'No, you don't know how we feel': Groupwork with children facing parental loss

Gillian Chowns[1]

Abstract: *Groupwork with bereaved children has become increasingly common, with closed and open groups, day and residential programmes, and even online chat rooms offering different approaches and purposes. However, working with children anticipating potential bereavement has received much less attention. Similarly, research within this area in palliative care has been notable for two things - its paucity and its failure to address the perspective of the children themselves.*

As a palliative care social worker, whose remit was to support children whose parents were receiving palliative care, I searched unsuccessfully for research that was child-centred and child-friendly, and which would enable children to articulate their beliefs and experiences effectively. Thus, for my doctoral thesis, I turned to the action research paradigm for an approach that would more effectively engage with and illuminate these children's experiences, and undertook a collaborative inquiry- where the research is conducted with *rather than* for, on, *or* about *the participants – with nine children aged from seven to fifteen.*

Collaborative inquiry raises - and challenges - many key issues in both research and groupwork, such as voice, power and identity, ethics and competence. This article addresses a number of these issues, with a particular focus on identity.

Key words: *collaborative inquiry; palliative care; power; children; co-researchers; voice*

1. Visiting Fellow, University of Southampton, and formerly Specialist Palliative Care Social Worker, East Berks Macmillan Palliative Care

Address for correspondence: 54, Ashley Rd, Farnborough, Hants. GU14 7HB. gpatgc@aol.com

Introduction

Groupwork with bereaved children has become increasingly common, with closed and open groups, day and residential programmes, and even online chat rooms suggesting a range of approaches and objectives. (Barnard, Morland, & Nagy, 1999; Monroe and Kraus, 2005) However, working with children *anticipating* potential bereavement has received much less attention, although the situation within palliative care is at last beginning to change (Heiney and Lesesne, 1996; Firth, 2000; Landry-Dattee, & Delaigue-Cosset, 2001; Naudi, 2002). Similarly, research within this area has been notable for two things – its paucity and its failure to address the perspective of the children themselves (Chowns, 2006).

As a palliative care social worker, whose remit was to support children whose parents were receiving palliative care, I searched and failed to find research that was child-centred and child-friendly, and which would enable children to articulate their beliefs and experiences effectively. Thus, for my doctoral thesis, I turned to the action research paradigm for an approach that would more effectively engage with and illuminate these children's experiences, a

> … participatory, democratic process concerned with developing practical knowing … it seeks to bring together action and reflection, theory and practice … in pursuit of practical solutions to issues. (Reason and Bradbury, 2001, p. 1)

Collaborative, or participative inquiry, identifies itself as a distinctive member of the action research family through its emphasis on a collaboration between people that values the non-academic as well as the academic, that refuses to privilege the latter above the former, and seeks to break down traditional barriers between 'experts' and lay people. Heron and Reason (2008) and others (Elliot, 1991; Bradbury, 2001) argue for moving away from research on, for or about other people with its attendant risks of patronage, censorship and reinterpretation, and for embracing a co-operative approach that is respectful of ordinary people and confident of their ability to contribute to the process of making knowledge. Thus, those involved are no longer subjects – a curiously misleading word that usually denotes the reverse, that they are simply the objects of the researcher's interest, and the means by

which she or he achieves personal and academic gain – but are defined as co-researchers, with the implication that they have genuine power throughout the process, from design to dissemination, rather than simply during the fieldwork period.

By definition, a collaborative inquiry is a research process which not only involves working with groups but requires a shift in the group dynamics, since, as noted above, it constructs all the 'inquirers' as co-researchers and recognises the expertise of those who have lived the experience which is being researched as equally 'expert' as the academics or professionals who, in other research paradigms, would be identified as the experts and leaders.

Background

Palliative care 'which affirms life and neither hastens nor prolongs death' and seeks to improve the quality of life for those facing a terminal illness such as cancer, has always recognised the importance of the family; there are frequent references to the family as 'the unit of care' (WHO, 2002), and to palliative care taking place 'in the context of the family' (Sheldon, 1997) but it seems that children are largely seen but not heard in palliative care (as opposed to bereavement care or counselling) literature and that the adopted research methodologies reinforce this.

In other research disciplines, however, there has been a lively debate about children and childhood (James & Prout, 1997; Christenson, 2000; Lewis & Lindsay, 2000). A key figure in this move towards a more competency-based model of child research is Alderson, who, well over a decade ago, was arguing powerfully that 'very little research is devoted to listening to children at length and seeing how their responses deeply express their individual experience' (Alderson, 1995, p. 40). She argues for an 'impact on children' statement to be attached to all research, in much the same way that 'impact on environment' or other sustainability measures are now routinely required for building and development proposals. While supporting the case for clear ethical guidelines, she also highlights a concern that too restrictive an approach may effectively disempower children because it will prevent them from participating on a more equal footing.

Within palliative care research, this call has gone unheeded, and even

those texts that purport to focus specifically on the family have little or nothing to say on family members below the age of majority, referring almost exclusively to adult partners, relatives or carers (Twigg and Atkin, 1994; Nolan *et al.*, 1996; Foley, 2001). With a few notable exceptions – Sheldon (1997) and Oliviere (1998), Christ (2000), and Kissane and Bloch (2002) – children rarely merit even a chapter of their own, and at the other extreme, they do not even make the index. The explanations for this lacuna must be tentative, but four factors can be posited:

- First, palliative care has historically been situated within a medical discourse where the emphasis has always been on adult autonomy, and children by definition have been dependent, subordinate and, paradoxically, specialised. Palliative care, theoretically applicable to many other diagnoses, has in reality always had a symbiotic relationship with cancer, a disease more prevalent in the elderly than in the child-bearing, and although this has changed substantially over the last half-century, professionals have been slow to identify and support this latter group.
- Secondly, there may be a reluctance to engage with this particular population. As Dyregrov (1991) argues, distressed children challenge our deeper, instinctual beliefs about childhood as a time of untrammelled innocence. So painful may it be to enter into the child's experience of uncertainty, loss and abandonment, that we turn away, unable to confront the challenge.
- Thirdly, the territory that is children anticipating bereavement is unpredictable, uncharted and swampy underfoot. It is difficult to remember – accurately – how we saw the world as a child. As adult professionals we may relate relatively easily to other adults, for we inhabit similar worlds; we cannot be confident that we can see or understand the child's world. Therefore we may fear doing further damage and feel it is better to do nothing than, potentially, do harm. This notion of children as vulnerable and fragile has had a long shelf-life.
- Fourthly, the needs of children who are themselves physically well, but distressed by their parent's illness have had to compete (in research terms) with the needs of children who are dying, or adults who are terminally ill. Inevitably, perhaps, they have come a poor third in the pecking order.

It is unsurprising then that there is relatively little research about the support needs of children facing the likely death of a parent.

Brief story of the project

Research in palliative care has always been problematic, from both practical and philosophical viewpoints (Seymour and Skillbeck, 2002), and pre-bereavement work, whether with those who are terminally ill or the children of the terminally ill, is by definition mired in uncertainty (Christ, 2000, Chowns, 2005). Collaborative inquiry requires a critical mass of people and time and it is difficult to guarantee either in settings of serious illness. Working with child researchers from a wide age range presented further challenges and it was imperative to find an approach that would hold the children's interest. The plan was for the children to make their own video, for public sale. The attractions of video were threefold: it was a contemporary medium, likely to appeal to children; it lent itself to a group process; and the product of the research was user-friendly in the sense that it was easily accessible to families and gave them control, since they could watch it together or individually, in snatches or from beginning to end.

The video, although part of the study and an output in itself, was addressed primarily to other families facing similar situations. The children identified the themes to discuss, examined them through debate, interviews, games and reflection and planned and executed the filming. At the same time, a static camera recorded all the sessions including the facilitators' debrief and supervision sessions, for a second aim of the project, discussed elsewhere (Chowns, 2008) was to research the process of a collaborative inquiry. Thus the Video Project was also an in-depth case study of an individual inquiry. The project therefore raised – and challenged – many key issues in both research and groupwork, such as voice, power and identity, all of which are interrelated to a greater or lesser extent. Ethics, competence and autonomy, are also particularly significant issues in a project involving children (Alderson, 1995 and 2000; Lewis and Lindsay, 2000; Christensen, 2004; Farrel, 2005) and life-threatening parental illness, and the Video Project was no exception. However, this paper will focus on the practicalities of groupwork within this particular research context.

The co-researchers

Given that cancer is largely a disease of older people, there are relatively few patients with young children, so there was not a large pool of families on which to draw, but we were able to begin the project with a total of nine children from five families and with four adult facilitators, one of whom was a participatory video expert. Our co-researchers ranged in age from 7 to 15. Both the youngest and the oldest were boys; the seven girls were much closer in age, from 10 to 14. Chronological age is only one indicator however; the seven year old was noticeably young for his age, and this posed considerable problems in ensuring that the sessions kept the attention of all the children.

Within the group there were three sibling sets: a brother and sister, three sisters, and a set of girl twins. The twins were of dual heritage (Japanese-English), the others were all white Commonwealth, with eight of the nine children considering themselves British. None of the children had a physical or mental disability. The five families included divorced, separated and two-parent families. Seven children had a sick mother, two a sick father. The parental illness was cancer in all cases but diagnosis, prognosis, length of illness and treatment varied considerably. Parental diagnoses included cancer of the bone (1), the breast (3) and cervix (1). In three of the five families, the parents had separated or divorced and the children concerned were living with the sick mother.

The age-range of our participants inevitably affected their performance as co-researchers in a number of ways. Jack, aged seven, clearly had a much more limited understanding of the notion of research, fewer social skills, and a more limited concentration span. On the other hand, one could argue that his spontaneity, lack of artifice, and emotional directness more than compensated. Nevertheless, he was unable to engage in the iterative process in the way that some of the others could.

The adult co-researchers

Three of the four adults were qualified social workers with substantial experience in working with families experiencing change and loss. Specific expertise included groupwork, counselling, adoption and fostering, disabled and seriously ill children, family therapy, teaching,

and for all three, palliative care. The fourth had substantial experience in participatory video-making, which included not only considerable technical skills, but also skills in enthusing and engaging young people. In contrast to the young people's family background, all the adults were in stable, long-term partnerships. The three female members, all with adult children, had each had many years of parenting; the male member became a first-time parent during the course of the project.

From preparation to practice:
The reality of collaborative research with children

The preparation phase was the key to the project's success and needed to address considerations of recruitment and retention of group members, ethical issues, the structure and content of the sessions, the dissemination process, the role and relationship of the adult facilitators and much else (Chowns, 2006). Thereafter over a concentrated period of seven weeks the 13 members met to research the children's experience and record the material for the film, with the facilitators meeting after each session to debrief and then to plan for the next one. Over a further three months the group reassembled to critique the editing process and approve the finished film.

Session One

In the first session, there were four main aims, which were unashamedly facilitator-driven: to get to know each other, to negotiate ground rules, to 'have a go' at using the video equipment, and to identify what the children wanted to work on. This last, though adult-initiated, was consciously child-centred, non-directive and collaborative. It was important to establish at the outset that all contributions would be valued and that the young people were the experts in the topic being researched. However, it was clear that the children initially saw themselves in the traditional role of pupils seeking information and permission from teachers. Contributions to the 'worry box' (a small post-box in which all participants were free to post anonymous concerns or questions) included:

Could we ask the others some questions – but not too personal?
If we don't want to be filmed, can we sit out?

However, although the children looked to the four adults for definitive answers to these questions, we were able to use those questions to continue reinforcing a more egalitarian message. So, we used the first question to prompt some discussion and indicate that it was not just the adults who would make decisions. And we used the second question to reiterate the principle that each participant had a choice – *'It's up to you, it's your choice'* was a constant refrain throughout all the sessions.

By the end of Session One, the children were becoming more confident. The brainstorming of themes for the video worked particularly well and Megan and Rachael and Laura C entered into the discussion enthusiastically, feeding off each other's contributions. In contrast Ellis, Jack, the twins and Laura and Becky did not volunteer contributions, but endorsed various ideas.

Sessions Two to Six

In these there was a mix of the familiar and the new. Each session began with welcomes and a feedback activity 'Good Things, Difficult Things' using post-its for everyone to identify what they had enjoyed and what had been more difficult for them in the previous session. Reading these out then generated discussion and reflection on commonalities and differences; causes and consequences were identified, and suggestions for future activities generated. Similarly, at the end of the session, the whole group would reassemble for a short period, with space to reflect on the session and think ahead to the next one. Over the course of the project the opening activity became very well-established; the closing slot suffered more from time pressures, lack of concentration and sheer tiredness.

In session two, there were some indications that the children were feeling more empowered:

First exercise to discuss and plan an interview – all looking down at their feet- then Laura gets the clock from the wall, takes on role of time-keeper, and Megan picks up paper and pen to write captions for interview – her own idea.

This empowerment was not consistently well embedded; at times the children reverted to dependent/pupil role, and the facilitators themselves failed to demonstrate sensitivity to child empowerment. After a later session my diary notes that:

Jack volunteered to operate the camera, but the adult facilitator did not follow this up (possibly assuming that he would not be competent?) and missed an opportunity to hand over some control to a child whose family life (his mother was deteriorating fast) was out of control.

Expressionists?

The 'meat' in each session was often new territory – operating the camera, interviewing each other, critiquing footage, exploring an issue such as stress or truth-telling, planning how best to capture the findings on film. Working with a wide age range, and even wider developmental range, meant an emphasis on action rather than talking, lots of variety, the concrete rather than the abstract, the visual rather than the verbal, and a constant attention to pace as well as to process. The painting activity in session 3 met many of these criteria. Depicting their emotions through art was something the children embraced enthusiastically; their paintings were graphic, powerful and triggered some passionate but thoughtful exposition of their meaning.

Jack, aged 7, produced a painting of a single emotion, which he identified as 'Sadness'. As he spoke, his whole demeanour and tone of voice exemplified this. When Laura C responded empathically, saying *'It looks like a face … like you're screaming … '* he simply nodded quietly. Nick then made a verbal leap of interpretation by saying, *'That was a picture of when you feel scared? When do you feel scared?'* to which Jack replied in a half whisper, *'When my Mummy's not well'*. During this exchange, there was a profound silence from the rest of the group, all of whose body language indicated the intensity with which they were concentrating on Jack. Nick then asked of the group, *'Do a lot of people feel like that?'* There was no verbal response, but Laura C put up her hand in assent .

Megan's and Rachael's paintings expressed a mix of emotions, but it was Laura C who both painted and articulated the maelstrom of

emotions most openly. During the discussion before starting to paint, Megan had asked the group to each choose one emotion to paint. Laura came up to the flip-chart sheet and unlike her peers who had underlined one emotion, she circled the entire map, containing every emotion suggested by the group within this circle. She then worked furiously at her painting, daubing a mix of darker colours in large spots and blotches all over the paper until none of the background white was visible. She explained her painting thus:

It's like NOTHING – mixed emotions. I always feel more than one. The idea of combining colours … combining emotions … You can't express the way you're feeling … One moment you're skipping, next you're kicking, you're playing with friends, then yelling (at them)

The welter of emotion which she had just put onto the paper seemed to be matched by the welter of ideas and words that she struggled to put together in a coherent form. There was a notable contrast between the disjointed muddle of paint and words at this point and her usual mode of organised planning and idea-generation, which may have indicated how difficult this capable, assertive child found it to 'manage' her experience.

Session Seven

In the final session three key tasks remained. All remaining film footage needed to be reviewed and consent obtained or withheld; the work of the group and the meaning of the experience needed to be celebrated; and the end of the group needed to be mourned and accepted (Firth, 2005; Doel & Sawdon, 1999). A fourth, less expected task required the death of the parent of two members to be sensitively acknowledged. In reality, the session bore little resemblance to the carefully crafted plans, primarily because two members arrived half-way through, one bereaved sibling came only for the celebration lunch and closing activity, and the other bereaved sibling chose not to participate in group activities but to work alone with one adult. Nevertheless, although the plan had to be abandoned, the preparation that had taken place enabled the adults to achieve these four tasks amidst what felt like constant chaos.

Out of these carefully planned but sometimes chaotically experienced sessions came the twenty-five minute film entitled 'No – You Don't Know How We Feel.' It celebrated the work of the child co-researchers and honoured experiential, presentational and practical knowing (Heron and Reason, 2001); as a case study it was able to demonstrate a significant shift in the power relations of research and provided evidence of its transformational power for both participants and for palliative care practitioners in the wider world. For participants, the inquiry took them on a journey towards empowerment (Warren, 1997) that was both challenging and positive. Although, as noted above, in the early stages of the project they were sometimes hesitant to use the power offered to them and looked to the adult facilitators to lead them, in later sessions they more readily took charge and, during the editing process, were able both to be critical of their own contributions and, ultimately, to recognize the significance of what they had achieved.

'*at first I was unsure* [of the value of the project] *but after watching the final video I realised how much it could help others.* (Ellis)

Reflections on the 'group'

The above section has described some of the group's activities; now I turn to the nature of the group. What sort of a group was it – or more accurately, what sorts of groups formed it?

The research group

Its avowed purpose and primary function was as a research group – a participative, collaborative group of individuals, each with particular interests and expertise that overlapped without entirely matching, but with sufficient commonality to be both manageable and effective. We did not all know and understand and experience the same things, nor were we equal in the skills we brought; but as Marshall and Maclean acknowledge (2001) co-operative inquiry is not about equality. Nevertheless we strove to be genuinely collaborative. We all signed up, as it were, to the task of exploring children's experience and needs. Within that all-embracing task, however, there were gradations of

interest. For all the young people the chance to help others was very important, as has been acknowledged above. For some the medium, i.e. the technology of video recording, was significant:

I wanted to learn more about video. (Ellis, Open meeting)

For Nick, running his own small business, it was both a commercial opportunity and a chance to use participatory video, a way of working to which he was deeply committed, with a new group and a new subject. For my two colleagues, it was an opportunity to learn more about children's needs and therefore to improve their own practice in palliative care, as well as an innovative project that enabled them to use their groupwork skills in new ways.

For myself, it was a vehicle to perform research in a way that accorded with my ontological and epistemological beliefs, and an opportunity to improve practice not just locally, for myself and my colleagues in our two teams, but more widely on the national stage for both professionals and parents.

There were also gradations of expertise. Typically, and sadly, it was the males in the group who had most expertise with the technology. Nick was the professional expert, but Ellis had above average skills. The three female adults contributed little in this area! However, we did lay claim to substantial skills in group dynamics, listening skills and knowledge of, in the sense of knowledge about, children facing potential bereavement – something about which Nick knew nothing. None of us adults however, had the experiential knowledge and expertise in living with parental serious illness that was located entirely in the children. I alone had an academic interest in the products of research, as a lecturer in palliative care; in generating research, as a doctoral student; and a knowledge of collaborative inquiry as a methodology.

The therapeutic group

While the group was undoubtedly a task-focused collaborative inquiry, it was potentially also a therapeutic, transformative group. That this was not its prime purpose did not invalidate the obligation to 'manage' that potential and recognize the meaning that the group had for its members. Before the group began, the children had some knowledge

in common and some variables. All of them 'knew' about the purpose of the group and its time-limited nature, and 'knew' that it would not continue beyond the 6 or 7 sessions scheduled. Some of them 'knew' some other members before the group began, either because they were siblings or because they attended the same school. Gemma and Natalie, the twins, 'knew' each other in a way that no-one else did, but considered the other seven as strangers, and Ellis 'knew' absolutely none of the other children.

Inevitably, their common background of parental illness and their enthusiastic commitment to the task meant that relationships were likely, and indeed needed, to develop quickly in order to achieve the prime purpose. By the third session, it was evident that the group had an identity and meaning beyond its practical task. This development of group cohesiveness and the altruism implicit in making a film to help other families were just two of the therapeutic factors identified by Yalom (1995) as significant for therapeutic groups.

The opportunity to talk about their feelings, to have them acknowledged and treated seriously, and to discover others had similar fears and feelings, was a powerful release and clearly cathartic. For example, in a discussion about feelings, nearly all the children could empathise with Laura C, who spoke eloquently about her frustration and confusion :

Your brain capacity basically just clogs up. (Final film version)

This confirmation of shared feelings was mutually helpful. Laura was helped by finding she was not the only one feeling that way and the others were helped by her honesty in opening up the subject. Sometimes, the therapeutic element was immediate and the children responded instantly. Other times, the reflective aspects of the inquiry facilitated this, at the end of a session or after a lapse of a week, when reviewing the week's footage, or when reflecting at the beginning or end of a session led to a more considered and thoughtful response to what had been said or done.

Interestingly, the potential for sharing emotions was almost as significant as the actuality, as this exchange in an early session shows:

'This is like a club' said Rachael during the tea -break, as she munched a packet of crisps. *'We can talk about what's happening.'* *'But you haven't'* commented Alison, gently challenging her. *'No, but it feels like we could'* was the response. (from debrief session 3)

And in later sessions, as different members recalled their experiences, relived powerful emotions and identified coping strategies, not only were the cathartic and existential factors very evident, but also that of universality.

This project is brilliant. I've never met so many people in the same position as me … I thought I was the only one. (Megan, in final version of film)

In echoing Megan, the twins go on to identify the interpersonal learning and imitative behavior that Yalom (1995) also highlights as key factors.

You feel so alone … no-one else knows what it's like … here you can share things … get ideas … a different perspective. (Gemma and Natalie, in final version of film)

In the course of the project, members were able to learn from each other and practise new ways of managing their emotions and communicating more effectively with family, friends and school. If this contributed to the development of socializing skills outwith the project, it appeared that such skills were readily accessed within the group sessions. This was evident when, occasionally, individual children became distressed as they recalled events in the past, or struggled with the reality of a parent's anticipated death. At these times, other youngsters in the group instinctively supported them, taking them aside to spend time with them, and explaining to the rest of the group what the distressed friend needed in the way of space or comfort. Although we adults were ready and willing to do this, it was their peers to whom the children most readily and in our view, appropriately, turned.

Multiple memberships

So far, I have written of the group in the singular, but I turn now to the reality – and complexity – of the multiple group memberships which, children and adults alike, we held within the collaborative inquiry group.

In terms of the children, there were two gender groups – seven girls, two boys – but there were also school and sibling groups. Megan and Laura C, from two different families, attended the same school and wee good friends. Megan was also a member of the D sibling group of three; Jack and Becky were a two sibling group, and Gemma and Natalie occupied a very distinct place as members of a sibling-twin group. But Becky and Rachael D (Megan's sister) were very close friends, and shared information and feelings about their parent's illness with each other that they withheld from their own siblings; this group membership took primacy, at times, over sibling group membership.

For the adults, memberships were equally complex. For example, as a reflective researcher, I myself struggled with the notion of identity and the related matter of membership. Where did I belong in this project? How possible – and wise – was it to hold membership of different groups? I was committed to collaboration as an ethical and effective way of researching, and saw, and deliberately constructed myself as a member of the 13-strong collaborative inquiry group. I used 'we' rather than 'I' and religiously reminded everyone at every available and sometimes inappropriate opportunity that we were all researchers together, and that the choices were ours together, not mine or the adults. But I could not avoid also being a significant and powerful member of other groups. Most obviously, I was a member of the adult group. However democratic we tried to be, we could not, and indeed did not, hide our responsibility for some matters – clearing up, negotiating the use of the room, planning the opening and closing sections of each session, and (very importantly!) purchasing the refreshments. But within the adult group there were sub-groups. I belonged quite clearly to the social work group, consisting of my colleagues Sue, Alison and myself. Just as clearly, I belonged to the middle-aged, experienced mother group, which was co-terminous with the social worker group. Both of these groups excluded Nick. I also belonged to the two-person Macmillan team group – which thereby excluded Alison and Nick.

All the children were recruited by this group, in which I occupied a particularly important role as the social work link to three of the five families and thus, six of the nine children.

Finally, and most problematically, I was the bridge between two distinct groups – the palliative care experts and the video expert. Neither group had expertise in the other's field, but I could claim some expertise in both, or at least some vision and enthusiasm for video as a medium. And it was I who met and appointed Nick and introduced him to the others. He was my choice, known slightly to me but not at all to the other two social workers. It was not easy for them to trust this stranger and I had to work hard to help each group accept the other.

> *I still don't think Nick realises the impact it will have on him, working with these children whose parents are dying – especially when he is just about to become a Dad.* (Sue – Supervision meeting)

> *Meeting at Sue's with Sue, Nick and Alison. Used Doel and Sawdon's exercise – very helpful. Good sharing. Alison was able to acknowledge how much she had shifted. I felt there was much more clarity re Nick's and our roles. Sue and Alison highlighted FUN -I'd forgotten this. We all shared fears and strengths.* (Reflective Diary).

Social worker to some of the children, facilitator to the whole group, lead researcher and project leader, employer of and collaborator with the video expert, link person, architect … . I came to see that the theoretical notion of self promulgated in some of the research literature did not adequately reflect these many memberships.

Ethical issues and groupwork principles

Researching sensitive topics requires particular attention to ethical issues (Greig & Taylor 1999; Christensen & James, 2000; Lindsay, 2000) and to the intangibles of ethos and atmosphere (Lee, 1993). Formal approval from the local research ethics committee was sought and obtained, but ethical research is much more than just this. In order to facilitate open exploration of potentially very sensitive subject matter, we adults had a responsibility to create a safe, secure and boundaried

environment that would not only permit free discussion but would also contain the distress and anxieties of those involved.

For this, we worked largely within established traditional patterns of groupwork. Ground rules were negotiated – collaboratively of course – during the first session, printed up and given out to everyone at the second session. At the end of each session the agenda for the next week was decided collaboratively. The adult facilitators consciously modelled principles such as respect for everyone's view, sharing concerns, and honesty and reflection.

Voice and choice

Most groupwork facilitators are concerned to ensure that all in the group have a chance to be heard, and that the articulate few do not dominate the reticent majority (Doel, 2006). In the video project, we were alert to this, but the collaborative endeavour provided the children with a much greater choice of ways in which to contribute. Laura D was a good example of this dynamic. On film she was often out of shot, and her voice was rarely heard. In the sessions themselves, she was quick to contribute ideas about the process of film-making or activities to generate discussion and she worked hard to encourage her co-researchers. But she was consistently adamant that she did not want to speak to camera about her experiences. In a small group preparatory exercise to help them marshal their thoughts before filming, each child was given one minute to talk about their feelings about parental illness, without interruption from the rest of the group, but Laura instantly refused, saying 'I'm not going to say anything.' Her two colleagues each spoke for a minute and when it came to Laura's turn, the facilitator acknowledged her wish not to speak but said they would still time the minute. The other two children broke the silence several times to try and persuade her to speak, and were gently reprimanded by the facilitator, who reflected at the end of the minute that it had felt like a long time, but that ' Sometimes it's good to just sit and be silent'. Laura's determination to resist the combined pressure of her peers spoke volumes (!) and the facilitator's support for her choice was significant; it valued Laura as an independent, important member of the project and it demonstrated graphically that

we adults would respect autonomy and independence in children –a principle we had made explicit from the beginning but a promise that adults often break in practice.

Though not a promise, or a principle, a guideline that we clearly ignored was the ratio of adults/facilitators to children. Notwithstanding the fact that, adults and children alike, we were all co-researchers, we adults could not abrogate our responsibility as facilitators of the group. But most groupwork theories (Bion, 1961; Brown, 1996; Whittaker, 2001; Doel & Sawdon, 1999) recommend no more than two facilitators per group, and all emphasise the importance of an appropriate ratio of leaders to participants. In our group of 13 members, four were facilitators, a ratio that most theorists would regard as not just excessive but counter-productive, particularly given the obvious imbalance in age and likely one in power.

Nevertheless, our experience appeared to challenge the accepted theory. We shared out the facilitator tasks between us, rotating roles in each session, so that each of us at different times was responsible for the opening or closing section, for refreshments, or for specific activities. Since there were often smaller, sub-groups working on different activities during the session, as well as Nick overseeing the technical side, all four of us were fully occupied throughout the early sessions.

In the later sessions, it was noticeable that there were times when two out of the four of us would be quietly observing or standing back – something that we considered indicative of just how engaged, focused and competent the young people had become. Heron and Reason (2001) suggest that a mark of good collaborative inquiry is the gradual shift in roles, in which typically the facilitators take a clear lead initially but gradually enable the group members to take greater responsibility.

On the other hand, in the very last session, a fifth facilitator would have been useful. Two of us were occupied reviewing video diary footage on a one-to-one basis with certain individuals, a third was working quietly with the youngest child whose mother had died four days earlier, and the fourth was explaining an activity to two of the children who had arrived late. In between all this, the pizzas for the celebration lunch were quietly burning unnoticed!

We were naturally anxious about what seemed the over-preponderance of adults in the group. However, feedback from our young colleagues

appeared reassuring. To the question in the formal feedback sheet, 'If we ran another group, how many adults should there be?' they could choose from:

1. just one
2. two or three
3. four, as in this group

All of them chose the third option. It is possible, of course, that they were simply being polite, but their trenchant comments at other times during the project suggested that they were quite capable of being critical when necessary. Perhaps we can at the least claim that they had not experienced four facilitators as overwhelming.

The other departure from convention concerned anonymity. The use of participatory video to make a film for public distribution immediately rendered anonymity impossible. To have asked the children to give themselves false names and to remember to address each other in this way throughout the sessions would have been inhibiting and impossible to achieve. The consequences of both anonymity and identifiability were discussed carefully with the children, and they were clear that they should use their own names. More importantly, they themselves decided how to introduce themselves – in the sense of how much family information to share – in the film, and, crucially, they had editorial power. Every tape was reviewed by the children and it was their decision as to whether it could be used in the final version or not. Thus their consent was retrospective as well as prospective; nothing appeared in the public film that they were not happy to own.

Discussion

Much of the literature on groupwork makes a clear distinction between task-oriented groups and therapeutic groups. Collaborative inquiry claims to straddle these types, arguing that the group is primarily task-oriented but inevitably therapeutic, since it is concerned with a holistic approach to people, values individuals for themselves and attends to both inner and outer experiences.

Similarly, it embraces some aspects of ethnography and may superficially appear to resemble a focus group, but is neither of these.

Like a focus group it is clearly a group brought together for a limited period for the express purpose of considering a specific topic. However, a major difference lies in the framing and power dynamics. In collaborative inquiry, the group is generally in charge of its direction – it is participative, collaborative, and in control. The focus group is more often set up by an outsider, the agenda is set by that person and, while the group may and often does take on a life of its own, ultimate control rests with the researcher.

Limitations

Although collaborative inquiry, by contrast, allows for significant transfer of power from the professional researcher to, and for a clearer articulation of the voice of, the participants, it nevertheless, like any methodology, has its limitations. Significantly, the social context in which collaborative inquiry with children operates will undermine its aims. In a world where children have fewer rights and powers than adults, one must question the ability of (even) collaborative inquiry to deliver a significant shift in the democratisation of power relations in research with children. Children's experience – at home, at school, and in the community – is that adults rather than children hold the power, make the decisions and see themselves as wiser, more expert and competent than children. Our collaborative inquiry with children asked them to believe, first, that the opposite could be true, and secondly and perhaps more importantly, that a set of adults could be trusted to do what they say, and share power. The two, three or four hour sessions predicated on these principles were brief interludes in an adult-centric social context that framed them largely as vulnerable, incompetent or dependent.

Secondly, the principle of collaboration was not always consistently maintained. For example, both the impetus and the method (making a video) came from the professional alone. This was not, therefore, 'bottom-up' research; it could be argued that the topic and the method was imposed on the children in a way not unlike most research is constructed. On the other hand, as Heron and Reason (2001) allow, there are as many ways of doing action research in general, and collaborative inquiry in particular, as there are people and topics. What may be modestly claimed, in this study, is that the topic and the

notion of producing a video were not experienced as an imposition by the young people but resonated strongly with them.

In addition, assessing how free the co-researchers considered themselves to be in both expressing views and shaping the activities remains problematic (Alderson, 1995). My practice experience and personal knowledge of the young people, together with the evidence of some very frank criticisms of, for example, 'counsellors who ask too many questions' and 'boring' bits of the film, suggest that they felt relatively able to express their opinions. The unsolicited comment from Gemma would seem to support this:

We wondered how much control we would have … but it turned out that we were in charge.

Fourthly, while the children's collaboration in the dissemination of the research was ground-breaking, it was nevertheless still modest. It grew not from a desire of the children but from my conviction alone of its appropriateness. Neither my adult colleagues nor the children sought to challenge the current thinking on dissemination; this was an aspect of the project that I alone imposed, or championed, depending on one's point of view. And it was a very limited participation – the selection of suitable conferences, the submission of abstracts, and the structure of the presentations was undertaken by myself alone. My co-researchers were free to construct their own sections as they wished, for I exercised no editorial control, but this again was a somewhat limited achievement.

Perhaps even more significantly, my own vision of collaboration did not extend to the key stage of data analysis. In part, of course, this was based on very pragmatic notions of time available, understandings of research processes and level of interest. Nevertheless, these were untested assumptions – I simply moved back into conventional researcher mode and denied them the opportunity to collaborate on a key aspect of the research process. As I reflect on this failure – while acknowledging the obvious difficulties and unlikeliness of their wanting to analyse the data – I see this as an illustration of the major challenges to achieving genuine collaboration with users who are non-adults. It is also a depressing example of researcher oscillation in respect of power-sharing!

Notwithstanding these criticisms, collaborative inquiry's particular emphasis on participation, its more radical interpretation of knowledge and its fundamental respect for users' perspectives were strengths that sat well with both the holistic approach within palliative care and the practical challenges of working with children.

Conclusion

This paper has identified the many facets of this collaborative research project and challenged some prevailing assumptions about the wisdom of encapsulating both multiple membership and purposes in one group. While it is both possible and important to distinguish between these in print, in the field and in reality these purposes and memberships merged and separated, competed and collaborated, collided, colluded and together shared in the creation of the film 'No- You Don't Know How We Feel.'

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