The Narrative Correspondence Method: What a Follow-up Study Can Tell Us About the Longer Term Effect on Participants in Emotionally Demanding Research

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The author has based this article on qualitative data gathered from the parents of young adults with cancer who, over the previous 4 years, had contributed narrative accounts to a research project on the experience of caring for a young adult son or daughter with the illness. In the follow-up study, she sought to understand the longer term effect of research participation on the parents. Results show that the parents valued their involvement, and many had found the process of writing therapeutic. Their feelings of isolation had been reduced, and overall, they believed they had benefited from contributing. However, there is also an acknowledgement of the emotional demands caused by recalling painful memories for research purposes. Participants experienced the outcomes of the research as significant and interpreted resulting publications as a lasting memorial to their son or daughter.

Keywords: research effect; therapeutic; emotional; memorial

The participants in the research that I discuss in this article were the parents of young adults with cancer; thus, the impact of the research on their lives as a result of participation were potentially far reaching. As a result, the design of the research and an understanding of its impact are of considerable methodological significance. In this article, I address the impact and longer term effects of participation through a discussion of the findings from a follow-up study undertaken a year after the end of the research project.

As Dyregrov (2004) has said, despite the existence of the ethical codes that govern the conduct of research, few studies document how participants experience their application. However, in a similar field to my own research, Dyregrov has conducted such a study on bereaved parents’ experience of participation in research, though the research methods differed considerably. Dyregrov’s three-phase study began with a quantitative approach, which was followed with in-depth interviews, and the third phase—evaluating the participation—was conducted via a questionnaire. Results from this final phase suggest that all the parents experienced their participation as positive, and none regretted taking part—indeed, one is quoted as saying, “Everybody should have the opportunity” (p. 395). The positive responses stemmed in part from participants’ being able to “tell their story,” the interview format, and the wish to help others. Nevertheless, 75% of the participants acknowledged that talking about their loss was painful.
There was a similar potential for participation to cause pain in my research. Participants had contributed narrative accounts of the cancer journey they had shared with their young adult son or daughter. Of the 28 young people whose stories were told by their parents, only 7 had survived their cancer; thus, in most cases, contributing parents were writing about the life, illness, and death of their son or daughter. To undertake such a task could have a lasting impact on the contributing parent (usually the mother), his or her partner, and others within and close to the family. In addition, the research resulted in a number of publications, including a book that carried extensive quotations from the narratives, through which many of the contributing parents were, at their request, identifiable by readers known to them. The impact of having such intimate details of a family’s struggle with illness and death made “public” also has the potential to alter relationships both within and outside the family.

In this article, I present the results of a follow-up study undertaken 4 years after the inception of the research and a year after the publication of the book based on the narrative accounts written by the contributing parents. To understand participants’ responses to and the impact of the chosen method, of necessity, I offer a detailed description of the initial study design. Following this is an analysis of the data generated in the concluding phase of the project, when I revisited the parents and asked them to reflect on the effects of participation.

METHOD

The research was precipitated by the death of a student called George. He had died at age 23 after a 4-year battle with osteosarcoma. During his illness, his parents had found no published work on the impact on family life when a young adult is diagnosed with cancer. After George’s death, his parents, Helen and Geoff, set up a charitable trust in his name to support research in this area.

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

With consideration for all these issues, my colleagues and I used a narrative correspondence method (Thomas 1998, 1999a, 1999b). Such an approach required 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. Neither are participants placed under pressure by the expectations of a researcher arriving on the doorstep or telephoning at a prearranged time. As Dyregrov (2004) documented, before the interviews in the research under consideration, participants had
been afraid that the interview would be agonizing and had had to “muster a lot of energy” in the days before.

The call for narratives was written by George’s mother and distributed through the palliative care network in the United Kingdom 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. Participants were asked to write about their experiences of their young adult son’s or daughter’s cancer journey. They were not asked to address specific issues, although the theme of Life Stage was mentioned in the appeal and taken up by some participants. Mothers, as might have been expected, wrote the majority of narratives (Riches & Dawson, 2000), but the form, length, and content varied greatly. Some were extensive, others were brief; some had been written prior to the call for contributions, others were written specifically for the research. Some of the narratives were analytical and structured, others were more akin to outpourings of anguish—but all, in whatever form or length and whatever the content, provided a rare and rich insight into the experience of accompanying a son or daughter on the cancer journey—very often to death.

There are, of course, limitations to such a method. Participants are self-selected, and it is impossible to quantify the original “sample.” We do not know how many parents of young adults with cancer had sight of the appeal, nor do we know how many might have begun to respond only to abandon the attempt.

There is a danger that contributors to such an appeal will overrepresent a particular socioeconomic background; thus, those most used to the written form might be the most likely to submit narrative data. However, it was clear from both the form and content of the narratives that the participants came from a wide range of backgrounds, both educational and social.

On receipt of the narratives, we sent a handwritten postcard thanking the contributor. In the postcard, we also asked contributors to verify their willingness for extracts from their narratives to be used in publications, and all agreed.

We analyzed the data submitted in the first 9 months to form the basis of a journal publication (Grinyer & Thomas, 2001), and we subsequently sent this article to all the contributors. Given the limited length of journal articles, not all the participants’ narratives had been quoted. However, an accompanying letter explained that all contributions had been valuable in informing the thematic analysis of the data, and although not all contributors were cited, this was a function of the genre.

Before submitting the article for review, we asked all the parents if they would prefer to have a pseudonym allocated to them and members of their family, or to have their real names used. Perhaps surprisingly, 75% of the parents replied that they would like their real names used. The remaining 25% requested, and were allocated, pseudonyms (Grinyer 2002). It is for this reason that extracts from parents’ contributions in this article are allocated an identifying name tag—usually avoided as a way of assuring anonymity.

After the publication of a book based heavily on the narrative material, all the parents were contacted and asked if they would like to receive a copy and to attend its launch. Fifteen families (26 people) accepted the invitation to the launch. There was an opportunity for them to meet each other informally before the launch, and we held a dinner for them afterwards. The following day, for those who wished to attend, we put on workshop discussions, supported by trained counselors, at the premises of a local cancer charity. The aim of this day’s activities was not defined or imposed on the participants. We offered a program of discussion topics, which
provided the framework for the day. However, attendees could drop in or out of ses-
sions, or suggest alternative or additional activities. There was no attempt to set up
a self-help group, but if contributors struck up relationships with each other, they
could make arrangements to stay in touch. There was a mix of parents whose chil-
dren had died and others whose son or daughter had survived. In addition, one of
the surviving daughters attended the launch, dinner, and workshop with her
mother.

It is tempting to make assumptions about the meaning of being a participant in
this research. As Frank (1997) has suggested, people tell stories to make sense of
their suffering and by turning their illnesses into narrative accounts find healing in
the process. Although the contributors in this research were not telling stories about
their own illnesses, they could still, in Frank’s terms, be viewed as “wounded story-
tellers.” Thus, it would be attractive to assume a cathartic or therapeutic effect.

However, telling the story is part of a larger and longer process, one that when
entered does not have predictable outcomes. The experience might be different for
different participants at different times. Many factors, such as other family life
events, might transform the experience. Thus, the only way to attempt to gain an
understanding of the meaning of the research is to return to the participants and ask
them to reflect on it.

Part of the purpose of the follow-up study was to ascertain just how ethical the
research had been in terms of its long-term effect on participants. It would, however,
be an oversight not to consider the impact of yet again contacting the contributors
and asking them for additional information. A year after the book launch, the par-
ticipants might be in the process of achieving some distance from the project and not
wish to reengage with it. They might feel under obligation once again to put pen to
paper and to address emotions likely to cause pain. However, the hope was that the
relationships established between the research team, particularly Helen (George’s
mother), and the participants were sound enough to allow the participants to refuse
the request.

FINDINGS: THE IMPACT OF THE
RESEARCH ON PARTICIPANTS

We received responses from participants to the follow-up study in a variety of for-
mats. Seven were sent by e-mail, seven were in the form of handwritten letters, and
two mothers asked me to telephone them. However, as with the original data set,
despite the differences in form, length, style, and approach, a number of themes
were repeated across the responses, and it is these themes that form the basis of the
following analysis.

Willingness to Participate: How the Approach is Made

It became clear from a number of participants that Helen’s role was of great signifi-
cance in their willingness to contribute to the research. We remember that she wrote
the original appeal as the mother of a young man who had died from cancer and
Helen V articulates the importance of Helen’s being a fellow bereaved parent:
The form of the invitation [to contribute] was very important to me: a letter [the appeal] from Helen, which created a very strong bond with Helen and Geoff. The source, too, was a big influence. The note about the study came from a social worker at the hospice in London where Simon had died (Helen V, mother of Simon who died)

It might even be that whether the envelope is handwritten makes a difference to the willingness to contribute. Official letters from a university department might be perceived as “cold.” Sue mentions the significance of the handwritten letters from Helen that arrived when she was questioning the wisdom of her participation:

I almost backed out of the project and would have done so without the letters from Helen. The personal contact, especially handwritten, meant so much . . . this personal approach, I feel, must be one of the keys to the success of your project. It is very, very important. I know if I had been faced with cold research, questionnaires etc. I would never have been involved. (Sue, mother of Paul who died)

In addition, thank-you postcards sent after the narratives had been received were also handwritten by me and signed by Helen and Geoff too. Such apparently minor details might, however, have profound effects on the recipients’ feelings about their engagement with the project. The widespread use of word processors makes the production of professional looking letters commonplace, but rather than denoting a “professional” image, it might be perceived as cold and impersonal. As Sue says, she would never have responded to “cold” research.

Sue also says that she felt that she could share her story with Helen, as she would be able to understand. Clearly, Sue knew that her narrative would ultimately be analyzed by an academic and that though Helen was making the request, the contribution would not remain with her or even be mailed to her, as the return address was to my university department. Nevertheless, the centrality of a fellow parent seems to have been crucial to Sue’s participation.

The Therapeutic Effect of Writing

As documented by Dyregrov (2004), bereaved parents might experience the opportunity to tell their story as positive. Dyregrov was reflecting on an interactive process with an interviewer present, whereas the research discussed here took the form of a written narrative. Yet, as part of the telling of the story, the actual process of writing might be regarded as therapeutic. However, several parents commented on the duality of catharsis and pain, which is typified in the following quote:

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. (Candy, mother of Sianne who died)

Brenda, the mother of Miles who died, had also lost her husband to cancer since the publication of the book. In a telephone interview with Brenda, she told me of the “burning desire” both she and Michael had to “put it down on paper,” but said she now no longer wanted to think about it, and she spoke of a sense of unreality about what she had endured during Miles’s illness. Thus, it seems that although recalling
the events surrounding the illness and death and committing them to paper might indeed be a burning need, such needs might change over time. These might be mitigated by other life events—such as births or other deaths—or might be a function of having already worked through the process on paper.

Using a more analytical approach about the function of the method, Carol assumes, in the following quote, that the act of writing was therapeutic for most contributors, thus suggesting that it was in some measure therapeutic for her. Yet, she also raises an important question: What would the research data have looked like had they not been gathered in this way?

As to methodology, writing, as we did, probably helped most of us because I do believe that writing things down is therapeutic. Would it have been possible for Anne to have interviewed us all? Probably not, but the telling would also have helped in my view. Possibly more would have come out—we can be selective in what we write—I’m aware of that. (Carol, mother of Sara who died)

Carol suggests that “the telling would have helped.” It is unclear whether she means it would have helped the research or the participant but seems to indicate the latter, thus acknowledging that the telling of stories verbally and in person might, for some contributors, have been a more therapeutic experience.

Helen V makes a slightly different point about the narrative method and the possibility of an alternative approach:

The narrative approach was, for me, the best in the circumstances. I use words for a living, really—writing reports, writing medical-type resources for the public—and that both helped and hindered. An interview would have been difficult, a focus group harder. The guidance we had—the “life stage” theme—was helpful. Talking to the researchers would have been helpful too. It’s not a burden to be asked to write, but there’s a risk that I will write too many words and not get to the heart of the matter. I don’t feel that there’s any value in what I wrote in itself; I virtually never read it. The value is all in the connections it gave me, and in the finished book. If the stories had only been used for one or two articles in academic journals, the effort would not have felt so worthwhile. There’s something very important in feeling that this work crosses boundaries—it translates real people’s accounts into an academic framework in a sensitive way, and that framework makes it accessible to policy-makers and people in the field, potentially changing their views and their practices, giving them further insight into what it means for a young adult to have cancer. (Helen V)

Here, we see that Helen appears not to have felt that the act of writing was in itself therapeutic, though she implies that it was probably the most appropriate method. Rather, for her, the satisfaction seems to lie in the outcome of the project. Had it remained at the output of only one or two articles in journals (no mean feat in itself!), she would have felt that her effort had not been worthwhile. This indicates the significance of outcomes for participants. Yet, at the time as we ask them to participate, we can offer no assurances that the project will result even in the minimum of two publications, let alone a book. Helen V also mentions the “connections” that participation offered, again not something that results from many research projects. Although the participants will usually have some personal contact with the researcher (though, in my project, not until near its conclusion) it is rare that they will meet each other unless they do so in a focus group. However, Helen indicates
that a focus group would, in this instance, not have been an attractive or easy option for her.

Continued Pain

The fact that the parents, on balance, found the writing process therapeutic and take pride in the outcome of the research does, not in any sense, suggest that the process will assuage their grief or loss. Grief, as Rosenblatt (2000) says, might not be a constant after the initial intense period but will be triggered by events and memories on an ongoing basis. Thus, it is unsurprising that even those parents who regarded their participation as therapeutic still experience intense feelings of loss, as typified by Michael’s mother, Elizabeth, who says,

I am glad that I wrote that story . . . I am on depression tablets again so when I am very depressed I just sit down and write a letter to Michael. The book has made me very proud. (Elizabeth, mother of Michael who died)

The Book as a Lasting Memorial

Some of the quotations already cited indicate that the contributing parent is proud that his or her son’s or daughter’s story is included in a book. Others, however, appear to attach even greater significance to the book. A number of parents articulated the positive effect of having done something for the son or daughter, and the lasting memorial represented by the book. Candy, whose daughter Sianne had died, says the following:

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. (Candy)

Iris, too, said that seeing the book in print was “some sort of tribute to Mat.” Brenda, whose son Miles had died, said that knowing her story was in the book was like having photographs that you do not need to look at but need to know exist, as a record for future generations of the family. This echoes Candy’s comment on the book’s being a “permanent record,” and those of Helen V, who said that she “wanted to get Simon’s name out there” and who goes on to say that it had to be his real name. Indeed, it would seem that for the book to have a “memorial” quality, it would of necessity need to be the real name of their son or daughter that is used.

Sue says, “The climax of the book’s publication allowed her to move forward instead of clinging to the past.” She also says, “Paul was still involved through your book he always will be” again suggesting a lasting memorial but one that has allowed her to move on—perhaps because Paul’s memory can be kept alive without the need for her to keep telling the story. It now exists in the world and, to some extent, has a life of its own and will be read by both those close to the family and strangers.
In contrast to these reactions, Carol S appears to feel that the book in some way failed to do justice to her son, “J”:

J’s story, I know, was unusual, but it showed a victorious spirit; an inspiration to all those who knew him and it continues to inspire people ten years later. This victorious spirit was not mentioned in the book . . . the story should be told. (Carol S)

Such a response tells us much about the importance of doing justice to the contributions from participants. The significance attached to the outcome of the research has been shown to have a powerful impact when it is perceived to be positive. However, in this instance, it seems that J’s mother is disappointed. The “lasting memorial” does not, in her opinion, reflect J’s “true spirit.” Thus, what is out in the world in his name has, in effect, failed for her. She finishes her response by apologizing that her reaction to the project “may not be of much help” but that she has to let us know how she feels. However, although it might not be what we “want” to hear, her response is of significant help for researchers concerned with the lasting aftermath of participation.

Ability to Read the Book

Brenda, who expressed her satisfaction in the book’s publication and felt that it would be an important resource, acknowledged apologetically that she had not read the book in the intervening year. However, she had, with one of her daughters, just begun to read the passages that related to her and her late husband’s narratives. Denise, too, addresses the difficulty of reading the book:

When I finally read my contributions in print it was quite surreal and I felt strangely uncomfortable and very emotional. I am so pleased to have played a part in such an important and valuable resource. It helped to focus my own feelings and to put them into some perspective and release some of my innermost grief. I consider myself (where appropriate in some text) to merely be the messenger of Alexander’s own words. It has gone some way to helping make sense of his death, although one year on I still cannot pick up the book and read freely. There are parts I have never attempted. (Denise, mother of Alexander who died)

Here, we see two mothers, both of whom regard the contribution of their stories as positive, acknowledging that the book presents a challenge to them. Both appear to have approached the book by seeking out their own contributions—a very understandable response—but although it is a valued and tangible memorial to their lost sons, it is not one that they can face easily.

Helen V’s response to the book reflects the fact that she felt that the article that was the first published output had been “too tidy, too contained—limited by the context. The topic needed a book.” Several weeks after she had sent her contribution, Helen says that she had a “set back,” when she suddenly feared that her account would be printed verbatim. This was her chance to tell Simon’s story “to the world,” and it needed to be perfect, but she describes her narrative as “like a dog’s breakfast, half digested and all over the place.” However, once the book was “in her hand,” she had mixed emotions about the fact that her narrative was not printed “verbatim,” at least in its entirety, and was, to some extent, “analysed”: 
It was odd seeing the author comment on my views at one point. My approach seemed too chaotic to warrant analysis. What I wrote was what came out at the time—what I felt able to write down. It wasn’t a considered, polished bit of work; the feelings were raw. I was grateful for the chance to do it, but it was more like free association than a comprehensive record of events (though I now see that I also wrote to justify what I’d done at different times). And this rag-bag was analysed as if I was, well, sane… I do think that reading the author’s analysis of themes helped me to take a fresh look at Simon’s story. I saw what had been missing in my account. I could also see what it had been like for others, and that was enormously helpful. I didn’t ever wish I could make another attempt at writing it down for Anne; I accepted the limitations of “my” story as they became apparent on reading the finished book. I think this acceptance reflects the sensitivity with which all our offerings were handled by Anne. (Helen V)

Helen V’s response to seeing her story analyzed is a salutary reminder to academics of the responsibility that they bear. In some ways, my analysis of the narrative material was minimal—certainly the least theoretical or “academic” publication I have ever attempted. I was mindful throughout the process that there was very little I could add to data that were so powerful. Yet, I could not present them without some commentary. Should this analysis have been shared with and approved by participants before publication? There are those, such as Caelli (2001), who would argue that they should. Yet, the complexity of the process of writing a book carries with it the need for pragmatic judgments. In addition, it is not necessarily a neatened, polished reconsidered version that will communicate most powerfully the emotions and experiences. Indeed, it is the neatness of the first journal article that Helen V feels missed the impact of the experience of having had a child die.

Lesley, the mother of Tim who survived his testicular cancer, comments on the contributions made by both her and her husband Jeremy:

We wrote our “piece” together and were surprised at how our memories differed, although I had written a diary at the time—now carefully hidden away. When I started to read the book I realised that we had only written about what happened, rather than the emotions involved. Perhaps this is because Tim is still with us, I’m not sure, I did find that the accounts from the parents opened up old wounds and I still have not read more than half way though it as it is too painful. All the accounts exactly mirror our feelings. (Lesley)

Tim’s survival provides a very different context through which to regard Lesley and Jeremy’s involvement in the research and the book. Lesley continues her response by saying that the family now want to “put the episode behind us” and acknowledges that although the scars will always remain, they are beginning to heal.

However, in contrast to these accounts of the difficulties encountered in reading the book, Sue says,

I have read it and re-read it, each time in a different way and never from cover to cover. Sometimes looking for “our bits,” sometimes comparing Paul’s ordeals with others or looking for similarities in the way we were treated or reacted but mostly I read it to share the pain and love experienced by all the families. (Sue)

Charlotte comments that you need to be “a bit careful who you lend it to.” In this case, she is referring to other parents at the start of the cancer journey who might
find it too painful emotionally. However, there are comments from other parents about lending the book. Carol, who comments on her feelings about its importance and relevance in a very positive way, says that she gave a copy to a close friend who never again mentioned it:

The whole concept of the book was very exciting and I feel indebted to both you and Anne for the doing of it because it was written with great sensitivity, and its relevance and honesty reached out to anyone who read it . . . I gave a copy to a close friend, and do you know, she has never mentioned it—in actual fact, I believe she has actually found it almost too painful to read. (Carol)

This might be perceived as a hurtful rejection by the parents, who are sharing a very intimate account of their experiences. Thus, there is a risk to the stories’ being “out in the world.” Although the reactions of others—wider family and friends—are not the focus of this article, they nevertheless have an impact on the participants. The personal has become public to some extent; the intimate details of family life can be scrutinized by others who might make judgments. This can engender ambivalent feelings that, in some instances, might even be experienced as a “betrayal.”

Sue had already written “copious outpourings,” which she located at the back of a drawer. These she reread, cried over, and then submitted, although as she says they were written without an audience in mind. As they had not been written for “public dissemination,” there was much material of a personal nature that could have been perceived as critical of others. Thus, before publication, I sent chapters that featured extracts from her narrative to Sue so that she could see them in context and agree their use or ask for them to be edited or removed. Sue gave consent for her material to appear as it stood, but her response a year later is as follows:

Your [Helen’s] personal letter which came with a typed up copy of my writing was so understanding and warned me that I may be upset reading it “in the cold light of day.” I was. I cried a lot. My story was no longer my personal property with my feelings expressed in my handwriting. My privacy was gone and worst of all I believed I had exposed our family and betrayed them. (Sue)

In a similar vein, although it is not clear if Moira’s friend has read the book and thus Moira’s comments about her, Moira expresses some concern about parts of her narrative’s being a betrayal of friendship:

I’m still cringing at what I wrote about my dear friend who is as tactless as ever, but at the time I wrote it I was not myself at all. (Moira, mother of Alasdair who died)

In contrast to some of the other contributors, Iris appears to have no ambivalence about either her own reading of the book or that of those who know her or her family:

I have read it over and over. I have lent it to family and friends—who have commented on how moving and yet informative it is. I intend to send a copy to my nephew who is a doctor in Brisbane, Australia, so that I can get his reaction to it. (Iris, the mother of Matthew who died)
**Reducing Isolation**

The fact that the participants realized they were not on their own and felt supported by the similarity of others’ experiences was perceived as positive. As Brenda said, when you read that some one else has been through the same experience, it is a comfort. A number of parents commented on this:

> It was a good feeling to be a small part in the research of something really important. It was a time of sharing something that in other respects is a very isolating experience. (Anne, the mother of Christopher who died)

Carol, too, recognizes the potential for the book to reduce isolation, both her own and that of any future readers:

> The most important thing for me was that the book made me feel less alone through the worst months of my life. If I can look back on that and not feel so alone, I hope other parents can too. . . . it was a very brave venture for us all. (Carol)

Moira makes a similar point about the support gained through reading the stories of others:

> It was good to . . . read of the similar problems and different problems that people had to us . . . From the book we learned that our time was easy compared to some of the others. (Moira)

Although none of the parents express anything but compassion for those whom they perceive as having undergone an even worse experience, nevertheless, such comparisons serve to facilitate a realization that their own journey could have been even more distressing for them, their family, and their son or daughter.

In a slightly different vein, Sue reflects on the effect her participation has had on understanding her relationships within the family. Sue’s original narrative indicated that the relationship between her and her husband, Mike, was beset with tensions resulting from the differing ways in which they dealt with their son Paul’s illness; she says the following:

> My involvement has opened my eyes to the dynamics of family relationships and the contrasting ways we deal with our problems. (Sue)

Although the other parents have reflected on the reduction of isolation in relationship to the illness and loss, Sue has taken some comfort in knowing that the tensions between her and her husband were unsurprising and a direct consequence of the illness and loss.

In contrast, Sue’s husband, Mike, has read neither the book nor Sue’s contributions to it. Although, as she says, she has left the book “around (deliberately)” for him to read, it has remained untouched.

**The Launch and Workshops**

Among the reflections in the parents’ responses to the request to consider the effects of their involvement were comments about the impact of the book launch and its
attendant activities. In general, these could be deemed positive, and Moira sums up well the positive aspect of the reactions as follows:

Bill [husband] and I were greatly helped by meeting the others. It started a healing process that was slow in coming. (Moira)

Most of the contributing parents were mothers; however, one of the effects of participation in the book launch and accompanying events appeared to have been to engage husbands to a greater extent than previously. The following quote from Gabrielle illustrates this well:

Incidentally, having met you all and being there at the book launch, I think Richard would be prepared to offer his thoughts and feelings about Steve’s illness and death, for the project . . . I was very surprised at how animated and involved he was in the discussions on the Saturday . . . I spent so much emotional energy writing after Steve died and I know that I excluded Richard from this, and from the research for the book. I had asked Richard if he wanted to be involved initially and having rejected the idea once, I never asked again. He said that what I was doing, was like rubbing salt into a wound . . . I didn’t realise how much I had left Richard out until the book launch gave him the chance to opt back in. I am very grateful for this as we can now share yet another path on our road to recovery . . . I haven’t had the urge to keep in touch with any of the parents I met at the launch. I really enjoyed meeting them all and talking to them, but the meeting felt part of the project and that stage has ended. I guess I wanted a rest from all the emotional involvement too. (Gabrielle, mother of Steve who died)

Denise also mentions the effect of the weekend’s activities in relationship to her husband, Phil:

The weekend launch was significant to both my husband and myself where we felt totally at ease with the group and where we didn’t have to pretend to be anything else but ourselves. An opportunity to focus our thoughts for the future about outcomes from the research we felt was particularly valuable and one year on are excited to hear how well received and well used the book has already been. Overall I do not feel that my participation has had any negative effect, rather the reverse in that it has helped to point me to a more positive thinking future. Phil feels that although the weekend was fruitful (he got more out of the weekend than he expected) it has not made a significant difference in any other way. (Denise)

In the following extract from Carol’s response, it is clear that there is some ambivalence about the role she played both in contributing to the book and at the launch. As a trained counselor, Carol agreed to facilitate some of the discussions at the workshops, and this dual role as both parent and facilitator seems to have resulted in some tensions on the day:

At the time I came up for the Book Launch, I was quite tired and had been in some pain from what I thought was a tooth. It wasn’t easy being in Lancaster—the build-up, and also my awareness that although I was one of the parents, I also had the additional role to play the next day, and my “counsellor” hat came on then, but actually it was mainly about me being just another parent too, and that wasn’t easy. Also, on the journey home, my whole face exploded with nerve pain, which was “diagnosed” later in that year as suppressed pain and stress—after two teeth had been extracted! So it was a strange time for me because of that, and it was why I
determined to have a more relaxed summer and to enjoy the moments. No way do I feel the book had anything to do with the nerve pain; I had just become too busy at work and on the farm, and I believe something did give—and perhaps it was also about a lot of suppressed stuff because I can do that too. (Carol)

There are a number of interesting and dichotomous feelings reflected in this extract. Previous extracts show that Carol values the book and her involvement in it and believes the project to have produced results potentially helpful to others in a similar position, but the book launch appears to have resulted in ambivalent feelings. Whether the events of the week-end, her dual role, or the release of suppressed emotion contributed to Carol’s physical pain on the homeward journey is a moot point.

However, one parent, Charlotte, a single mother who attended both the launch and weekend activities on her own, appears to have no ambivalence about the event:

When I met everyone, I felt the people who organised the launch had gone out of their way to make all the participants in the book feel special almost like royalty. We had cheerful discussions (but everyone was sensitive to other people’s feelings). This kind of gesture helped me—a treat … once or twice I felt very emotional about Sean inside. All this helped me. With all the other parents I could tell they had been affected like me and their discussions with me helped. We were all wounded. Some parents I felt had more traumatic experiences than I did and I was delighted to hear of the occasional success story. (Charlotte, the mother of Sean who died)

Charlotte suggests that feelings of envy for those whose son or daughter had survived were not an issue; rather, there was joy on their behalf. Similarly, Helen V makes the following observation:

What I remember most, just now, is the parents’ meeting the next morning. Some of us had told our stories over dinner the previous night, but others I was hearing for the first time. I remember the passion at the meeting to do things, especially for the siblings. The best thing for me, though, was simply to be in a room with other parents who’d been through a similar experience. Even when their children hadn’t died, it was such a different feeling to be among these wonderful people. Then on the way back to London, on the train, we sat with a couple … who’d also had a son die. They were special people. (Helen V)

Nevertheless, Geraldine expresses concern about being the parent of one of the few survivors in the cohort and, in addition, bringing her daughter to the launch. Here, she reflects on her attendance with Katy:

I was pleased I had taken part and hope our story can be used to help others in a similar situation. The book launch was very interesting and I thought it was good to meet others who had been (or were currently) in the same situation. My own misgivings had been our positive outcome compared to most where the young person had died. The reverse was actually true as a number of participants found it reassuring to see Katy looking so well 9 years on. This was especially true of parents whose son or daughter had recently been diagnosed with cancer. Katy found it useful to attend the book launch and discussions. Reading the book and taking part in the discussions revealed many other parents had felt things that I had felt but had not written. (Geraldine)
One contributing parent who did not attend the launch and reflects on this decision is Sue, whose narrative data were not originally intended for public scrutiny. She says,

The involvement with the book launch was another very difficult time. To go or not to go? I desperately wanted to be there to meet all the special people who were involved but at the same time I felt it would be too emotional...a colleague made the blunt comment that I didn’t need to share “other people’s baggage,” as I had enough of my own! I was shocked and hurt but knew that though her words were ill-chosen, the sentiment was true. I wasn’t ready to hear others’ stories and meet them face-to face... Once the launch was over, I know I felt an enormous sense of relief. I felt as though I’d reached the end of a long and tiring journey and that another chapter in my life was over. (Sue)

This reaction to the book launch was unanticipated. It seemed realistic to suspect that the launch would prove to be an emotionally demanding event for those who chose to attend. It might also have been predictable that some attendees would achieve an element of closure through their attendance. The fact that a similar emotional response was experienced by a nonattender, who also experienced relief and a degree of “closure” after the event was over, might initially appear surprising. However, on reflection, nonattendance was as emotional a decision as attendance, and the knowledge that many of the other contributors were gathering together might have engendered a sense of isolation and separation. However, after the event, the decision had been taken, and no further agonizing over ambivalent feelings was necessary. In addition, in contrast to her previous ambivalence about continued involvement in the project and her relief that is was over, Sue also says that when she saw Helen’s writing on an envelope as she picked up the mail, she could not wait to read her letter. When she saw that the letter was a request for further information to “close” the project, she was glad to be involved once again. This response resonates with Charlotte, who said what a lovely surprise it was to receive Helen’s letter and hear further news of the project. Helen V also valued the fact that another opportunity for involvement had been offered. As she says,

By allowing us to do this on four big occasions so far, the project has changed my life, helped to keep me attached to life: the writing; the launch; the meeting; and now this. (Helen V)

CONCLUSIONS

Many of the findings of this research endorse those discussed by Dyregrov (2004), in that participants valued the chance to help others, experienced recounting their stories as therapeutic, and did not regret their participation but also acknowledged that recalling painful memories was distressing.

However, the process analyzed in my research is somewhat more complex. Not only did the participants contribute their stories, they also developed relationships over time with both Helen and me, and with each other. They were also confronted with the tangible outcome of their contribution in terms of the book, its launch, and the activities surrounding that event.
It is difficult to separate the experience of being involved in the research and the impact that had with the additional effect of the book. When the call for narratives was made, neither the researchers nor the participants could have anticipated the extent of the outcome. Thus, in some ways, the participants’ contributions have been used more extensively and with greater impact than might have been assumed at the outset, and they have also been confronted with a tangible product that is, in some instances, viewed with a degree of ambivalence. The pride with which the parents regard the book is clear, yet the guilt that the inability to read it engenders is perhaps surprising. There is, after all, no reason that they should read it, but there might be an assumption made by friends, family, and them that it is the “obvious” course of action. Of course some parents have read it and keep rereading it, thus indicating the range of reactions to involvement. In addition, the intimate details of family life have been laid bare to public scrutiny—again engendering ambivalence—the lasting memorial versus the potential betrayal.

The project was designed to contribute knowledge about a little understood or researched area, and resulting publications were intended in part for use by other parents undergoing similar experiences. Yet, in the responses, we see the contributors themselves using the outcome in just such a way.

We have also seen that many participants experienced their involvement in the process as therapeutic. Yet, the research could not have been intended as “therapy.” Indeed, Bingley (2002) has discussed the need to separate the research process from offering therapy. Bingley argued 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, one of the beneficial—albeit unintended—consequences of this project has been the therapeutic nature of the experience for many contributors. Such an effect can never be assumed or used to justify intrusion into the lives of participants, yet we can learn much from the process when such effects are reported.

In addition, the research was atypical in certain fundamental ways. Those who instigated it had firsthand experience and then acted as the interface between the researchers and the participants. The process began remotely from the participants but engaged them on an increasingly personal basis for an extended period. Many of the participants met each other and struck up relationships independent of the research environment. Furthermore, of course, the topic of the research was one of the most painful that can be imagined—the life-threatening illness and, in many instances, the death of a son or daughter.

By examining the effect on the lives of the participants in such an extreme case, issues relating to the vulnerabilities and needs of research participants are thrown into sharp relief. We can see the significance to participants of being consulted throughout the research process and of retaining power and control over their involvement. It is also clear that once their active participation is over and the data have been gathered participants continue to be engaged in the outcomes of the research. They need to feel that the results justify the demands made on them and that they have been fairly and adequately represented, a particularly important issue when they are “paying tribute” to those whom they have loved and who might have been lost.

The responses also indicate that participation might present risks to contributors. Nevertheless, the value attached to having contributed to such a project is also
made clear. Attention from a researcher might act as validation, and the telling of stories can be therapeutic. Yet, we cannot assume this will be the case, and, indeed, it is clear from the responses in this article that a range of emotions have been generated among participants despite the similarities of their involvement and experiences.

However, despite the need for care to be exercised, and an acknowledgement that research might result in discomfort for its participants, the general tone of the responses here is positive. It seems fitting that the final words should be from a participant, who illustrates this as follows:

I can now value Alexander’s death with the same equal measure as his life, for its profound effect on shaping our future lives and the whole experience being used for the future benefit of others. It has given added meaning to our loss. It will continue to reinforce my newer need to work helping children and adolescents with cancer and their families. (Denise)

REFERENCES


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