities?
- Does it display reflexivity, authenticity, fidelity, and believability?
- Is it engaging and evocative?
- Does it promote dialogue and show potential for social action?
- Does the account work for the reader and is it useful?

While fully accepting Sparkes's argument that the qualities of autoethnographic texts need to be understood in new and different ways, I think that Shulamit Reinharz raises an even more fundamental point when she suggest that some of the criticism of such texts is 'grounded in a deep mistrust of the worth of the self' (1998: 212). It feels unsurprising that it is a feminist researcher who is pointing this out to us, as Jane Tompkins did when she identified the gendered phenomenon of 'the trashing of emotion'.

[337] Sparkes, 1998. Validity in qualitative inquiry and the problem of criteria: implications for sport psychology. *The Sport Psychologist*.

Making a related point to Reinharz and Tompkins, Mykhalovskiy argues that the claim of narcissism rests upon an individual/social dualism that obscures and confuses

> how writing the self involves, at the same time, writing about the 'other' and how the work of the 'other' is also about the self of the writer (Mykhalovskiy 1996:113, in Sparkes, 2002: 216)

and that this dualism is reductionist in that it denies the connection between self and society, and ignores the relational aspects identified by Bakhtin and Gergen.

If autoethnographic texts are not to be dismissed as being simply self indulgent memoiring they need to demonstrate an understanding of the connection between the individual and their cultural and historical context, and they need to reclaim the worth of critical self examination in the same way that feminist research has claimed a place for everyday knowing and the personal as political.

The argument for vulnerability

The vulnerable text harnesses a particular power to engage its readers through the process of telling more of the whole story, of which a consequence is evoking feelings, including those of vulnerability, in the reader. As Tierney explains so clearly and simply:

> The power the author has is the ability to develop a reflexive text. Such a text enables readers to understand the author a bit better, to come to grips with the individual whose life is retold, and to reflect back on their own lives. A reflexive work ... leaves a writer and speaker and reader vulnerable. Vulnerability is not a position of weakness, but one from which to attempt change and social fellowship. (Tierney, 2000: 551).

This thesis has as its focus telling my practice as a facilitator of emancipation, including telling my own life story.

Bearing witness

> Whoever survives a test, whatever it may be, must tell the story.
> (Elie Weisel quoted in Matthew Fox, Confessions).

Autoethnographic texts have the power as authentic stories to evoke strong and powerful reactions in their readers. Here I choose to focus witnessing the experience of illness because of my own lived experience of MS.

Frank, who writes of autoethnographies in the context of illness, raises the issue of the potential for autoethnographic texts to be an act of *witness*, for both author and reader and to be understood (or heard) in more than simply intellectual ways. Frank notes that in the life experience of illness being a witness means taking on:

> a responsibility for telling what happened. The witness offers testimony to truth that is generally unrecognised or suppressed. People who tell

> stories of illness are witnesses, turning illness into moral responsibility … Illness stories are not only about the body but *of* and through the body'. (1995: 137-140).

Frank believes that this testimony implicates others (the reader) in what they witness and that witnessing implies a relationship. 'Part of what turns stories into testimony is the call made upon another person to receive that testimony' (1995: 143), again making the point that the performance of stories is relationally embedded (Bakhtin's theory of dialogue 1984, 1986; Gergen, 2002).

Sparkes, along with Ropers-Huilman (1999) notes that witnessing has a number of obligations; including our engagement in meaning making and recognising that witnessing changes others, and Sparkes forms a set of desirable qualities for such witnessing, writing that the role needs to be undertaken with:

> (G)reat intentionality and sincerity; we have to be open to change; we have to tell others about our experiences and perspectives; we have to listen to the interpretations of other witnesses; and finally, we have to explore multiple meanings of equity and care and act to promote our understandings of these concepts (Sparkes, 2002: 222).

Audre Lorde says of her own experience of breast cancer:

> I had known the pain and survived it. It only remained for me to give it voice, to share it for use, that the pain not be wasted'. (Audre Lorde, 1980: 16).

Stories call out to be heard through that pain, defy the censorship of the pain by self and others, and the ears that try to close so as not to hear and share the pain. These can be very scary stories that need sensitive telling in careful conditions (e.g. facilitated Making Sense meetings) if they are to be heard and the reader is to be engaged and persuaded to pause and to take into themselves the things that are being communicated.

Frank, who has specialised in researching stories of life threatening and chronic illness since his own experience of cancer, offers a perspective on how we can understand the value of these 'illness narratives' for both society and the individuals directly involved. He suggests that the experience of such illness is one of *disenchantment;* the sick person's self image is damaged or violated, they lose the potential of themselves as a 'well' person (with all that that means to them). And he describes a process of potential *remoralization* (from morale) through writing.

For those who become ill, whether acutely or with a serious chronic illness, there are daily reminders of what we will now never do. Frank is right when he identifies that it is our *morale* that needs nurturing (Frank, 1995, 2002; Goffman 1961). I recognise his description of this phenomena of disenchantment from my personal experience, and wrote about it

shortly after diagnosis expressing anger, pain, grief and bitterness, but also the additional (internalised) pressure on me to constantly reassure myself and others that I was 'ok', that things are not as bad as we know they are (see Appendix F.)this piece[338] also speaks of me rejecting the victim role and starting to re-find my power. However I note it was very necessary for me to have the space in which to fully experience the loss, without any need to appear heroic, before I could move through the feelings to reclaim my sense of personal power and understand what that means in my new situation.

> Shortly after my diagnosis of MS I remember being left speechless by a colleague's observation that maybe there was something to be valued, an advantage over others, in knowing more clearly what the future held for me, whereas the 'well' could only speculate on their future.
> The point is however that *they don't*, or rarely do so, and that we are socialised into believing ourselves immortal and immune from serious harm. For most of us it's only in times of despair, depression or acute anxiety that we can imagine real damage to our selves. In this way we can continue to think of people who are sick or disabled as the 'other' (January 2005).

Autoethnography can become a way to *remoralize* or restory our lives (White and Epsom), not as 100% healthy people but with all the potential we care to explore through our stories. Frank writes that:

> Stories are told by a self that has been disrupted out of its place in society's moral order and seeks a new place, but the story also compels recognition that the moral order itself requires re-evaluation. The story joins these two levels of remoralization; the personal and the political (Frank, 2002: 368).

reminding us that this first person inquiry (tool) opens up the potential for second and third person action research as the political is addressed through narratives that can challenge the way our society situates those who become sick or disabled, as it does to others who are stigmatised.

[338] As does Appendix A Crow – see discussion with Peter Reason.