

# Telling the Story of Illness and Death

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This paper is based on an analysis of narratives written by parents – mainly mothers – of young adults with cancer, many of whom died. The paper is situated within the context of literature on the role of writing in a ‘confessional culture’ and this is contrasted with the limited opportunities to talk about death in modern western society. An analysis of the narrative material considers the motivation for writing about illness and death and the need for non-professional writers to legitimate such an activity. The form the writing takes and the way in which it is presented are discussed, as is the potential for the writing being therapeutic. Among the conclusions reached are that to some extent a person who has died can live on through the telling of their story, thus enabling ‘retention’ of the dead through a continuing bond. Limited opportunities to talk about grief may be assuaged by writing and the resulting account can act as a lasting memorial while also being written to help others. Nevertheless, despite the evidently therapeutic nature of writing in a culture that can be increasingly defined as ‘autobiographical’, writing may need legitimating – in this case by being a contribution to research – in order for the writer to feel justified in undertaking an activity that can be perceived as the preserve of the professional.

## INTRODUCTION

The narratives that form the basis of this paper are written by the parents of young adults with cancer – most of their sons and daughters died from the illness – thus they are narratives of illness and death. The narratives have been analysed elsewhere in terms of the life-stage issues they address (Grinyer, 2002; 2004a; 2005b; Grinyer and Thomas, 2001; 2004). However, the embedded material on the reasons for writing and the effects that writing had on contributors, coupled with the form of the writing, appeared to be of significance. Thus, an additional layer of analysis has been applied to the narratives to understand better the meaning that writing has under such circumstances.

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After a discussion of literature that addresses the meaning and purpose of writing, and its relationship to grief and loss, the paper presents an overview of the methods used to gather the narrative data. It then continues by addressing the themes raised by the form and embedded content of the narratives in terms of the glimpse given to the writing process, the motivation for writing and the need for legitimacy, even in an increasingly 'confessional culture' where the opportunities to talk about death may be limited.

According to Garro and Mattingly (2000: 1), narrative is a fundamental human way of giving meaning to experience and is suggested by Bruner (1986: 11) both to order experience and construct reality. Ahmed and Stacey (2001: 1) claim that the desire to testify pervades contemporary culture; thus, witness is borne to traumas of many kinds. Similarly, Frank (1995) argues that people are motivated to tell their stories to bear witness and to act for others and that story telling is informed by a sense of responsibility, not only to work out the story tellers' own changing identities but also to act as a guide for others who will follow them.

Telling stories allows narrators to communicate significant events (Rosaldo, 1986) and lets the reader or listener glimpse what it is like to be in the world of the teller. The language is frequently 'image dense' and those that feature highly charged human dramas tend to engage the audience in an imaginative journey into the 'story world' (Garro and Mattingly, 2000). But these authors acknowledge the difficulty of definition, given that stories are 'as common as air' (2000: 9) and ask 'when are we not telling or hearing stories?' Indeed Plummer (2001: 78) claims that the telling of life stories has become such a 'voluminous business' that it could be argued that we live in an auto/biographical society where autobiography is becoming ubiquitous in everyday life in a variety of forms from TV talk shows to CVs.

It is not just 'life stories' that flourish, but also 'death stories'. In what Hawkins (1990) describes as a striking reversal of an absence of writings about death in the early half of the twentieth century, there is now according to her almost an obsession with death. These pathographies describing death appear in a variety of publications from the learned and scholarly to the self-help manual. Personal accounts of the illness journey have been produced by such notable writers as Ruth Picardie (2000) and John Diamond (1999), both facing death themselves. Books written by parents after the death of a child include Grant's (2002) on her son Alexander's illness and death from osteosarcoma and Rose's (1997) on his son David's illness and death from chondrosarcoma. Both are personal testimonies written after the death of their sons. Thus it seems that 'death writing' or 'pathography' (Holloway, 1990; Walter, 1996) is a growing genre.

Walter (1994) has analysed the significant genre of deathbed or bereavement 'pathography' which consists of confessional accounts, often in the

form of such books that chart the experience of terminal illness and loss. This may reinforce the notion of a confessional culture, but as Frank (1995: 7) says cultural legitimacy is needed for the expression of 'this voice'. In addition to published material much writing exists that does not appear in the public domain. For example, many journals written during bereavement or intense grief may not be intended for publication (Holloway, 1990) and this may be in part because the writer is not a professional writer and thus does not believe that they have cultural legitimacy.

So is writing perceived as the preserve of writers – an activity not to be tackled by the amateur and therefore not culturally appropriate? Plummer (2001), as we have seen, suggests that auto/biography is ubiquitous in a variety of forms, so does this mean that the written form has yet to be adopted as widely as other forms of story telling? As Speck (1978: 116) observes, in times of stress people use culturally acquired methods of coping and one question to ask of the narratives is how widely accepted writing is in our culture as a way in which to deal with grief.

#### **WRITING IN A CULTURE WHERE 'DEATH TALK' IS DIFFICULT**

While we tell each other stories daily in what could be claimed as an auto-biographical culture, it is perhaps less usual to write them down, or having written them to share them with others. Despite Hawkins's (1990) claim that we are 'obsessed with death', there may still be a cultural resistance to talking about it. Different ways of grieving may result in family members being unwilling to talk about a lost family member, and fragmented lives lived in separate spaces may result in others being unable to engage with such a discourse, thus leaving the bereaved with no outlet. As Walter (1996: 16) says, 'It is not surprising . . . if neighbours do not know what to say and cross to the other side of the street.' Such a reaction may be exacerbated by the death being that of a young adult, death in any case being a generally taboo subject that others find embarrassing and difficult to engage with (1996: 17). Rosenblatt's (2000) interviews with bereaved parents also convey the difficulties of engaging others in talking about death and the loss, and Klass *et al.* (1996) report that a father whose son had been dead for 10 years said that early in his grief people seemed afraid to talk to him about his son. However, where through determination they succeeded – 'we just had to jam it right down their throats' (Rosenblatt, 2000: 171) – they found their words to others a healing experience for themselves. Nevertheless, not everyone coping with bereavement has the capacity for such a determined approach.

What are the options under such circumstances? Walter suggests that there are two: to close in upon oneself or to find another prepared to listen, such as a counsellor or self-help group. But, there is a third option that

involves writing about the experience. This may act as a way to tell the story in the absence of opportunities to talk.

Frank (1995: 2), whose concept of the 'wounded story teller' is central to understanding how stories of illness are told, claims that 'the *personal* issue of telling stories about illness is to give voice to the body', the assumption being that it is the person who is ill who is telling the story. But what if they cannot tell their own story, if they are dead? Then it is up to another to tell their story and who more appropriate than a parent? Thus, the parents are giving voice not to their own bodies but to their (lost in most cases) sons' and daughters' bodies.

The writing of such stories about death and loss may take the place of telling stories that are too painful for the narrator to speak. Indeed, Davis (1999: 303) says that for weeks after her brother died she 'had no words', yet three weeks after his death she began to write 'obsessively', hoping that the documentation of the facts surrounding her brother's death would bring her closer to him. Each journal entry began with a statement of the time that had elapsed since his death and keeping track of time in this way helped her. The journal was also a place to remember who her brother had been – lest she should forget. The entries in the journal sometimes took the form of letters to her lost brother, a way in which to tell him the things she would have shared with him had he been alive. In sum, Davis says that she wrote to transform her brother's death into something more than the end of his life (1999: 311).

Morrison (2004: 1) documents the significance of the diary he kept after his father's diagnosis of inoperable cancer:

Keeping a diary kept me going. But after the funeral, and the cold hearth of Christmas, I sank into depression. The only solace came from memories of childhood featuring my father in disgusting good health. I began typing them into my Amstrad, as though to resurrect him.

Though this quote comes from a man – a writer – it is unsurprising that it is the mothers and not the fathers who were the predominant contributors to my research. As Riches (2002) says, men tend not only to grieve for shorter periods than women but also to deny the extent of their feelings. Mothers, he argues, are more likely to be far more preoccupied than fathers with the emotional impact after the death of a child and suffer long-term emotional distress. He cites Masters *et al.* who confirm the 'myth' that 'women express, men repress' (2002: 81). Thus, it would be predictable that mothers would be more likely to express themselves by responding to an appeal for narratives than would fathers.

Blank (1998) found her husband did not share or support her desire to talk about their daughter who had died at the age of 39 from breast cancer. In the absence of being able to talk of the loss with her husband, Blank

invited the bereaved parents of other adult children to tell their stories and discovered that her reaction to the loss was not abnormal and wrote a book based on this response. Prince (1996) similarly wrote an account of her brother's death 25 years earlier as a response to the silence imposed by her parents who could not endure the mention of his name.

As we have seen, both Blank (1998) and Prince (1996) found no outlet for sharing their loss within the family through talk. Here it seems that it is not that the words were too painful to speak (Davis, 1999), but that they were too painful to hear. Instead, these authors found their expression through the written form. Walter (1996) argues that the purpose of grief is to construct a durable biography that enables the living to integrate the memory of the dead into their lives in an ongoing way, and suggests that this is primarily achieved by talking. Yet, he acknowledges that talking may not always be an option and that there are features of modern western society that limit such opportunities.

### WRITING AS THERAPY

The definition of 'writing therapy' as used by Wright and Chueng Chung (2001) includes all expressive and reflective writing whether self-generated or suggested by a researcher. Thus all the material discussed in this paper could be included under this definition. The benefits of writing as therapy have been acknowledged by both a 'scientific' and 'humanities' approach. Wright and Chueng Chung claim that in the humanities the therapeutic benefits of writing are explored with an enthusiasm 'verging on the evangelical' (2001: 278), while in the sciences experiments demonstrate benefits both physical and mental.

The participants in this study had, however, not entered into a therapeutic relationship with the researcher. Indeed the need to separate the research process from that of offering therapy is discussed by Bingley (2002) who argues that confusion about the difference between research and therapeutic work can be dangerous and that researchers need to be aware of the limits of their skills. Nevertheless, as Wright and Chueng Chung (2001: 280) argue, it is the therapeutic potential for writing that makes it such a viable alternative for those who choose to write whether or not they enter therapy, and is according to Bolton (1998) available at any time to any one with basic writing skills.

Klass *et al.* (1996: 212) suggest that part of the resolution of grief is 'making the pain count for something'. One of the ways this can be achieved is through helping others. In addition to continuing the bonds and acting as a therapeutic outlet, it may also be the case that contributing narrative data to a research project may be a way of bringing something positive from the loss.

## METHOD

The narratives were contributed to a research project as the result of a request from a bereaved parent. The research project to which they were contributed was founded by the parents of a young man called George who had died from osteosarcoma at the age of 23 after being ill for four years. After his death, George's parents Helen and Geoff set up a charity to support research in this area. While the stories told by the parents are of illness and its effects on the family, in most cases the story is also of death and loss as the majority of the young people did not survive their cancer (only seven of 28 survived).

Designing an appropriate methodological approach to the collection of data on this topic posed many ethical problems. The research design clearly had far reaching implications for participants in that the investigation, of necessity, required that they recall events and feelings likely to generate distress. Dyregrov (2004) says that participants in such a study are so vulnerable that special consideration and sensitivity are required in the research design. She also claims that some researchers have advised against research on such traumatized populations. Yet as she goes on to say, there is growing evidence that bereavement research may have a positive effect on participants who have been 'the focus of interest, concern, and caring attention, which they experienced as being taken seriously' (2004: 392).

With consideration for such concerns a 'narrative correspondence' method was used (Thomas, 1998; 1999a; 1999b). This approach asks contributors to write about, or record, their contribution in the absence of the researcher. This allows participants to remain in control of the process. If they decide to contribute they can do so at their own time of choosing, at their own pace, picking up and putting down the narrative according to their feelings on any given day.

The narratives were submitted by parents of young adults with cancer in response to an appeal for narratives written by Helen, George's mother, who summarized her own story and asked other parents with similar experiences to contribute their accounts. This appeal was distributed through the palliative care network in the UK in both written form in newsletters and journals, and also through word of mouth by health professionals engaged in the care of young adults with cancer. While the contributors knew that the resulting narratives would be sent to an academic at a university rather than to Helen, they were nevertheless responding to a fellow parent with whom they could identify.

The appeal resulted in narratives being sent by the parents of 28 young adults, only seven of whom had survived their cancer. Mothers, as might have been expected, wrote the majority of narratives (Riches, 2002; Riches and Dawson, 2000), with the exception of one married couple who wrote a

joint account, a husband and wife who wrote separate accounts and one father who wrote the account with no contribution from his wife. Thus gender appeared to be an overarching factor in the willingness and ability to respond. As Ahmed and Stacey (2001) argue, entitlement to tell the story of illness is to some extent culturally specific. Thus it is not surprising that given the dominant model of family structures in Britain (where most responses came from) and the increased likelihood of emotional engagement from mothers (Riches, 2002), that they were more likely to contribute.

There are of course limitations to such a method in which participants are self-selected and it is impossible to either quantify or characterize the original 'sample'. There is a danger that contributors to such an appeal will over-represent a particular socio-economic background; thus those most familiar with the written form may be the most likely to submit narrative data. However, it seems from both the form and content of the narratives that the participants came from a wide range of backgrounds, both educational and social. Citing McLeod, Wright and Cheung Chung argue that: "writing therapy" has also been restimulated by the development of narrative approaches and computer mediated methods where key board and cyberspace have replaced pen and paper' (2001: 278), and indeed my assumption when putting out the appeal for narratives was that the majority would be submitted electronically, or at least be word-processed. However, this turned out not to be the case. Only two narratives were submitted via email, the remainder were posted, and half of those were handwritten.

The narrative data, consisting as they did of a range of styles and approaches to story telling, presented a challenge when it came to the process of analysis. Nevertheless, the importance of rigour was recognized and a systematic data reduction, display and conclusion-drawing method was used (Miles and Huberman, 1994). Miles and Huberman stress the importance of codification to facilitate the identification of themes and patterns, and warn against jumping to hasty or unfounded conclusions or the over-weighting of particularly dramatic passages. Applying such a rigorous approach to data analysis should assist in managing text that is, as Miles and Huberman say, by its very nature poorly structured, dispersed and bulky. Additionally, the handwritten texts lent themselves to an analysis based on presentation, for example, the use of capitalization and other emphases perhaps less likely to be implemented when using technology.

The data had already been analysed for the substantive themes relating to life stage. The subsequent analysis focused on here relates to more embedded material that suggested why the narratives had been written, under what circumstances, for what purpose, who wrote – mother or father – and what the emotional impact had been. The headings that follow are based on the themes suggested by such an analytical approach.

### THE MOTIVATION FOR WRITING

The appeal for narrative contributions reflecting on the life-threatening illness and in many cases death of a son or daughter expected a great deal of participants. So, why should anyone respond to such a request that was inevitably going to result in the recall of painful memories – whatever the outcome of the illness? Few of the narratives were explicit about the motivation that lay behind them, but in some of the accompanying letters, the writer articulated the hope that having access to their experience would help others, thus echoing Frank's (1995) claim that those who tell stories of illness and loss feel a sense of responsibility to others and Klass *et al.* (1996) that the pain 'count for something'. But in addition, embedded in some of the narratives were other indications of motivation.

In the following extracts from her contemporaneous diary, Sue, whose son Paul subsequently died from Hodgkin's disease, reflected on the reasons that she wrote – or did not write. Some of the themes are picked up individually in other narrative material discussed in this paper, but the range of Sue's comments raises a number of interesting and sometimes conflicting issues relating to motivation:

Can't write at the moment as I am confused and need to reflect before I write.

Well – shan't write much more – I don't feel I need to.

I can write no more – I'm angry, worried and upset.

I am writing again not because I need to but because I felt I should attempt to keep the record straight about emotions, frustrations, visitors and Paul.

Sadly today I write because I need to put my feelings on paper. I cannot understand what is going on. Mike is being unpleasant, no, unsympathetic towards Paul. I cannot really explain and do not know what to do.

Just realised its Friday morning. I cannot sleep. I have many things to write. Here I am again. This time I need to put thoughts down to get them out of my system.

Well, here I go again. It's Sunday lunch-time and probably the first time I've been alone for ages. I'm mixed up about what's happened and the right order but I'll have a go.

I don't know how to write at the moment or if I want to put down on paper some of the negative thoughts which have gone through my head recently.

That's all I can write now as I'm a bit mixed up at the moment.

Well, that's all for now. This saga is turning into a story of self pity. I will overcome it.



Hello again. I need to put my pen to paper once more – this time to say that everything will be OK. I feel at last that hope has outweighed the gloom and this time I'm not writing it just to make myself believe it.

(Sue)

The reasons for writing – or not writing – listed above are many and varied. We see that Sue writes 'not because I need to' but to keep the record straight, to work out her feelings of confusion and distress, to get her thoughts 'out of her system', because she cannot sleep, because she finds a rare moment alone, or to make herself believe that the outcome for Paul will be good.

But Sue also gives reasons for not writing or abandoning the attempt. At one point, she says she does not feel the need to write any more, implying that the writing she has done has served its purpose. At another point, she ends her writing because she is 'mixed up' in contrast to her rationale above of writing being used to work through such perplexity. She also questions whether she wants to commit her negative thoughts to paper and finishes her writing using the words 'saga' and 'self pity' to explain her cessation.

Interestingly, Sue also reflects on what her son Paul would think of her writings about his illness:

I had to break off as Paul came down. I don't think he would approve of my writings. Come to think of it – what's it all about? I suppose I needed to talk at first and then I couldn't... I have decided to continue because one day it may help us or others to overcome similar problems.

Unlike the other writing considered in this paper, Sue is the only parent to write while her son is still alive, and she concludes that he would not approve. Though she is not specific about why. She also mentions her difficulty in talking. Writing presumably is the viable alternative and here we are reminded of Davis's (1999) writings after her brother's death, when she 'had no words', and the reluctance of others to listen to such talk (Walter, 1996), leaving writing as an alternative outlet. In addition, the notion of helping others (Walter, 1996; Klass *et al.*, 1996) is expressed as a hoped for outcome. So it seems that Sue's reasons and motivations for writing are multifactorial, complex and changing across time and circumstance. Nevertheless, they correspond in broad terms to the themes discussed in the literature.

Sue's rationale that one day it might help, either her own family or others, echoes Frank's (1995) suggestion that illness stories demonstrate a responsibility to others who follow them, but as Sue's writings were apparently not intended for public consumption (Holloway, 1990), it is unclear what outlet she had in mind. Did she require the legitimization of the research project to justify the activity despite the claims of Ahmed and

Stacey (2001: 1) and Plummer (2001) that we live in an autobiographical culture where personal testimony – particularly relating to trauma – is ubiquitous?

The following quote from Gabrielle is more explicit about the need for legitimation as it is her participation in the project that she views as validating her writings and giving them purpose:

There is much more writing, in long hand ... It is ... muddled and raw, written just after Steve died. Then there are the things I still need to work out now, hastily jotted down on scraps of paper ... Your project gives me permission to think, write and talk about Steve and this is an unexpected comfort.

(Gabrielle)

It is interesting that this quote says that the telling and sharing of Steve's story requires an explicit purpose that gives 'permission' to his mother to engage in what otherwise might be interpreted as a maudlin or even self-indulgent activity. Gabrielle, unlike many of the other contributors had not written her account as a response to the appeal, but rather had used the appeal to legitimate that which already existed. This response was echoed by other participants and raises the question of why such writings need justification in our culture. The parents (mothers) were after all writing about the most momentous of experiences – so why is the telling of the story of illness and loss not an accepted part of the process?

The majority of narratives contributed to the research were purpose written, thus indicating something about the motivation, or at least a rationale, for writing. But what of those writings that predated the appeal? It seems likely that the motivation may differ significantly as contemporaneous writings may have less to do with a sense of responsibility towards others, as claimed by Frank (1995), and be more closely related to the therapeutic dimensions of narrative suggested by Bolton (1998) and Wright and Chueng Chung (2001). Nevertheless, it seems that whatever the motivation at the time of writing, the decision to submit the writing to the research project was motivated by the belief that the writing may help others, thus 'making the loss count' (Klass *et al.*, 1996).

### **THE FORM OF WRITING**

We see from Gabrielle's quote above that she reflects on the form of the writing and refers to its 'raw' state, handwritten on scraps of paper. Plummer (2001: 98) suggests that 'the old low-tech is being shifted into the new high-tech' and that story telling increasingly utilizes such technologies – indeed half of the narratives were word-processed. Nevertheless, this means that half were handwritten. For a few this was

perhaps accounted for, as in Sue's case, by the fact that they were submitting contemporaneous journals written, possibly some years earlier, during the illness.

Not only was the form of writing related to the use or non-use of technology, the length of the narratives also varied and was not related directly to whether they were handwritten. Some of the shorter submissions were sent by email. To some extent this may subconsciously have affected the form of the narrative. Email has for many replaced the art of letter writing. Although they may be kept by the recipient either electronically or printed and stored as a 'letter', we send emails that contain mistakes and spelling errors and which may be written in 'shorthand', using abbreviations or note form in a way that would not be acceptable on paper in a conventional letter. Whether these new conventions shaped the email contributions is not clear, but it seems that the writers adopted the brief, note-based approach in emails rather than the more lengthy, reflective style of the handwritten missive.

The following is an extract from an email written by Mary, whose daughter Nicola had died 20 years earlier:

She developed a malignant melanoma on her arm when she was 15/16 years old. This was surgically removed and she was given a large skin graft. Five years later the disease returned in the summer of 1977 and she died after six months on 3rd January 1978, her 22nd birthday. We were living abroad in Africa and were consequently quite out of touch.

(Mary)

Again the story is being told biographically with information about the facts of the situation. The sentences are short and to the point, but Mary finishes the three-page email (lengthy for the medium) by saying: 'This has been a rambling message.' It is also significant that Mary was the contributor whose child had died the longest time before the writing was undertaken. Yet as the following quote shows, had she not acknowledged this, there appears to be no clue from the tone to suggest it differs from the emotions or motivations portrayed in writing done only a few months after the illness or death, thus reflecting the 'continuing bonds' theory of Walter (1996) and Klass *et al.* (1996).

I knew at the time she was ill that after she died would be the hardest part, that it would take for ever to reach any sort of peace after she'd gone. But that was for later, not for now. Of course, you're never prepared for a death. And although I knew that the hardest part would come after she died. Even so, I had no idea the pain would be so excruciating in the event . . . I still can't talk about her, or write about her, without brimming eyes and falling tears.

(Mary)

Some of the narratives were professionally produced by word-processor, while others were apparently impulsively handwritten on small pieces of notepaper in a variety of styles – as Gabrielle’s quote shows. Indeed, Gabrielle used a variety of devices, as not only were her writings ‘hastily jotted down on scraps of paper’, she also wrote a series of poems for Steve, which were submitted bound, with a photograph of him on the front cover, perhaps denoting a ‘tribute’ or ‘memorial’ to him. Poems, according to Plummer (2001), can be a more rewarding medium through which to write about personal trauma, though it may not be as populist as other forms.

Some scripts used devices to emphasize strength of feeling, anger and pain by underlining and using capital letters. Where this was the case – primarily in the handwritten texts – the original emphasis was kept during the transcribing process and, where quoted in publications, has been retained. The following extracts demonstrate the use of such devices:

Our friends have been wonderful, but Bill and I can’t come to terms with the fact that Alasdair was snatched away just as he was beginning to achieve, to live. No-one understands this. They can’t. A friend who lost her husband when he was 52 tries to compare this – Jim had a lot of life left to live. **BUT HE HAD A LIFE – Alasdair DIDN’T GET A CHANCE.** She doesn’t understand she didn’t watch her child suffer agony and be helpless to do anything about it.

We badly need to be in touch with someone who knows the HELL we are going through even 6 1/2 months down the line. I don’t seem to be getting over him at all. I still cry every night. I still want to scream and shout and kick – which so far I have not done. I just want to.

(Moira)

Here we see the visual impact of the capitalization and underlining used both independently and in combination. It is a powerful signal of the strength of feeling behind the words. Moira is almost shouting at us. Candy uses similar devices to emphasize her feelings:

When my husband died friends tried to keep me going by reassuring me that life would get better and then Sianne got cancer and they really became lost, there was no more they could say and everyone virtually backed away because **THEY COULDN’T COPE!**

(Candy)

Persuasiveness may take a variety of guises, so that the listener identifies what is at stake for the storyteller, and in this case the visual devices appear to fulfil such a function. Here we can see that the emotional and powerful account gains perlocutionary force from the form as well as the content (Garro and Mattingly, 2000). In the absence of the opportunity to speak the story the writer utilizes devices that substitute for the spoken emphases.

### THE THERAPEUTIC EFFECT OF STORY TELLING

Much of the literature on narrative and writing therapy (Bolton, 1998; Wright and Chueng Chung, 2001) and the concept of the wounded story teller (Frank, 1997) suggest that there may be a cathartic or therapeutic effect from story telling. As Morrison (2004) says, writing was all that kept him going. Although in his case and with the parents in this study, the story tellers were not the ones who had the illness they were, nevertheless, wounded by the experience of their son or daughter's illness and thus could themselves be deemed wounded story tellers. Indeed as Peretz (1970: 20) says, 'Bereavement may be viewed as an illness' since it represents an altered state of feeling, thought and behaviour. Thus, in some senses, the parents were also telling the story of their own 'illness'.

The impact that participation in the research project had on their lives has been documented in detail in a follow-up study of the parents (Grinyer, 2004b). This was particularly important to understand as extracts from their narratives had been made public through the publication of several journal articles and a book based on their data (Grinyer, 2002; 2004; Grinyer and Thomas, 2001; 2004). Results from the follow-up suggest that participation was primarily viewed as positive and beneficial by the parents. Amongst their reflections were comments on the therapeutic nature of writing the narratives – or telling the story. However, it seems that the act of telling such a distressing story was also experienced as painful and challenging. The quotation from Candy, whose daughter Sianne died, typifies responses:

The main thing I found was the therapeutic effect it had on me, although very painful remembering I think it is one of the best ways of dealing with the death of someone close to go over and over it just trying to make some kind of sense of the nightmare.

(Grinyer, 2004a)

Despite the pain involved in committing the story to paper, the longer-term effect – on reflection – was regarded positively. This was for a number of reasons. First, the act of telling the story – the story being a lasting memorial – not having to carry the burden of relating the story to each new family member but there being a tangible record for future generations. Candy continues by saying:

I think it has also been important for Sianne's siblings as it gives them another reason to feel proud of her, especially as she is mentioned in print. It is not only a permanent record for them but another way that Sianne is still with us all ... I was very pleased to be involved in the study and it gave me another way of doing something for Sianne. I know that she would have wanted to help anyone in a similar situation in any way she could.

(Grinyer, 2004a)

Here we see that in some senses Sianne continues to 'live' through her story, thus retaining Sianne rather than letting her go (Walter, 1996). As Candy says, she is 'still with us all'. The story, and by extension the writing of it, perpetuates not only her memory but allows her to have a continued existence where new events related to her are occurring and finally the recurring theme of helping others who follow (Frank, 1995). That her siblings should be proud of her is echoed in Rose's (1997) book, written about his dead son, in which he says 'I wish to pay my permanent tribute to a remarkable young man' (1997: 12).

Two parallel events are occurring in such activity. The first is the act of writing, which may in itself be experienced as therapeutic; the second is the perpetuation of the story of the lost loved one while paying tribute to their memory. Thus writing and story telling may be viewed as separate actions – not mutually dependent. The story could be perpetuated without 'writing' and the writing could be undertaken without being accessed by others, thus not perpetuating the story amongst the family or for the benefit of others. Nevertheless, given the personal and social limitations of talking coupled with the will to help others, the two actions together would appear to offer the most promise in terms of therapeutic benefit while also serving the function of a lasting tribute.

## DISCUSSION

We can see from the extracts above that the act of writing their narrative helps story tellers to make sense of their experience, to rehearse their feelings, both at the time and after the event, and in some senses to come to terms with the unacceptable; thus, it could be viewed as therapeutic. The rationale for contributing was articulated by some participants as being based on a wish to help others, and this may indeed be part of the motivation, but resulting publications also act as a lasting tribute and validate the participant's experience. The need for continuing bonds with the dead (Walter, 1996, Klass *et al.*, 1996) can be maintained through the writing itself but extend beyond the process to the resulting artefacts that sustain the relationship and allow new relationships to incorporate the dead. Thus the act of writing represents the 'internalization' of another. As Pearl (2004: 37) says of White's (written) dialogue for his dying, then dead lover:

It is as if the internalized dialogue is another kind of totem standing in the place of the other who can no longer speak because he is dead: a signifier of, but also a substitute for, absence. The internalized dialogue is a way both to sustain the lost other and to deny that he is gone.

The lost 'other' can be sustained in some sense, if not through their corporeality, at least within the body of a text. We can see that the bereaved

parents have adopted such a stance towards their lost sons and daughters, giving them a continued 'life' through a written narrative. The life of the narrative after submission then takes on an additional meaning and a life of its own. The publication of their story allows something new to be said about the dead son or daughter. The adult children of others who thrive and achieve and move through life's stages have new stories that can be told about them by their parents. The act of writing about the lost children provides another means of continuing their stories even after death. Something new can be said about them – they have appeared in a book, been mentioned at a conference, their photograph has been used to illustrate an academic paper – they in some senses continue to 'live'. Their story has been taken seriously and been used to help others – and they continue to live within the text. As Pearl also says: 'the mechanism of mourning is functioning here as well ... Perhaps it is literature's purpose to deny loss; to sustain in print what one cannot bear to lose in life' (2004: 42).

Walter's (1996) 'new model of grief' suggests that rather than grief being a process where the goal is to move on and let go of the dead person, an alternative way of understanding grief is to find a way of retaining the dead. However, what appears evident from the narratives is that despite ubiquitous story telling (Plummer, 2001) in the confessional culture of modern western society apparently obsessed with death (Hawkins, 1990), the ability to talk about death is still unacceptable for many. Even if talking has been socially acceptable in the early stages of loss, we can see through the literature (Walter, 1996) that the loss is ongoing. So long after it is no longer considered appropriate to talk about the death, the bereaved parent may still need an outlet in order to retain the lost loved one, and writing may be the only option.

While many contemporary accounts of death writing may not be by professional writers (Blank, 1998; Prince, 1996; Rose, 1997), it seems that writing is still largely seen as the preserve of the 'writer'; thus, writings may not be shared with others (Holloway, 1990) and on occasion even concealed. The research in some cases has offered an outlet for the participants, and the therapeutic effect has been extended from the writing process to the satisfaction of sharing the story with a wider audience, both keeping alive the memory and contributing to others' needs.

Thus the writing may be seen as part of the grieving process. But what of the contributing parents (the minority) whose son or daughter had survived their cancer? What was the purpose or motivation for them? According to George's mother, as the cancer journey is embarked upon without knowing the outcome, many of the effects of accompanying their son or daughter may be the same whether they live or die. Thus parents are still dealing with grief, trauma and pain – despite the outcome. They too are trying to make sense of the experience and possibly still dealing

with the legacy of the illness and its impact on their son or daughter and the wider family. There will have been a different kind of loss and though death may not have been the outcome, a residue of that fear may remain. For whether or not their son or daughter has died, parents are experiencing losses that may be interpreted as forms of bereavement. These emotions need to be worked through and the writing process may help to clarify them. As Frank says of his book, the unspecified topic here is suffering – and suffering creates a need for stories or testimony. ‘Remaking’, he says, begins when suffering becomes an opening to others (1995: 176).

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#### NOTE ON CONTRIBUTOR

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