

Open Research Online

The Open University's repository of research publications and other research outputs

Cancer, life review and the boundary between the 'personal' and academic research

Journal Item

How to cite:

Watts, Jacqueline H. (2009). Cancer, life review and the boundary between the 'personal' and academic research. *Electronic Nottingham Quarterly for Ideas, Research and Evaluation - ENQUIRE*, 4 pp. 1–22.

For guidance on citations see [FAQs](#).

© 2009 ENQUIRE

Version: Accepted Manuscript

Link(s) to article on publisher's website:

<http://enquirenottingham.co.uk/images/documents/4th-watts.pdf>

Copyright and Moral Rights for the articles on this site are retained by the individual authors and/or other copyright owners. For more information on Open Research Online's [data policy](#) on reuse of materials please consult the policies page.

oro.open.ac.uk

Cancer, life review and the boundary between the ‘personal’ and academic research

Dr Jacqueline H Watts
The Open University, UK
J.H.Watts@open.ac.uk

ABSTRACT

Much social research and commentary derives from the personal position and interest of the writer with, in recent years, a marked increase in the use of case histories, vignettes and auto ethnography, as legitimate methodological research tools. This article, drawing on that tradition, is a reflective commentary on the author’s experience of supporting a friend through a critical life-threatening illness, highlighting the dual aspects of personal engagement and academic reflection. The ways in which the ‘personal’ can be opportunity for methodological and empirical reflection, but also serve as ethical constraint, are considered. An underpinning concern is the requirement for ethical probity, both in maintaining confidentiality within the account and in considering the issue of consent, in reporting the personal details of the author and those of the friend whose critical health episode is central to the discussion. Attention is also drawn to the importance of life review on the part of those who face life-limiting illness. Discussion focuses on the experience of life review from the perspective of both the author and friend, suggesting that this may be a more meaningful support in the form of intimate exchange rather than as clinical therapeutic intervention. The article argues that the personal, rather than disrupting critical social research, particularly in the field of health and well-being, can contribute positively to shaping new understandings and insights.

Key Words: *cancer; confidentiality; consent; life review; research; the personal*

Introduction

The article adopts a case study approach to explore different aspects of life review from the dual perspective of the personal and the academic researcher. In particular it questions the value of life review as an intimate personal exchange and as professional therapeutic encounter, drawing attention to the established primacy of the latter approach within institutional health and social care contexts. As part of this exploration, consideration is given to the ways in which the boundary between the ‘personal’ and the ‘academic’ role of the author has given rise to a number of ethical dilemmas both in relation to the shared experience of the events presented in the case study and to their reporting herein. The importance of both understanding and negotiating a cross-boundary presence when, as an academic, there is potential for the ‘personal’ to be located within a quasi-research context, is the focus of the main discussion theme.

The article begins with consideration of the way in which life review is conceptualised in the literature, particularly in relation to people with life-threatening

illness such as cancer. The second section discusses a number of ethical concerns that have informed both the lived experience of events discussed in the case study narrative and the subsequent reporting of these in this article. In particular the concepts of consent and confidentiality are considered to frame discussion of the cross-boundary elements of the personal/academic divide that is the central contribution of this commentary. This is followed by narrative that outlines details of the case study that is the basis of this article. It introduces the story of Stephen to give the reader a sense of his life and the circumstances leading up to the diagnosis of his cancer and the time beyond, when he spontaneously began to undertake his life review. The third section considers issues related to the conduct of the life review process contrasting a structured professional approach with a more informal and intimate process. The next section is a reflection of my role within Stephen's life, particularly its later stages, and considers a range of practical and ethical issues related to being an intimate participant in the life review process as well as an interested academic 'user' of the resulting material. This raises the issue of the crossing of role boundaries.

The article closes with discussion that draws together the key themes to suggest that the boundary between the 'personal' and academic research and scholarship can be uncomfortably permeable and should be rigorously kept in view by all those engaged in sensitive research. I argue that the support of a research mentor with whom issues of concern can be shared may be one way of mediating some of the difficulties that can arise in sensitive research contexts.

Life review in the face of life-threatening illness

Being faced with a life-limiting illness can be a time when people look back over their lives to consider what it has all added up to. Life review is an important part of bringing one's life to a close with a focus on issues such as who am I and what have I contributed? Sheldon (2008: 64) argues that 'reviewing the past to put the present in context can be very affirming to the dying person'. Butler (1963) highlights the feature of evaluation, characterising life review as a spontaneous process by which a person evaluates his or her life as it nears its end. He argues that this usually occurs in older age especially when one is confronted by death or a major health crisis. It can take different forms but most commonly is a form of oral personal history that Butler (1963) claims engenders serenity and a philosophical acceptance of what has gone before, giving greater capacity to live fully in the present. Because human beings are fundamentally storytelling creatures (Schim and Raspa, 2007: 202), the recounting of personal events and memories is often readily undertaken. Despite this, life review is selective and not all past experiences are remembered or shared and for most people it is a combination of some hard truths as well as joyful memories. The most tragic life review is one whereby a person decides that their life has been a waste, with this reflection experienced as a form of suffering.

The opportunity to openly discuss and reflect on one's life that may include thinking and talking about sensitive issues and regrets as well as joys, may be a positive and affirming experience resulting in a decrease in emotional pain and a greater satisfaction with the time that remains (Lester, 2005). Life review, both as structured therapeutic engagement and as informal social encounter, is comprised of a variety of features and processes that can be broadly characterised as open communication

(Garland and Garland, 2001). The form that life review, as open communication, takes will be determined by the participants, and this will be considered below. First, however, some discussion about the different interpretations of the term life review presented in the literature will serve to establish the context both of the case study and of the critical reflection that concludes this article.

A number of writers have contributed to understandings of life review and what, if any, purpose it serves for those who are facing their death. Sandman (2005) argues that reviewing our life involves looking back over its components specifically to try and give it certain features like value, meaning, direction and coherence. He develops the concept of value in this context in terms of value to oneself and value to others. The feature of direction, he argues, is connected to the achievement of goals. His further point is that a life can have value without a goal in as much as there may be no overarching goal or aspiration that has given that life direction but, nevertheless, that life has been meaningful both to oneself and to others. Conversely a life can have a goal such as for example, a personal career achievement, but the striving to attain this may not add value to the lives of others. The question of whether or not the undertaking of a life review can contribute positively to a better death is complex and Sandman's (2005) position is a pragmatic one suggesting that this will in part depend on whether the life review has constructive or disappointing outcomes.

The theoretical foundation of life review as a therapeutic tool was conceptualised by Butler (1963) who describes the process as a person (usually an older person) reflecting on their life course in order to understand and integrate events and also to reorganise unresolved issues or conflicts. He asserts that life reviews are usually complex, often contradictory and nostalgic frequently filled with irony, comedy and sadness. His work has been developed by others and used in relation to those who have terminal illness. Wholihan (1992), for example, found that life review reaffirms a sense of identity and increases self-esteem amongst people who are facing death. Ando et al (2007a), reporting on research that explored the outcomes of structured life review with twelve patients in a Japanese palliative care unit, found that these were effective in improving the spiritual well-being of people terminally ill with cancer, with this connected to a balanced evaluation of life.

Dissemination of research into the effectiveness and impact of structured life review with people coming to the end of their life has initiated debate amongst clinicians about how training in this area can be given to health care professionals. This debate is predicated on the assumption that this type of formal practice intervention is desired by patients and brings them benefits. The potential for life review to be experienced by patients as disturbing and intrusive is little discussed in the literature. Ando et al (2007b), writing about the primary concerns of patients with advanced cancer, stress that the potential for benefit is contingent upon clinicians being mindful of the patient as an individual so that life review therapy is tailored to the individual with them cautioning against the use of uniform or standardised approaches. Trueman and Parker (2006) highlight a range of positive outcomes for patients and argue that life review should be more widely integrated into existing palliative care services that operate in hospices, hospitals and in the community. Many hospice settings already use formal techniques for life review, sometimes with participation by loved ones who also benefit from the communication process and by the creation of an historical record. The importance of an historical record is encapsulated in the concept of

biography that Levinson (1980) describes as the 'story of self in the world'. This, he argues, is shaped by both the 'developing self' that looks forward and the 'reflective self' that is most commonly a feature of later life particularly as preparation for death.

An individual biography may have innumerable components and life review often involves exploration of a variety of topics. Lester (2005) identifies the most common themes within structured life review as: the family, one's career or work, health and body image, the role of money, love and hate, sexual identity, experience of loss that includes divorce and death, goals and achievements, values and belief systems that may include religious adherence. Several of these themes featured prominently in Stephen's reflections. A brief account of Stephen's experience of illness is recounted below; it traces his 'unwellness' that developed into what turned out to be the most significant biographical disruption of his life (Bury, 1982). However, before reporting these case study details, it is appropriate to first consider ethical concerns in relation to consent and confidentiality.

Ethical issues of consent and confidentiality

Banks and Gallagher (2009), writing about ethics in professional life, argue that in the practice setting it is the particularities of the situation that will guide decision-making about ethical conduct. Often, they suggest, it will be the potential for harm to a service user or client that influences the actions of practitioners and they cite as an example the mistaken assumption by some that there is always an absolute right to protect patient confidentiality. For instance, where a client or patient discloses that they have harmed or abused a 'vulnerable other', the sharing of information with other professionals without the consent of the client may be necessary. Banks and Gallagher (2006) make the further point that ethics in professional practice domains are often complex requiring responses that are not simply formulaic or rule-bound, but related to individual circumstance. Whilst it is not the aim of this article to develop a critique of ethical conduct within professional health care delivery, there is merit in highlighting, through this example, the reality of an ethical continuum, rather than the application of absolute ethical precepts. This ethical continuum has relevance for social research practice and elsewhere (see Watts, 2008a) I have written about the practical ethical issues that can face researchers in the field.

Although this article does not report research, it does critically explore personal experience that, in the process of reporting, becomes a type of data. All reported social data pertaining to human subjects carries obligations on the part of the person reporting on the data to be ethically aware of the issues of consent and confidentiality. Some brief discussion of what this may mean in practice will be valuable in helping to demonstrate that this is a complex area. Focus on the concepts of harm and vulnerability in influencing approaches to dealing with sensitive topics will elucidate that at the core of ethical probity is the role of integrity on the part of the researcher or commentator.

In the literature on research ethics consent is discussed in relation to informed consent whereby participants agree to take part in research about which they are fully informed, understanding its aims, potential benefits and the opportunity they have to withdraw at any stage (Sheldon and Sargeant, 2007). Much has been written about the nuances of this concept and space does not allow for a detailed critique of the

interplay of different factors that may, in reality, inform or compromise the full application of this precept. Where someone cannot give consent to the use of personal history as case study material, either because they do not have capacity or because they have died, does it necessarily and always follow, that this information cannot or should not be used in the public domain?

Consideration of the concepts of harm and vulnerability are helpful in guiding thinking in this area. Where the reporting of personal information brings distress to parties involved, even where informed consent has been granted, this action cannot be seen as ethically sustainable. Harm, however, is a highly subjective term but, in this context in relation to harm to participants, this can be understood to include aspects such as physical harm; psychological distress; threats to safety; loss of self-esteem (Bryman, 2004). The term vulnerability within social research usually refers to individuals who have reduced autonomy due to physical/psychological factors or status inequalities (Liamputtong, 2007). Although much of the emphasis in the literature in this area is on vulnerable research populations and the harm they may experience as a consequence of taking part in research, it should not be forgotten that researchers, as participants, can also be vulnerable, particularly those working on sensitive or difficult topics who may find the research experience disturbing and emotionally challenging (Watts, 2008a). Liamputtong (2007) points to how in some instances researchers have 'pent up' emotions that they have to suppress and hide from research participants. In such cases the provision of a mentor to offer ongoing support is one strategy that can be considered to counterbalance the potentially negative impacts of the research experience.

The issues of consent, harm and vulnerability within research more widely connected to the work of scholars and academics are further addressed in ethical codes by advocating care over the rigorous maintenance of confidentiality. This injunction means that care should be taken when data is published to ensure that individuals are not identified or identifiable (Bryman, 2004). In quantitative research it is relatively easy to anonymise records and data but within some types of qualitative research (in some ethnographic work, for example) this is more difficult. In some types of covert observation research, ensuring confidentiality of both the setting and participants' identities is essential and is especially so because informed consent is not viable; participants are involved whether they like it or not (Bryman, 2004). And so it is with the reported data that follows below. Because of his premature death, Stephen was not given the opportunity to refuse to co-operate; the imperative, therefore, to strictly apply principles to ensure confidentiality and thus protect his identity has directly informed the account of his illness and my role in, what turned out to be, the last phase of his life. It is this scrupulous attention to the protection of Stephen's identity that underpins the claim to integrity in reporting his story below.

Stephen's story

In early September 2008 my friend of many years, Stephen, started to notice that he had begun to have what he called a 'dry throat' and that on occasions he was having difficulty swallowing. Tests eventually confirmed a diagnosis of throat cancer with him immediately thereafter referred as an in-patient to a leading teaching hospital where he would undergo more extensive tests to determine the extent and type of carcinoma and the best way of treating it. During these weeks I visited almost daily.

Stephen had no partner and a small and dispersed family and I arranged to be at the hospital so that we could see the consultant together to learn about the way forward. Stephen was very anxious because, although he had accepted the first cancer diagnosis, he was optimistic that the tumour would be found to be localised and removable but was also aware that his condition might be more serious than at first thought. The meeting with the consultant was difficult; he told us that Stephen's cancer was advanced and widespread and would require radical surgery that would involve the removal of his voice box. In addition he was found to have prostate cancer and there was a shadow on his liver. This news was devastating and the consultant sensitively gave Stephen and I time to be alone together to try and absorb this information. Because of my role as a health and social care academic with a specialist interest in palliative care and death and dying, Stephen sought my advice and clarification about what we had been told. Already the boundary between the personal and the academic had been crossed.

In the weeks that followed prior to his surgery he mainly used our time together for what can best be described as a joint reflection on his life. This was not in any sense systematic or comprehensive but was rather fragmented recalling single incidents as snap shots of particular people and places in his life. Sometimes he was emotional and at others we laughed and laughed; humour had always been central to Stephen's spirit and world-view. The principal characters in his life review were his family (most of whom had died), his friends from the local model club and those he had worked with before his retirement seven years previously. I noticed that talk of the future, any future – his or that of others was now absent from his discourse.

The period immediately following Stephen's surgery was a poignant time; he had no power of speech and communicated by writing his words. He had been a heavy smoker for almost fifty years and on my first visit to the hospital the day after his surgery he wrote 'it's the smoking that's done this'. His life review had taken on another dimension as he sought to understand some of the 'whys' of his predicament. Heaven and Maguire (2008) make the relevant point that those whose lifestyles may have contributed to their illness may feel stigmatised with this acting as an obstacle to open communication of any kind with health professionals. With his loss of speech the opportunity for prolonged interaction was curtailed and our 'conversation' was necessarily focused on instrumental matters – hospital food, his medication, further treatment and, most importantly, when he would be able to go home. He was discharged just under three weeks after his surgery and was doing well, very well. Two weeks later, following a very positive outpatient's appointment at the hospital at which his radiotherapy was planned, he died of a heart attack later that day. He was sixty-seven.

Life review as a professional therapeutic tool or as an intimate exchange

The relationship with Stephen had always been close and warm and as soon as he told me about his developing health problems I was concerned. My interest in his health, however, extended beyond the personal and from an early stage in his illness I started jotting down my reflections on what he told me, how he and I felt, details of his medical appointments that included how long he had had to wait and how he was treated, issues relating to family matters and interactions with a range of clinicians in different settings. I soon came to realise that this, for me, was not just Stephen's

cancer story, but also a cancer story that could be charted and interrogated for academic purposes and one that could potentially be shared in some or other form. Also because of my practical and emotional involvement it gradually became 'our' cancer story.

It was during his periods of hospitalisation that the talk of life review began in earnest and I found myself making copious notes about our conversations on the train home and also in the periods when he was visited by clinicians and I moved from his bedside to the day room. I wanted to capture both the detail and essence of what he told me about the various aspects of his life that in some measure was 'our' life. His life review, therefore, became a shared reflection and one that was deeply meaningful for us both.

The literature contains details of approaches to structured life review (see, for example, Ando et al, 2007a and Lester, 2005 above); the concept of structure and form in this context frames a professionalised, mainly clinical, approach to this work that is understood as therapeutic engagement. In the case of Stephen there was no structure, no thread and very little coherence in his review because we just seemed to gently meander through different eras and topics together. Because of my knowledge and involvement with much of his life, the review was a familiar tale and stopping and starting again was very easy. Often he would say 'Do you remember the time when' and of course I would. Or another of his frequent prompts for joint reflection was 'Do you ever think about' and off we would go. Humour characterised much of his reminiscence and so he would frequently say 'Wasn't it funny when'. Returning to Lester's (2005) thematic paradigm, the focus of Stephen's reflection was centred on family, holidays, his hobby of model making and the role of money, particularly how more of it would have made his life easier. He articulated his life satisfaction in terms of supporting family and friends with him steeped in the values of hard work, neighbourliness and independence.

Our talk was very much an intimate exchange built on a lifetime of love and trust; it was not judgmental or conclusive and neither did it have what I will term 'explanatory value', mainly I think because Stephen did not feel that there was anything significant to explain or resolve. His life had been as it was. He accepted it, enjoyed it; he was content with his lot and he did not appear to feel the need to justify or make active sense of its components. His was not a life of great career achievement, high social status, scholarly education or great wealth. Given that he was essentially a very private person, I wonder how he would have felt talking about his life to a 'professional', particularly as throughout his life he had tended to see professional mastery of any kind as something beyond his experience other than that of his being an occasional 'consumer' of professional services. I tend to think he may have felt exposed and vulnerable thinking about what he *should* say and also hesitant about the possible value placed on his life by others with the abstract dichotomous notions of success or failure to the fore.

The issue of continuity as one impact or 'product' of life review is discussed in the literature (see Lester, 2005) but a key question is continuity of what and for whom? Cobb (2008), writing about the assault on personhood that can result from debilitating and life-threatening illness, frames continuity from the perspective of the dying person as the understanding that they will be remembered and valued by those who

live on after them. Continuity in this context can be conceptualised as the connection with aspects of the dying self that will endure almost as a form of legacy. One consequence of legacy is that, although death may be seen as a material boundary marking the cessation of life, this does not necessarily mean that the dead person has no place in the reflective consciousness of those they have been close to. In terms of professionally initiated structured life review that may take the form of a questionnaire, unless there is opportunity for family and friends to participate in the process (as is sometimes the case within hospice settings) or unless there is a record made of the review, the value of this formal intervention in terms of continuity will be limited.

Stephen's reminiscence represented to me the gift of continuity. Everyone has a story to tell and everyone is unique but not everyone will feel comfortable or able to share their story with professional strangers, however kind and sensitive they may be. Lester (2005), commenting on professional but unstructured life review interventions, warns that these are likely to be non-evaluative and seen as diversionary and in turn may be disempowering. This is in direct contrast to the intimate life review outlined in this case study. It was precisely the flowing unstructured and non-evaluative aspects of the exchange that were so affirming and comforting to Stephen.

Talk without the rigour brought by structure or professional direction has enormous potential for relaxed self-expression with no expectations of outcomes that can be assessed or measured. This kind of exchange that takes place within a caring intimate relationship falls outside the clinical paradigm of needs assessments, interventions and the scientific model of the clinician-patient relationship that Randall and Downie (2006) characterise as one whereby the patient is seen as a 'case' with a diagnosis and a set of symptoms. The increasing dominance of clinical approaches to the care and support of people with life-threatening illness marginalizes informal social and community approaches (Kellehear, 2005; Randall and Downie, 2006). Given the increasing scarcity and consequent rationing of health and social care resources in the UK I argue that it is these informal care-giving strategies that should be encouraged and developed.

Ethics, positioning and boundaries in academic work

The discussion above has drawn on literature that explores some of the complexity that surrounds ethical research and academic conduct, particularly in respect of sensitive topics. Despite the measures taken in the above account to protect confidentiality, the reporting of aspects of someone else's life history, without their consent, is an ethical issue. In this particular case, my position as both trusted intimate and academic specialising in the broad field of death and dying presented and continues to present me with some complicated ethical issues that remain difficult to resolve. Central to these is the integrity of my role in Stephen's life at such a pivotal time together with the need to understand and reconcile the dual perspectives I brought to the circumstance of his illness.

The writing of a journal about Stephen's experience referred to above served several purposes; the noting of 'facts' about his illness as well as my responses to his situation were the dominant themes. Also, though, I documented observations of different behaviours at the hospital, his reactions to his illness and his understandings

of cancer that he always referred to as ‘the big C’. These entries had both personal and academic significance and over this period I found myself going to the literature to critique Stephen’s experience in light of published accounts. His experience was fast becoming an object of academic interest with me starting to analyse behaviours and events drawing out possible interpretations. My friend and his critical health episode had gradually become my data and, in a characteristically academic way, part of my response to Stephen’s illness was to turn it into a reflective piece of scholarship. Although Stephen was aware that I was writing a journal about our conversations and reflections and he was entirely happy with that, I did not tell him about the less personal and more ‘academic’ part. At the time it had not occurred to me that I would write up his illness experience as a discrete case study, thinking that the notes and critical reflections in my journal would at some point make a useful contribution integrated within other scholarly writing.

Given Stephen’s sudden death I have not been able to seek his consent to the writing of this article and, although the case history has been thoroughly anonymised with personal and clinical details changed, I find myself ethically compromised. This compromise is framed by concerns about what his wishes may or may not have been in relation to the writing and publication of his story, albeit stripped of its identifying characteristics. In addition, I continue to reflect about the extent to which I may have objectified my friend’s experience thus reducing it to a data set for interrogation and deconstruction for reflective academic purposes. This leads to the question of whether or not the position of ‘the personal’, as valued individual experience alongside its critical interrogation, can, in ethical terms, ever be fully reconciled.

My decision to recount Stephen’s illness story has eventually turned on the issue of academic integrity centred on my perception of his illness experience, a shared experience, as a ‘gift’ to be treasured and cared for in its reproduction as knowledge (Iphofen, 2005). It is unique and ‘precious’ and, in both conveying it authentically and ensuring anonymity, I believe that I have cared for it well. Furthermore, the potential for the reporting and interpretation of this story to contribute to the understanding of the experience of life-threatening illness sits comfortably with the concept of altruism that was a guiding principle of Stephen’s life. The honest and critical reflection about the dilemmas of reporting this story that was a ‘suffering together’ (MacLeod, 2008: 16), allows me to claim that my ethical integrity remains intact (Watts, 2008b).

My attentive presence in Stephen’s life over those last difficult months also involved other practical cross-boundary elements beyond those of a directly ethical nature. The principal boundary concern was the boundary between the personal relationship and my work as an academic and social researcher. As an example, Stephen sometimes questioned me about different clinical aspects of cancer fully expecting me to have the answers; in explaining that I was not a clinical specialist his response was usually ‘you know more than I do’. He recognised that, by virtue of my job, I might have some ‘expert’ rather than ‘lay’ knowledge to contribute and saw this as a potential asset within the frame of his life that had been transformed by illness and uncertainty. This was particularly the case in respect of the meeting with the consultant at which we were told the gravity of his condition.

The giving and receiving of bad news of this kind is always stressful and anxiety laden (Seamark et al, 2008) and, as reported by other writers (see, for example,

Stacey, 1997) was characterised by talk from the consultant about generalised risks of treatment and statistical probability of outcome. This was recounted in sensitive, but routine and 'typical' terms. Discussion by clinicians of 'generalisability' is a form of distancing and depersonalisation in the cancer narrative that can negatively impact on the adjustment of the patient (Heaven and Maguire, 2008). On this occasion it was clear from Stephen's response that he saw me as his 'route back to the personal' and was reliant upon me for explanation of clinical terms, clarification about possible treatments and information concerning financial help. Although Stephen wanted to make sense of what was happening to him and retain control, he did not want to learn the language of oncology or to understand the principles of chemotherapy or radiotherapy. He thus saw my role, at least in part, as one of language/knowledge broker. He was expecting more than personal support from me and this placed me in a position of responsibility that I saw as a privilege but one that was also emotionally demanding. At these times I was keenly aware of the sensitivities associated with this kind of cross-boundary presence and tried to allow my friend to take the lead in determining which aspect of my presence would be at the fore. Looking back, I feel satisfied that this responsive approach on my part to the cross-boundary issue enabled Stephen to retain his dignity and also maintain control of our 'knowledge' interaction in both private and public spaces. My non-personal input was thus strictly mediated by his leading.

Discussion

What has been outlined herein are not methodological reflections on a carefully crafted empirical research study that has been subject to critical design and ethical protocols, but a commentary on how the personal can become the subject of theoretical and empirical reflection and thus 'migrate' into the research realm. Much academic knowledge is heavily (auto) biographical and increasingly we are seeing the widespread use of personal case histories as tools for exploring particular theoretical constructs as well as instruments for reflecting on practice issues in the field of health and social care. This illustrates the different modes or 'registers' of writing, the personal, the theoretical and the empirical. Provided that confidentiality is protected and the ethical precepts of integrity and participant well-being are upheld, the use of the 'personal' is now seen as a legitimate strategy for the purposes of both teaching and critical enquiry. In terms of research, though, there are some major epistemological issues to be addressed and Stark and Torrance (2005) argue that, even where case studies are the principal data form in the research design, where to draw the boundary about what to include and what should be excluded are critical concerns and making decisions about these issues may be far from straight forward. They assert that this decision will be informed by different disciplinary assumptions and by the context of the enquiry. A further consideration is the extent of consent granted by those whose lives are the subject of critical enquiry.

All qualitative social research, and some would argue all research including quantitative research, will be informed by the standpoint of the researcher and I would argue that it is impossible to completely 'factor out' the influence of the personal from research design and conduct. I would also argue that in much qualitative research aspects of the personal can enhance both the research conduct and output and trying in any sense to eliminate the personal of the researcher is not a legitimate or useful goal. The potential, however, for the personal to be a problematic as well as a positive

feature of social research requires further exploration. First, it is important to be clear what in this context is meant by 'the personal'.

In some kinds of research that may be particularly sensitive, the researcher may have a personal interest in the topic and, indeed, this personal interest may be at the root of the enquiry. Campbell (2002), for example, writing about her experience of both supporting rape victims within a voluntary community setting and someone who researches rape, highlights the ways in which researchers can become emotionally involved with the research topic but contrasts this with the expectation of social scientists that the researcher's role in the scientific process should be one that carries the unemotional passive voice. Liamputtong (2007: 167) identifies autoethnography that she describes as often involving 'personal narratives of the author's life experiences within a cultural setting' as an increasingly common method within social and cultural research. This positions the personal of the researcher at the centre of the research enterprise.

In the case of palliative care research, a highly sensitive research domain, Portenoy and Bruera (2003) have edited a collection of essays that discusses a wide range of research topics in this area; nowhere in this collection is there mention of the 'personal' of the researcher. Instead, she has been displaced by discussion of randomised controlled trials, checklists of ethical protocols and clinical measurements, with this attesting to the increasing medicalisation of palliative care. A welcome contrast to this approach is that offered by Ingleton and Davies (2004) who acknowledge that research in this area is emotionally demanding and 'personal' work in the sense that the researcher may want to give their whole self to the research in trying to fulfil participants' expectations of the outcomes of the research. They also make the point that there can be a propensity for the researcher in this context to become personally over-involved and move beyond both the tasks and process of the research and this may impact on the type and quality of the data collected. Over-involvement can also lead to difficulty in disengaging from the research when it has been completed. The provision of a mentor who can offer supervision can be an effective support in this situation and Gilbert (2001) argues that this is good practice where researchers are at risk of experiencing emotional overload.

Conclusion

The above gives a sense of the different kinds of 'personal' from the standpoint of the researcher that can influence social research and the literature holds many other examples (see Watts, 2008a for a discussion of researcher emotion as one example). What is important in any discussion of social research is how the research design and outcomes reflect the aims, preferences and bias of the researcher. It is only then that we can begin to evaluate the claims made. In respect of case studies as a research tool they must be seen as exemplars and not as a vehicle for definitive judgements about a particular theory or practice. Also, as reported accounts, these narratives are inevitably vignettes offering only a snap shot or partial representation of a situation or life history, with absences and gaps in the story often presented as stripped of competing and multiple meanings. Despite this, as tightly structured accounts, they do afford opportunity for the testing of ideas and theory and can be the site for comparative analysis.

The case study of Stephen has suggested that life review, as a tool for reflection when life is threatened, can be spontaneous, informal and unstructured, particularly as intimate mutual exchange. It also suggests, contrary to some ideas presented in the literature, that its therapeutic effectiveness may not rest only on its evaluative content rather its comfort value may derive simply from the space to be expressive and just 'tell'. The potential for story telling to provide temporal continuity and spatial coherence should not be underestimated. Sandman (2005: 127) echoes this view arguing that there can be intrinsic benefit in telling the story of one's life because of the interest of the listener; this he suggests 'will raise the well-being of almost anyone'. Clearly, however, the importance of to who one is 'telling' cannot be overlooked, returning us again to the 'personal'. Milne and Lloyd (2009), commenting on the researcher-participant dyad within end-of-life research, make the salient point that participants involved in qualitative interviews may not want to respond to questions because they do not like the researcher who is asking the questions. The same may apply with respect to formal structured life review carried out by professionals suggesting that the assumption on their part of rapport contributes to ethical conduct. In particular, having a professional health care role does not confer an automatic right to become the recipient of someone's innermost thoughts and feelings. Also, we should not assume that because clinicians make claims for a particular therapeutic good, that patients will see the benefits on the clinician's terms.

The contribution of this article to understandings of the complexity of social research is centred on its engagement with the personal as the starting point for research and scholarship that embrace both thinking and feeling as mutually constituted aspects of the research paradigm. Such an appreciation allows us to move away from the constraining duality that hierarchically (and, I would argue, artificially) separates thinking and feeling, intellect and emotion. The incorporation of reflective analysis of the gathering and reporting of data can provide theoretical insights as the above critique of life review demonstrates. Furthermore, careful attention to the affective experiences of the researcher and participants, that focuses on them as individuals specifically located, contributes to ethical academic and research practice.

Names and personal details have been changed to protect confidentiality

References

- Ando, M., Tsuda, A. and Morita, T. (2007a) 'Life review interviews on the spiritual well-being of terminally ill cancer patients', *Supportive Care in Cancer*, 15(2): 225-231.
- Ando, M., Morita, T and O'Connor, S. J. (2007b) 'Primary concerns of advanced cancer patients identified through the structured life review process: a qualitative study using a text mining technique', *Palliative & Supportive Care*, 5: 265-271.
- Banks, S. and Gallagher, A. (2009) *Ethics in Professional Life*, Basingstoke: Palgrave Macmillan.
- Bryman, A. (2004) 2nd edition *Social Research Methods*, Oxford: Oxford University Press.
- Bury, M. (1982) 'Chronic illness as biographical disruption', *Sociology of Health and Illness*, (4) 2: 167-182.

- Butler, R. N. (1963) 'Recall and retrospection', *Journal of the American Geriatrics Society*, 11: 523-529.
- Campbell, R. (2002) *Emotionally Involved*, London: Routledge.
- Cobb, M. (2008) 'Spiritual care' in M. Lloyd-Williams (ed.) *Psychosocial Issues in Palliative Care*, 2nd edition, Oxford: Oxford University Press, pp. 191-206.
- Garland, C. and Garland, D. (2001) *Life Review in Health and Social Care*, London: Psychology Press.
- Gilbert, K. R. (2001) 'Collateral damage? Indirect exposure of staff members to the emotions of qualitative research' in K. R. Gilbert (ed.) *The Emotional Nature of Qualitative Research*, Boca Raton: CRC Press, pp. 147-162.
- Heaven, C. and Maguire, P. (2008) 'Communication issues' in M. Lloyd-Williams (ed.) *Psychosocial Issues in Palliative Care*, 2nd edition, Oxford: Oxford University Press, pp. 21-48.
- Ingleton, C. and Davies, S. (2004) 'Research and scholarship in palliative care nursing' in S. Payne, J. Seymour and C. Ingleton (eds.) *Palliative Care Nursing: Principles and Evidence for Practice*, Maidenhead: Open University Press, pp. 676-696.
- Iphofen, R. (2005) 'Ethical issues in qualitative health research' in I. Holloway (ed.) *Qualitative Research in Health Care*, Maidenhead: Open University Press, pp. 17-38.
- Kellehear, A. (2005) *Compassionate Cities: Public Health and End-of-Life Care*, London: Routledge.
- Lester, J. (2005) 'Life review with the terminally ill – narrative therapies' in P. Firth, G. Luff and D. Oliviere (eds.) *Loss, Change and Bereavement in Palliative Care*, Maidenhead: Open University Press, pp. 66-79.
- Levinson, D. J. (1980) 'Towards a conception of the adult life course' in N. J. Smelser and E. H. Erikson (eds.) *Themes of Work and Love in Adulthood*, Boston: Harvard University Press, pp. 265-290.
- Liamputtong, P. (2007) *Researching the Vulnerable*, London: Sage Publications.
- MacLeod, R. (2008) 'Setting the context: what do we mean by psychosocial care in palliative care?' in M. Lloyd-Williams (ed.) *Psychosocial Issues in Palliative Care*, 2nd edition, Oxford: Oxford University Press, pp. 1-20.
- Milne, M. and Lloyd, C. (2009) 'Keeping the personal costs down: minimising distress when researching sensitive issues' in S. Earle, C. Komaromy and C. Bartholomew (eds.) *Death and Dying: A Reader*, London: Sage Publications, pp. 221-229.
- Portenoy, R. K. and Bruera, E. (2003) *Issues in Palliative Care Research*, Oxford: Oxford University Press.
- Randall, F. and Downie, R. S. (2006) *The Philosophy of Palliative Care: Critique and Reconstruction*, Oxford: Oxford University Press.
- Sandman, L. (2005) *A Good Death: On the Value of Death and Dying*, Maidenhead: Open University Press.
- Schim, S. M. and Raspa, R. (2007) 'Crossing disciplinary boundaries in end-of-life education', *Journal of Professional Nursing*, 23(4): 201-207.
- Seamark, D., Seamark, C. and Hynson, J. (2008) 'Life-limiting illness: the illness experience' in G. Mitchell (ed.) *Palliative Care: A Patient-Centred Approach*, Oxford: Radcliffe Publishing, pp. 47-78.
- Sheldon, F. (2008) 'Social impact of advanced metastatic cancer' in M. Lloyd-Williams (ed.) *Psychosocial Issues in Palliative Care*, Oxford: Oxford University Press, pp. 49-68.

- Sheldon, F. and Sargeant, A. (2007) 'Ethical and practice issues in qualitative research' in J. M. Addington-Hall, E. Bruera, I. Higginson and S. Payne (eds.) *Research Methods in Palliative Care*, Oxford: Oxford University Press, pp. 163-180.
- Stacey, J. (1997) *Teratologies: a Cultural Study of Cancer*, London and New York: Routledge.
- Stark, S. and Torrance, H. (2005) 'Case Study' in B. Somekh and C. Lewin (eds.) *Research Methods in the Social Sciences*, London: Sage Publications, pp. 33-40.
- Trueman, I. and Parker, J. (2006) 'Community nurses' perceptions of life review in palliative care', *Journal of Clinical Nursing*, 15(2): 197-207.
- Watts, J. H. (2008a) 'Emotion, empathy and exit: reflections on doing ethnographic qualitative research on sensitive topics', *Medical Sociology Online*, 3 (2): 3-14.
- Watts, J. H. (2008b) 'Integrity in Qualitative Research' in L. M. Given (ed.) *The Sage Encyclopedia of Qualitative Research Methods*, Thousand Oaks, CA: Sage Publications, pp. 440-441.
- Wholihan, D. (1992) 'The value of reminiscence in hospice care', *American Journal of Hospice and Palliative Care*, March/April.

Word count: 7554