UNIVERSITY OF SOUTHAMPTON
FACULTY OF LAW, ARTS AND SOCIAL SCIENCES
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"No - You *Don't* Know How We Feel"

Researching the experience of children facing the life-threatening illness of a parent, through collaborative inquiry

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ABSTRACT

FACULTY OF LAW, ARTS AND SOCIAL SCIENCES
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"NO - YOU *DON'T* KNOW HOW WE FEEL" RESEARCHING THE EXPERIENCE OF CHILDREN FACING THE LIFE-THREATENING ILLNESS OF A PARENT, THROUGH COLLABORATIVE INQUIRY

By Gillian Chowns

Most research into the impact of cancer on families has been adult-focused and adult-controlled, typically within an oncology setting. There is a paucity of research which focuses on the experiences of children with parents receiving palliative care and which privileges their voice.

This study illuminates both this experience and the process of researching collaboratively with children on a sensitive topic. Nine young people and four adults co-researched the children's experience, through the mechanism of making a video for public use, while the project simultaneously served as an in-depth case-study of the process of collaborative inquiry. Two sets of findings emerge.

Children unequivocally prefer to be informed and involved. They wish to be told the truth as fully and as soon as possible. Delay and deception, for whatever motives, are experienced as destructive of trust. Children seek support and understanding rather than protection and prevarication. Facing the life-threatening illness of a parent brings a sense of isolation and the uncertainty about their parent's and their own future is all-pervasive. Nevertheless, the research demonstrates clearly that the children are capable, competent individuals who are active, reciprocal family members, not only carefully selecting coping strategies but also endeavouring to support and understand their parents.

The study also demonstrates that the principles of collaborative inquiry are well-suited to empowering young people to participate in the design, data generation and dissemination of research. Nevertheless, the socio-political construction of childhood runs counter to many of the values espoused by participatory inquiry, and thus limits the potential of the approach when applied to young people.
In the light of both sets of findings the thesis argues for a reconceptualising of childhood and offers a new model of the Able Child-Citizen, which is more respectful of the capacities and competences of the children, as revealed in this study.

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CHAPTER ONE: INTRODUCTION

"Doubt wisely; ...on a huge hill Truth stands and hee that will
Reach her about must, and about must goe..."
John Donne

Children of Dying Parents in Palliative Care Literature

Most definitions of palliative care have emphasised the importance of the family, with references to the family as 'the unit of care' (WHO 2002), and 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 (as opposed to bereavement) care literature and that the research methodologies adopted reinforce this. 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. 'Family' in practice refers to adult partners, relatives or carers (Twigg and Atkin 1994, Nolan *et al*, 1998, Foley 2001) and children are mentioned only in passing. With a few notable exceptions - Sheldon (1997) and Oliviere (1998), Christ (2000) and Kissane and Bloch (2002) - rarely do they 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. Although this has changed substantially over the last half-century, for example with increasing rates of breast cancer in the under-60's meaning that there are many more dependent children potentially needing help, professionals have been slow to identify and support this 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, as this thesis will demonstrate, 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 come a poor third in the pecking order.

It is perhaps unsurprising then that there is relatively little written about the support needs of children facing the likely death of a parent. As a palliative care social worker, whose remit was to support such children and their families, 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. It was then that I chose to embark on the research that informs this thesis and came to adopt an action research design and methodology that would more effectively engage with and illuminate these children's experiences.

Outline of the Thesis

I begin with an examination of the literature in two key areas related to my original research question, "What is the experience of children living with the life-threatening illness of a parent?" In Chapter Two I consider the research on supporting distressed children, beginning with the broader counselling perspective and then focusing down on investigations into the impact of cancer on families. I argue that much of the work excludes children from its definition of family and that it is overwhelmingly adult-driven, adult-oriented and adult-interpreted. I conclude that children are a marginalised group, their experiences under-researched, and their views obtained by proxy through the voice of parents and other adults. In my view this is indicative of assumptions about childhood that should attract a robust critique.

In Chapter Three I therefore move on to examine our understanding of the child and childhood. A brief historical overview is first offered before four key developments of the second half of the twentieth century are examined. The case of Maria Colwell demonstrated, *inter alia*, that the wishes and voice of the child were not sought, never mind attended to, while the Gillick case, despite muddying of the waters by subsequent rulings, indicated a substantial shift in both society's and the law's approach to children's rights. Nationally, the Children Act 1989 and, internationally, the UN Convention on the Rights of the Child 1989 gave greater recognition both to children's rights and to their competence to make decisions that affect them.

The second section builds on the notion of children's rights by examining whether their right to be heard as users in health and social care is acted upon. A consideration of the literature on user involvement leads me to argue that the language of involvement, partnership and participation, and the models favoured are context-dependent; the jargon is less important than the day-to-day **practice** of involvement which alone demonstrates commitment to the user's experience and expertise. Within palliative care, which lays claim to a holistic approach that defines the family as the unit of care, there are some encouraging examples of user involvement, but almost no evidence that the children of sick parents are recognised as users of palliative care services.

However, the final section notes an encouraging shift in the approach to child users within research. In considering the history of researching children I identify the dominant approaches within the health and social care and sociology fields and then review the more recent trends towards privileging the voice of the child as expert in their own experience. The international development community's work, using participatory rural appraisal techniques, provides evidence that children can be active participants in the research process. How I might achieve this, in the context of palliative care, is the subject of Chapter Four.

As a signatory of the UN Convention on the Rights of the Child, the United Kingdom has a responsibility to enable the voice of children facing serious parental illness to be heard in the first person, rather than by proxy. The literature review had revealed a paucity of research that located the child's voice and experience as central. My study was intended to fill this gap and as such, needed to honour the principles of user involvement and to respect the child's capacity and competence. In considering the traditional research methodologies, I identified a qualitative approach as more appropriate than a quantitative one, but found that while established methodologies, such as ethnography and phenomenology, all had something to offer, there was a fundamental failure to address the power imbalance between researcher and researched. I then moved on to consider action research and its place in the canon of competing research paradigms.

Next I discuss the claims of one particular branch - collaborative or participative inquiry - to challenge those power dimensions and to reflect 'the real world' and I critique those claims as inadequately accounting for the context in which all research takes place. I also note that collaborative inquiry has been constructed almost exclusively in terms of adults but I nevertheless conclude that it may offer the best approach for researching the experience of children, from the children's perspective. In Chapter Five I chart the process of translating the research design into the practice of conducting a participative inquiry with children into the highly sensitive topic of living with the life-threatening illness of a parent.

The story of the Video Project is set out in detail in this chapter. The chosen method for researching the children's experience collaboratively was the making of a video, by a group of children themselves. 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, for, as described in Chapter Four, my original aim had been expanded to include a second strand - that of researching the **process** of a collaborative inquiry. Thus the Video Project was also an in-depth case study of an individual inquiry. The chapter addresses considerations of recruitment and retention of group members, ethical issues, the structure and content of the sessions, and gives due emphasis to both the planning and preparation stages and the often neglected dissemination process. It also examines the role and relationship of the adult facilitators and includes a reflective section on the use of self.

At various stages it reiterates the caveat that the writing process imposes a more linear, logical and contained structure on the story than was evident in the practice.

Chapter Six consists of the final product of the Video Project - a twenty-five minute film entitled "No - You **Don't** Know How we Feel". It is the collaborative outcome of the research process and presents the children's voices unmediated by adult exegesis. As such, it is the closest it may be possible to get to collaborative research within the constraints of a doctoral thesis. I locate it intentionally at this point in the thesis - before the two chapters on the findings of the study. Chapters Seven and Eight are a re-presentation; an analysis that is individual, not collaborative and that is academic rather than experiential. Chapter Six celebrates the work of the child co-researchers and honours experiential, presentational and practical knowing. Theoretical and propositional knowledge are foregrounded in the following two chapters, one focusing on the findings related to the case study of conducting collaborative inquiry, the other on findings related to the children's experience of living with serious parental illness.

The key findings from the case study concern the appropriateness of collaborative inquiry as a research methodology to illuminate the children's experience. Collaborative inquiry enabled the children to be involved almost from the beginning by being in control of the decisions as to which aspects of their experience to research; through the fieldwork; and into the dissemination stage, when the work was presented at conferences to local, regional and national audiences. However, the findings also suggest that both adults and children are not able to consistently subscribe to and practise the ideals throughout the entire life of the project, and in particular, the analysis phase presents major problems for genuine collaboration.

I further argue that the findings suggest that the success of participative research approaches depends not so much on the principles of participation as on the day-to-day practice of relationships between co-researchers and the creation of a safe space for reflection, debate and disagreement. Notwithstanding the success of this project, the findings suggest that the social context in which collaborative inquiry with children operates - where they are seen as vulnerable, incompetent or dependent -will undermine its aims. Nevertheless, I conclude that this case study 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 that was both challenging and positive.

The following Findings chapter draws on Bronfenbrenner's ecological system (1979) to frame the findings. The children's experience of living with serious parental illness is illuminated through a consideration of the micro, meso and exosystems in which they operate. The major finding is that children experience a dysfunctional mismatch between their own and other systems' perceptions of them. The study revealed that children were conscious, active, reciprocal players in their family and school settings, rather than passive victims of a tragic situation. They selected a range of coping strategies in order to manage the stress and uncertainty of their lives and demonstrated a mature concern for their parents and significant others. No one strategy was endorsed by every single participant and the study resists the temptation to make generalised claims except in one respect - it found that all co-researchers were unanimous in wanting to be told the whole truth as early as possible.

In the penultimate chapter of the thesis, I return to the critique of the literature made in the early chapters and in the light of the findings from both the study of the children's experiences and the case study of collaborative inquiry within it, I argue for a revision of our understanding of the child and childhood. I contend that the dominant models of the child are inadequate to conceptualise the reality of childhood as it is lived and legislated for in the twenty-first century, and I offer a more holistic model, that of the Able Child-citizen - a model that better matches the evidence from this study. I also offer a modest revisioning of the concept of the reflective self in research.

The thesis concludes with a final chapter that serves as a signpost, one arm pointing back to the journey that has been undertaken and the other pointing forwards to destinations not yet reached. The study underlines the need to reconceptualise the child and childhood in a more active and central role, and I argue for the privileging of this new model of the Able Child-Citizen in palliative care practice, in research and in society itself.

Summary

An avowed intention of this study was to be transformative in terms of palliative care practice - to understand in order to effect change. The findings from this research highlight the need to move palliative care practice further along the road on which it has begun to travel - a road towards more genuine partnerships with clients, whatever their chronological age, physical, mental or emotional capacity. It is my hope that this thesis will make some contribution to this goal.

CHAPTER TWO: BACKGROUND TO THE STUDY; SUPPORTING DISTRESSED CHILDREN

"The technology of helping needs to be rinsed through with the wisdom of helping"

Gerard Egan

Introduction

Children of a parent who is seriously ill with cancer are less well represented in the oncology, palliative care and counselling literature than children who are already bereaved. (Furman 1974, Silverman and Worden 1993, Christ 2000, Worden 2002) The literature on bereaved children is substantial, and shares the same themes of change and loss, but its major difference is that it deals with children who are in a 'known' place; that is, their parent or significant other is dead, and they themselves are bereaved. Those certainties cannot change, even though their response to them may well change over time. Thus the needs, experience and challenges facing such children are distinctly different from those of children who may fear but do not know for certain whether or when they will join the ranks of the bereaved.

The uncertainty surrounding the situation of children with a seriously ill parent may account in part for the relative paucity of writing on this subject, and a rather diffuse theoretical base. This uncertainty is mirrored in the terminology itself - 'child bereavement' is used to refer to the experience of both a child bereaved of a parent and parent(s) bereaved of a child. As a result, searching databases is particularly frustrating, since it generates many inappropriate 'hits'. Equally, the term, 'child facing bereavement' has become ambiguous, losing its implied emphasis on the present or future and becoming synonymous with 'bereaved child' - someone who has faced bereavement and is in the continuous state of being bereaved.

The theoretical underpinning of work in the palliative care context with distressed children draws on two sources - the literature on counselling distressed children and that on the impact of cancer on families. Both of these are predicated on some taken-for-granted assumptions about children and childhood which shape the research methodologies adopted and the findings that emerge. Such an unsatisfactory foundation propels me towards a more egalitarian and respectful approach to research with children. I begin, however, with the literature on counselling children, and then focus more narrowly on the cancer literature, which is situated largely within the oncology rather than the palliative care field.

Counselling Children

Though not all of them may acknowledge their debt directly, many writers draw extensively on the work of Egan (2002). The principles he expounds (and he emphasises that they are principles, not formulae) are present in much of the literature on child counselling, even though his own work is entirely adult focused - to the extent that the term 'children' does not even appear in the index. Nevertheless, his chapters on attending and listening, empathy and probing and helping clients tell their stories are largely transferable to work with children. The increasing emphasis in later editions of the book on client action, both covert and overt, is welcome and entirely appropriate for adults, but raises issues for those working with children for whom, as this chapter will demonstrate, the rhetoric around autonomy and rights does not always translate into action.

For example, Parkes *et al* (1996) argue that the patient's needs must come first, but claim that this does not imply that the family should be ignored. Clearly though, it implies that they will take second place. The amount of space devoted to children's needs for support is perhaps indicative of their low priority; in a work that asserts the importance of the family, the emphasis is on *adult* family members.

Within the body of counselling literature, there is a growing section on counselling children (Bryant-Jefferies 2004). Daniels and Jenkins(2000) offer a cogent and compelling case for children's counselling, focusing specifically on the ethical and legal arguments. Their consideration of parental rights and reluctance to agree to therapy for the child is helpful in terms of parallel situations in palliative care where a parent blocks offers of support to a child. In general, their strongly psychoanalytical approach and the nature of the client group - young people facing abuse, bullying or long-term issues such as low self-esteem, where the impact of statutory intervention by police or Social Services is problematic - renders this text less relevant for palliative care professionals.

Barwick(2000)and Lines(2002) similarly are limited by their context (schools) but are more ready to acknowledge the impact of this context. Theirs is a more systemic approach, acknowledging that a shift in any one part of the system will impact on all other parts; but the impact of parental illness itself is not discussed, although Lines includes a chapter on bereavement.

Though less recent, but perhaps of more direct relevance is Noonan (1983) who writes specifically about adolescents, moves equally readily between theory and practice, identifies change as a core issue in the work, and is commendably reflective about the place of self and the (worker's) "individual struggle with the ideas and feelings aroused by the daily encounter with individuals in distress" (px). Her use of mourning as a model for transition is interesting; she argues that the loss of childhood is indeed a bereavement for adolescents and she prefigures the oscillation model of Stroebe and Schut (1999). Disappointingly, there is nothing about parental illness, the section on life-and-death issues dealing exclusively with potential suicide.

The theoretical framework is avowedly psychoanalytical, and Kleinian, although Noonan manages to combine this with a pragmatism that is very welcome, as when she writes of the pressure from other professionals for the counsellor to perform miracles. This resonates with palliative care social workers who frequently find themselves in this position, and need to mark her words - "they might like to be able to do the magic, and might think they should be able to, but on the whole they can't!" (Noonan 1983 p137)

Much more ambitious in its scope, yet with similar limitations, is Geldard and Geldard's "Counselling Children" (2000) which covers familiar ground in its consideration of counselling skills - but applies them to a wider age range than Noonan (1983). The chapters on play therapy and worksheets are particularly useful for those working with younger age ranges, although the debate about the efficacy of worksheets continues to rage among practitioners. They are likely, however, to welcome the emphasis on observation and the key task of helping the child to tell their story. And there is little to quarrel with in the bulk of the chapter dealing with resistance and transference - regression, denial and projection are met with in children as much as in adults, and as often in palliative care as in other life crises. However, the discussion on resistance may be less easily transferable to situations of serious illness, since it takes no account of the possibility of resistance in the parent, whether well or ill, which inevitably complicates the work. In addition, the section on transference and counter-transference is understandably based on the premise that the parent(s) will continue to be active participants in the child's world, whereas the prime reason for counselling children in palliative care is that there is no certainty at all that their parent will continue to have a physical existence in that world.

Geldard and Geldard (2000) do not claim to write for palliative care workers, and offer their 'Spiral of Therapeutic Change' with the caveat that it presents only a "general understanding ... and is not intended to be an exact model" (p 57). Nevertheless, they go on from this to build a model - which they also describe as a theoretical basis - called 'Sequentially Planned Integrative Counselling for Children' - which draws on a number of adult-based theories, but is constructed, as its name implies, specifically for children. This model advocates deliberate and purposeful change of therapeutic approach over five stages of intervention.

Like Kubler-Ross's stage-based model, this is seductive in its clear, stage-based structure, and equally vulnerable to the same critiques. It is also seductive in its incorporation of so many major counselling theories. There is undoubtedly much that is valuable for professionals seeking to support children who are distressed by the serious illness of a parent or parent figure, but there is also much that does not match. This model assumes a child client who is 'the problem', who is largely internally distressed, who usually does not like herself, who needs to deal with 'self- destructive' beliefs and then move on to 'new behaviours'. The implication is that difficulties have been long-standing, chronic, and dysfunctional. It does not appear to be a situated model; there is little recognition of the context in which the child operates. Its emphasis on the child's ability to generate change, both cognitively and behaviourally, is encouraging, but is hard to apply to the children of seriously ill parents. As will be seen later, these children, quite realistically, do not see themselves as having much real control over their parent's illness. Of course it is possible, and often desirable, to help change the way the child thinks about and reacts to this life crisis, but it is not possible to change the crisis that has precipitated the need for intervention, and which is usually located well outside the child's inner world and inside the parent's sick body. Furthermore, the overwhelming likelihood is that this crisis (parental illness) will become much worse and will be totally outside the child's locus of control. Far from experiencing opportunities to control or reduce problems, the child usually finds herself faced with a continually deteriorating situation. In essence, the problem is located outwith and beyond the child. Finally, the psychodynamic emphasis fails to give due, if any, weight to two significant issues - the need for factual information about the illness and its consequences, and the need for communication between the child client and the owner of the 'problem' - the sick parent.

This last issue is partially addressed by the authors in the succeeding chapter, where there is a brief acknowledgement of the impact of external events, and a more considered discussion of family culture, interactions and influence on the child. Overall, however, this model is of limited value in the palliative care context.

Supporting Distressed Children in a Cancer Context

More helpful is Jewett (1994) who writes persuasively and succinctly about separation and loss in childhood from a broad social work practice perspective; Mallon (1997) pragmatically, from a counsellor's perspective; and Monroe (1994), Sheldon (1997) and Oliviere (1998) from a specifically palliative care perspective. These all draw on extensive practice experience, thus offering a different type of knowledge, encompassing reflection, intuitive knowledge and the art of the autonomous rather than routine practitioner (Benner 1984).

Within 'formal' research Rutter (1966) was one of the first writers to highlight this area and discuss the impact of parental illness on the child, albeit from a broader perspective than exclusively life-threatening illness; and there then followed a wealth of material allegedly focusing on families. In reality, children were noticeable by their absence. Once again, the semantics are illuminating; 'families' refers overwhelmingly to husbands, wives, spouses, partners and carers - but not usually to children (Twigg and Atkin 1994, Nolan 1998, Northouse 2002, Ferrel 2002)

The bulk of the work, whether research or practice-based, is North American in origin, usually from US universities and occasionally from Canada. Less has been written from the Western European perspective, and it needs to be recognised from the outset that American work may not necessarily be applicable to the UK context. This caveat applies to a lesser extent to mainland European work.

From an examination of the key research papers, summarised in Appendix One, the following major themes emerge.

Range of literature

Provenance: This review concentrates on literature from the North, by default. Searches did not uncover any contributions from the South, where the focus has tended to be on childhood response to trauma, and parental loss by war, rather than illness.

Authorship: Writers are predominantly academic and health oriented; there are only rare contributions from social work professionals or other practitioners.

Research participants: Papers investigate 'children' in the age range 3 to 18 (occasionally up to 35!) with an emphasis on adolescents. There was little consistency in the sub-division of children into different age-groups; some researchers using three groupings, others distinguishing only between pre-adolescence and adolescence, but with variable cut-off ages. Given the undoubted differences - cognitively, physically, emotionally - between a five year old and an eleven year old, the usefulness of these groupings is open to question. In the majority of studies the 'family' was white, two-parent and not living in poverty.

Nature of the cancer: the type, extent, stage and immediacy varied considerably but breast cancer was the most widely researched.

Attending to the voice of the child

Lichtman *et al's* (1985) paper continues to be quoted despite the fact that only nine of the 78 sick parents' children were interviewed, and of these the youngest was 12 and the oldest 35. Roy's (1990) critique that "information was obtained only in **exceptional** circumstances from the children" (p119) but **normally** from the parents, can be applied to a disturbingly high number of frequently-cited articles. Armsden and Lewis (1994) interviewed parents about their children's behaviour and gave children a self-report scale of self-esteem. Parents reported positive behaviour from the children, but the latter scored themselves as noticeably lower in self-esteem than a control group of children with healthy parents. Nelson's (1994) English study seemed surprisingly coy about open discussion of cancer with the children; it was agreed with parents that the word would not be used by the worker unless the child uttered it first. More significantly, Compas *et al* (1994) interviewed 110 children, using mainly scales, inventories and rating measurements, but then commented that "the low reliability for children indicates that their scores must be interpreted cautiously." There was no discussion as to the perceived reliability of adult responses. Birenbaum (1999) included a self-report measurement for adolescents, but not for children, and, interestingly, while some studies used parental and child assessments of the child to produce a more 'balanced' picture, no study sought to obtain child perceptions of parental adjustment in order to balance parental self-assessment!

Zahlis (2001) who was a co-author of the Shands *et al* (2000) paper on mother-child interactions which was based on interviews with mothers only, has conducted one of the few studies that seeks children's views directly. Its retrospective nature - between three and six years had elapsed since the parent was diagnosed, and all parents were currently well - limits its value considerably.

Issel *et al* (1990) interviews children directly. The work of Helsell and Ulfsaet (2003), as one might expect from a country, Norway, with a noticeably child-centred culture, is unique in setting out to explore the issue of quality of life - not of the ill parent but of the children in the family. Huizinga *et al* (2003) interviewed both children and parents, but unlike other studies found that parents reported more problems than did the children. The most recent study (Forrest *et al* 2006) however, confirmed the majority finding that parents underestimated child concerns and stress.

Child/parent relationships and gender.

Although bereavement research findings are clear that the relationship of the surviving parent with the bereaved child is crucial, most of the studies considered here do not investigate family relationships in any depth. While some studies find that sick mother-well (adolescent) daughter relationships improved, others found them to be more at risk (see below). Another study considered adolescent boys to be more vulnerable.

Age

Yet again there were conflicting findings, with some studies suggesting that younger children were more distressed and others identifying teenagers as more vulnerable. Difference in the way studies defined their age groupings and gathered their samples make direct comparisons unhelpful.

Methodology

Compas's study (1994) is commendable for its thoroughness and its consideration of variables - age groups, same-sex parent/child dyads, stage of illness etc. Nevertheless, the choice of a positivistic paradigm, and quantitative methods and highly structured interviews may limit its usefulness in accessing the experience of the child.

Two key findings are of note - that children's stress was independent of parental stress, and that adolescent daughters of mothers with cancer were the most distressed group. This contradicts Lichtman (1985) who found that the majority of mother-daughter relationships were strengthened.

Siegel(1992) compares children of cancer patients with a control group using various scales and inventories. In a later paper(1995) she compares depression in children of cancer patients, both before and post-death, noting significantly higher symptomatology in the pre-death group. In another quantitative study (1996) of communication patterns, she finds the gender (female) of the well parent and the age (younger rather than older) correlate significantly with open communication. Useful those these findings are, the quantitative methods fail to capture in any meaningful way the experience of the children.

Some studies (Issel *et al* 1990, Nelson 1994) recognised the importance of the peer group for adolescents at this time, and the impact of parental illness on their peer group activities and relationships.

Compas (1996) and Welch, Wadsworth and Compas (1996) note the lack of problem-focused coping in each age group and the association of avoidance and increased distress. They find adolescent daughters of mothers with cancer to be the most distressed group. Yet again, the mismatch between parental assessment of children's adjustment and the children's own assessment is revealed, as it also is in Birenbaum (1999). They also argue that not all children are distressed by parental cancer, whereas Heiney's (1997) research finds higher state and trait anxiety in this group than in a normal population. Birenbaum (1999) seems to support Compas and colleagues in concluding that most children and adolescents are well-adjusted, but then qualifies this by claiming that school aged children and adolescents have more behavioural problems than expected.

Hoke (2001) concludes from her research that there is no significant difference between adolescent offspring of cancer patients and those of parents with a benign biopsy - but that some adolescents facing parental cancer actually do better in academic and social spheres.

Practice-based papers

Though they do not claim to be research in the way it is traditionally understood, the practice based papers are significant for highlighting the importance of groups for children with seriously ill parents. As noted above, Issel *et al* (1990) and Nelson (1994) also acknowledge the role of peers and support networks in their studies

Qualitative studies

In the latter half of the 90s a trend towards more qualitative research methods begins to emerge. Zahlis and Lewis's (1998) study of maternal breast cancer offers rich, thick description which effectively illuminates the topic, but in terms of the child's experience is another proxy study, since it deals with the mother's perspective only. In contrast Gates and Lackey (1998) investigate the experience of young caregivers, using phenomenological and ethnographic methods as well as a semi-structured survey, and ably describe the previously unacknowledged work that children and young people undertake. A later paper (Lackey and Gates 2001) considers the effects of childhood caregiving in later life, and is therefore beyond the scope of this literature review. First person voices and views feature strongly in a video, "Hear how I feel", which has some similarities to the one made as part of this research. Petingola (2002), an American social worker, reviews the response of both teachers and young people to the film and finds that the adults were reluctant to show the video to young people without additional support from trained professionals; in contrast students found it helpful and had no reservations about its use.

Both qualitative and quantitative methods are employed by Nelson and White (2004), who identify low self-esteem and poor parental adjustment as the key factors in children's adjustment. It endorses previous findings that daughters are more anxious than sons, adolescents likely to be less well-adjusted than younger children, and mothers likely to underestimate children's anxiety. But, surprisingly, it does not find communication to be a significant issue. Single-parenthood is, however, suggestive of greater risk.

The work of Christ

A highly significant addition to the research literature is the work of Christ (2000), a thorough, careful and comprehensive study rich in both practice wisdom and research rigour. It is based on the study of 87 families with over 150 children begun in the 1990s, and brings together a number of findings previously reported in a series of articles spanning the last decade of the twentieth century.

From the perspective of this thesis, the strength of this study is its engagement with families *before* the death of the parent, its rich description of family relations and the opportunity it gives for the children involved, pre-school to eighteen, to articulate their concerns. They were interviewed over a period of up to 20 months, beginning around six months before the anticipated death and continuing up to a maximum of 14 months post-death. This discussion, however will be confined to the material gathered preceding the death.

Unfortunately, at times the narrative does not always distinguish between pre- and post-death comments. Christ's commendable desire to consider the entire experience holistically is understandable but creates some difficulties in relating her work to the focus of this inquiry - the needs and experience of children not necessarily knowing when or if they will become bereaved.

Similarly, her review of the literature focuses almost exclusively on bereavement. She does, however, briefly consider 'anticipated parental death' although even here this appears to be another description of death from life-threatening illness, rather than 'living with parental illness'. Overall, there is little on pre-bereavement research, primarily because, as Christ acknowledges (p 19), it is itself an under-researched area with particular problems relating to access and recruitment.

Though her focus is child bereavement, Christ cautions against assuming that the death itself is the major problem. Particularly relevant to this study are two of her findings - that "the terminal phase of the illness...may provoke greater psychological stress"(p19) [than the bereavement], and that other contextual factors may be crucial for the outcome. For example, poverty, illness-induced separation, and difficult family relationships may each have a greater impact on the child than the death itself. This is a welcome assertion to balance against the emphasis on bereavement as a separate and over-arching loss.

Christ is careful, too, to caution against 'predictive algorithms' and using the recommendations from the research findings too prescriptively. She describes them as "a source of ideas, not methods" (p 243) or formulae, a perspective that sits comfortably with the claims for holism that palliative care espouses.

An interesting feature is her stage-based, and somewhat medicalised model of the illness period, which she postulates as having distinct initial psychosocial stages leading up to and beyond the end stage into bereavement. However, as will be argued in Chapter 9, from a child's perspective (and often from the parents') these stages are rarely distinct, frequently undefined and unacknowledged, and even when clear, may be significant to the child for quite different reasons than for the adult. For example, advanced disease in the palliative stage may sometimes be a relatively calm and ordered period for the child, as opposed to earlier treatment stages when his life is heavily disrupted by parental preoccupation with clinic appointments, tests, results, and admissions. During this 'stage' the parent may be much less physically and emotionally available to the child, whereas at a later stage, her focus may have moved back from threats to her own life to maximising the relationship with the child.

Almost by definition, a stage-based model is retrospective, since it is not possible to identify the end of one stage until the next has occurred. While professionals with accumulated experience may feel they have some foresight in this respect, most families may only be able to do this with hindsight.

A limitation of Christ's sample is that it is exclusively white, middle-class and maritally intact. As such, many of the factors which she acknowledges to be possibly significant for outcome - poverty, single-parenthood, economic instability, discrimination etc. - are largely absent. The sample thus represents a very idealised population - emotionally stable, economically productive, generally affluent and very articulate. From the British perspective, its American origin raises some issues of transferability. The emphasis on school performance and 'honours' in academic or sporting achievement is culturally specific; it is quantitatively, if not qualitatively, different from the culture of British schools and families, where school performance is naturally often a cause of concern but not, I believe, so all-pervading.

In the history of pre-bereavement research, Christ's work is noteworthy for its combination of both quantitative and qualitative methods. The size of the study sample permits quantitative analysis that produces some useful findings, while the qualitative interviews allow her to "go beyond numbers" (p xvii) to gain "a more complete understanding of the processes involved " (p xix). As she rightly claims, "both quantitative and qualitative methods are necessary to begin understanding such a complex issue" (p xiv).

The other main strengths of Christ's (2000) research is her focus on the relation of developmental stages to the response to illness and death. She identifies five separable developmental age groups and argues that understanding each developmental stage is crucial to working with the child's response to their parent's cancer. Under-fives were not capable of experiencing anticipatory mourning, having little understanding of the permanence of death. Separation during the terminal illness, and strong parental emotions were difficult for them to tolerate. The inability to reverse thinking processes was a natural consequence of their stage of pre-operational thinking. They did not consider themselves to blame for the parent's death, nor did they ask many questions about the illness. Five to eight year olds experienced anticipatory anxiety rather than mourning, were more emotional, found school stressful and tended to personalise events. That is, magical thinking was evident - their wishes or bad thoughts had 'made' the parent die, and they also interpreted adult behaviours as related to their worth - because a mother was preoccupied with a sick husband she therefore did not love the child.

Nine to eleven year olds were much more capable of operational thinking, but were reluctant to share feelings. They needed information, but because parents misinterpreted their efforts to contain their fears, they did not always get it. They had stronger defence mechanisms, and involved themselves more in outside and school-based activities.

Christ makes a convincing case for the complexity of the early adolescent (12-14 years) phase, identifying the cognitive, psychological, social and biological changes that all contribute to this difficult stage. Like other writers, she describes the tension this age group faces as it begins to detach from parents at a time when there are diametrically opposite demands for closer involvement. This centrifugal-centripetal conflict is hard for all in the family to manage. Older adolescents (15-17 years) displayed maturing cognitive abilities and consequentially, a more profound anticipatory grief. On balance, they were allocentric rather than egocentric, but this was not consistently true.

These stages illuminate the young people's behaviour and guide the interventions by family and professionals. As such, they provide a helpful framework for practitioners. Nevertheless, for each thoughtful teenager or emotionally contained eleven year old featured in her research, practice experience can point to the exact opposite - the seventeen year old completely 'off the rails' and the articulate, emotionally open ten year old.

Overview

The literature on counselling children is substantial; so is that on families facing cancer. But there is relatively little that focuses on children who are well themselves but living with a seriously ill parent and likely to be bereaved. This is a marginalised group, and an under-researched area. What there is, as discussed above, is variable in focus, method and relevance. Nevertheless, five key factors emerge.

First, the literature is generally adult-centred. Large-scale quantitative studies have generally failed to capture the lived experience of the child. Indeed, most studies have relied heavily - or even exclusively - on the parents' perceptions rather than the child's. This raises doubt as to their validity and relevance to practice. Those that have investigated both have all noted the discrepancy between parental assessment - that the children do not react noticeably - and the children's accounts - which detail their fears, confusion, sadness, changes in family and peer relationships and activities, and much more.

Secondly, the findings are conflicting as noted earlier. Thirdly, missing from many of the studies is any consideration of the social and cultural context. In particular, there is an implicit assumption that, in two parent families, the marital relationship is positive. None of the studies explores parent-to-parent or parent-to-child relationships in terms of their serving as either a buffer or stressor for the child. Fourthly, the significance of support networks is unclear.

Finally, immediacy is not a feature. A number of the studies deliberately avoided interviewing families where the diagnosis was very recent, or the parent was in the terminal stages. In some cases, interviewees were being asked to recall events from some years past, with the likelihood that the unpredictability of the experience would not be well represented.

Much in the counselling literature is undoubtedly helpful for those in palliative care supporting children whose parents are seriously ill. However, as I have argued above, there is also much that is less transferable. Sadly, the limited research which specifically addresses the experience of children facing parental illness is inconclusive, contradictory and, largely adult-centred. Moreover, it assumes rather than critically examines the understandings of children and childhood on which it is predicated and therefore engages with children in a limited, conventional way which may fail to fully capture the child's experience. These assumptions have recently begun to be challenged and I therefore now turn to this wider context of childhood and examine its changing construction and legislation, in order to work towards a suitable research design with the potential to illuminate and transform our understanding of these children's needs.

The Construction of Childhood

Introduction

All research is constrained and conditioned by time and place, and any research into children's experiences must consider the contexts in which it is located. This section therefore focuses on notions of childhood. That children are our future has worldwide acceptance but while all cultures are unanimous in their emphasis on the importance of creating future generations, the concepts of childhood and the rights of the child are much more contentious. Those under eighteen make up forty per cent of the world's population, but one quarter of those live in absolute poverty with minimal access to adequate health services, leading to 30,000 deaths every day(SCF 2005). Globally, there is little consensus about the parameters of childhood. Over 246 million children under fifteen are forced to work to survive (UNICEF 2006), with child slavery common in much of Asia and Africa, whereas in the UK children cannot legally be employed full-time until they are 16. The recognised age of majority throughout Europe is 18 but a Kikuyu boy will be initiated into manhood by the time he is 14. And while war is initiated , prosecuted and won by adults, it is children who are its greatest victims - from the 300,000 child soldiers carrying arms, to the 20 million displaced, and the 2 million dead in the last decade of the twentieth century (UNICEF 2006).

Unsurprisingly, therefore, the diverse experiences of children reflect the nationally different concepts of childhood. However, the 1989 UN Convention on the Rights of the Child attempted to establish some internationally recognised standards. A later section of this chapter considers its impact, but for the purpose of this thesis, the main focus will be on the concept of childhood in the UK.

Childhood

Childhood, characterised by Holland(2001) as a relatively modern concept, was for many centuries but a brief interlude between birth and productive and re-productive activity, with most children required to contribute their labour to the family before their teens (itself a notion not in existence until the 20th century) and many moving into parenthood shortly after puberty. It was perhaps only in the nineteenth century as formal education became established that childhood became a distinct concept. Children's school-leaving age has been steadily extended from 10 in 1876 to 16 in 1972, with over 80% now remaining in full-time education until 18 (UK Census 2001); and the law has steadily revised the age at which it recognises their right to an opinion. A child of eight may now refuse to consent to a medical examination, (Children Act 1989), a 12 year old's views on family breakup (divorce) or creation (adoption) must be sought and considered, (Children Act 2004) and a 15 year old may seek contraceptive advice without parental consent (Gillick ruling).

Thus we have gradually moved from the notion prevalent in previous centuries that a parent had absolute right to chastise, control and decide for his (for the right was invested in the father not the mother) child, to an acknowledgement of children as individuals with rights of their own, and a growing capacity to think and decide for themselves.
How did this change come about?

De Mause (1991) may have exaggerated the history of childhood as "a nightmare from which we have only just begun to awake", but until the last century children were clearly regarded as chattels, the private possessions of parents who were free to treat them as they chose. Rabelais' assertion that a child was "not a vase to be filled, but a fuse to be lit" (Knowles 1999) was a rare dissenting voice. The concept of the State having some responsibility for children, and of children having some rights independent of or equal to those of their parents, is relatively recent (Cunningham 2005). Although Shaftsbury, Kingsley, Dickens and others did much to change public attitudes in the nineteenth century, the law trailed far behind.

Aries (1973) suggests that this change had begun in the eighteenth century and was due in part to a change in the function of the family. From being an institution whose purpose was to transmit property, status and title, it became both the repository and provenance of morality and spirituality. In consequence, it was necessary to acknowledge that children, previously viewed as fairly fully functioning individuals once they were able to feed and dress themselves, were not incipient adults;-
"it was recognised that the child was not ready for life, and that he had to be subjected to .. a sort of quarantine, before he was allowed to join the adults" (Aries 1973 p396-7)

As in his other wide-ranging review of death through the ages (1974) Aries tends to rely on a rather one-sided view of history, drawing on literature, art and poetry that was created largely by the educated for the literate, so that his view of childhood may be less accurate and universal than he claims(Cunningham 2005). Nevertheless, he is right to highlight the impact of education and industry on society's view of children. By the mid-nineteenth century, the plight of (many of) Britain's children was recognised as a social scandal, and the drive to delay their entry into the labour market and to provide a universal education system grew apace. In 1882, the NSPCC was founded (forty years after the animal charity the RSPCA). Another oppressed minority, women, had benefited, some 40 years earlier, from the passing of the Custody of Infants Act 1839 in which the custody of a child under the age of 7 could be granted to a mother. Hitherto, custody had automatically been awarded to the father, women and children both being viewed as inferior, weaker vessels (Lindsay and Elsegood 1996). It is important to note, however, that even this ruling focused not on the child's needs but on the 'fitness' of the parent. And the right of a mother to custody of an over-seven (and the right of a child to have a mother) was not granted for a further thirty or so years.

But while the debate was in terms of adults' rights rather than the child's needs, the outcome was usually to meet the child's needs.

Thus, by the beginning of the twentieth century, the needs of children and the recognition of childhood as a particular, and precious, time between birth and adulthood had gradually gained some acceptance. Nevertheless, the recognition of children's rights to their own views and opinions lagged behind. Thus, the first half of the twentieth century did no more than mirror the prevailing medical practice of paternalism - a genuine and well-founded concern for others, but based on the assumption that the expert knew best.

The work of Bowlby (1969) and the Robertsons (1989), though focused on the impact of separation on the child, had a profound effect on child health and social care professionals, and the films themselves are an early, if limited, example of giving children a voice. Major changes to the way children were dealt with in the health care system then followed.
Later decades witnessed a rapidly evolving social climate, to which the social construction of childhood was not immune. The right of adolescents to have a say about their own lives was widely proclaimed, sometimes disputed, but gradually accepted; however, this did not mean that all was well within childhood. Younger children were still seen, but not heard, and the story of Maria Colwell was a case in point.

Maria Colwell

The death of Maria in 1969 gave the tabloids, with some justification, a field day at the expense of social workers; despite the latter's considerable involvement with the family, Maria, aged seven, had been physically and emotionally abused by her stepfather, persistently neglected, and finally beaten so severely that she died of her injuries. Yet she had said clearly that she did not want to leave her aunt and return to her mother and stepfather; she had acted this out in her behaviour, running away from home back to the aunt on several occasions; but her voice was not heard. Indeed, her own GP, when examining her for suspected abuse, did not give her a voice (Reder *et al* 1993); she was a body to be assessed, but not a person to be heard.

The public outrage at Maria's death and the subsequent Report (Reder *et al* 1993) influenced the 1975 Children Act which stated that the "child's own wishes and feelings" were to be taken into account in any decisions about their welfare, and promulgated the now-accepted principle that children should have a right to express themselves on matters affecting their future.

This was not of course in itself a new idea. The needs and rights of children involved in fractured families had already been championed by Lord Denning. A parent's automatic claim to a child was "a dwindling right" which the law would be reluctant to "enforce against the wishes of the child, the more so the older he is" (Hewer v Bryant 1970). Thus, although case law was strengthening the rights of the child, practice lagged behind - a not unfamiliar tale.

Some fifteen years later, it was still necessary for Lord Justice Butler-Sloss to remind adults, in the Cleveland Inquiry (1987) that "the child is a person and not an object of concern" - one of the key lessons of the Colwell Inquiry. Subsequently, Bush (1996) felt it necessary to remind his medical colleagues that in matters of child health, "although parental views are important, as the child grows older, they should be given less weight"(p 576). Nevertheless, the Victoria Climbié case showed yet again the failure of adults to seriously listen to a child (Beresford 2002) - no translator was sought for the French-speaking Victoria.

If practice is still less than perfect, the principle of children's rights had nevertheless become well-established by the last decade of the twentieth century. 1989 proved a particularly important year, with three significant legal documents encapsulating the new thinking about children.

UN Convention

The 1989 UN Convention of the Rights of the Child asserted not only fundamental rights to **receive** such things as education and shelter, but equally importantly, the child's right to **contribute** - their views and opinions on matters affecting them. The emphasis on not only a right to life but also to a 'good-enough' quality of life was welcomed by many; while protection **from** harm and provision **of** services were familiar 'rights', participation **in** decision-making was more radical (Sharp and Cowie 1998) and an early step in politicising childhood. Nevertheless, like much well-intentioned legislation, the Convention was more often 'honoured in the breach than the observance thereof'. Countries as disparate as Somalia, the USA and the UK were slow to sign up, and implementation was slower still. The UK became a signatory in 1991 but while the then Department For Education urged schools to educate their children for active citizenship, by 1995 there was still nothing within the law giving children the right to be heard on any educational issue; children still appeared to have little control over their own lives.

Article 13 states categorically that "The child shall have the right to freedom of expression ... to impart information and ideas..." and Article 12 elaborates this, highlighting the responsibility of 'state parties' to "assure the right of the child, who is capable of forming his or her own views, to express those views freely in all matters affecting her or him" This right is then qualified by the adverbial clause "the views of the child being given due weight in accordance with the age and maturity of the child." Limiting though this phrase is, it is important to recognise the flexibility it offers. Age is not the only factor, and while 'maturity' may be a contentious word, it clearly acknowledges the need to move away from a universal yardstick towards a more individual appraisal.

The emphasis on protection in some Articles e.g. 19 and 36 is still apparent, but counterbalancing that is a welcome acknowledgement of the child as an active member of the human race. Article 14 enshrines the right of the child to freedom of thought, conscience and religion - a far cry from eighteen and nineteenth century beliefs about children - and Article 23 refers to the need to "ensure dignity, promote self-reliance and facilitate the child's **active** (my emphasis) participation in the community". The fact that it is here referring to disabled children only underlines the assumption that this already applies to all 'normal' children.

Even though some countries have still refused to ratify it, the Convention clearly demonstrates a significant shift in attitudes towards children.

Children Act 1989

A second key piece of legislation was the 1989 Children Act, which was in part influenced by the Cleveland cases. Both protectionists and liberationists found some fault with it (Lowden 2002), but the latter welcomed its emphasis on parental rights and responsibilities as a helpful redressing of the balance in favour of families rather than professionals. The former, however, criticised it as a knee-jerk response to 'social-worker bashing', that made it more difficult to protect children successfully. Nevertheless, two central planks of the Act were the need in all situations to establish "the ascertainable wishes and feelings of the child", and the principle that "the best interests of the child" were "paramount". Although we may note the strengthening of the child's claims over against the adult's in this legislation, in comparison with the 1975 Act, the definition of these terms, as Morgan (2002) reminds us, remains in adult control.

The ethos of the Act was important, but there were also practical extensions of children's rights. For example, a child "of sufficient understanding to make an informed decision" was legally entitled to refuse a medical examination, or any other assessment. However, this principle has been challenged on a number of occasions (e.g. South Glamorgan County Council v W and B), on a number of grounds - that Court powers are not curtailed by the Act, that parental consent overrides a child's refusal, and that a child is not competent to refuse. The last, as one writer has tartly remarked (Kennedy 1992) often demonstrates a certain inconsistency, since a young person's consent is rarely queried as incompetent, precisely because it is convergent with the adult view; whereas their refusal is often challenged on the grounds of competence. However, when consent is withheld its 'incompetence' may owe more to its divergence than any innate failure of competence. And the general assumption of the incompetence of younger children is criticised (Lowden 2002, Buckingham 2000) for being too developmentally stage-based; there is an echo of Lord Donaldson's view that children will only become competent if adults treat them as competent.

Although this particular section (part V 43 (8)), refers specifically to refusal to consent to processes or interventions, the principle that children should be both seen and heard is explicit within the Act. It clearly directed Courts, professionals and parents to view children as partners, albeit unequal, in the decision-making process. The tension between, on the one hand, the desire to protect and control, and on the other hand, the wish to respect and empower minors, was considerable and continued to generate heated debate. "As intelligence and understanding grow, so will the scope of decision-making which should be left to the minor... good parenting involves giving minors as much rope as they can handle without an unacceptable risk that they will hang themselves" was the view of Lord Donaldson, the Master of the Rolls in 1993 (BMA 2001 p 6) but, in the decade since, the debate has shifted somewhat from rights, which are not disputed, to (unacceptable) risks - which are (re M 1999, quoted in BMA 2001). Some of this shift may be attributable to the highly significant dispute about parental versus child rights that eventually gave the English language a new phrase - 'Gillick-competent.'

Child Competence and the Gillick case

The Gillick case turned on the question of the right of a teenager to access contraceptive advice from her GP, without her parents' knowledge. Mrs Gillick went to court to assert her parental right to be informed of, and decide on, her daughter's wish for such advice. The law (Family Law Reform Act 1969) was clear that over-16's could decide for themselves, as if they were adults, about health issues; but it did not specifically rule on under-16's.

This case highlighted many of the arguments about childhood previously rehearsed, such as the nature of informed consent, age versus maturity, and rights of the child versus those of the parent. The presiding judge was of the view that an under-16 could give consent if of sufficient maturity and understanding. The nature of the consent required would be a factor, and the child needed to be capable of weighing up the advantages and disadvantages and coming to a reasonable assessment. Thus, significantly, neither age nor parental rights were crucial factors; the child's maturity and competence were.

On appeal the outcome was reversed. Appeal judges declared that children should not be treated as prematurely capable of adult decision-making, and found in favour of parental rights. Lord Templeman was famously quoted as saying "there are many things that a girl of 15 needs to practise, but sex is not one of them".

Because this case was not only about consent but also about the far more interesting issue of sex, it attracted widespread media coverage. The Department of Health (DoH) therefore took the case to the ultimate legal authority, the House of Lords. Despite their advancing years and distance from modern-day teenage life, Lord Scarman and his fellow Law Lords reversed the former Appeal Court decision in favour of the original one. In their judgement, they unequivocally set out the purpose of parental rights (to protect the child), their limitations ("they exist only so long as needed for the protection of the child") and the current understanding of the child ("a person with capacities and rights recognised by law"). In their view, parental rights have never been "sovereign or beyond review and control" (Gillick v West Norfolk AHA 1985).

This landmark ruling, indicative of a significant shift in conceptions of childhood, continued the process of reducing parental rights that had begun towards the end of the nineteenth century with legislation authorising intervention in families where violence and neglect were evident, by either the state or agencies such as Barnados. The Children Act 1944 and the Children Act 1975, influenced by the Maria Colwell case as described earlier, also belonged to this reductionist and interventionist mode. The Children Act 1989, while emphasising parental responsibilities rather than rights, and the importance of partnership, was also in this tradition. The Gillick ruling, however, while paring down parental powers to three key areas - education, protection and maintenance - did not necessarily redistribute this power only to the child (Bainham 1988, Kennedy 1989).

Nevertheless, this change in the Courts' attitudes to children has both been reflected in, and is a reflection of the wider society in which we live. As recently as January 2006 the principle has again been upheld in the High Court.(Axon v Department of Health).

Human Rights Act 1998

Another potentially significant development was the Human Rights Act 1998, which further shifted the balance away from the State and towards individuals, including children (BMA 2001). Fortin (1999) was critical of the Act's simplistic acceptance of the European Convention on Human Rights which, she argues, assumes that children's and parental rights are identical, and therefore privileges parental autonomy, and so far the Act has been invoked mainly for adults. Nevertheless it has stimulated further debate on the rights of children and reminded professionals that human rights apply to children as well as adults.

New millennium, new attitudes?

The new millennium not only saw the Human Rights Act come into effect but also saw the UK government signalling its commitment to children's rights in its new Children and Young People's Unit, tasked with the creation of a "vision for how childhood should be." (www.cypu.gov.uk). This vision includes aspirations such as "chances to contribute to the local community" - indicative of a changing view of children which sees them as not exclusively in need of protection but more crucially as entitled to support to enable them to be active, *competent* contributors to society. There was an emphasis on the responsibility of agencies to engage with service users rather than, as in the past, expect young people to fit in with the service offered by and defined by adults. In 2004 much of the thinking contained in the Government's paper 'Every Child Matters' (2003) was encapsulated in the new Children Act (HMSO 2004) which gave the new Children's Commissioner the task of examining how well government and public bodies listen to young people.

Summary

The limited literature on the impact of cancer in families is adult-directed and oriented. The counselling literature, derived from an adult model, is often contextually inappropriate. Both bodies of knowledge reflect underlying assumptions about children, childhood and competence that are examined in the latter half of the chapter. The history of childhood is briefly traced and some key legislation that encapsulates changes in society's attitude to childhood is discussed. The emphasis (or rhetoric) from Government on listening to and involving its citizens, including children, is also part of the context that has been shaping research, and the next chapter begins by addressing the issues in user involvement and then relates them to research with users who are minors.

CHAPTER THREE: CHILDREN 'R' USERS AND RESEARCHERS

"Understanding and engaging with children and young people is the key"
Al Aynsley-Green, Children's Commissioner

Introduction

We have noted in Chapter Two how limited pre-bereavement research is in relation to children of seriously ill parents, and I have argued that this in part reflects limited, though changing, understandings of the concept of childhood and competence. Although the growing recognition of children's rights is welcome, this does not so far seem to have been translated into any notion of empowering children within palliative care research. In this chapter I consider empowerment in terms of the movement towards user involvement, as a background to the study's choice of design and methods. As with the palliative care literature, the substantial body of literature on User Empowerment is almost exclusively adult-focused. That children are a body of users, whose rights - as strengthened by the legislation referred to in the preceding chapter - should be upheld is not well argued.

I then apply this to children as users, before reviewing the literature on researching children, where I critically analyse its limitations and note the potential in more participative approaches which encapsulate this notion of empowerment in both their principles and processes.

Empowerment

To begin with, I trace the historical development of the concept of empowerment, before considering attempts in the literature to define and distinguish between various associated terms. The main criticisms in the literature are then reviewed.

With the fortunate facility of hindsight, one can trace the various pressures - cultural, social, technological and professional - that have contributed to the current emphasis on empowerment and patient participation in health and social care. Perhaps the most revolutionary, rather than evolutionary, of these has been the Information Technology explosion. Signalled by some as the other 'great leveller' which would give unlimited information, and thus power, to ordinary people, it has perhaps merely widened the global gap between the poor and the rich. But within the broad context of Western Europe and the specific context of the UK, it has enabled almost any patient or family member who chooses, to search for a wealth of information about care, costs, cures, statistics, strategies and star ratings. The general public are undoubtedly better informed (in terms of volume, detail and currency) than half a century ago when the NHS was founded. Rightly or perversely, depending on one's perspective, their expectations have also grown. As the press have always argued, information is power, and the public's desire for more power, in terms of choice and control, has had to be acknowledged (Monroe and Oliviere 2003). In the education sector came the Parents' Charter; in health, The Patients' Charter (DoH 1991). Six years later, the birth of a new NHS (The New NHS; Modern, Dependable, 1997) was much trumpeted by the new Labour Government, though some saw it more as a rediscovery of good principles and practice , and others as simply spin. Since then, more than seven 'good' years of White Papers, Plans, Institutes (e.g. NICE) Organisations(e.g. CHI) and Programmes (e.g. HIMP) have passed, as well as more than seven years of scandal that have seriously shaken the user's trust in both health professionals and institutions. Cases such as the Harold Shipman trial, as well as the Bristol Royal Infirmary inquiry and the Liverpool Children's Hospital scandal, have radically weakened the public's trust in the health profession, and strengthened their demands for much greater lay involvement and professional accountability to the community. As Small (2003) astutely argues, high profile incidents do as much if not more to shift policy as do statistical data and careful research. Shifting the Balance of Power (DoH 2001) was in part a paper about decentralising the NHS and offering more local freedom, but its much quoted preamble claimed that it was also about "putting patients and staff absolutely at the heart of the NHS" - a clear recognition of the need to attend, and respond, to at least one group of users.

Within cancer and palliative care, The NHS Cancer Plan (DoH 2000) required cancer networks to involve patients and carers in planning, which encouraged a number of user groups to link in with these networks. Meanwhile local PCTs were tasked with developing Patient Forums and more recently, the Commission for Patient and Public Involvement has begun operating.

Nevertheless, Papers, Plans and Programmes do not necessarily guarantee genuine user empowerment within health care - nor in social work.
The Children Act 1989 emphasised participation with parents but spoke only of consultation with children, while the Community Care Act 1990, and later the Community Care Act (Direct Payments) 1996 began to strengthen the legal requirements for, mainly, adult user participation.

By 2001 the Consultation paper "Building a Strategy for Young People" produced by the Labour Government's Children and Young People's Unit had benefited from input from (potential) users and had created considerable debate. But while the language of participation was flowering, there was not always a fruitful harvest. Participation was largely limited to influence on front-line practitioners; at the macro-level of planning and policy-making users were notable by their absence, and so there was little real change.

There was confusion too as to whether participation was a means to an end or an end in itself. Although traditional social work values - such as respect for the individual's autonomy, a bias towards the poor and marginalised, a commitment to fight oppression in all its forms, and therefore a willingness to challenge society - all lent themselves to embracing empowerment and participation, the practice was more problematic. Practitioners were more willing to countenance client participation if it could be seen to be therapeutic, whereas an emancipatory purpose seemed to raise more problems and resulted in greater gatekeeping. Even when participation was achieved, there remained philosophical doubts. Three main criticisms were levelled at what was characterised as a 'consumerist' approach. First, no matter how strongly the consumer voice was articulated, it did nothing to alter the balance of power in terms of provision of services - which were delivered, controlled and owned by agencies or professionals. Secondly, as Barker and Peck (1987 p 1) had memorably remarked, the analogy with commercial life was false - "survivors of the mental health system are no more consumers of services than cockroaches are consumers of Rentokil". Thirdly, the consumerist approach was fundamentally individualistic, based on the notion of meeting individual needs rather than on making collective provision. It was a child of Thatcherism, a legacy of the reorganisation of public services on market principles, which, so some have argued (Beresford 1992, Shaw 1997), was flawed from the start since it owed its genesis to the failure of the private sector to provide for health and welfare in the first place. Other voices too disputed the impact of user involvement in health and social care.

While identifying users' experience of what had already happened to them has always had a role in health and social care, Pound *et al*, (2000) argued that the subjective element of the experience was usually excluded, victim of successive governments' emphasis on measurable targets such as bed occupancy and waiting lists. And such audits had not involved users in their conception and design, thus further disempowering patients and carers.

The charge of tokenism was also levelled by Shaw (1997) who warned against an uncritical acceptance of the concept. More recent research (Payne *et al* 2005) suggests that the rhetoric-reality gap is still an issue and that evidence for effective good practice is scant. It may well be that there is still much to achieve before service users are fully involved in strategic decision-making.

Whose terms?

One factor in the rhetoric-reality gap is the plethora of terms employed and confusion resulting. Is involvement the same as empowerment? Is one a concept, but the other a process, or state? Are they both outcomes or ideals? What is the difference between consultation and partnership?

The literature does not entirely clarify the situation, since different authors offer their own typologies; some champion the claims of participation, arguing that it has stronger conceptual foundations than user involvement, while others (Beresford and Croft 1993) disagree.

Ward, also (1997) sees participation as frequently little more than an empty shell, claiming that it has often been subverted by those with power into yet another mechanism for maintaining control. He is briefly more hopeful about partnership, claiming rather curiously that it is not such an 'ambiguous' term as participation, and cites some good practice (DoH 1995) as evidence. Therein of course lies the dilemma. It is as easy to cite examples of good practice in partnership, and poor ones in participation - or involvement, consultation or empowerment - as *vice versa*. The language is less the problem than the execution of the principle.

Arnstein (1969), Hoyes (1993), and Hart (1992) offer typologies of empowerment. They all argue for empowerment as the top rung of the ladder, while Treseder (2004) challenges the very notion of a hierarchy, arguing that full participation is not necessarily appropriate in every situation (see Figure 3.1).

Typologies of empowerment

Arnstein S, 1969	***Hoyes et al 1993***	***Hart 1995***
Citizen control		User initiated and directed
Delegated power	User authority to make decisions	Shared decisions
Partnership	User authority for selected decisions	Consultation
Consultation	Consultation	Assigned/informed
Placation	User initiative to influence decisions	Tokenism
Informing	Dissemination/ explanation of decisions before implementation	Decoration
Manipulation	Information	Manipulation

Treseder - non-hierarchical 2004

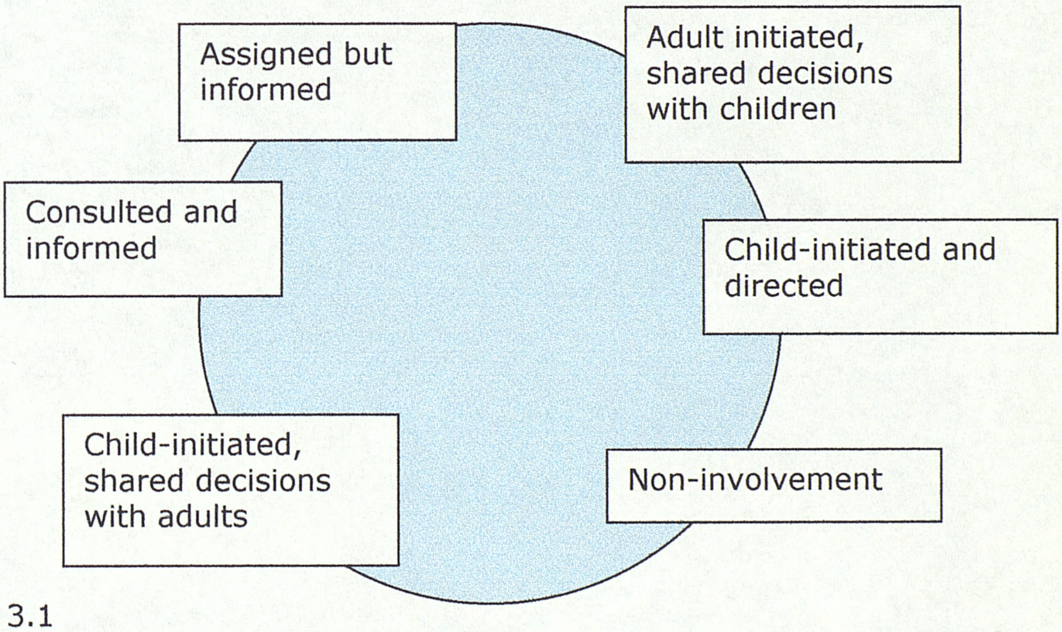


Figure 3.1

My own position is that the definition of terms and their place in a conceptual hierarchy are less important than the actual practice. While tokenism and manipulation may be inherently unacceptable, it may be that a genuine **consultation** may be more empowering than a **participation** that is so in name only. Perhaps the litmus test of all these terms is in the outcome - does the individual, or group, feel more empowered than before?

Ward (1997) takes the argument further in positing a linear model with consumerism metaphorically and politically on the right, and citizenship on the left; explicit is the belief that involvement/participation/partnership is more fully exercised at the left-hand end. There is a salutary reminder that user involvement is not the same as public involvement - which the current government has been keen to promote. For example, it is seeking to involve ordinary citizens in the NHS - a commendable aim - through its Commission for Patient and Public Involvement. However, while one could argue that all citizens are 'users' of the NHS, the moment they have a specific health need, say radiotherapy, they become service users with a very particular, though legitimate, agenda that removes them from the 'citizen as member of the general public' category. It is therefore important to ensure that this category of 'non-users' are also empowered.

One way through this linguistic and conceptual morass is offered by Monroe and Oliviere (2003) who optimistically reframe it as a richness and remind us that the concept of empowerment, however we label it, is evolutionary. They suggest that user involvement is "concerned with the means of achieving a person-centred service and the meaningful participation and consultation of service users." Perhaps the adjective 'meaningful' is the key word here for both theorists and practitioners; without that, arguments about the noun are irrelevant. Implicit in this statement, and made explicit by Mullender and Ward (1991) is the transformational nature of empowerment. It is not something that professionals present to the less powerful as an attractive but inessential accessory; it is a utilitarian, living, active ability, to be exercised fully from now on and into the future.

This is very much in line with Freire's work (1972) which sought to engage, and empower the people to change their own situation. From reflection, awareness and understanding came action. However, both Freire and Foucault (1980) were clear that the nature of power was not necessarily oppositional - either one has it, or one hasn't. On the contrary, every individual both exercises power and experiences others' power. Thus empowerment is not competitive and conflictual, seeking to wrest power away from others, but is participative and collaborative, seeking to challenge and change both the individual herself and the society in which she lives.

The Dictionary of Social Work (Thomas and Pierson 1995) emphasises this **collective** aspect when it defines empowerment as being concerned with how people gain a collective control over their lives to achieve their interests, and the **individual** aspect when it describes it as the method by which social workers seek to enhance the power of people who lack it.
Ruegger (1999) offers a simpler definition; empowerment is "concerned with altering the balance of power between groups or individuals in favour of those who are traditionally in a weaker position" (p 75). This of course begs the question as to whether there is ever a 'right' balance. Nevertheless many social work theorists would argue that this has implicitly or explicitly been a key remit of social work since its inception.

This growing body of literature on users and empowerment (Beresford and Harding 1990, Croft and Beresford 1991, 1993, Oliver 1992, Payne 2005), was welcome, but there was little that specifically addressed children, or palliative care.

The literature on groupwork has also long recognised empowerment as an important concept (Doel and Sawdon 1999). Groups instantly change Ruegger's balance of power(1999) by virtue of numbers alone - the therapist/professional/leader is outnumbered by the group members, and dependence roles are reversed, in that the worker is more dependent on the clients for the group to work successfully.

Ward (1997) argues convincingly for groupwork as uniquely situated within the empowerment model and, less convincingly, as in serious decline and diverted into a compliance and control mechanism. But it is difficult to dispute his two key assertions, first that empowerment is the dominant issue in social and health care, and secondly that "the terms participation, user involvement and empowerment are used almost interchangeably". The two further terms - partnership and consultation - can be included, but for the purpose of this thesis I use empowerment as the concept which encompasses the other terms.

Nevertheless, many of the charges laid against participation are also laid at its door. Ward himself (1997) dismissed it as a 'conceptual deodorant' masking the underlying and unacceptable inequalities in social life, and others question its ability to fully engage and empower the least able, articulate and accepted members of society.

Oliver (2002 SWRA lecture) has argued vigorously that empowerment is not something that can be done **to** people; they must do it for themselves. However, once they decide to empower themselves, then professionals, including researchers, may have a role to play in this process.

Empowerment in social research

Empowerment within research has run parallel with but behind empowerment in practice. Critical inquiry, feminist research, and action research (Biggs1989) have each challenged the primacy of the 'objective' researcher, and called for, if not a privileging of the user, a partnership that empowers rather than the traditional process of patronising them (Oliviere, Hargreaves and Monroe 1997).

Oliver (2002) is rightly critical of much social research and argues that for research to be truly empowering, it needs to be experiential and action-oriented - experiential so that it genuinely captures the 'truth' of the users' lives, and action-oriented so that it will be taken into the real world and achieve social and political change. Though identifying some of the limitations inherent in these two approaches, Oliver argues that research framed in this way has a better chance of genuinely empowering the marginalised, be they disabled, black, mental health survivors or otherwise disempowered.

But as Broad (1999) has noted, "respondent power is generally underplayed or absent in accounts of research", and somewhat surprisingly Shaw (1997) suggests that user involvement is becoming discredited - largely because of its association with consumerism? This he sees as part of the new managerialism in social work, which has both commodified and routinised the needs of users.

A more critical tone still is evident in Beresford and Evans' editorial (1999), which argues that the move towards evidence-based research has reinforced the position of the professional as knower, and that even where user feedback has been incorporated, it is the paternalistic professional interpretation and presentation that has legitimated it. What is required, in their view, is a more radical approach - distinct from the consumerist approach to user views - which attempts to change the role and relations of research. Beresford and the Toronto group have been in the forefront of this movement. Recognising that research is only one basis for the production of knowledge and that "research is a particular, privileged and partial source of knowledge" (SWRA lecture 2002), it eschews the traditional orthodoxy of objectivity and detachment - which it considers to be false, alleging that it is no less partial and biased - in favour of privileging individuals' direct, personal experience as a basis for knowledge, so that they are recognised as 'true knowers' as much if not more than the academic researcher. Thus the user's social relation in the research process is validated as on a par with the academic/researcher. In that respect it shares common ground with much qualitative research, including feminist and social action approaches (Mullender 1999) and builds on Schon's seminal work (Schon 1983) which celebrates tacit knowledge, artistry and reflexivity. But it also makes much wider claims, seeking to replace research as an activity which increases the power of the professional, with research which leads to the "liberation and emancipation" (p 672) of research participants, a claim echoed by Shaw (1997) when calling for a "commitment of the powerful to changing relationships of exclusion and dependency". This is not a new call; Barnes and Wistow (1992) had identified the need to shift the balance of power between service users and providers, but it seems that the battle has yet to be won. Beresford is rightly critical of much social and policy research which he argues has benefited social and policy researchers much more than the communities on whose behalf it was theoretically conducted (personal communication 2002).

He identifies the material relations of research production as a major obstacle to real empowerment, citing the requirements of funding bodies, the expectations of customers and the academic definition of what counts as knowledge as inimical to effective user empowerment in research. All of these, as Denzin has observed (Denzin 1997) mean that the arenas that we study are delineated, in part, through the texts that we produce. For those texts to more accurately reflect the worlds of the marginalised, the material relations will also need to change.

A third issue relates to the dissemination of research. The need for researchers to take greater responsibility not only for the potential impact of the research on the rest of society, but for user-participants to be involved in the dissemination process has been highlighted by several writers (Oliver 1992, Robson 2002, Dominelli 2005)

Beresford and Evans' typology of empowerment research shares many similarities with the new paradigm of collaborative inquiry as articulated by Reason and others (Reason and Rowan 1981, Heron and Reason 2001, Reason and Bradbury, 2001) and will be considered further in the following chapter.

Palliative care

Within palliative care, the story is mixed. The hospice movement (not the same thing as palliative care despite the tendency by many to conflate the two) claimed its *raison d'etre* as giving a voice to the voiceless (Saunders 2001) - that is, its users, the dying - and it was unique in its determination to involve volunteers and thus avoid over-professionalisation. It was both a breath of fresh air and an uncomfortable challenge to the heavily bureaucratised and medically dominated Health Service. Yet, half a century on, the movement stands accused of being increasingly medicalised and routinised (Field 1994, Lawton 2000) and, in more subtle ways, patronising to its patients and families. User-centred though most hospices may be in terms of their focus on meeting individual patient needs, the broader concept of user involvement - in structures, policies and future planning - is poorly understood and rarely embraced. Reasons for this are so far speculative, as there is little research available (Payne *et al* 2005), but the endemic hospice disease of 'terminal niceness' may be one factor. User involvement may be suggestive of user dissatisfaction with a service and there is no shortage of research that shows that the seriously ill are reluctant to bite the hand that feeds them. When there is no charge for being fed (or anything else) it may be even more difficult for grateful users to suggest that they could help the organisation do better (Oliviere 1998).

In the past, palliative care has also justified its reluctance to involve patients in research with the dubious ethical argument that this would be an abuse of the vulnerable for whom day to day survival is the overriding concern, rather than a longer term goal of improved services from which they, long dead, will be unable to benefit. This view has been widely criticised (Oliviere 1998), as being "perhaps the ultimate in a patronising attitude" and there has been a growing lobby for user involvement in palliative care research.

The emphasis on user involvement and empowerment in health, social care, and research is not, however, without its critics. Frank's vision of "an ethic of voice, affording each a right to speak his own truth, in his own words" (Frank 1995 p xii) remains a contested one. Some argue that there is now an expectation that users **should** be involved and that professionals are imposing an additional burden on vulnerable people, who now feel unable to say that they do not wish to be involved. Others invoke the spectre of 'decibel diplomacy' - that the articulate, middle-class, confident (and usually white) voice of the users will drown out the whisper of the hesitant, modest minority. This inevitably raises the allied issue of whether to meet the greatest need or the need of the greatest number.

Then, in direct contrast to the criticism above, there is the argument that a user cannot represent anyone other than herself, since all experience is individual, and that it is unhelpful, and often dangerous, to build a policy or practice on the views of the user.

While these are significant criticisms, it is tempting to ponder whether they are sometimes offered to mask professional unease with anticipated outcomes. "User involvement is only welcome when it conforms with what the professional wants to hear" (Pearson 1995 p 106), mirrors the situation noted in Chapter Two, where children's consent was unquestioned when it endorsed adult opinions but was challenged where it conflicted with them.

It is the contention of this thesis that children of parents with life-threatening illness are also users with rights and needs. Yet palliative care has been slow to involve them in research into their situation. This mirrors the position of research in general on children, which is the final issue to be analysed in this literature review.

Researching Children

The literature on researching children has expanded considerably over the last few decades. It is notable, however, that this material generally resides within the literature on children, childhood or education, and is largely absent from mainstream work on research (Denzin and Lincoln 2000, Reason and Bradbury 2001, Mason 2002). This suggests that the adult world is the norm in health and social research, and it is only more recently that a debate has developed as to whether researching children requires different methodologies and methods or whether the one-size-fits all approach is justifiable.

Even where the challenge of researching children is articulated, the focus has tended to be on ethical issues in general and informed consent in particular(Farrel 2005), and less attention has been paid to the appropriateness of the design of the research.

Changing nature of 'researching children'

As with some of the earlier topics, language is again illuminating. The phrase 'researching children' usually has 'children' as the grammatical *object* - they are subjects only in the sense that they are the focus of interest for the researcher. We are rarely talking about children as grammatical *subjects*, in the sense that they are in *the act of researching*, say pocket money rates or school policies on bullying - although the work of the Children's Research Centre is beginning to change this (www.childrens-research-centre.open.ac.uk). Thus much of the debate is to do with the problem of researching a particular human group and this group of non-adults is problematised primarily in terms of intellectual understanding, verbal fluency, vulnerability and trustworthiness - themes which are implicit throughout the thesis.

In this study therefore, I make a distinction between 'researching children' in the sense of researching a topic related to or involving children, and 'researching with children' in the sense of collaborative/participative research with children. Inevitably, however, the second owes much to the first and I turn to this now.

Researching childhood

Earlier sections have considered the changing status of children in society, with their gradual transformation from possessions of parents to participants in society; now the research literature on the experience of childhood is briefly considered.

The issue of researching children's experiences is historically located in the (adult) conceptualisation of childhood, which has been based until recently almost exclusively on a biopsychophysical model of the child, with little emphasis on the social context and construction of childhood (Christensen 2000, Foley et al 2001).

Children have been defined in terms of adults, that is, as non-adults or 'not-yet' adults. The preferred mode of human existence is adulthood and children are therefore marginalised and seen as less than, and not fully, adult. They are considered less mature, less capable, less developed and less reliable than adults. They have therefore frequently been excluded from most social and health research, and have both failed the first and exemplified the second test of the old adage "children should be seen and not heard", having been statistically invisible and studiously ignored as respondents in their own right (Alderson 1995, James and Prout 1997, Christensen 2000).

As objects of research, children have been conceptualised in three ways. The first, highly influential, framing has been that of 'becoming' (Clarke 2001) - the idea that children are not-yet adults, and that childhood is a process of becoming increasingly more adult-like. Childhood is for making good the deficiencies in children, and acts as a temporary training ground of primary socialisation for the state of adulthood. This functionalist approach to childhood dominates most of the literature on children in most of the twentieth century (Clarke 2001).

The other two, mutually opposed, framings have been defined as discourses of welfare and control (Foley *et al* 2001, Beresford 2002). The former has been highly influential in shaping the child care services of this country from the 1940s onwards, while the latter has impacted on legislation on youth services, juvenile justice and education. On the one hand children have been characterised as vulnerable, non-competent individuals in need of protection from strangers, from parents and also from institutions (for example, through censorship and controls on TV scheduling, film certification etc); on the other hand society has proclaimed the need for *its* protection from children and young people who are characterised as out-of-control, intimidating, disrespectful and potentially or actually violent (Taylor 2000).

This third framing may be seen as an exaggeration of competence and a tendency to ascribe more power and intentional malevolence to children than may be warranted. Some commentators argue that this framing has been largely generated by the media from one or two high profile cases, such as the Bulger trial, but it is a discourse that has undoubtedly influenced both Government and lay thinking (Watts 1997).

More recently, a fourth framing can be discerned - that of the child as a financial unit. Whereas in Victorian times, and earlier (Aries 1973, Cunningham 2005), childhood was not only shorter but also more economically productive since children contributed to both the domestic and the State economy, the child is now a significant economic unit, not as a producer but as a consumer. Hood-Williams (1990) claims that they are again objects - objects of conspicuous consumption, and objects of their parents, to be enjoyed by adults. Alderson (2000) however, takes issue with this, pointing to the way consumption may be forced upon children and families with her telling example of the closure of public spaces (parks, school playgrounds etc.) and consequent commercialisation of play space - leisure centres, theme parks, play zones).

But both Alderson and Hood-Williams recognise that childhood is a social construction. The dominant discourse of child development, with its assumption of a gradual, stage-based development of competence towards adulthood, was challenged by writers such as James and Prout (1997) who drew on anthropological and ethnographic studies to highlight the way childhood is constructed in different societies. This construction is embedded in the culture of each society and is owned by adults but acted out by children. While this attention to the sociological aspects of childhood recognised the social forces exerted on children, it still had considerable limitations (James and Prout 1997). They and others argued for a much more radical paradigm, in which children were no longer seen as passive objects or victims, but as people in their own right, active members of both their family and society. It followed therefore that in researching childhood, children should be central to the research and their views directly accessed, rather than extrapolated from adult proxies, or adult researcher interpretation.

Until recently, this was rarely the case; evidence about children and childhood was provided not by children but mainly by parents, teachers and other adults - possibly reflecting an assumption that it was adults who were the stakeholders or consumers of children's services, rather than children themselves. This was perhaps most obviously demonstrated in Education, where the voices of parents and educationalists rang loud but those of children were barely heard (Lansdown and Newell 1994).

Children in research

A similar marginalisation has also been evident in the second major statutory service, the NHS. Most health care research on children has been concerned with physically ill children and it has long identified with the protectionist framing described above and has insisted, for 'ethical' reasons, that children should not be approached directly by researchers unless unavoidable. The laudable intention, predicated on a paternalistic approach, to prevent unnecessary distress to a child, has in effect distorted or even silenced the child's views.

Health care's adoption of the protectionist framing derives, in essence, from the dominant bio-psycho-physical model. The conceptualising of children as 'becoming' and incomplete has led to an approach in many instances that has equated them to animals or inanimate objects. The scientific objectification of children who are not ill has seen them measured, weighed and watched in laboratory conditions that have attempted to screen out extraneous factors and have succeeded in ignoring key relational and social dynamics, and contextual aspects, that are crucial to child and family well-being. Some of the twentieth-century experiments conducted in these controlled conditions would be quite unacceptable ethically nowadays.

Much of the palliative care literature on parental illness and its effect on the family - reviewed in chapter Two - appears to demonstrate this protectionist approach to children, with an emphasis on the well child as vulnerable, unreliable and less than competent.

The third major statutory agency, Social Services, has a somewhat better track record in listening to child users, as detailed earlier in the chapter, and perhaps is now closer to the liberationist model, which recognises children as having rights and competencies of their own.

Alderson represents a key figure in this move towards a competency-based model of child research, 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 goes on to argue 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.

Thus, in the early years of the twenty-first century, there is a growing consensus about the need to ensure children's involvement and participation in research. However, this tends to focus on the fieldwork stage, and stop short of the key stage of dissemination and action. Asking and listening, involving and collaborating are clearly important, but so is action for change. As the Children's

Rights Director for England, has commented, "actually doing something with them [i.e. children's views] is the largely unmet challenge" (Morgan 2004).

The current situation

While earlier models of childhood - and therefore ways of researching children - have been subjected to sustained and well-argued criticism in recent years (Fox Harding 1991, James and Prout 1997), many ethics committees appear still to be working from the protectionist-based model.

In consequence, much of the literature on researching children has focused, understandably, on eliminating risks, avoiding distress, and arguing from whom consent should be obtained, and how informed it should be. These are legitimate concerns, but there has been less attention paid to the consequences of an overly safe-guarding approach. In the pursuit of non-maleficence, there is a concomitant risk of unwittingly sanitising and diluting the child's experience, thereby doing injustice to the richness and totality of her testimony. In the concern not to pressurise children into participating, children may have been denied the opportunity to contribute. In the concern to be ethically correct and obtain parental consent, or to respect its withholding, researchers may have been profoundly disrespectful to children who did not share their parents' views. In designating their research as, say, 'The impact of cancer on the family' while using parents as proxies for children who are not recognised as competent to articulate their own experience, such researchers consciously or unconsciously reveal their philosophical bias in favour of the protectionist model, and therefore the limitations of their work.

However, it is too simplistic to see protectionism as the sole issue. Alongside the notion of vulnerability in children stands that of unreliability. This also has its roots in the 'becoming' concept of children, in that it emphasises the progressive but incomplete development of children; they are not yet able to reason logically, handle abstract concepts, consider the long-term rather than just the short-term, or to distinguish between fantasy and reality, truth and deception. As Scott

(2000) indicates, by the time children have reached the pre-teens they have (unfortunately?) mastered the art of impression management and may therefore say what they think will be acceptable rather than what they genuinely believe. But this notion of children's unreliability may contribute to infantilising them (Alderson 2000) and it also inevitably carries with it an assumption of adult adequacy. This has come to be vigorously challenged more recently. Scott (2000) acknowledges that it is not only pre-teens who are expert at impression management but also adults, the implied criticism being that they are no more trustworthy than children. Reflective accounts of research (Shakespeare *et al* 1993, Broad 1999) have revealed the less than linear, perfectly controlled progress of research with adults, and exposed the vulnerability of adults to irrationality, short-termism, desire to please the researcher, inadequacy of recall and much else. This leads Alderson (1992) to suggest that the question those researching children need to ask is not whether they understand, but whether they understand enough. Indeed, one might equally appropriately ask this of any research with adults.

Children's competence

In each of the various models outlined earlier, there is a clearly identifiable theme of competence; St Exupery comments that 'grown-ups on their own can't understand the world from the child's point of view, so they need children to explain it to them' (2002 p 6). This recognises children as the experts on their own world and competent to be guides or translators for inexpert adults. Indeed, Alderson (1995) makes the point that competence may be quite different from either intelligence, as measured by reading or maths ability, or compliance. It may well be fostered by adversity and therefore be less well demonstrated by children unaffected by the topic of interest to the researcher. This acknowledgement of both children's ability to understand what is being asked of them, and their ability to express their opinions, has resulted in research that has moved from more quantitative methods, such as surveys, questionnaires and charts, through adult observation and interpretation of children's behaviour and talk, to other qualitative methods that actively involve children as interviewees, either one-to-one or in focus groups. This type of research clearly links with consumer/participant/liberationist notions of childhood and also with Rogoff's idea of children learning **through** participation rather than learning **to** participate before being taken seriously (Rogoff 1990).

While welcoming this move away from protectionism, some writers (Keflyavew 1996, Treseder 1997) have criticised the participant model for not going far enough. There is an absence of reciprocity, they claim, and they argue that such research, while more respectful of children, is still adult-dominated in its design, methodology, tools and dissemination. The unequal power base is not fundamentally challenged, since the adults decide the topic and pose the questions. Although the expertise of the children is honoured, it is shaped and constrained by the adult's determination of the research problem and the initial set of questions asked. Yet, as Hart (1992) argues, adults have little expertise in recognising the capacities of children and themselves need help in developing this skill. Partly this may be because adults confuse children's inherent dependence with structural, social dependence (Lansdown *et al* 1995).

This question of power and status (Morrow and Richards 1996, O'Kane 2000, Farrel 2005) is central to any discussion of research, and the issue of power relations runs right through this thesis. I deal with it in more detail in later chapters; here I consider how the current assumptions about researching children reflect this power imbalance. What is noteworthy is how often texts that argue for a much more liberationist approach to researching children then focus on qualitative interviewing as the preferred *modus operandi*, with little discussion of the power imbalance (Greig and Taylor 1999, Lewis and Lindsay 2000). Even the body of writing which considers complex and multiple roles that researchers working with children may have to adopt (Mayall 1994, Morrow and Richards 1996, Davis *et al* 2000) betrays an underlying assumption that power naturally rests with the adult researcher and that whatever role is adopted the adult will exercise power on behalf of the children. This is almost certainly true with regards to initial access to resources and opportunities, but does not necessarily hold good throughout the research process. As Foucault (1980) reminded us, each person, adult or child, both exercises power and is constrained by it; power is dynamic and does not reside exclusively in one place or person but is constantly negotiated.

From participation to collaboration via PAR (participatory action research)

The term participation is very broad, as has been seen earlier. At its most basic, it may refer to children being respondents to questionnaires or interviews set up by adults for research purposes defined by adults. At its most expansive, where it may claim the term collaborative, it denotes both a process and a structure that is much more inclusive and attempts, not always successfully, to share power and control, from initial vision to dissemination.

The growing emphasis on user involvement, together with the increasing body of research into international development issues, have both been contributing factors in the shift towards more collaborative working with children. The former, user involvement, has been discussed above; the latter, international development work, is now summarised briefly. In the later decades of the twentieth century many development agencies, both NGOs and parastatals, became frustrated with the failure of large-scale programmes which manifestly failed to meet the needs or engage the interest of the poor. More participatory and collaborative approaches to research were adopted. These were sometimes gathered under the umbrella label of Participatory Rural Appraisal, characterised either as a methodological approach or as a collection of tools appropriate to emancipatory, empowering work with human groups traditionally seen as marginalised, uneducated and undervalued.

This action-research approach, where researchers sought to understand the local community's needs and work with the community's insights and expertise, rather than coming in as outside experts with a pre-defined problem and solution, requires researchers to give up substantial amounts of power and control. The inability of this research approach to achieve real equality with child co-researchers is discussed later in the thesis, but there is nevertheless a recognisable shift in favour of children compared with the traditional or even participative models.

Four key features emerge from the literature. First, liberating children from the narrow confines of the fieldwork and enabling them to exercise some power over the research topic, design and/or dissemination inevitably changes the dynamics of the process of the research (Keflavew 1996, Alderson 2000).

Second, creating a space for children to be listened to and heard is essential. Sometimes this is a literal space (outside the home, school or care facility), sometimes it is an atmosphere and ethos that is not susceptible to definition or measurement, but that is recognised by children. Usually, it is also dependent on the facilitative skills of one or other of the adult researchers involved.

Thirdly, sharing decision-making is crucial. This may not pertain throughout all stages of the research cycle, but unless children are conceived of and accepted as co-researchers, the claim of collaboration will have little meaning.

Fourthly, and certainly equally importantly, the imaginative use of appropriate tools to elicit the children's views is fundamental to engaging them in the research and enabling them to express themselves freely.
While none of this is easy, an increasing number of research projects have demonstrated the viability of this approach (Treseder 1997, Alderson 2000, Kirby 2004).

Tools for the job

A brief consideration of the strategies and activities that are conducive to involving children meaningfully in research is therefore useful. In contra-distinction to much conventional research with adults, for children visual rather than verbal modes are significant. Pictograms, free drawing and painting are all likely to engage children and elicit a response from quite a wide age range. These are sometimes justifiably criticised for being open to unchecked interpretation from adults, so it is important that it is the children's own explanation of their work that is sought. Charts and ecomaps can also be useful in clarifying perceptions.

Activities that involve prioritising - often again in a visual form, by positioning topics or themes in a line or a diamond - are particularly valuable (Treseder 1997) because they provide opportunities for discussion and debate among a group, as well as requiring and demonstrating comparative values.

In contrast, activities that give free rein to imagination, such as drama, role-play and story-telling (fictional or autobiographical) all provide opportunities to explore meaning, emotions and contexts. Circle time, feedback activities, and quickthinks may provide space for reflection, analysis and mutual valuing in a safe and unthreatening way.

These may seem a far cry from the Depression Inventory Scales, multiple choice questionnaires, or Likert scale surveys familiar in 'hard science', but their proponents are convinced of their effectiveness. That is to say, they generate data that increases children's understanding of their world (outcome) and they enable children to feel valued, heard, competent and in control (process). However, a caveat is required here; so-called child-centred methods do not guarantee genuine collaboration, unless the child's explanation and interpretation of the activity is as respected as the observable output - the finished painting, clay model or prioritised list of statements.

Summary

The history of researching children has been shaped by underlying philosophical beliefs about the nature of children and the purpose of childhood. There is still considerable debate, stemming from these competing and cherished beliefs, about the vulnerability, competence and expertise of children to participate in and undertake research. Nevertheless, there is now sufficient evidence to suggest that it is possible to research respectfully **with** child-users rather than **on** or **about** them, and that our understanding of their worlds can be considerably enriched by so doing. The next chapter addresses this issue in more detail.

CHAPTER FOUR: METHODOLOGY

"Research itself is a form of practice"
Hammersley (1995)

Introduction

In the preceding chapter I have demonstrated that there is a paucity of research addressing the needs and experiences of children facing the life-threatening illness of a parent. While there is useful literature from the different, and dismayingly separate, disciplines of the sociology of childhood, of counselling and of user involvement and children's rights, little of this has so far been directly applied to researching the situation of physically healthy children in a family where a parent is seriously ill with cancer. Yet children are users of palliative care services and their rights, as Chapter Two has shown, have been increasingly recognised by the legal system, both nationally and internationally. Much research and practice, however, has been slow to apply these insights to the palliative care setting. It is widely acknowledged (Sheldon 1997, Kissane and Bloch 2002) that effective palliative care requires consideration of the whole family and there is general agreement that psychosocial support is valuable for both the sick person and other family members (Christ 2000) but there is much less certainty about the needs of children.

In this chapter I first trace the development of my interest in the topic, then consider the research approaches available, with their respective strengths and limitations, before arguing for collaborative inquiry as an appropriate choice for my study. The claims it makes for itself and the criticisms it has drawn from others are analysed, with particular reference to issues of voice, power and groups. I then move on to consider its application to research with children, and discuss the development of the second strand of the study - a case study of the **process** of collaborative inquiry.

Finally, I return to where I began the chapter - to myself, and reconfigure the accepted notion of the significance of self in the research process as an exploration of the multiple selves co-terminously engaged in a complex and sometimes chaotic process.

Background

My own professional background is in social work, specifically with children and families, often in situations of change and loss, and most recently in palliative care, offering support to children where a parent is seriously ill. It is here that I have been challenged to rethink my own understanding of children, and my teaching of other professionals.

An early, awkward question from a colleague in a Child Guidance Clinic (where I was giving an introductory talk about my role as a specialist palliative care social worker) was, "What framework do you use?" I parried it at the time, but it continued to trouble me on three levels. First, I had a healthy wariness about trying to force families in all their complexity to fit in to the world of theories and frameworks inhabited by most therapists and researchers. Secondly, however, I wished to better conceptualise the way I carried out the work I did. Thirdly, in my role as an academic, teaching palliative care to mature professionals, I had identified a gap in the literature; I could find little useful research to offer to my students or to use as an underpinning for my own teaching.
In addition, I had an overarching wish that those at the centre - the children - should be central in any attempt to address these concerns. Thus was born the notion of embarking on my own research into this issue.

However, 'this issue' was not one neat simple entity, and the more I reflected, debated and discussed it, the bigger it revealed itself to be. But, however many layers or levels I explored, it seemed to me that the kernel at the centre was the experience of the children themselves. The two preceding chapters have highlighted the failure of the existing research into the impact of cancer on families to capture the children's experience from their own standpoint. I was therefore concerned that any theorising about frameworks or concepts should grow out of a fuller understanding of this experience, rather than be grafted on to an assumed knowledge of someone else's experience. Thus the research question became "What is the experience of children facing the life-threatening illness of a parent?" Two expectations underpinned this; first that this would illuminate the children's experience as they themselves perceived it, and second, that there would be an intention to act upon the outcomes. Although this was implicit rather than explicit in the question, the research design, which I discuss later in this chapter, would make this much more explicit. The intention was to give a voice to the children rather than to seek corroboration of adult beliefs and assumptions. An exploration of the literature, as revealed in the preceding chapter, confirmed that children were largely treated as research 'subjects' and their views, obtained at best by interview or at worst by proxy through their parents, were then interpreted, constructed and presented by a third party, the 'expert' researcher.

This was despite the fact that there was sound evidence, as demonstrated in the previous chapter, and in my own practice over the past nine years, that, provided they believed they were genuinely being listened to and taken seriously, children were capable of articulating their concerns and beliefs with a maturity and clarity that many adults did not expect.

I therefore wished to capture the children's experience and expertise in a way that would be respectful, direct and ethical. My primary concern was to illuminate the complexity of their situation and provide a rich, detailed and thick description (Geertz 1973) out of which some tentative theorising might arise. Since palliative care attends to the whole person and celebrates the uniqueness of each individual rather than emphasising universality, I do not claim that this research offers a blueprint or a single truth or indeed that it is representative of all children's experience. Nevertheless, it makes a modest claim to enlarge our understanding of a poorly researched area, and a marginalised group.

Having settled on what I wished to research, I then needed to address the how and why; questions of philosophy, ideology and methodology became paramount.

Choosing the research approach

Of the two broad philosophical stances identifiable in social and human science research, I am drawn more strongly to the social constructionist/interpretative paradigm than to positivism and its empirico-analytic paradigm. I understand social constructivism to emphasise individuals' beliefs and ideas as significant determinants of social reality, although I would not fully endorse Schwandt's (1997) claim that the world has no existence independent of human minds. I argue for a broad but flexible distinction between real, three dimensional objects and equally real, but intangible entities such as relationships, emotions, traditions etc. These latter, while less susceptible to Compte's test of being publicly verifiable by sense data, are also significant and worthy of investigation. I attach considerable importance to language and the way it conveys thoughts and meanings and both defines and reflects individuals' inner and outer worlds. Writers such as Shakespeare, Cervantes and Ngugi wa Thiongo demonstrate that 'facts' are rarely entirely objective, indisputable, measurable entities, while my training and experience as a social worker have authenticated this belief that we all, to varying degrees, construct reality 'in our own image'; I therefore favour an interpretivist and constructionist paradigm.

Since my field of study concerned not only external events but also the internal world of emotions, beliefs and values mediated through individual personalities, and sought to understand and illuminate rather than prescribe, measure and systematise, I judged a qualitative methodology to be an appropriate approach. Had I wished to map the pre-bereavement work being done with children within palliative care, then I would have recognised the strengths of a positivist paradigm, since I would be seeking to quantify and categorise a more 'objective' reality - the precise extent of pre-bereavement work. However, even this example demonstrates the limitations of polarising the strengths and weaknesses of these ontological positions. Mapping pre-bereavement work could equally well benefit from a more constructivist approach, which would recognise multiple mental constructions of what pre-bereavement work might be, and would see these as created not only by the 'subject' but also by the interaction between the subject and researcher. Similarly, although a naturalistic inquiry seeks to understand 'real life' and does not wish to reduce a situation to a completely controlled, compartmentalised and mathematically measurable set of experiments (in itself an extreme of the positivist position, and manifestly inappropriate and impossible in palliative care) it may benefit from recognising *a priori* theoretical frameworks that are implicit in the setting and in participants' and researchers' beliefs and behaviours, as well as from attending to the frequency and strength of specific 'themes' which are susceptible to counting and categorising.

Nevertheless, on balance my ontological position in relation to the world of children facing bereavement was largely relativist: there would be multiple constructions, which would be 'true' for the person holding them, and relative to time, locale, age and other factors. Since I wished to understand and lay bare their day to day experiences in a manner which captured richness and detail and individual meaning, rather than seeking to predict outcomes or prove hypotheses, an interpretive paradigm seemed more suitable. The understanding I hoped to gain would be an interactive process, in which both I as a researcher and children as participants would be fully engaged, each bringing and acknowledging competing and overlapping values. The process would involve transaction and negotiation, with a broad research design framework identified at the beginning but open to revision and re-negotiation as the research progressed.

Such an exploratory, descriptive and emic inquiry does not claim objectivity; indeed it challenges the notion that objectivity is either desirable or feasible. Instead it endorses an approach that is involved, engaged and proactive; it embraces subjectivity, within a framework of disciplined and rigorous reflection and recognises that it presents **a** truth, rather than **the** truth. As Mason (2002) points out, it seeks to understand contexts, diversity, nuance and process; it works with the "epistemologically modest concepts of perspective and difference" (Mason 2002 p 16) rather than grand claims of universal realities.

Although most writers characterise constructivism as concerned with practical knowledge (Denzin 1997, Lincoln and Guba 2000, Silverman 2000) its emphases on the world of meanings and human interaction have been criticised for discounting the influence of powerful social structures and values on participants and settings (Lincoln and Guba 2000). Critical theorists argue that individuals are shaped and limited by the norms and values of the culture to which they belong and the society in which they operate. I support their view that there is also an objective reality that is partially apprehendable (and certainly influential) which exists alongside and sometimes in contradistinction to the individual's interpreted reality. Further, I identify with their emphasis on praxis and intentionality - that research has a responsibility to act upon the situation it is examining , in order to change it. I brought to my research endeavour a dissatisfaction with the way in which society supported children of seriously ill parents and a wish to change this for the better. Critical theory spoke to this concern of mine that in my research there should be an intention to act upon the conditions existing - that is, the marginalisation of children facing parental loss.

I therefore found myself critical of the research community's rigid definitions of philosophies, paradigms and positions, which led to unhelpful polarisation - such as Popper's alleged remark that "science is the art of over-simplification". While drawn to both constructivism and critical theory, I remained fundamentally dissatisfied with the way each of these approaches positioned the researcher both in relation to participants and to the definition of what counts as knowledge in research.

Many practitioners and educationists have become increasingly frustrated by the way knowledge is claimed and framed by researchers who draw on the experience of participants but who then interpret it and give (their own) voice to the 'findings'. This uneasiness with the power relations apparently inherent in research left me uncomfortable with the critical theorists' and the constructionists' methodologies, and attracted me to the possibilities of action research, whose claim to be a paradigm, methodology or approach is still contested.

The emphasis of action research on situated, self-evaluative, relevant and functional knowledge (Cohen and Manion 1985), sat well with my practitioner and educationist identities. Kemmis (2001) develops the focus on praxis even further and aligns himself with the critical theorists in defining action research as a critical social science. He argues that its embodiment of democratic principles allows its participants to critique social conditions, and he, like others (Morrow 1994) approves this emancipatory potential. This accorded with my belief that this research should be openly political, in its intention to achieve change in the way adults support children of seriously ill or dying parents. Its democratic principles were an important value for me as they both recognised and challenged the skewed power relations referred to above, and had the potential to redress the balance to a limited extent. In this way, it aligned itself with Mies' (1983) call for conscious partiality rather than value-free research.

In addition, action research takes a more inclusive approach to the nature of evidence. The assumption that there is a fully accessible body of data which speaks the objective truth has been increasingly discredited, at least within social research (Mason 2002). Action research embraces a broader understanding of what constitutes data and therefore knowledge. Although more purist researchers would argue for drawing very clear distinctions between different paradigms and positions, I consider this somewhat rigid and unrealistic, since there are often elements of one to be found in another, for they are not all mutually exclusive. In the later decades of the twentieth century, there had developed a growing consensus that all research is an interpretation of a disputed reality (Usher 1997). McKenzie, Powell and Usher (1997) have argued that there is neither a universal correct practice nor a superordinate methodology within social research but that both critical scrutiny and reflexive analysis of the research process are crucial. This echoes the feminist and postmodern perspectives with their emphasis on reflexivity and their assertion that all research 'constructs' a world to be researched. The world researched in this thesis is characterised as one of contexts, meanings and experience of diversity, inconsistency and difference. It seeks to offer interpretation of social meanings, rather than 'scientific' truths, and thus provide some understandings of the social world of children rather than immutable laws. I therefore situate my research within a philosophy of idealism, drawing on an interpretivist/constructivist paradigm, and an action research approach that identifies with some of the critical theorist beliefs. Within the action research approach, I have elected to use collaborative inquiry , since this closely matches values to be found in social work in general - partnership, and individualizing problems and solutions in order to help people and to achieve social change - and palliative care in particular - the uniqueness of each person's response to death and dying.

Collaborative Inquiry

In this section I use the terms collaborative, co-operative and participative inquiry/enquiry interchangeably, for two reasons - primarily because the literature draws no significant distinction between them, and secondly for stylistic variation.

The notion of interactive research was beginning to appear around the last quarter of the 20th century when writers such as Rapoport (1970) began to call for a more collaborative and less hierarchical approach. Bryant (1996) traces the origins back to Lewin's work on theories of change (Lewin 1948) but argues that this was still within a positivistic perspective. Schon (1983), Cohen and Mannion (1985) and Kemmis (1993) all developed the idea further and insisted on a "commitment to the improvement of practices" (Kemmis 1993 p 185). Kemmis currently locates action research as a process - one that brings together individuals with shared topical concerns and issues (Kemmis 2001). It was recognised that all forms of knowledge are socially constructed and within social work the call for a collaborative effort between practitioners and researchers (Smith 1987) became stronger. While Payne (1997) adds a cautionary note about so-called collaborative research in which, typically, nurses have been little more than data gatherers, most writers subscribe to a more radical vision than this superficial approach that she critiques. Action research, according to Reason and Bradbury (2001) is "best understood as a way of being and doing in the world"(p xxvii) that attempts to draw scholarship and praxis together in order to "change the relationship between knowledge and practice"(p xxiv). They offer a definition of action research as 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)

Though originating in education research (Bryant 1996) action research has now established itself throughout the research community as a methodology, if not a paradigm, in its own right and applicable in many disciplines. A primary aim is to integrate the production and use of knowledge; the purpose of such knowledge is to change the world not simply to study it (Orme 1997). Fundamental to this is the notion that practitioners - or those involved in the issue being researched - should be recognised not just as participants but as co-researchers. Because such research concerns itself with situations of uniqueness, uncertainty and instability (Freidman 2000) which do not lend themselves to the application of theories and techniques derived from science in the mode of technical rationality, it operates by different criteria and argues that relevance is equally as important as the rigour prized by positivists, but which may often degenerate into mere rigidity (Schon 1983).

Co-operative inquiry, also known as participatory inquiry, identifies itself as a distinctive member of the action research family, claiming the key hallmarks enumerated above, but also covering new ground in its avowedly radical interpretation of epistemology - how we know what we know and who creates that knowledge, and how the power of knowledge is exercised and shaped by political and social systems and values (Crotty 1998). Its prime concern is to promote human welfare and it claims to be much better placed to do this than conventional research, whose participants are frequently excluded from key aspects of the research process and often given limited opportunities to exercise any choice.

Collaborative inquiry makes strong claims for inclusivity, emancipation and action. The opening sentence of Heron and Reason's chapter (Reason and Bradbury 2001, p 179) stakes its claim - it is "a way of working with other people who have similar concerns or interests to yourself, in order to 1) understand your world ... and 2) learn how to act to change things". Consideration of the language is instructive; the first preposition 'with' is significant and sets out the motivating philosophy behind this paradigm -"a way of doing research in which all those involved contribute to both the creative thinking that goes into the enterprise, and also contribute to the action which is the subject of the research" It is 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. The adverbial phrase 'in order to' is another deceptively small but important phrase; collaborative inquiry aligns itself with feminist critical theory (Roberts 1981) in particular and action research in general in its bias to the marginalised and its politicisation of research (Winter 1989). Research in the collaborative inquiry mould is openly purposive, informative and transformative both of the self and of society. Clearly then, those undertaking it aspire to be engaged, involved and committed, rather than distant, detached and indifferent.

Language again is instructive when it comes to the terminology used for those involved. 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 - the participants 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. Heron and Reason (2001) 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.

Within the literature on participative inquiry, there is broad agreement as to its defining characteristics.

- Co-researchers should be fully involved in both action and reflection (Schon 1983) - even though this may not always be true of everyone all of the time.
- Experience and action, reflection and interpretation based on self-awareness and an ability to be self-critical, are essential to the methodology and feed into and develop each other.
- Several cycles of action and reflection are required in order to ensure depth and rigour, whether these occur within one activity or several.
- Emotional competence, or intelligence, is a pre-requisite, since such inquiries place great value on a holistic and humanistic approach, valuing the individual as a whole person contributing all of themselves to the inquiry process. Wholeness, rather than separateness and objectivity, is the aim.
- The inquiry may be either informative or transformative in its purpose or both: equally, it may be one in its process and the other in its outcome.

Four forms of knowing are proposed - experiential, presentational, propositional and practical. Reason argues (Reason and Bradbury 2001, p 179) that practical is the highest form "since knowing-how consummates the other three forms" which underpin it.

In their typology of ways of knowing, Heron and Reason (2001) challenge the primacy of theoretical, propositional knowledge associated with academia and argue for what they describe as an "extended epistemology" (p 183). Experiential knowing, as its name suggests, is based on direct, first-hand experiences and honours the intangible - the emotional connections, the felt and intuitive. This tacit knowledge, earlier highlighted by Benner (1984) is acquired through experience and practice and is difficult to articulate through conventional means such as the written word. Schon articulates similar beliefs (Schon 1983) when he champions learning from doing, judgement and experience as aspects of the skilled professional that often elude analysis and measurement but that indubitably exist. From this comes presentational knowing - capturing the meaning and significance of that experience and knowledge largely through the arts (drama, drawing, dance and many other forms) which enables the private to become at least partially public. Propositional knowledge equates more closely to the traditional form of knowledge privileged by academics - knowing about something, and formalizing that knowing in theories and models for debate. Lastly, practical knowing is claimed to be the pinnacle of this epistemology, in that it is expressed in the ability and skill to do the 'something' that the foregoing ways of knowing have explored.

Heron and Reason make a seductive claim when they write "knowing will be more valid if these four ways of knowing are congruent with each other; if our knowing is grounded in our experience, expressed through our stories and images, understood through theories which make sense to us, and expressed in worthwhile action in our lives" (Reason and Bradbury 2001 p183).

These are major claims; they have provoked major criticism.

Better, worse or different?

"So-called participatory design...is about as sloppy as one can get, short of participatory authoring of the final report " (Scriven 1997, p 486). This criticism focuses its wrath on design, but carries an unspoken implication that participative inquiry as a sub-set of action research and a methodology in itself is unsystematic, irrational, subjective and lacking in rigour. Scriven apparently supports Thyer's view that controlled experimental research, guided by the philosophy of science known as logical positivism and the tenets of hypotheticodeductive process is the approach of choice(Thyer 1989). But collaborative inquiry explicitly challenges the old order; one is reminded of Becker's caustic comment (1970) that the sociologist is likely to attract charges of bias whenever he or she says something that denies the legitimacy of the hierarchy of credibility.

Positivists are reluctant to recognise that they, as much as interpretivists, are also interpreters of data, whether qualitative or quantitative, and thus are engaged in a subjective endeavour (Dzurec and Abraham 1993). As they argue, findings from both camps are based on description, probability and inference. The data does not necessarily speak for itself, and what counts as knowledge varies according to researcher, design and context - and is thus subjective. Social work is located in a messy, complex world that is rarely susceptible to the apparently neat, controlled certainties of experimental work favoured by the logical positivists.

Current re-evaluation of such past research has undermined these certainties and revealed similar processes of interpretation and inference as those more openly acknowledged in interpretive approaches. And social work research does not occur in a vacuum. Like all research, it is a profoundly political and value-laden activity. Emancipatory research and critical theory claim that researchers have a duty to actively adopt anti-oppressive research practices, as so-called objectivity and neutrality is oppressive by default (Mason 2002). Usher (1997) argues that the quest for 'neutral' knowledge should be replaced by a clear emancipatory commitment to knowledge from the standpoint of women's experience and feminist theory. Jordan (2003) endorses this when he writes that positivism ignores power issues in social settings, but the emancipatory researcher, in recognising these power dimensions, must take sides. In doing so he or she will need to redress the balance by involving service users and is likely to favour qualitative research methods which are better suited to illuminate the strategic, cultural and institutional aspects of power relations, and capture diversity and pluralism.

Writers such as Brian Sheldon (1978) who espouse an evidence-based, rational-technical approach to social work, operate from a paradigm that values objectivity and distance as mechanisms for guaranteeing reliability and reality. They criticise the notion of participants as co-researchers because the research will then inevitably be biased, tainted by the subjective perceptions of those involved, and therefore not generalisable and valid. Theirs is an etic approach, believing in a separation between researcher and researched, in which the researcher is superior, detached and omniscient, like the astronaut surveying the world from space, able to observe the full picture from the 'outside'.

While it is important to take seriously the criticisms that each makes of the other, the claim of the positivists to be unbiased is in itself biased; those who start from a position that it is not possible to be totally objective, but that it is possible and essential to investigate and explicate the causes and consequences of that bias (Peshkin 1988) demonstrate, if not an objectivity, at least an honesty and transparency missing from much 'hard' science, that may enable the reader to make a more considered judgement about 'bias'.

It is clear that these paradigms practise in different worlds (Schon 1992) and therefore call for different criteria. Most qualitative researchers actively value subjectivity (transformed by self-awareness into a critical subjectivity), involvement and emotion. Personal involvement enables people to begin to 'know' each other and to give them entry into their own lives (Roberts 1981). Indeed "it is difficult to see how societal and individual values might actually be absent from the research process" (Williams and May 1996 p 132); for them, the positivists' Holy Grail of objectivity is unobtainable and their attempts to eliminate bias are a fool's errand.

Lather argues that all research is "constructed, contested, incessantly perspectival and polyphonic" (Lather 1991). Qualitative researchers, then, whether defining themselves as critical theorists, action researchers or feminists -

or refusing to confine themselves to any one of those labels - construct the research process as to be inevitably political and impossible to be value-free. Moreover, they actively embrace this bias for change, claiming that being explicit about it is to avoid the subliminal bias implicit in the assumption that values have no influence on research interests and methods (Powell 1997).

Thus, collaborative inquiry embraces researcher 'subjectivity' seeing it as a strength that allows for a more emic, holistic and hermeneutic process that encapsulates the dynamic relationship between all those involved and captures both detail and depth in the inquiry.

Generalisation is also critiqued; Mackenzie (1997) points to the futility of over 2000 years of search for universal propositions, while Usher (1997) argues that it is not generalisation and prediction that should be the test of knowledge but illumination, meaning and interpretive power.

Collaborative inquiry therefore reframes the traditional concerns of generalisability, validity and reliability; the criteria by which it seeks to be judged are primarily transparency and an honesty as to the consequences which accrue from the choices made. It is important that the research is well-founded - that it is solidly based on the experiences of co-researchers, empathetically involved in the process of inquiring co-operatively - and that the experience is constructed and interpreted through cycles of reflection and action. This critical evaluation occurs during the process of fieldwork as well as retrospectively, and applies both common sense - does the research make sense to practitioners working in the field? - and considered judgement - do the co-researchers themselves recognise it as a valid description and examination of their activity?

In summary, collaborative inquiry makes its own, distinct attempt to answer the key questions about knowledge - what it is, who creates it, what its relationship is to truth and power. It is not uncritical of the Marxist dictum that the important thing is not to understand the world but to change it; action researchers argue that to aim for the latter one must first achieve the former. However, to then stop at the former is to fail to activate the potential and moral imperative explicit in participative inquiry.

It is mindful of Roberts'(1981) criticisms of academic discourse - that it is a notably male discourse elevating rationality, reliability and falsifiability above intuition, tacit knowledge and emotional intelligence - and attempts to value these feminine (or human?) aspects in its epistemology. It rejects the implicit devaluing of 'soft' data and revisioning of words such as 'emotional' to mean 'over-emotional' and seeks to attend to the whole person. This approach would seem highly congruent with the espoused values of palliative care, with its holistic approach to the care of the dying.

Key Issues in Research

Power relations

The unequal power relations within the research process have, as indicated earlier, been the subject of increasing criticism in recent years and collaborative inquiry specifically aims to address these concerns and shift the balance of power. Yet intention is no guarantee of success and it is important to scrutinise this approach for evidence of a redistribution of power.

It is a relatively simple matter to label all those involved in the research project as co-researchers; it is another matter to achieve the equality that the prefix 'co' may imply. Lay people (a term that implicitly and unhelpfully categorises them as non-professional and therefore possibly un-professional) may not feel on an equal footing simply because of a title that they may feel has pretensions to expertise that they do not claim. Both their own understandings of 'research' and society's construction of it may veer more towards the traditional concept of 'scientific positivism' than towards the notions embraced by action researchers. They may therefore come to the collaborative inquiry with less inner conviction of equal standing than the academic co-researcher committed to values of equality, participation and power-sharing.

When the initial idea for the research has come from the 'professional' (academic or practitioner) a power dynamic is already in place that may be difficult to shift in the course of the project. And it is likely that issues relating to funding, resources - of time and space and equipment - and dissemination will be mediated by that professional, whose place and power within various networks, often unfamiliar to the other co-researchers, is already accepted. When it come to dissemination, the research world is likely to be experienced as a rather rarified world with language, codes of behaviour and presentation totally unfamiliar to 'ordinary' people. All of these factors may militate against the avowed intent of all to create a more democratic, collaborative approach.

Thus, while acknowledging the potential for collaboration and the power-sharing implicit in this, one must recognise that that potential may be only partially realised, and that external factors, beyond the control of either the lead researcher or the collaborative group itself, may prevent the ideal of participant power from being fully achieved (Dominelli 2004).

Nevertheless, in comparison with, say, focus groups or even in-depth interviewing, collaborative inquiry is arguably more democratic since the agenda is collaboratively negotiated and renegotiated whereas in the two former the research topic, questions and processes are largely controlled by the researcher.

Just as the claim to redress the balance of power is open to criticism for its ambitiousness, so the parallel claim of 'giving voice' to those whose expertise is rarely acknowledged must be examined.

Voice

Voice is a concept capable of various definitions, but may be broadly described as articulating faithfully, with as little interpretation as possible, the world-view (embracing emotions, values, experience and knowledge) of a particular individual or group. It stems from a belief that in both professional practice and in research, there has been a tendency for those in power to re-form or transform the experience (voice) of clients or participants in a way that does not do justice to that past experience and may not promote justice in the future. Additionally, voice is also seen as related particularly to making space for those who are marginalised - minority ethnic groups, lesbians, gay, bi- and transsexuals, those with disabilities, older people and children - whose views are discounted or unsought within mainstream society.

Worthy as the intention to 'give' voice may be, it raises the question of whose 'voice'? As noted in Chapter Three, involving service users does not necessarily mean that they can speak for all users. The power dynamic, as has been argued above, may mean that the voice is muffled or distorted, but even if it is clear and faithful, it will be a particular and partial voice. Qualitative methods seek to illuminate an experience in all its depth and richness, and in so doing, inevitably particularise and individualise.

This may be both their strength and their weakness; they cannot necessarily claim the voice to be representative. The argument that is often applied across the board about qualitative research participants, that research attracts a particular type of person and that they are therefore not representative of the general population, may be levied with even more fervour against action research in general and collaborative inquiry in particular.

Nevertheless, it is important to recognise both the clear intent in collaborative inquiry to 'give voice' to those who are otherwise unlikely to get their voices heard, and also the ability, limited though it may be, of the collaborative process to access and honour those voices.

Groups

The use of groups also requires critical consideration. The experience of the collaborative research group (the Video Project) is discussed in the following chapter; here, some methodological issues are highlighted.
Working with groups, as opposed to the social work or community work notion of groupwork, is a well-established tradition in research. Much quantitative research works with particular groups, or populations, and focuses on aggregation, producing findings or hypotheses that are claimed to hold good for all in the group. Increasingly, in the last half-century or so, qualitative researchers have worked differently with groups. Ethnographers have immersed themselves in a group (a tribe, school, disaffected teenagers) to produce rich, detailed, nuanced studies that both illuminate the members' experience and world view and enable 'outsiders' to understand and possibly begin to address the issues raised. Others have used focus groups to generate information and ideas in a way that one-to-one interviews, dependent only on the interaction between participant and researcher, may not so readily achieve; the group discussion generates debate and disagreement that is missing from the individual interview. It thus has the potential both to reinforce individual ideas - when the group identifies enthusiastically with someone's comments - and to provide a range of views - as when disagreement with a group member exposes diverging views and engenders a lively debate.

Collaborative inquiry by definition involves group work. It embraces some aspects of ethnography and may superficially appear to resemble a focus group, yet it is neither of these. There may be a sense in which the group of co-researchers become immersed in themselves as a group, as they study some aspect of their own personal life or work, but the 'life' of the group is not a naturally occurring one. It is task-oriented, time-limited and created for a particular purpose. Their topic may be a concurrently existing one (living in a family facing life-threatening illness) but the group itself is not living out those experiences within the group: in fact the group acts as a pause in, and interruption to, that experience.

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, who then processes the data. Focus group members may be asked to check transcriptions, but this frequently marks the end of their involvement in the research process.

A participative inquiry group attempts to minimise the distinction between researcher and participants. In some cases, all the participants will have experiential knowledge of the topic - as in a group of doctors conducting a participative inquiry into surgery consultations. In other cases, there might be a lead researcher who is not a doctor but wishes to investigate this topic; she might gather together a group of doctors interested in co-researching the matter and then take the lead in explaining the nature of collaborative inquiry before stepping back to enable them to define the boundaries of the inquiry and the strategies to adopt. Her role might move back and forth from instigator to consultant.

However, managing these changing and dynamic roles is complex and requires considerable interpersonal skills and self-awareness (Marshall 2001). It may be much more in the **execution** of these roles than in the **principles** of participative inquiry, that the difference is demonstrated.
This leads to a further aspect of group work. Much of the literature on group work 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.

The emphasis on iteration and reflection, and the avowed intention to be transformative predispose the process to be therapeutic.
Mixing the two - task and therapy - is open to criticism, but the collaborative approach perhaps acknowledges more readily the therapeutic consequence of much (qualititative) research. Certainly within palliative care, many researchers have found it difficult to terminate interviews and have frequently been the recipients of grateful thanks from interviewees who have emphasised the cathartic and healing nature of what the researchers characterised as distressing and difficult interviews (Klass, Silverman and Nickman 1996, Worden 2002). It would seem that while clarity about the nature and intent of groups is essential, and honesty of purpose paramount, the process and outcome of group work may (fortunately) be more diverse.

Applying Collaborative Inquiry to Research with Children

Research on aspects of children's lives has become a growth area in recent years, as the preceding chapter has demonstrated. However, although there has been a gradual adoption of some of the techniques employed in Participatory Rural Appraisal, it would seem that collaborative inquiry with children is rare. And to date there appear to be no examples of the use of collaborative inquiry with children in the palliative care field. The application of this approach to children impacts on the issues considered above.

Power relations

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 of adults is that they rather than the children hold the power, make the decisions and see themselves as wiser, more expert and competent than children. Collaborative inquiry with children would ask 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. This would require a considerable act of faith.

On the other hand, there is a growing acknowledgement that participants, interviewees or groups are not passive in their participation but are able to wield considerable power in terms of engaging with the topic and the researcher, and withholding or contributing data. In this respect, collaborative inquiry with children is no different, as the later chapters on the study's findings make clear. Nevertheless, it is not possible to be confident that collaborative inquiry in itself will automatically transfer power to child participants. The most that may be claimed is that it provides a more favourable setting for working towards this, in a culture that is controlled by adults largely in the interests of adults.

Voice

The critique of voice, addressed to studies of disabled people, women and other oppressed groups, can also be applied to children. That those young people who participate in research may be more likely to come from stable, conventional families, to be well-educated and to be more compliant than their peers, is one argument; the other represents the opposite end of the scale, in characterising such children as more unconventional, extreme and anti-authoritarian. Either way, the 'voice' is liable to be marginalised by a label of unrepresentativeness.

A second aspect is the temptation to categorise children (as adults also may be) in terms of their gender, age or class, and thus ignore variations that cross these boundaries. The voice then may become primarily the voice of class or gender, rather than the voice of children.

Collaborative inquiry is subject to these risks, but in principle pays great attention to the process of exploration and reflection within the group, and seeks to value every individual's contribution, rather than constructing a spurious consensus. Again, the two findings chapters present a broad and sometimes conflicting range of opinion, rather than an aggregated majority view.

Group work

Groups are acknowledged to be potentially very powerful entities and this in itself can redress some of the imbalances identified above. A collaborative inquiry, by its nature, may allow for some transfer of power from the professional researcher to, and for a clearer articulation of the voice of, the participants - but equally it runs the risk of enabling power and voice to be exercised by dominant members of the group at the expense of less vocal and confident children whose experience is nevertheless equally valid.

Collaborative inquiry, therefore, like any methodology, is limited in its ability to perfectly encapsulate the matter under consideration. However, its particular emphasis on participation, its more radical interpretation of knowledge and its fundamental respect for users' perspectives are strengths that make it an appropriate approach to the initial research question of this thesis.

Researching the Process of Collaborative Enquiry

Despite the limitations of collaborative inquiry that I have acknowledged in preceding sections of this chapter, I would - to borrow a useful social work concept - still characterise it as 'good-enough' for my particular research purpose. However, I was unaware of it having been used with children; the literature entirely focused on collaborative inquiry with adults. I was also unaware of its application within palliative care. It therefore seemed worthwhile to also research this new application of collaborative inquiry, in tandem with the research into the children's experience. My final research design therefore incorporated

two inquiries - one into the needs of children facing parental bereavement and the other into the process of conducting a collaborative inquiry. This second strand, which could be framed either as a compressed longitudinal study or a case study, ran in parallel with the first, so that this research is the story of two stories, one within the other, or perhaps more accurately each entwined with the other in a symbiotic relationship. For this purpose I obtained permission, as indicated elsewhere, to record the whole process of the Video Project - the research sessions, the debriefing and the supervision sessions.
Within the second strand of the research (the process of collaborative inquiry with children) the issues of power, voice and group process are further addressed in Chapters Seven and Nine.

During the first session I sought and obtained permission to use a static camera continuously. It was explained that this was for the purposes of my thesis and that the tapes would not be for public use. Should there be any footage from these 'process' tapes that we subsequently wished to include in the final film, it would be subject to the same rules as 'intentional' footage - it would be viewed by the group and it would be their decision.

Participatory video

The philosophy behind participatory video has strong parallels with collaborative inquiry. It seeks to make films **with** rather than for, on or about people. It eschews the documentary approach, wherein outsiders plan, produce and edit a story about other people, who have little or no control over any of the process. Participatory video seeks to enable those 'other people' to tell their own story in their own way (Robertson and Shaw 1997). So, although the topic may have been identified by someone outside the group, the group itself decides the shape and content and final outcome. Thus, one of its strengths was its congruence with the methodology I was using.

Data sources and analysis

This research has drawn on the following data sources:-

Audiovisual	Process tapes from static camera recording each session of the Video Project
	Unedited tapes shot for potential inclusion in the finished video
	Final tape of video on sale: "No - You Don't Know How We Feel"
	Debrief sessions for facilitators
	Supervision sessions for social workers
Written	Reflective Diary
	Summary of each Video project session
	Products of project sessions - post-its, mind maps, feedback sheets etc.
	Speeches at conferences, presentations
	Case notes and emails
Visual	Paintings

The data for this analysis is drawn from the following sources and is abbreviated in the text as follows:-

Videotapes

Videotape **(V)** - material filmed for possible inclusion in final video for public viewing, and carrying both prior and retrospective consent of the young people. Coded A to F and covering Sessions 1 to 7. Thus an extract labelled S5 VE 1.35 refers to Session 5 of the project, Videotape E, one minute and 35 seconds into the track.

Process tape **(P)** - material filmed primarily in order to record the process of conducting the collaborative inquiry. Normally, the camera was in a fixed position in the room and was left to run undisturbed; occasionally, the participatory video-maker operated it. Thus an extract labelled S5 P5b 42.01 refers to Session 5 of the project, process tape 5b (the second recorded tape of the session), forty-two minutes and one second into the track.

Documents

Video Diary - notes written by the author immediately after each session, documenting both practical matters, observations and reflections, including occasional interactions and conversations not recorded by either camera. Thus, VD S5 relates to the author's notes of Session 5.

Reflective Diary - begun a year before embarking on doctoral studies and continued throughout the research process. A personal, reflexive account of the experience. Thus, Reflective Diary 12/10/03 refers to an entry in the diary on October 12th, 2003.

Correspondence

Letters, emails and memos to or from any of the co-researchers are referred to by date and name of sender and recipient, e.g. Email to facilitators from GC, 12/10/03 refers to an email the author sent to the three other adult co-researchers on 12th October 2003.

Products of the sessions

These include such things as flip-chart sheets, post-its, paintings, ground rules etc, and are referred to by name.

Interrogating the data

I watched all the tapes (V and P) after every session and made preliminary notes. At the end of Phase Two, after the final session, they were again reviewed, for the purpose of editing a final version of the film.

Subsequently (over a year later), a full analysis of all the tapes was made, identifying who said what to whom.

Finally, after a lapse of many more months, which allowed me to distance myself from my role as facilitator, project leader and social worker and to focus on my role as doctoral researcher, I re-viewed all the tapes again, twice. On the second occasion, I watched them without sound, in order to attend to any significant visual evidence, which might have been previously unobserved.

The benefits of this time-consuming process were two-fold. First, a comparison of the notes made on the first review, made directly after each session, with the later notes made over a year later, showed a welcome consistency and accuracy in recording on paper both the words and events. Secondly, the strategy of turning the sound down enabled the behaviour and activity of the children to come to the fore, and allowed mis-matches between the verbal and the behavioural evidence to be exposed. Although the advantage of video, as I argue elsewhere, is that it literally provides a much fuller, naturalistic picture than does audiotape, that visual content is often marginalised by the human tendency to value sound over vision. It was important, therefore, to maximise the benefit of using videotape by consciously attending to the visual. Although this technique was particularly valuable for the analysis of the collaborative inquiry process and thus features more strongly in that chapter, it was also helpful for analysing non-verbal signals of agreement with and dissent from particular views about living with life-threatening parental illness.

Analysis

Identifying data sources is relatively straightforward; they can be enumerated clearly. Analysing qualitative data is much less so, even where it is enhanced understanding rather than confident prediction that is the purpose of the study, for it is a complex process, rigorous but inferential, organised but intuitive (Polit and Hungler 1999) - a process in which crystallisation and creativity are as important as categorisation. Reason has argued that action research is in some senses a work of art (Reason 2005) and that hold true for the analytical process. Any analysis is a creation, in that it is a particular, individual construction; it reduces, expands and extrapolates from the data to construct theories, concepts, or sets of findings. As Froggatt (2001) suggests, "there is no one right way to work with the data, and it is a process best learnt by doing." My aim was to stay open to possibilities for as long as practicable, rather than to arm myself with a fixed template, and my approach therefore closely paralleled that identified in Crabtree and Miller (1999 p23) as the immersion/crystallisation method in which the researcher's "prolonged immersion into and experience of the **text** (my emphasis)... and concerned reflection" enables one to emerge with 'an intuitive crystallisation of the data'. In this approach, the organising, connecting and editing aspects of the analysis are collapsed into one, or more accurately overlap, merge and separate over a time period that precedes the fieldwork and continues up to and into the writing phase.

The expert advice to achieve immersion in the data was followed almost by default; the process of making the video meant that I endlessly reviewed the tapes during the fieldwork and almost as endlessly watched the final film every time I prepared to present a paper or show the film in public. And the process of coding, categorising and identifying the emerging over-arching themes was concurrent with the group sessions; at the debrief immediately afterwards, at supervision sessions, when writing my reflective diary, or reviewing the week's tapes - the themes and codes began to *emerge.* This reflective, iterative interrogation of the material took place both consciously and sub-consciously and the gradual construction of a theoretical framework was both inductive and deductive. While the theoretical framework is mine alone, the video "No - You Don't Know How We Feel" is nevertheless a form of member validation of the data analysis, for all thirteen co-researchers were involved in agreeing not only what went into the final version but also what should be left out. In this sense, the video is authenticated by the co-researchers not only as an accurate transcript but, just as importantly, as a faithful presentation of their analysis of their situation. It is one, first-order framing. The written analysis, presented in Chapters Seven and Eight, goes beyond this and is acknowledged as the particular interpretation - as are all academic analyses - of the thesis writer, myself. Any analysis is an artefact (Alldred 1998) and mine is no exception. I have a particular standpoint, a life experience unique to myself, a position circumscribed by power and relationships, and it is inevitable that the interpretation, or second-order framing, will be influenced by all these. Finally, it must be acknowledged that all attempts - including this one - to simplify and summarise ideas will do a disservice to the truth that living with life-threatening illness in the family is both immensely complicated and extremely challenging.

The Self in the Research Process

> "Can you love or respect the people and assist their/our inquiry without imposition of your will? Can you intervene in the most vital matters and yield to events their courses? Can you attain deep knowing and know you do not understand? Conceive, give birth and nourish without retaining ownership? Trust action without knowing outcome, guide by being guided? Exercise stewardship without control?"
>
> (An interpretation of Lao Tzu c. 550 BC)

In keeping with Glesne and Peshkin (1992), I take a position that embraces the presence, prejudices (in the sense of preferences) and power issues brought to bear on the research process by the researcher. The fact that this was a collaborative process does not invalidate the need to openly acknowledge and examine the impact of **my** self on the project and the impact of the project on my **self**. While it is possible to make a distinction in writing between these two themes, in practice they were interwoven, each being cause and effect at different times. The discussion which follows may therefore present a neater and more clearly 'constructed' picture than was being created at the time of the fieldwork itself.

The attempt to be self-aware is almost a contradiction in terms, in the sense that the very act of reflection and analysis acts upon the 'natural' self that one seeks to observe, and has the potential to change that self. Indeed, there is an argument that the self is not *revealed* through reflection but is *created* by the process, that one constructs a self in the process of reflecting on the self.

Notwithstanding that caveat, my prime vehicle for consideration of the use of self was the reflective diary which I began a year before I registered at the University of Southampton, while undertaking a research module at the university where I am currently employed. I have kept this diary throughout the research process. I began with the intention of writing something each time I attended a lecture, had a tutorial, spent a day studying or engaged in a video session. Unsurprisingly, I was not totally successful in this; the rest of life intervened and sometimes there were no diary entries for days or weeks on end. Surprisingly, however, there was a counterbalancing drive - many times I **wanted** to sit down at the keyboard and capture in print my ideas, frustrations, moments of enlightenment, flashes of enthusiasm and excited or irritated reactions to something I had read. The diary was no longer a task or burden, but a confidante, a map and a jewellery box - full of nuggets and gems - or a box in which I stored pieces of the jigsaw puzzle, mixed up with other pieces that maybe belonged to another picture and that I would not eventually need - but were there for safe-keeping until I knew what picture belonged on the cover of the box.

It is clearly not possible to prove the honesty of a diary and many would argue that all diaries are written with an audience in mind and never for the author alone - "*un produit d'un autre moi*" (Proust 1871-1922). Nevertheless, my diary, written by my 'researcher-self' offers a picture, admittedly partial, that is both artless and full of artifice; artless in its spontaneity, immediacy and directness, full of artifice in the sense that it stands back, reflects, and analyses, in an attempt to understand both the personal and political in the research in which I was engaged. Two short examples will illustrate this.
A highly personal reflection:-

> *"Felt thoroughly demoralised by end of first session (*of a taught research module)*...no real introductions...I didn't understand some of the terms, and was not confident enough to ask questions. Further demoralised when I couldn't find things in the library - felt totally useless (Reflective Diary 11/10/00)*

And a more political one:-

> *Have been reading "Doing Feminist Research" - at last. Very good - and so much of it still true!*
>
> *Thoughts re methodology - use of 3rd person is a spurious objectivity, but use of the reflexive "I" and location of self is a spurious genuineness?*
>
> *(Reflective Diary 18/04/03)*

The second mechanism I adopted for exploring the use of self was the group supervision process that ran parallel with the Video Project. While this was standard social work practice in groupwork, it also served as another opportunity for reflection on the self, as facilitator, social worker and researcher. For example:-

> *Supervision with P. Shared concerns re managing the time. Agreed that Alison and Sue would share this responsibility - use humour, joking to convey point to Nick. Self does not have to have role of strict parent!*
>
> *(Reflective Diary 11/03/03)*

Of course, supervision was not confined to reflection on my self alone; there was an opportunity for all three social workers to reflect on their own as well as others' selves. One negative aspect was the absence of the video expert, Nick, who occupied a difficult and anomalous position within the group. Not only was he a young male among three middle-aged women, but he was also an employee of mine, contracted to provide a service. He had no experience of palliative care, death and bereavement. He was about to increase his family and become a first-time father, and was surrounded by three experienced mothers, and several children whose families would decrease through death. The prime reasons for excluding him from the supervision group sessions were logistical and financial. As a self-employed commercial operator, he needed to charge for his time and this would have taken us well over budget, since we had originally not envisaged the cameraman as being anything more than just that and so had not costed in supervision or related travelling time for him. Moreover, we three social workers were all familiar with the notion of group supervision and had seen ourselves as the facilitators of the group. In our preparation session beforehand we began to see that Nick might contribute much more than we had anticipated, but how much only became apparent in retrospect.

Despite the limitations of his absence, the group supervision sessions were very valuable. We met twice before and then fortnightly during the fieldwork, with a last session after the final meeting of the Video Group.

Although Nick was not part of the formal group supervision, he was included in the debriefing sessions that we held directly after each Video Group meeting. These provided yet another opportunity for reflection:-

> Nick *"Too much of the adults... too much talking"*
> Gillian *"But it was important to do the ground rules stuff early on"*
> Nick *"I think we could have left the quickthink til later"*
> Alison *"I'm not so sure. We needed to do this in the first session - it's what we will work on for the rest of the time"*
> Sue *"You did sound a bit teacherish, Gillian, when you said we'd only got 3 minutes left"*

I hadn't realised this when I had intervened in an activity that was running over time. I was struggling to hold in tension the groupworker self who valued the process that was unfolding, and the researcher who was desperate for the group to decide on the themes to be researched. Reflection on the discussion enabled me to appreciate how I had sounded to others and also to model the important principles of honesty and self-disclosure in the next session. There, I was able to apologise to the whole group for having sounded like a teacher and to reiterate the collaborative nature of our group.

A fourth opportunity to reflect on the use of self was provided by a 'critical friends' group. I was influenced by Ely's (1991) account of this and felt that a small group of interested colleagues would, as she argued persuasively, both challenge and support me. I invited the two other social workers in my team and the former team manager, who had been very committed to providing a service for children, to form the group, and was confident that they would be able to perform the dual role of critic and friend. We met irregularly, as the need arose, but profitably.

For example, my reflective diary of October 2002 records an appropriate challenge. Not yet having any source of funds, I tended to minimise the costs. My colleagues urged me to be realistic and for a number of items, they doubled my estimates. Though demoralising at the time, this was in the long term extremely useful; my final projections were much more sensible and accurate, the project was more credible, and I did not have to go cap in hand to the funders for extra cash.

Equally importantly, the critical friends were supportive when needed. Some months before the group was due to start, some colleagues had suggested that the attractions of video might lead children to glamourise or distort their real feelings. I was left feeling full of self-doubt...One of the critical friends urged me to hold on to my beliefs about children's competence and right to be heard. She spoke of a professional health colleague who had always espoused openness and honesty between family members in the face of illness, but who was now seriously ill herself, and avoiding communication with her distressed children. My colleague's point was that this person 'knew' in principle, but not in practice. "You must help children be heard" she said, "it still isn't happening". This gave me the courage to continue, in the face of others backing off with justifications as to why it was too difficult. Further reflection helped me to see that yet again there was a parallel between research and palliative care; families and researchers embrace principles, in theory, that at the time of crisis are difficult to sustain; one is tempted to retreat from the principled stance.

One self, many selves - or the Emperor's new clothes?

While we cannot fail to impact upon the research process, much of the discussion around this notion of self suggests a coherence and unity that is both attractive and inaccurate. There were many selves within my self - or perhaps more accurately, there were layers of self that like an onion formed the whole self. The self of greatest longevity was probably the social work self, for I qualified as a social worker some thirty-five years ago and it had been my major career for most of that period. The palliative care social work self was a more recent incarnation - but however different the dress, the body within was social work. Then there was the self as researcher. These clothes sat uncomfortably to start with; I did not feel they belonged to me, or I to them. Impostership has been well documented (Shakespeare 1993) - suffice it to say that it took time to feel and think my way into researcher mode. And it was a particular style of researcher that I modelled, one that claimed a much closer kinship with the social work practitioner that I had always been than the style advocated by Compte and others. As argued earlier in this chapter, mine was not a so-called purist approach, divorced from the realities of daily practice and unsullied by political or personal bias; mine was a practice-oriented, liberationist, intentionally praxis-focused style. This was a different dress from that of the social worker, but it was from the same couturier.

So much for the professional selves. Although I have dealt with them first , they perforce follow on from the personal selves.

How had my self, as a child, influenced my self as social worker and researcher? I had given this little direct thought until I came to write this chapter. I had a happy, uneventful childhood. I knew I was loved, although I do not recall that I had ever debated it, for it was simply a given. I was not aware at the time, but the benefit of hindsight shows me that a particular gift from my father was his individualism, his willingness to challenge accepted wisdom and his respect for those prepared to speak their mind, including children. Because I had been able to make myself heard as an individual, when a child, maybe I was motivated to help other children to be heard?

And myself as an adult, a parent? I had been fortunate, once again, in my family relationships - they were generally open, honest and loving. Most of the time - which is as much as perhaps any of us should ask - my children and I could communicate honestly, and trust each other. This was an experience that I could not manufacture for the families with whom I worked, but it was a value that was part of myself and clearly a coping strategy that I advocated and endorsed in my work.

I have used several analogies, because no one analogy captures the situation in its entirety, to suggest how these different selves co-existed. Layers of an onion, different outfits in the wardrobe or simply separate items in the wardrobe from which to mix'n'match - none entirely serve, since it is academic to distinguish selves that do not exist in isolation and contradistinction.

Similarly, as I struggled with the notion of identity and sought to be selves-aware, I also struggled with the 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, as highlighted in the earlier discussion about supervision. Just as clearly, I belonged to the middle-aged, experienced mother group. Both of these groups excluded Nick. I also belonged to the two-person Macmillan team group - which thereby excluded Alison. 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.

> *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 24/02/03).*
> *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 24/02/03)*

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 in the research process that I had uncritically absorbed as a novice researcher did not adequately reflect these many selves.

Summary

This chapter has presented the rationale for my approach to researching the experience of children living with life-threatening parental illness. It has traced the evolution of my concern, born out of both practice in child care and palliative care, and my frustration with the limitations of conventional research approaches. The merits of action research in general and collaborative inquiry in particular have been argued, and the specific issues of voice, power and groupwork have been addressed.

Participatory inquiry has largely presupposed an adult constituency, and this leads to a consideration of its application to research with children, in which I argue that it is congruent with a position that values children in their own right and seeks to empower them to be heard in an adult-centric society.

Nevertheless, it has to be recognised that, however egalitarian its moral values may be, co-operative inquiry is limited by that self-same adult-centric society, and I therefore move on to consider this dilemma briefly. This leads into a description of the second strand of the thesis - the study of the process of a collaborative inquiry with child co-researchers - and the use of participatory video as a key data source to investigate this. This is followed by a summary of all the data sources and how the analysis was conducted.

I conclude this chapter with a section on the use of self in the research process, in which I challenge the notion that there is only one self, and argue that while it is both possible and important to distinguish between these in print, in the field and in reality these selves merged and separated, competed and collaborated, collided, colluded and together shared in the creation of something new and exciting.

CHAPTER FIVE: THE STORY OF THE VIDEO PROJECT

'It feels as if we're on the cusp of chaos'

Adult facilitator's comment, last session

Introduction

In this chapter, I tell the story of the Video Project. All research is contextualised, limited and partial (Lovelock, Lyons and Powell 2004) and in the following sections I set out the context in which my research took place, the practical limitations that constrained it and the standpoints of those participating. This chapter does not claim that this was the only way to undertake this research; it simply attempts to be transparent about three issues: how we came to do it; why and when things changed; and what the consequences were. Each of the three main phases - the preliminary phase, the group sessions, and the editing and disseminating phase - are discussed in turn.

Translating the two inquiry strands into practice was complex.
The vehicle for the first theme - for children to research their own experiences - was to be the making of a 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 approach to the second theme, the study of the collaborative inquiry process, was to film all the meetings, including debrief and supervision sessions.

Research in palliative care has always been problematic, from both practical and philosophical viewpoints (Seymour and Skillbeck 2002). I consider the ethical issues in a later section, but now consider the pragmatics.

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.

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. Discussion with both social work colleagues and the participatory video expert suggested that a group of between six and twelve children would be realistic, in the light of limited family referrals to the service, in terms of group dynamics and given the practicalities of filming; it would hopefully also provide a sufficient range of experience.

1. Preliminary Phase

The time scale for the project was as follows:-

Year One	Emergence of initial idea
Year Two	Preliminary investigation and planning. Informal discussions with agencies and individual children and parents
Year Three	Open meeting to discuss project.
February	Information and consent forms distributed.
March	Formal consent forms completed. First group meeting
March - April	Group meets weekly, rushes reviewed
May - June	Editing and reviewing
June	Preview showing to co-researchers and their parents
July	Final print
September	First run of 200 copies produced
November	Official Launch of the Video

Ethical issues - informed consent

In considering the issue of informed consent, two questions arose; one applicable to all research and one specific to research with children. I deal with the former first, that of how informed any consent can be when the process and outcome of the research can never be fully anticipated. Traditionally, participants are given verbal and written explanations about the intended research, assured of confidentiality and anonymity, and in the case of most qualitative research (Mason 2002, Denzin and Lincoln 2000, Farrel 2005) are afterwards provided with copies of the transcript to approve or amend. Although they can, of course, withdraw their consent at any point, the fact remains that they give it *in advance* and their control thereafter is relatively limited. While I would argue that it is virtually impossible to give a totally informed consent, the design of this research allowed for a more informed, appropriate and continuous exercise of consent.

It began with the initial, informal discussions with the children with whom we were already working on an individual basis, followed by similar discussion with the parents. I then held an open meeting for all the families we had approached at which they were given copies of the Information Sheet and Consent Forms (see appendix). The format of that meeting, with parents and children having some time to discuss the project in separate groups, write down their concerns and questions, and then coming together in a plenary session in which the facilitators responded to the questions, was in itself empowering. Parents, and children, gained confidence from the small group discussions and were probably better able to articulate their concerns than if we had had the more traditional format of leaders inviting questions from an audience that did not know each other.

Everyone present was keen to commit to the research, but was given further time to discuss it at home. The facilitators then visited the families over the next two weeks to obtain their formal consent. However, this was less the end of the consent process than the beginning.

During the first meeting of the group, the children themselves identified - and therefore gave consent to - the **themes to be researched**. This process of negotiated consent to all/most aspects of the research was a feature of the sessions. For example, in the second session, **prioritising** the themes was jointly agreed. Similarly at the beginning of the third session the children reviewed the previous week's footage and withheld **consent to its use**, commenting with brutal honesty that "it wasn't good enough". Their (withholding of) consent was demonstrably better informed (because they knew what it was they were being required to consent to) than the consent normally obtained prior to research commencing.

As well as an informed consent to individual and group pieces of work, there was also a considered and informed consent to the style, tenor and content of the final film. Many participants in television documentaries have discovered to their cost that, while they have consented to interviews and observation of activities, the edited film presents a particular and very partial account that they themselves do not recognise as valid - and over which they have no power of veto. In this research, the opposite was the case. For example, in the viewing of the first rough edit, several of the youngsters commented that the film was "too serious" and that it needed to "lighten up and have more fun activities". We duly included more 'fun' footage, even though this meant cutting out more 'serious' material that we adults had considered important. We also responded to individual concerns. Rachael was unhappy about a particular sequence, not because of what she had said but because of the visual impact. So we retained the sound-track and used it as a voice-over of some more acceptable shots of her. A similar technique, using slow-motion shots, enabled us to meet Gemma's and Natalie's concerns about over-use of zoom distracting from important comments they had made.

A further issue around consent was that of individual or group consent. Because this was a collaborative piece of research, we were clear that we would need the consent of everyone to any footage that included the whole group, even if some of them were peripheral to the action or sound-track. This ran the risk, of course, of having every second of the entire footage vetoed by someone! However, we could see no way round this, and indeed felt it was essential to demonstrate that our commitment to the principle of consent was unreserved. It was an enormous relief to find that this problem was in the end purely theoretical and did not arise in practice. As far as footage of individuals was concerned, consent was necessary only from the person themselves. Nevertheless, this required careful thought, as the following example will illustrate.

Some members of the group had recorded their own 'video diaries' during one session. Normally, we would show the previous week's footage to the group at the next session. For the video diaries, we altered this. Having reviewed the footage myself, (as was my usual practice and had been agreed by everyone at the first session) I was aware of how powerful some of it was. This presented an ethical dilemma, in that it was clearly going to make very good 'copy' - but might expose the children in a way they might regret (Alderson 1995). I resolved this in the following way. Each child watched the rushes of their video diary alone with me. Prior to rerunning the tape I reminded them that it was perfectly acceptable to re-do parts, cut out passages or cut the whole diary. I also reminded them of the potential audience and asked them to think about how they would feel about strangers watching it, school friends and teachers, and - especially - their parents. After they had watched the footage, I gave them another opportunity to request any cuts. I also made a conscious decision to highlight the likely impact of some specific comments on their family or other individuals to whom they referred in their diary, as I felt a responsibility not only to help the children think about their own reactions to recording their feelings for posterity, but to help them think about the consequences for others. None of the children chose to delete anything; a typical comment was:-

> *"No, that's how it is, so I want it in, it's the truth". (Laura C.)*

Insofar as it **was** the truth for that child, it felt ethically acceptable to keep it in. Nevertheless, I was aware of how seductive video can be (Robertson and Shaw 1997) and how in the intensity of the group activity and loyalty, there could be a risk that a child would give a consent that they would later regret. Clearly, I could not guarantee that in years to come the child might not regret their contribution, but that is a risk in all research - research with adults, quantitative or qualitative, from whatever paradigm, philosophy or viewpoint it is conducted (Broad 1999, Mason 2002). Ensuring that each child was able to view their diary in peace and privacy, with the opportunity to consider the issues I had raised, seemed the best approach. But in keeping with the overall ethical approach, it was not a one-off consent, but a process of continual negotiation (Simons 2004). A further opportunity to change their minds came with the group viewing of the first rough edit. For some of the group, this was the first time they had seen their peers' video diaries and had an opportunity to comment. For those who did their diaries, this was a first chance to experience the impact and see the reactions of others. As such, it was a useful dry run for eventually 'going public'. At the end of this session, we were careful to provide an opportunity for individuals to approach us privately about any clips with which they were unhappy. Thus, with the benefit of several weeks' distance both chronologically and psychologically from the group sessions, the children were perhaps in a stronger position to be critical. One co-researcher did take up the opportunity to discuss something, but it did not relate to a video diary but to a different sequence.

A final veto opportunity came with a private showing of the film to the young people's parents. If any of our co-researchers had wanted to withdraw consent, because of parental reaction, we would have been prepared - though admittedly very reluctant - to consider this. Thankfully, none of the children wanted to change their mind - or, more accurately, expressed such a wish. Whether the power dynamics inherent in the situation may have prevented them is an issue that is debated later in this thesis. The showing was not, however, an invitation for the parents to exercise a veto. But we felt it ethically right to give them a preview, both so that they were prepared for its public launch and also so that we could all acknowledge the impact that the project and the finished film had made.

There is a sense in which consent could no longer be negotiated or varied once the final approved version of the film was 'in the can'. But in another sense, one can argue that consent continues to be more and more informed each time the young people share in presenting their research at conferences. There is clearly an ongoing process of reflection and personal growth in which their understanding of what they consented to do continues to deepen and their conviction of its value increases. This I suggest is not informed consent at its most perfect, but does represent a more open, empowered and complete consent than is often the case in research (Robson 1993, Lewis and Lindsay 2000).

Parental consent

This discussion of consent has so far considered three aspects of informed consent - in relation to individuals, to the group, and over time. I now turn to the issue of *whose* consent - child, parent, or both?

I have defined consent primarily in terms of the child's consent, for three reasons - because the co-researchers were children, the research question is focused on their experiences, and my critical theory approach actively endorses a bias in favour of the marginalised. Nevertheless, I also had a responsibility to consider the ethical issues relating both to parental consent and to potential conflict if parent and child did not agree (Christensen et al 2000).

In keeping with convention, I actively sought parental consent. Without it, the proposal would not have been accepted by the ethics committee, and without it, a child participant would have been in an uncomfortable position. The nature of their research meant that they were likely to experience both stress and distress, so that experiencing indifference or hostility at home would have been very difficult. On that count alone, parental consent was extremely desirable. From the legal perspective, as opposed to the purely ethical, it was clearly also extremely desirable, but perhaps not essential. A strong argument could have been made that Ellis and Gemma and Natalie and Megan were Gillick-competent (BMA 2001) to give their own consent. Indeed an argument of varying strength could be made for all but Jack, the youngest participant - and even he demonstrated an effective ability to withhold consent in his own way. None of us were left in any doubt when Jack did not wish to do or say something - his blocking, distraction and avoidance techniques were impressive.

I dealt with my dilemma over this by ensuring that I either spoke first to the children, or to the children together with the parents, about the project. I therefore had an initial sense of whether they themselves were interested or whether it was parental influence pushing them on or away. Further informal discussions with children and parents separately, as well as the open meeting, enabled me and my co-facilitators to make a judgement about parental-child choice and conflict. In fact, we were pleasantly surprised by the amount of parental support for the research. We had anticipated possible reluctance to have family dynamics exposed, fear that they would be criticised as parents and a protective instinct that would militate against such a demanding project. Instead we were met with convictions that closely matched our own. One parent urged their children:-

> *"Say what you want, without us (adults) around...this is your chance" (case notes).*

Another thought it was

> *"a brilliant idea...if it can help other families, it's really important" (case notes).*

At the open meeting, few misgivings were expressed about what the children might say about the parents, and all of them accepted the clear principle that this was to be the children's work and that they, the parents, would not be included in the editing process. This welcome convergence of parent and child consent was heartening, and meant that we did not personally need to confront any conflict; the larger question, as to whose consent should be privileged, still remains for researchers, and as explored in Chapter Two, hinges on beliefs about children, competence and empowerment. My own particular standpoint, that the child's consent should be privileged above the adult's, did not in the event need to be tested.

However, our own ethical stance could not always guarantee what we would have considered to be appropriate ethical standards from the families themselves, either before consent was obtained or during the project. The Dodds family (not their real name) were a case in point. They did not ultimately take part but had been very enthusiastic in the weeks before the open meeting. One parent had openly expressed their determination that the children should attend, despite facilitators frequently reiterating the need for a free choice by the child.

As the open evening approached, we anxiously debated the appropriate ethical response we should take if we felt that the three children were being coerced into participation. The evening came and the family did not appear. The family's social worker, one of the facilitators, was then informed that the father had changed his mind. Instantly, we were on the horns of a different ethical dilemma.

> *"Dodds family not participating - Dad has decided against it. Ethics! Where are the children in all this? Mum wanted them to take part - all three - now Dad doesn't. What did/do the children themselves feel? What about their rights? So powerless and voiceless. (Reflective Diary 19/02/03)*

What if the children, regardless of parental urgings, had themselves wanted to take part? Now they were being denied the opportunity. How ethical was that? How ethical was it to accept the parental decision without challenge? Academic accounts often discuss these issues in a rarified way, as if they are unrelated to practicalities of everyday life. This neat, logical representation of research is perhaps less than ethically honest; this account attempts to acknowledge other real, if ignoble, factors that influence the research process. Pragmatics overwhelmed principles at this point; it would have been impossible to arrange other transport for these three children both to and from the sessions each week if the parents were reluctant to help, and it was not possible to arrange an appointment to see everyone in the family before the first session took place. It was likely that the children would have found it very difficult to engage with the research in the face of such outright parental refusal. Reluctantly, we did not pursue the issue any further. It was presented and accepted as a *fait accompli*, but we remained unhappy at the children's obvious lack of power either, initially, to counter parental enthusiasm or later, to challenge parental antagonism.

A less difficult dilemma - and one that we learned of after the event - concerned Laura C. Since we only learnt of the problem after it was resolved, we were again disempowered as facilitators. Contrary to what the literature often implies(Lewis and Lindsay 2000, Farrel 2005), ethical decisions are often taken out of the hands of researchers, as participants and their families exercise their own autonomy.

The situation generated an interesting ethical debate, fortified by the dubious advantage of hindsight, but it was entirely hypothetical since the family had resolved it without reference to us.

Laura C, and her mother, had been enthusiastic about the research from the very beginning. Laura already knew Megan and also the Dodds children, who lived close by. As described above, the Dodds family changed their mind shortly before and did not attend the open evening. The day before the collaborative inquiry group was first due to meet, Laura announced to her mother that she did not want to go. Her mother urged her to attend, pointing out that she had made a commitment and would be letting people down if she did not go. She argued that Laura should attend the first session regardless, but that if it was not enjoyable she need not attend further groups. Laura arrived on the first morning looking tense and troubled, but we were unaware of the reason. By the end of the session she was animated, articulate and at the centre of activities.

> *"After that, she loved it - she wouldn't have missed a session for the world,"* was her mother's unsolicited comment. *(case notes)*

Had we known of this reluctance, we would have felt ethically obliged to respect Laura C's decision. Her mother, as a mother, exercised her parental responsibility to encourage, guide and support. Hindsight, it would seem, had proved her right..... Both Laura C and the collaborative inquiry would have been the less for her non-participation.

I offer these examples not as answers to ethical issues but as an illustration of their complexity and the reality that they do not stand in isolation from issues of parenting, power and pragmatics. In both these examples, parents wielded power over their children; and while the outcome was positive for the research and the family in the latter case, we can not know whether a different decision would have been more beneficial for the stakeholders in the former case.

Autonomy, as in consent, in relation to child or parent, was only one of four key principles to be considered (Beauchamp and Childress 1994, Gillon 1994). Beneficence, non-maleficence and justice also required careful thought.

To take the second first, there was obviously a risk of doing harm to the children both during the research and in dissemination. As experienced practitioners in palliative care social work, we put in place strategies for acknowledging, containing and supporting distress. We did not, however, take the view that distress in itself was harmful, or that the research itself was generating distress. It was the children's situation - anticipating the possible death of a parent - that was distressing; the research provided another, different way of their ventilating and our supporting that distress, than traditional one-to-one work.

As for the dissemination process, the same caveats applied as in any research. Once the work is made public, the researchers' and the participants' control over it is negligible. No research can offer any worthwhile guarantees about the consequences of dissemination in terms of either harm or benefit, for intent is no guarantee of outcome. Our intent was not simply to contribute to the pursuit of knowledge; in keeping with critical theory and action research, ours was an emancipatory research designed to improve the way children are supported, and our choice of video as a medium actively sought to increase the beneficent aspect, since it was a medium much more likely to appeal to our intended audience, 'users', than most academic products of research. Nevertheless, video could be argued to increase the risk of maleficence, since it instantly destroys the treasured principle of anonymity. We could not obviate this, but we sought to minimise it. It was impractical to ask ourselves to use imaginary names - it would have inhibited spontaneity and would have been impossible to maintain successfully. We therefore used real first names for ourselves, but agreed a rule together with the children that no-one else should be identified by name. Thus teachers, friends, social workers - and schools, hospitals and addresses - were never named. The video sleeve carried a still from the film that could not be used to identify the location, and since we could not avoid having some form of contact address on the sleeve, we used an email address only. This was less than completely anonymous since it contained a county and organisational identity. The NHS, however, is a major employer throughout the country, so this was not quite as revealing as it might sound, and in the last analysis was the best we could do.

The fourth principle of justice is often less fully considered in research activity (Froggatt 2001). In this case, it was perhaps the starting point, in that I wished to redress the balance and achieve a more just and equitable distribution of knowledge and voice. Pre-bereavement research, as the second chapter has demonstrated, is less well represented than bereavement research; and within this the child's voice is barely heard at all (Chowns 2005). In the collaborative inquiry itself, we sought to be as inclusive as possible, by specifying as wide an age-range as possible (5 to 18) and recruiting from all the known palliative care providers in the locality. In the event, we gained no recruits from the local institution for which Alison worked, and all of the children had had contact with the organisation in which Sue and I were social workers, though not all were previously known to the two of us. Despite a more limited 'spread' than we had hoped, we succeeded in reaching a range of families within what was, fundamentally, a very small pool of potential research participants.

The ethics of Ethics Committees

The principle of Ethics Committees is well established within the health field but less so in social work. At the time of embarking on this thesis, no such committee existed within the University Social Work Studies Department. In responding to the ethical challenges this research raised, I was guided by three things: the teaching and discussion in the Faculty's Core Programme for Research Students; the combined practice wisdom and research experience of my original doctoral supervisor; and the BASW Code of Social Work Research Ethics (2002).

Since I was recruiting my co-researchers from families with whom I worked as an NHS employee, I then submitted my research proposal to the local Research Ethics Committee. It was approved at first submission. What now follows is a personal reflection on the ethics of ethical approval.

I begin with the composition of this committee. Attendance is by invitation rather than election and the basis for that invitation is not transparent. The committee is overwhelmingly medical in its composition although it does have some lay representation. The committee's expertise lies in positivist, quantitative research and it is weaker around qualitative, collaborative methodology. The underlying principle that research on or with humans should be open to scrutiny and should be subject to mechanisms designed to provide quality control and protection to potential participants is one that all would endorse (Lovelock, Lyons and Powell 2004); my concern is not with the principle but the application of that principle in practice. If recommendations for new committee members come largely from existing members, there is a risk both of abuse of power, ossification into a majority mindset, and reluctance to properly risk - that is, to encourage and support research at the cutting edge.

This committee makes its decisions on the basis of the written submission only. This raises two major concerns. First, the submission form - in its layout, language and leading questions - favours positivistic, quantitative, randomised controlled trial type research. The consequence of this was that it was hard to present a fluent, cohesive argument on paper for my research - which patently did not fit the assumptions behind the form. Moreover, this implicit assumption about the nature of research forces the research applicant to defend her work on positivistic terms, rather than enabling her to justify it according to its own appropriate paradigm. Conveying the nature, rationale and strengths of collaborative inquiry with children was made unnecessarily challenging by this format.

Secondly, allowing the researcher no voice - in the sense of opportunity to attend or speak at the meeting - is problematic. Even given the pragmatics of managing the extra time required, it should not be impossible to balance the competing needs of efficiency and fairness. It seemed ironic that a project focused on empowering children to have a voice should risk failure through lack of researcher voice in the preparatory process. The committee's paperwork offered no justification for this decision and no process for appealing the principle as opposed to the individual case. Moreover, the consequence of this denying the applicant the opportunity to *debate* the proposal was often a very unethical, though unintentional, unfairness through uneven advocacy. For those applicants who had personal or professional links to any of the Ethics committee members, there was a perfectly legitimate opportunity to talk through the research, rehearse particular arguments and counter-arguments and bring alive the research in the mind of the member. My argument is not that this is wrong in itself but that it should be an opportunity open to all applicants, via a formal hearing, rather than resting on personal networks or pure chance.

Two further aspects seem unsatisfactory. The lack of familiarity with qualitative research meant that the one person who had experience of it was in a particularly powerful position. If she was convinced of the worth of the project, her advocacy of it was less likely to be challenged. This was the situation that I faced and from which I benefited. It is unethical that the fate of a piece of research should depend so much on one person. The fact that she also had some personal awareness of children's distress at facing bereavement was my good fortune, but again is not a recipe for sound ethical decision-making.

A final point about the Ethics Committee process is worth noting. Nowhere in the form was there a section to consider any personnel employed by the project. Participatory video required the active collaboration and involvement of Nick, the cameraman, but his part in the project was not subjected to any scrutiny by the committee. I had myself ensured that he was police-checked and in the course of meetings had discussed with him at some length the issues around working with vulnerable children. I was satisfied that he presented no risk to the children and was experienced at maintaining appropriate boundaries. But the Ethics committee form and process did not require me to do any of this - the impetus came from my understanding of my professional role as a social worker.

First revision - from documentary to participatory filming

Reason suggests (R 1981) that it is quite acceptable for the initial idea for content and process to originate from just one or two people, who then recruit others. Two other palliative care social workers were interested in understanding more about children's experience and so I discussed my ideas and introduced them to the concept of collaborative inquiry.

An introduction from a community worker to a participatory video company led to a meeting with Nick which profoundly influenced the course of the project. I had originally conceived of the video as using a documentary, 'fly-on-the-wall' approach, but Nick argued persuasively in favour of participatory video. This faced me with my first problem. I was committed to working collaboratively but found myself wary, as I saw it, of losing control to someone else. However, a re-reading of Reason (1981), much inner debate, and some external debate with Alison and Sue, enabled me to shift my thinking. I was able to recognise the congruence between my research design and the principles of participatory video - that everyone should have the option of being involved from planning through execution to editing, that the content should come from the participants, and that the finished product should be faithful to their voice. Participatory video therefore had the potential to achieve a key aim - to enable the voice of the child to be heard, unmediated by adults or academia. Thus the process of making the video came to match the research methodology.

The Open Meeting

The next stage was to hold an open meeting to outline the project. Six families were invited; four attended, with their seven children. Nick's presence was significant on two levels - gender and technology. The two boys responded well to a male and several of the children were keen to 'have a go' at holding the video camera and trying to film. Information leaflets and consent forms were given out, and in the next two weeks each family was visited individually and all the children and adults who had attended the meeting gave consent. The enthusiasm and excitement that the project generated was gratifying but daunting. One further family, only very recently referred to the palliative care team, expressed interest, was visited, and after time for reflection, chose to participate.

Co-researchers

The composition of the Research group was as follows:-
Intention: 2 or 3 adult facilitators, 6 -12 children, 1 cameraman.
Actuality: 4 adult facilitators; Gillian, Sue, Alison, Nick
9 children; seven girls, two boys
Jack, 7; Becky, 10 (siblings)
Laura, 10; Rachael, 11; Megan, 14 (sibs)
Laura C, 12
Gemma and Natalie, 14 (twins)
Ellis, 15

It was now clear that Nick would be not simply a cameraman but also a facilitator and a co-researcher. Since I was the lead researcher and project manager, it seemed preferable that members of the group did not include children with whom I was already working, since it would be difficult for me to 'hold' so many roles at once. However, as time wore on, it became clear that such a idealistic stance could not be maintained. I have referred above to the very small pool of potential families; discounting those that had been referred to me (one half of the social work staff in the agency) made obtaining sufficient members highly problematic. Secondly, children with whom I was working attended the same school as a child with whom my colleague was working, so were aware of the planned project and interested in knowing more. Excluding them seemed unethical. Thirdly, we were asking children - and their parents - to do something potentially very challenging. The personal relationships - and fundamentally the trust between family and worker - was probably a highly significant factor for the majority in their decision to participate.

Characteristics of child co-researchers

Co-operative inquiry has, to date, generally been conducted with adults (Baldwin 2001, Heron 1998, Swantz *et al* 2001). Applying the methodology to children brings its own challenges. The first was to define the notion of 'child'. In an endeavour not to exclude any interested child, but conscious of the need for them to be able to express themselves and to handle the camera, we set an age range of 5 - 18 and a requirement that they must be able to express themselves in English. In fact, our co-researchers ranged in age from 7 to 15 (see Appendix 6). 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 English. 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.

Eight of the nine children considered themselves British. None of the children had a physical or mental disability.

The age-range of our participants inevitably affected their performance as co-researchers in a number of ways: Jack, aged 7, 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.

As might be expected, staying 'on task' was at times difficult for all the young people - but perhaps no less so than for adults involved in collaborative inquiry, who also engage in displacement activities (Keflyavew 1997, Reason and Bradbury 2001). As young people, their preference was for doing, rather than talking about doing, in the sense of planning (Greig and Taylor 1999). Most of them were very comfortable with talking about their feelings, but they were less eager to talk about and plan how they would convey these on film. Their instinct was to simply get on with it. Nevertheless, it was possible to identify a fluid, if rather diffuse iterative process taking place, as they viewed the rushes, criticised their work and decided to try again.

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 group work, 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.

I have discussed in the preceding chapter the sub-groupings within the adult facilitator group; here it is simply noted that, 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.

2. The Inquiry Process

Intention: To meet fortnightly for two hours for 8 to 10 sessions

Actuality: 6 (later amended to 7) weekly meetings, from 90 minutes to 4 hours duration, plus additional meetings to edit, review and preview the finished film.

Collaborative planning changed the original plan. My colleagues argued, rightly, that fortnightly meetings would not provide enough continuity and momentum for children, and that, moreover, it would mean that the project would be spread out over some four months with a much greater risk of a parent dying during its course. Six sessions were agreed as a more realistic commitment to ask of the children. When to meet was heavily debated; eventually we settled on a mix of shorter, Friday after-school sessions, and longer, Saturday morning meetings. I had originally wanted to leave the choice of this up to the children, in a desire to be as collaborative as possible. Practically, this was not feasible, as rooms had to be booked, space cleared in the social workers' diaries and a written contract established with the one person directly employed by the project, Nick. It was he who wisely suggested a provisional seventh Saturday morning meeting, in case we needed it - which of course we did. Halfway through the project, the facilitators suggested to the group that the Saturday sessions be extended to last 4 hours and this was agreed unanimously.

The meetings were held in one of the clinic areas of the hospital in which my own office was based. Though not ideal, the location was adequate. The hospital itself did not offer any direct treatment or services to cancer patients, so there were no difficult associations for the children or the parents who transported them there. The area was reasonably private, lighting was adequate for filming, there were tables to work at, chairs to sit on, soft carpeting to play on, a TV to replay the video tapes, and a kitchen area for refreshments (very important).

Structure

Practical constraints shaped the programme throughout and there was a constant tension between the 'research' ideal and the reality of working with thirteen different diaries and priorities. As with all research, we would have liked longer, but a working compromise was finally produced as follows:-

Session	**Day & Time**	**Duration**	**Key activities**	**Attendance**
One	Saturday 10 -12.30	2 hours 30 mins	Getting to know each other, ground rules, eliciting issues, using the camera	9 children, 4 adults
Two	Saturday 10 -12.30	2 hours 30 mins	Interviewing each other	7 children, 4 adults
Three	Friday 4.30 - 6.00	1 hour 30 mins	Painting	8 children, 4 adults
Four	Friday 4.30 - 6.00	1 hour 30 mins	Small group interviews	6 children, 3 adults
Five	Friday 4.30 -6.00	1 hour 30 mins	Video diaries	8 children, 4 adults
Six	Saturday 10 - 2pm	4 hours	Tips for teachers, points for parents	7 children, 4 adults
Seven	Saturday 10 - 2pm	4 hours	Statement game, review of all tapes, celebration and close	8 children, 4 adults (9th child attended celebration lunch and close)

Attendance

The four adult co-researchers committed themselves to attend all sessions. However, it was recognised that an exception might have to be made for Nick, for one session, due to the expected arrival of his first child around the middle of the project. This turned out to be Session Four. The major consequence of this was less film footage and very little process footage, partly because the three other facilitators were fully absorbed in working with the young people and partly because there was only one camera available for this session.

The importance for the young co-researchers of attending all the sessions had been made clear at the open meeting but had also needed to be balanced with the right to withdraw at any time (Robson 2000, Mason 2002). Attendance was broadly very satisfactory. One sibling pair missed the second session, when their parent was admitted to hospital suddenly. Another member had a long-standing invitation to a Friday sleep-over, which resulted in her missing a Saturday session. The least engaged of the young people was one member of a sibling pair, whose parent was deteriorating rapidly. An admission to hospice meant that the two siblings moved to live with the other, separated, parent. The older sibling was sporadic in attendance during this critical period; in contrast, the younger one never missed a session.

Strategies

Each session was planned as a 'sandwich' - feedback and reflection at the beginning and the end, and games, activities and filming as the 'meat'. However, the 'wrapping' was of crucial importance in both making the session safe and in shaping the atmosphere, establishing the participatory style and challenging the power dimensions noted in earlier chapters.

Session One

The first session had 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. Out of this 'quickthink' came the children's concerns, the themes that they identified and which they then addressed and re-addressed in the following sessions.

Sessions Two to Six

These sessions contained 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.

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. Other activities, such as painting their emotions, or the Statements game, combined familiar activities with sensitive, personal experiences. 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.

Session Seven

Three key tasks needed to be achieved in this session. 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 and 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.

Participatory video

The philosophy behind participatory video has strong parallels with collaborative inquiry, as noted earlier, in enabling a group to tell their stories in their own way.

Perhaps the most telling demonstration of this philosophy of handing over control to the participants is the fact that the camera is literally handed over. We aimed to make it clear that the group, rather than Nick or the social workers, would be in control of filming. This immediate assumption and expectation that the children would be behind the camera as well as in front of it was a powerful statement about genuine collaboration rather than adult lip-service to it.

Likewise, during the first full session a substantial part of the time was spent learning video skills (adults and children alike) - and practising them. Once again, promises ("everyone will be able to use the camera") were acted upon; everyone had an opportunity to focus in, frame, zoom and film someone else. By the end of the session, and much to their surprise, the children had drawn a storyboard, acted and filmed the story, and then re-run the tape and seen their own efforts on the television screen. This was participation in, literally, all its technicolour glory.

A comment from Gemma some months after the project was complete indicated both the children's initial wariness and our relative success in sharing control:-

> *"We wondered how much control we would have...but it turned out that we were in charge"*
>
> *Gemma (comment at first presentation session Sept 03)*

Two principles were clearly demonstrated in this exercise: that the children built their own story(though admittedly from a theme provided by Nick), and that the collaborative reflection/action/analysis cycle was integral to all activities. First, the children worked on the storyboard together, then they agreed who would act in front of the camera, and who would shoot each scene. Everyone who wanted to act or film, or do both, had an opportunity to do so. After they had performed and filmed, the tape was re-run and everyone had a chance to see their acting and camerawork and to discuss it. Thus, feedback was immediate, and on two levels; the children saw straightaway what they had done, and were then encouraged to give their own feedback on the footage. This was an important demonstration that the footage did not 'belong' to the adults, that there was an expectation that they, the children, would become critically engaged, and that their views about what they said and how they filmed the shots would be respected. Although the phrase 'iterative process' was not used, that is what was taking place.

Researching the process of collaborative inquiry

When we adults obtained permission to use a static camera to record the process of making the video, we explained that this was for the purposes of my thesis only. Should there be any footage from these 'process' tapes that we subsequently wished to include in the final film, it would be subject to the same

rules as 'intentional' footage - it would be viewed by the group and it would be their decision as to whether to include it.
Although we would have liked to be able to begin this recording of the process somewhat earlier - for example, it would have been ideal to have been able to record the open meeting - this was not practicable, since we could not fully debate the use of a process camera until the group itself had convened and consented to the project itself.

The iterative process

Over the course of the project, the group worked on the themes identified in Session One. This cycle of reflection on experience, action, reflection in action and reflection on action was never as neat and logical as putting it in print suggests, and was not necessarily contained and complete in each session. Rather, in some sessions there was an obvious cycle, even a spiral, in others the cycle was interrupted, went back on itself, or appeared to miss out a stage. At times like this I held on rather desperately to Heron and Reason's words of reassurance about living with the messiness of collaborative inquiry and resisting the temptation to impose a spurious order on it too early (2001).

Working with an age range from 7 to 15 was immensely challenging and there was always a difficult but healthy tension between staying faithful to the iterative process of collaborative research, respecting the principle of participant experience and therefore expertise, and recognising the limits of children's concentration, interest and grasp of the theory of research. The following comment is evidence that we did not always manage this tension successfully. From the 'Good Things, Difficult Things' reflection on a previous week :-

> *"Too much talking and not enough filming" (Anon)*

Groups

The discussion above has, I believe, demonstrated the genuinely collaborative *modus operandi* of our group, and highlighted the difference between it and a focus group, to which it bore a superficial likeness. Although there were frequently times when I, in my doctoral student persona, was deeply frustrated at (what I perceived to be) the lack of progress, I resisted the temptation to act as focus group leader, change agendas or channel discussion to my own ends. Planning for a painting session was a case in point.

> *"Feel it is a mistake to do painting in the next, Friday, session - there won't be enough time, it will be too rushed. Would have preferred to wait til a Saturday session - but Alison, Sue and Nick all keen and so were the children."(Reflective Diary 15/03/03)*
>
> *Painting session very rushed - and then very little time for reflection from each youngster. But some brilliant stuff, nevertheless*
> *(Reflective Diary 22/03/03)*

Moreover, at times I had also to resist the pressure from my adult colleagues, who had their own anxieties and priorities:-

> *"I'm just worried that we won't have enough decent footage for the film"*
> *(Sue - Debrief tape no 5)*

Nor was I an ethnographer. I was not a participant observer of a group that pre-existed, immersing myself in their daily work, and then making my own interpretations of their behaviour and speech. Our group existed primarily for the purpose of researching the children's experience, through the children's eyes. I could not participate in their experience in the same way as ethnographic researchers participated in the life of street gangs, or Melanesian tribes, even if I wanted to, since I had not had the experience of living with a seriously ill parent.

Even if I had, it would be irrelevant, since it would be retrospective; the unique claim of this research is that it investigates the children's experience as it happens, rather than after the parent's death, with hindsight.

So 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.

Thus the group came together with a diversity of skills: through working collaboratively we all left the group with new skills learnt, old skills honed, and extended experiential, presentational, propositional and practical knowledge.

The therapeutic group

While the group was undoubtedly a task-focused collaborative inquiry, I realized from the outset that it was potentially also a therapeutic, transformative group. That this was not its prime purpose did not invalidate the obligation to 'manage' that potential. I deal with the importance of support groups as a finding of the research in Chapter Seven; this section concerns itself with 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 to, 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 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)*

Others spoke specifically to camera about the meaning of the group:-

> *"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)*

> *"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)*

Once or twice, individual children became distressed as they recalled events in the past, or struggled with the reality of a parent's anticipated death. On these occasions, 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.

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 innately therapeutic. 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.

Groupwork principles

Researching sensitive topics requires attention to ethical issues, discussed elsewhere, and to the intangibles of ethos and atmosphere (Lee 1993). 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 (see Appendix 7), 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.

All the above are familiar principles of groupwork (Stock Whitaker 1995, Doel and Sawdon 1999) in almost any setting. However, where we perhaps diverged most from received wisdom was in 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 theory (Bion 1961, Stock Whittaker 1995, Doel and Sawdon 1999) recommends two facilitators per group, and all emphasise the importance of an appropriate ratio of leaders to participants. In our group, 4 out of 13 members 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. Reason (2001) suggests 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:-

a) just one
b) two or three
c) four, as in this group

All of them chose option c). 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. We can perhaps claim that they had not experienced four facilitators as overwhelming.

3. Editing and Dissemination

Editing the video raised a major dilemma. It presented perhaps the biggest challenge to staying faithful to the principles of collaborative inquiry. It required exceptional amounts of time, skill and technical equipment - and the young people possessed little of these. Nick, however, had both the skill and the technical equipment, and I had (some) funds to pay for his time, as well as my own research time. The ideal would have been for the entire group of thirteen to sit down, review the two and a half hours of 'official' tape, and the many more hours of process tape, and agree what should go in and what should be cut. This was manifestly impossible - far too time-consuming for the children, and for the most part far too boring. We therefore took a pragmatic approach. Primarily for the purposes of this doctorate, I had already reviewed all the process tapes, so we agreed that I would repeat that review with the specific aim of identifying any footage worth including in the finished film. Our young co-researchers had already assessed all the 'planned' footage and given or withheld consent for its use, so some of the selection process had already started.

Much more needed to be done, however, to create a coherent video from all the material. Reluctantly, the adults decided that the only feasible way to achieve this would be for them to meet to agree a first draft of the film (see Chapter Seven for a critique of this). Armed with the original 'quickthink' flipchart sheet to help us stay true to the children's concerns, we agreed an outline sequence that took account not only of those themes, but the need to maintain a balance of exposure of each youngster, as well as inclusion of opposing views. It was then Nick's task to cut, paste and edit this first draft.

Approximately one month later, the whole group reconvened to watch this first attempt. We then followed our familiar practice of reflection and debate. Interestingly, whereas the three social workers wanted to be sensitive to Nick's feelings and were concerned to respond positively and tactfully, our younger co-researchers showed no such inhibitions. They had three major criticisms; it was too serious and boring, they didn't like some of their camerawork - and it either had too much or too little of each of them on camera!

So it was back to the drawing board - or rather, the editing suite. Once more, simply because of time constraints, it was Nick and I who met again. Nick had re-edited the film in the light of both adult and children's comments, and I had separately reviewed the draft tape again, in the light of later comments from my colleagues, as they reflected on the video in the days following the showing of the draft. Nick showed me the second edit, and I made still further suggestions, both for material to include (for example, a section on belief in God) - and for material to excise (much more difficult). This was not in any way a question of censorship, but simply one of practicalities. All the advice we had had from others involved in video production, education or marketing was that 20 minutes was probably the maximum length we should aim for. Even so, it took a herculean effort to reduce the first, thirty-minute draft to 25 minutes. Not only did we have to identify 5 minutes of tape that was less crucial than the rest (how could we consign to oblivion even a second of what the children had given us?) but for every extra minute of footage we included we had to find another corresponding minute to cut out.

Our third version was then viewed by the other two social workers, who pronounced themselves much happier with it, before being shown to the whole group, where it met, thankfully, with general approval. A fourth 'final version' incorporated one or two very minor amendments, such as incorrect spellings in the credits at the end and longer fade-ins or slow -motion sequences, and then it was ready for public distribution.

Dissemination

One of the strengths of collaborative inquiry is its attention to the bread as well as the filling of the research sandwich - to research design and dissemination as well as to fieldwork and data generation, their being integral parts of the whole research process.

Designing the research has been discussed earlier in this chapter, so I now turn, briefly, to the ethical issues in dissemination raised by a collaborative approach. The outstanding one is the issue of ownership. Traditionally, the research is claimed, presented and published in written form by a single 'researcher' with academic or practice qualifications. Collaborative research challenges this and designates users, facilitators, and academic researchers as co-researchers. Consequently, it also challenges the ownership of the products of research and gives parity to the claim of 'lay' researchers not only as owners but as disseminators. Sadly, one of the hallmarks of research in the past has been the near-complete exclusion of participants from the process of interpretation and dissemination of the findings (Oliver 1992, Beresford and Evans 1999, Bradburn 2005).

This research has made a modest attempt to change this in two respects. First, the young people's involvement in the editing gave them the power to interpret and endorse the key messages conveyed in the film. The product of the research (the film) represents, and literally is, their voice; it is not overlaid with adult interpretation, censorship or 'slant'.

Secondly, I adopted the principle of collaborative dissemination wherever possible(see Appendix Eight). Thus the very first presentation at the International Visual Sociology Conference at the University of Southampton in 2003 was shared equally between two of the co-facilitators and one of the youngsters. Similar presentations at local, regional and national level have involved between one and four of the children and have included question and answer sessions as well as formal powerpoint slide presentations and video extracts. The practical constraints have often militated against this and once again the assumptions current in academia and the conference world not only do not lend themselves to a collaborative approach, but are actively inimical to it. Taking leave to attend a conference is more problematic for schoolchildren than professionals. Justifying several hours' travelling, or even an overnight stay, for the privilege of speaking for perhaps a maximum of 30 minutes is equally so. Very often the platform time is a bare twenty minutes - acceptable for a single speaker but hardly cost-effective for collaborative presenting. The usual requirements for abstract writing and submission deadlines make it extremely difficult to offer any genuine involvement to the young people in the initial stages of bids to present, so we adults have concentrated on helping them identify a particular aspect which they then present in their own words. Our only influence is in suggesting which part of the presentation they might like to take responsibility for; the content of their speech is entirely their own.

As with the making of the video itself, the children were able to choose whether or not they wished to help present their findings. The two whose parent died before the project was complete had moved 50 miles away to live with the other (divorced) parent, and have not participated in any of the presentations. A third youngster moved overseas with her parent but has stayed in touch through email and contributed an email message to the Launch. Four of the remaining six have contributed to a number of conferences, each of which have involved both prepared presentations and question and answer sessions.

At the public launch of the video, four of the nine young people were involved in presenting the project. One of them introduced the session and each of them spoke on a particular topic. They wrote their own speeches and were free to express their own opinions. After the video had been shown, they took questions from the floor and handled these with aplomb, responding with honesty, humour and challenge - as when one of the children turned the tables on the audience with devastating directness and posed a question to them about her parent's illness.

Over the course of the twelve months appearing in public to discuss their work, a further part of the iterative process occurred, with the children reflecting in a very mature and articulate fashion on the meaning of the experience as well as on the original findings.

> *"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 - reflection in November 2003 at third presentation)*

Their understanding of the significance of their research, the importance of its dissemination, and the impact of the whole project on their self-esteem and their families has developed considerably from the first open meeting they attended.

> *"It gave me a chance to tell people, especially my Mum, of how I really felt about her cancer. I know this really helped her to deal with it."*
>
> *(Ellis - Presentation speech at national conference November 2003)*

Although this has enabled us to present successfully to a wide range of audiences, the experience has not necessarily been either user- or child-friendly. Most conferences (with the notable exception of Involve) are designed to benefit academics or practitioners, but rarely consider the needs of those on whose behalf they claim to be researching, the users. And the unspoken but all-pervading assumption is that dissemination is for adults by adults to adults. That users might include children appears not to have been considered; that presenters might **be** children is nowhere acknowledged. The assumption is that presenters will be adult, professional, and identifiable; abstract formats assume one lead researcher rather than several collaborators; they require full identification and biographies of speakers whereas first names only and an element of anonymity is more appropriate for our young co-researchers; and they require commitment to name presenters some months in advance whereas which of our youngsters will participate depends on their life-situation much nearer to the day, in terms of deteriorating parental health, what else is on at school, or whether they fancy a trip to Taunton rather than Teesside.

Finally, once they have participated in the presentation, there is likely to be little else in the conference with which they can connect in any meaningful way.

Despite these difficulties, we remained convinced of the ethical importance of demonstrating collaborative working beyond the fieldwork and into dissemination.

A last ethical dilemma remains. At the time of writing, the product of the collaborative research, the video, has sold four hundred copies. Though modestly priced to increase accessibility, in keeping with our political, emancipatory intent to achieve change in practice, it is making a profit. This raises an issue around the lay ownership of the products of research. The young co-researchers were not paid for their involvement - but should they profit, financially, from the success of the video. If not them, then who? Currently, the profits reside in a charitable account within the agency for which two of the facilitators work, but who controls that account is debatable.

Summary

Conventional research wisdom requires that the research methods should be described in sufficient detail that another researcher could replicate the study. The story of my study offers sufficient detail and context for the reader to track its genesis, growth and maturation, but it is axiomatic that any replicated study would be quite different, simply because the co-researchers would be different individuals. Nevertheless, this chapter attempts to illuminate some significant issues pertaining to this study. Preparation is arguably the key issue that affects the ultimate success of research projects and the chapter describes the groundwork necessary to bring the project to birth. Within this section important ethical principles are critiqued and I argue for a more ethical construction of Ethics Committee arrangements.

Thereafter I describe the session-to-session reality of working collaboratively with children facing the potential death of a parent. This section sets out the intended structure and strategies that we employed but, in keeping with the principle of transparency, openly acknowledges where these were amended, diluted or executed unsuccessfully. It also describes the burgeoning identity of the group, the processes of collaboration and the significance of participatory video in both capturing this process and in encouraging the iterative process so essential to collaborative inquiry.

The final section of this chapter argues strongly for dissemination to be considered as an integral part of collaborative inquiry. It addresses the barriers to collaborative dissemination which exist in the academic world and demonstrates how these were challenged. However, it is critical of these limited attempts and concludes that dissemination remains the weakest link in the collaborative inquiry chain.

CHAPTER SIX: THE VIDEO

*"No - You **Don't** Know How We Feel"*

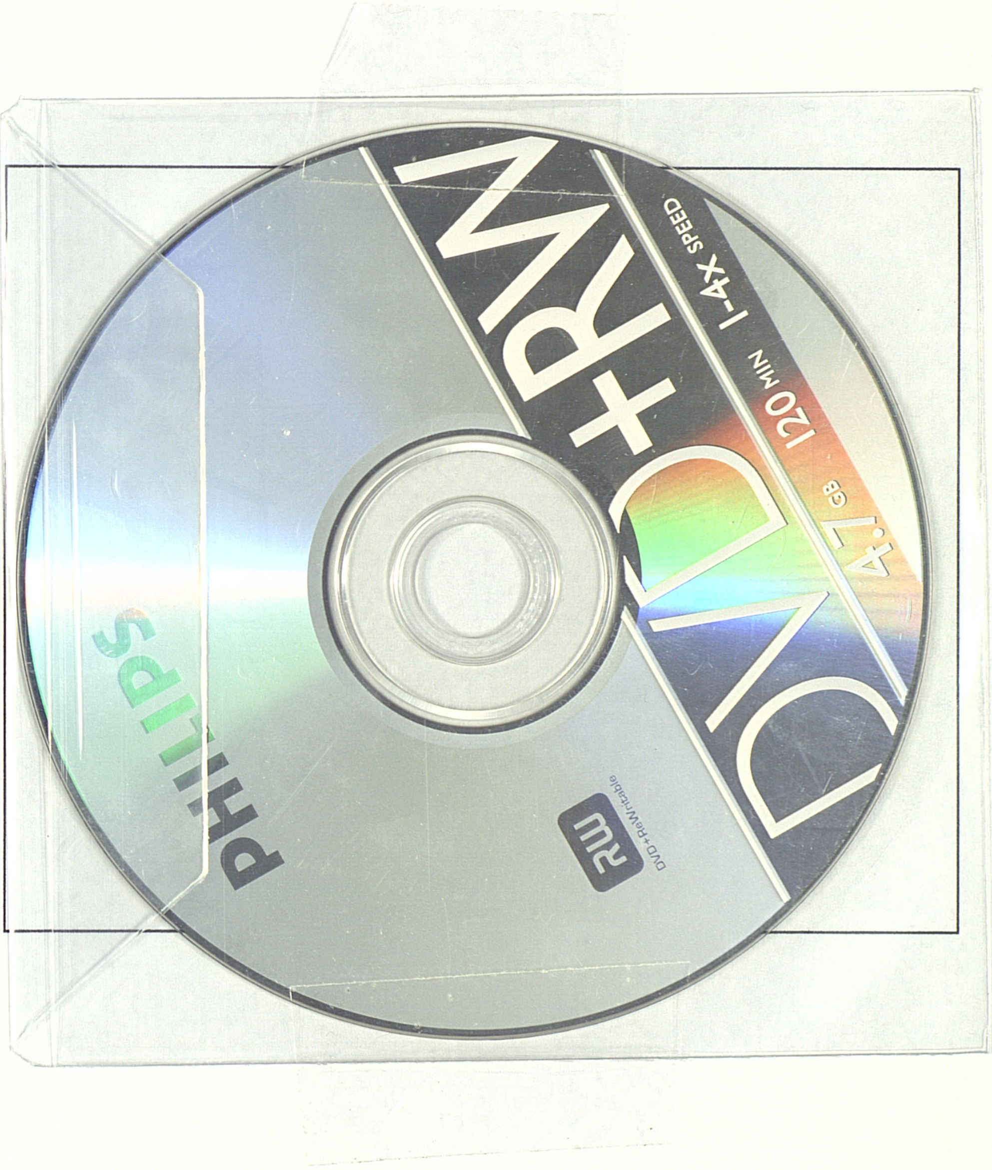
Notwithstanding the critique of dissemination offered in the last section of the preceding chapter, embedded in this study has been a dissemination tool that draws on the four typologies of knowledge discussed earlier and is also accessible to the general public. The video "No - You **Don't** Know How We Feel" is both an outcome and an output of the study - but it is also integral to the whole process and so presented here as a chapter in its own right. The thesis so far has set out the reasons for conducting the study, the inadequacies in the research and practice literature, and the ontological and epistemological arguments underpinning the research design. The previous chapter attempted to be transparent about the reality of the process. These chapters have been written from the perspective of the 'lead' researcher, myself, but Chapter Six departs from the norm in two aspects; it challenges the 'tyranny of the written word' (Derrida 1930-2004) since it is in DVD format, and it is a collaboratively constructed artefact. In a thesis predicated on collaboration, it seems appropriate to foreground the collaborative voice at this point.

Later chapters privilege my voice as academic, researcher and doctoral student, as I (re)present the findings, discuss implications and make recommendations for their application to palliative care, and to the social construction of childhood. The claims spring from **my** framing of the research process and are not necessarily owned by all the co-researchers. The video represents a first-order framing; it is the combined, considered, consensual re-presentation by the children of their experiences. The study's aim was to illuminate the experience of children facing the life-threatening illness of a parent and this chapter privileges their voice.

Gillian Chowns

The Video Project

'No - you don't know how we feel'



CHAPTER SEVEN: FINDINGS - COLLABORATIVE INQUIRY WITH CHILDREN

"You were lucky to have such articulate children"

- comment after a conference presentation.

"No, it was the process that provided the space"

- reflection on the way home.

Introduction

Despite the presentation of much research practice as conforming effortlessly to the theories or models espoused by leading academics (Denzin and Lincoln 2000, Bryman 2001) the actual practice has proved much messier than many texts would suggest and in recent years there has been a new, welcome and refreshing honesty about the realities of research practice (Glesne and Peshkin 1992, Shakespeare, Atkinson and French 1993, Broad 1999).

In this chapter I turn my attention to the research process itself and I attempt to examine the claims made for collaborative inquiry in the light of this particular example of the methodological and philosophical approach.

My intention to examine the process had been an integral part of my initial thinking and thus I had always planned to record all the fieldwork sessions. However, in the spirit of openness and honesty about the research process to which I have alluded above, I admit that the initial second strand of my original proposal was a separate set of individual phenomenological interviews, with the examination of the collaborative inquiry process lying outside the doctoral thesis. However, the rich data generated during the process seemed worthy of fuller consideration and it therefore became the second, co-equal strand of this thesis.

Data generation and retrieval

The data on which this analysis is based is largely co-terminous with that of the following chapter. It includes:-

- Videotapes of all the video project sessions.
- Video and audio tape of debriefing and supervision sessions (not considered in the following chapter).
- Reflective diary.
- Notes written up after each of the sessions - my 'video diary'.
- Notes and emails setting out planning and thinking prior to, during and after the Video Project sessions.
- Written speeches/reflections by the co-researchers.
- Evaluation forms and freeform evaluation by the children of the project.

The data are of five types:-

1. The videotapes are immediate and impersonal; they record what actually happened at the time, and while still partial, since they cannot record what is occurring beyond their view, they are impersonal in the sense that they make no judgement and generally do not select or de-select, since the camera is (usually) static and there is no human operator moving the viewfinder.
2. The tapes of the debriefing and supervision sessions are less immediate but more personal. They record the process of reflection, analysis and debate among the adult facilitators both at the end of each session and, at a greater distance of some days, in supervision with an experienced outside practitioner. The evaluations also fall into this category.
3. The notes and emails written before and after each sessions are a mixture; they contain evidence of the planning, structure and execution of the inquiry process and also reflection upon it from the author of the thesis.
4. The contributions of the young co-researchers to various conferences and presentations represent a further group of data, generated at even greater distance from the actual fieldwork.

5. Finally, the writing of this chapter itself represents an additional layer of the process of collaborative inquiry and extends the iterative process further, even though it is the least 'collaborative' part of the research activity. I consider this further in Chapter Nine.

The nature, timing and sources of the data are both variable and overlapping, and while it is important to acknowledge their provenance and 'angle' I have chosen not to attempt any 'weighting' of the sources, believing that each makes a valid contribution to the multi-layered and complex process of collaborative inquiry.

Preliminary Phase - The Idea Germinates

I had spent my career working with and listening to children who were frequently ignored, unvalued and unheard. How to reverse this experience within a research framework was a substantial challenge. But participative action research appeared to offer a potential way forward. For some time, however, I struggled with the apparent contradiction between the espoused value of working together with children and the fact that the idea of the video was entirely mine and would therefore be imposed upon them from outside.

A more careful reading of some of the literature, in particular Heron and Reason (2001) enabled me to see that the approach did not require that every aspect be totally collaborative, and thus reassured I then turned my attention to the issue of group composition. Groupwork, as highlighted in the Methods chapter, often works best with more than one facilitator, and collaborative facilitation seemed a natural corollary of the research design. I therefore offered the opportunity to participate to the three local palliative care social workers in my area. Two of the three accepted, while the third was co-opted into a 'Critical Friends' group whose role was to both support and challenge me through the entire period of my doctoral research (Ely 1991)

The benefits of this were immediately apparent. I now had two colleagues with whom to collaborate; their ideas, enthusiasm and cynicism (!) would undoubtedly enrich the process and make the facilitation of the group more genuinely collaborative. But the disadvantages were equally apparent; I had now to begin to share power, for the act of empowering others to participate immediately potentially disempowered me. I was clearly still the lead researcher - neither of the others wished to embark on a higher degree - but if I were to be true to the principles of this research approach, I would need to exercise the role of *'primus inter pares'* with considerable care. My colleagues were interested in collaboration, partnership and involvement, not in consultation and assistance only.

Similarly, although the Critical Friends group was advisory only, it also shifted the balance. There was little point in setting it up if I were not prepared to engage with it and respond to its challenges. Its name encapsulates its tasks but there were inevitably times when I experienced more challenge than support:-

> *"Lots of questions, plus recognition that it will generate a lot of work - who will commit to that? Reservations are understandable but hear a note of reluctance rather than support from colleagues ..." (Reflective Diary 27/02/02)*

There were other more specific reservations. For example, some months into the preparatory process one member expressed concern about the use of video, suggesting that the children might "play to the gallery" and that perhaps the disadvantages of video were considerable.

My first reaction was to feel undermined, since video was crucial to both the research and the group task. I was forced to confront this issue. The outcome was that I was better able to argue the case for video, to both recognise its limitations and appreciate its strengths, and thus to make a reasoned case for it.

On the other hand, there were occasions, following meetings of the Critical Friends group, when I doubted both my own capacity to manage this project successfully and the value of the research.

> *"I am now getting much more anxious about the actual project -can I really do it? Is it all a mistake? Why am I putting myself through this?" (Reflective Diary 15/11/02)*

It was at this point that I was in turn empowered by one of the group. A palliative care practitioner of long standing, she had always championed the needs of families in general and children in particular. Her intervention on two counts was timely. She set out her assessment of my strengths and how they matched the needs of the project, and equally importantly, illustrated the real need for my research and the importance of respecting children by the story of the colleague referred to in Chapter Five. After this meeting, I returned to the research with more confidence in both my own ability and in its inherent importance. Knowing that I was sharing the burden of the project with two co-facilitators was immensely encouraging.

However, recruiting adult colleagues was only the first stage within the preliminary stage - enabling them to catch the vision of collaborative inquiry was harder.

Catching the vision

As a doctoral student, I had invested heavily in learning about research paradigms, methodologies, design and methods, but, understandably, my co-facilitators were less interested. I had explained my earlier thinking to them and over a period of some months had had some informal conversations in which I had enthused about action research in general and collaborative inquiry in particular. I recognised that this did not adequately equip them for the shared journey on which we would embark, and so I sought other ways of enabling them to understand the nature of collaborative inquiry. That I was not entirely successful is perhaps unsurprising given that I was a beginner myself and had no direct experience.

I attempted to inform them in three ways. First, I gave them copies of an article summarising the approach (Heron and Reason 2001). I hoped this would convey its strengths and principles in a logical, clear form, and that a written account would enable them to read, and re-read, and refer to, the principles, as the work progressed. I also hoped that it would legitimise the approach as an academically respectable and serious one, should they be unconvinced by my less fluent and coherent descriptions.

In doing this, I assumed, but did not check that they had read, understood and endorsed what was in the article. I failed to allow for the likelihood that the day to day demands of their work would militate against a thorough and considered examination of the paper. In addition, I did not allow for all the practical concerns that initially were of more interest to them than the theory.

> *"Planning a children's group, particularly one that involves painful and sensitive issues, and where the situation for individual members can change dramatically at any time, feels seriously problematic. Add into the equation a plan to make a video with the group which will be for public consumption, and the hurdles are likely to feel insurmountable. They certainly did for me as a Palliative Care Social Worker when Gillian began talking about this project at least a year before it actually took place. Although wanting to be supportive, I was sceptical that it would ever be possible because of a whole variety of problems: engaging a viable group; finding sufficient time; overcoming the issues of consent and confidentiality; getting funding; finding a suitable venue; coping with the group if one of the parents dies; and, finally, producing a suitably professional product when I, for one, knew absolutely nothing about video. Talking to children about difficult issues was the least of my worries, given*

> *that it was my daily work within a palliative care team, but the practicalities of this project seemed impossibly complex."*
>
> *Sue (reflecting in June 2005)*

Next, I began regular meetings with them to discuss the process of the project, and endeavoured to model the principles in both the content and context. Thus at different times we met on the home territory of both organisations (the hospice and the palliative care team). I circulated notes of each meeting and included an acknowledgement that they represented my 'truth' and also an invitation for them to challenge this. Which one of them did!

> *"I actually said [.........] Sorry to be pedantic, but if you quote me I need my truth in!".*
>
> *Alison (handwritten note, undated - March 2001)*

Thirdly, I opened up my tentative plans for negotiation - which proved extremely fruitful.

Comments from my reflective diary capture some of the issues on which we had differing views - this suggested, at the least , that my co-facilitators were becoming more fully engaged, wanting to shape the process and work with, rather than, under me.

> *"Sameness versus heterogeneity - in the group. But do we want clones?*
> *Want variety in children's age, gender, ethnicity.*
> *Use of bereaved parent and child to talk at Open meeting - too threatening to group?* [i.e. my colleagues]"
>
> *(Reflective Diary 2/12/02)*

Nevertheless, it took time for my colleagues to catch the vision and the same diary entry refers to this.

> *"Age range too big to make it work? But principle of inclusivity, choice etc. is clashing with traditional 'rules' re groups. Evidence here of pressure and*

> *tension re staying collaborative and true to principles... Uncertainty around programme - tension between [my] faithfulness to principles of participative inquiry and their need for structure, bonding exercises etc."*
> *(Reflective Diary 2/12/02)*

At the end of this session, I had noted that

> *"the others at pains to emphasise how exciting/important this project is and how committed they are to it. A repeat of end of first session comments - what is this about?" (ibid.)*

Their reiteration of their commitment conversely led me to question it, and I turned to my diary to disentangle my emotions and values.

> *"How do I hold on to my vision, my understanding of and commitment to collaborative research -* ***and*** *be flexible?" (ibid.)*

I had been resisting pressure to map out possible programmes for the sessions, but began to see that it was

> *"difficult for colleagues to feel confident, when so much of it is in my head. But reluctant to commit to paper, because a) not entirely sure myself* b) *not compatible with participative approach if professionals have it all cut and dried beforehand c) setting it down inevitably shapes and, possibly, constrains others' thinking."(ibid.)*

My colleagues' desire to make the experience of the group 'safe' - a key principle of groupwork - was entirely reasonable, but "*some conflict here with the paradigm - uncertain, diffuse, opportunistic" (ibid.).* We were discovering that working collaboratively asked us to take risks, to trust each other and hand over much more power and control to other co-researchers.

Participatory video - voice, choice and control

At the same time as I was wrestling with the dilemmas outlined above, the choice of cameraman was throwing them into relief. My original idea had been to employ a cameraman to film the project in documentary, fly-on-the-wall style. I approached Nick with this in mind, but, as described in an earlier chapter, he quickly argued for his own preferred method of participatory video. Further discussion with him, and the opportunity to watch some of the films he had made with rural communities, street children and other marginalised groups persuaded me of the benefits of this method and its philosophical underpinnings were of course entirely consonant with those of collaborative inquiry. Nevertheless, there was still work to be done before the four of us could collaborate effectively. At the first Supervision session for the social workers, our supervisor highlighted the need for the three social workers to meet with the PV (participatory video) facilitator to clarify roles.

When it happened, this first meeting was less than ideal.

> *"Got up from sick bed to go to meeting, feeling awful. But important for Alison and Sue to meet him and for us all to clarify some misconceptions. Useful meeting but still concerned re balance of adults and children and wider involvement of Nick."*
>
> *(Reflective Diary 19/12/02)*

What this meeting forced us to recognise was that we now had four facilitators, each with their own 'take' on the project, each with their own expertise and anxieties, and all now keen to participate. I had already had to learn to share power with my social work colleagues; now they were being asked to share it further with a person they knew not at all, from a different discipline and background. They had become accustomed to the idea that the cameraman would be unobtrusive, simply filming the project; now we had to embrace him as a co-facilitator, coming in with different ideas and challenging some of our own. This represented a considerable shift in the evolution of the project. Nevertheless, we began the new year on a positive note, as the diary records:

> *"Meeting with Alison and Sue -very encouraging - they were more enthusiastic, contributing ideas and I felt were beginning to catch the vision. Both keen to stay involved. Useful discussion re Nick's role. Came away feeling much better."* *(Reflective Diary 17/01/02)*

A further, positive shift in the group dynamics occurred, as mentioned before, when the four co-facilitators met specifically to explore our potential working relationship.

> *"Used Doel and Sawdon exercise (1999); very helpful, good sharing. Alison able to acknowledge how she had shifted. Sue and Alison highlighted FUN - I'd forgotten - and we all shared fears, strengths etc. Felt we got to know each other better and that the whole thing was shaping up OK. Left feeling very positive. Felt there was much more clarity re Nick's and our role."*
> *(Reflective Diary 24/01/02)*

Although most research textbooks focus on design and methods, (Lincoln and Guba 2000, Mason 2002) collaborative inquiry attempts to acknowledge also the human, transformative aspect (Fals Borda 2001). It was my experience that this aspect was a key factor in the inquiry, and I would argue attitude and ethos are as, if not more, important than the structure of collaborative inquiry. It is relatively easy to profess a commitment to working collaboratively; the test is in the small but significant activities that demonstrate the valuing of others' expertise and opinions.

This is not to negate the added value that participatory video as a medium brought to the research. When one of the child co-researchers commented,

> *"We're not video experts, but we do know what we're talking about," (meeting to review first edit, May 2003)*

Nick later responded:

> *"As a practitioner of Participatory Video (PV) I believe this comment underlies the fundamental essence of this process: PV is a most powerful way to develop the participants' control over the project. The first steps of any PV project I facilitate are concerned with developing confidence and trust in each group member. Empowerment of the individual comes through working as a group together to overcome shyness and lack of self-esteem; and through the instrument of a video camera, to enable participants to transfer their knowledge and experience. A PV message comes across in the participants' own words; they are in control of how they represent themselves. Rather than develop people's technical ability as videographers or filmmakers, PV is used more as a process to develop confidence and group working skills and take people through a process of change as they realise their abilities and affirm their views and beliefs."*
>
> *Nick (personal communication to author, June 2005)*

The Open Meeting

The final part of the preliminary stage was the Open meeting to which potential participants and their parents were invited. We (for by this time it felt like a genuine 'we') saw this as a pivotal point in the whole enterprise. We needed to engage the children and to demonstrate our values and commitment to real collaboration from the outset. We modelled the value of the children being central to the inquiry by addressing the invitation to the meeting and information leaflets (see Appendix 2) to them individually (so in sibling groups every sibling had their own letter), by sending separate, differently worded invitations to the parents and by consciously addressing our presentation on the day to the children, using appropriate language, and where necessary, addressing the parents in parentheses.

> *"I think it would be good if we direct our remarks* ***to the young people*** *i.e. when we say "you" we are meaning the youngsters rather than the parents -this reflects our commitment to them* (children) *as central to the whole project....*
> *Please, everyone, emphasise that the content of the video will not be decided by the facilitators, but by the group"*
> *Gillian (Notes for Open meeting, sent to Alison, Sue and Nick, 8/02/03)*

We also included some groupwork, and invited the children's group to give their feedback first, and the parent's views were then added in. Our presentation emphasised our belief in the children's capacity.
Some of the questions generated in the children's group were indicative of both their desire to be pro-active and their ability to foresee difficulties:

> *"Are we allowed to use the camera and take turns?"*
> *"What about if the filming runs over (the six weeks)? "*
> *Flip-chart from children's group (14th February)*

While these behaviours/actions may seem minor in comparison to the theory of action research, they are in fact the very fabric of it. It is in these actions that the values of collaborative inquiry are subtly explicated, in them the theory and principles are actioned.

It is reasonable to assume that we were at least partially successful, since all the young people who attended not only gave their consent to participate but actually presented themselves at Session One. However, a later reflection by one member indicates that the original consent was both guarded and qualified: *"I wondered how much control we kids had..." (Natalie, in a speech to Leeds University assessors, September 2003)*

We had made a beginning - but collaborative inquiry is a process, not a one-off or single event.

Stage Two - the Video Project Sessions

The process of inquiring collaboratively into the experience of living with a seriously ill parent was many-layered, dense, rich and nuanced. For the purpose of this chapter I attempt to examine particular strands in isolation but it needs to be remembered that the weaving of these strands into the final 'cloth' of the project was a complex art and that dissecting the process does not necessarily capture that complexity entirely. In particular, while this account includes perspectives from many of the participants, it is nevertheless a particularised and individual 'truth' seen primarily from the perspective of the lead researcher; inevitably, the other participants would produce twelve other 'truths'. With that in mind, the following issues are now critically examined.

Power

Participative inquiry makes a major claim in arguing that it addresses the imbalance of power inherent in conventional research (Elliot 1991, Bryant 1996, Reason and Bradbury 2001). Before considering the evidence generated during the seven sessions, it is important to acknowledge the contextual setting. Research never occurs in a vacuum - all are already shaped and constrained by the society in which they live. Thus, whatever the adult facilitators' beliefs and intentions, the fact remained that both we and the young people lived in a society where adult-child relations were played out - in school, at home, in the media - on the basis that adults were powerful, expert and dominant, and children were subordinate, incompetent and dependent (Prout 2000, Lewis 2000).

Shifting that balance of power within the sessions was not achieved simply by stating our beliefs and characterising the project as collaborative. It was a gradual, incomplete process that drew on modelling, challenging and supporting, and that required the adults to initiate it. Thus, we adults worked hard at modelling equality and handing over power and responsibility. Literally handing over the camera, as cited earlier, was one method.

A simple thing like providing each of the children with an attractive, stylish plastic file in which to keep any hand-outs, and a glossy-covered notebook to use as a diary, or for jottings, reinforced the message that we believed they had something to say and that their contributions were important.

Paradoxically, it was also important to value them for themselves as individuals with lives outside cancer rather than as co-researchers, as the following reminder to the facilitators makes clear:

> *"Alison - please acknowledge Megan's birthday last Saturday and Laura's next Monday - I've got a tube of mini-eggs for her as she was so clear last week that she didn't like crème eggs! Also an opportunity for Nick to acknowledge his baby's birth(day)!"*
>
> *(Email from Gillian 27/3/03)*

In the first session, it was clear that the young researchers 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.

Nevertheless, these, and other, concerns that were posted in the Worry Box ("*Is the video going to be classified - invasion of privacy?; I'm worried about seeing myself on TV; feeling too shy to talk*") suggest that the initial fears and worries felt by group members exercised an inhibitory effect on the avowed aim of participation.

By the end of Session One, however, 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 *(S1 P1 53.00 onwards)*. In contrast Ellis, the twins and Laura and Becky did not volunteer contributions, but endorsed various ideas.

A specific adult anxiety was the presence of the process camera, and the inhibitory effect this might exert. On balance, however, it appeared to be perceived as positive by our younger colleagues. In response to a query as to its acceptability, in session 3, at least two of the children suggested that it might have captured useful footage that would not be on the 'proper' camera *(S3 P3 12.03)*. Megan pointedly confirmed that her group of the previous week (Ellis, herself and Laura D) would be happy for the process camera footage to be used if we wished (*noted in Session 3 video diary)*.

By session two, they were feeling more empowered:-

> *First exercise to discuss and plan an interview - all looking down at their feet- then Laura gets clock, takes on role of time-keeper, Megan picks up paper and pen to write captions for interview - it was her idea. (S2 P2 43.10)*

But this empowerment was not well embedded and at times the children reverted to dependent/pupil role. For example, during a small group discussion which I had initially facilitated but then withdrawn from, the young people began talking about the way they swore in times of pressure and Megan then drew me back into the conversation to check about this. Her underlying assumption seemed to be that it would be unacceptable, and we would want to delete any offensive language *(S2 VA 16.30).* In later sessions, autonomy was better established.

Nor did the facilitators themselves consistently demonstrate sensitivity to child empowerment. In Session 4:

> *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. (S4 VA 23.32)*

As the children became more confident, they began to take the lead and there were many situations when one or all of the adult facilitators were on the margins, hanging back or simply observing. We did not always find this easy and had to develop our capacity to stand aside - see below. This was not a smooth progression and despite Heron and Reason's argument (2001), that leadership could be gradually transferred to the co-researchers, our experience was that the children oscillated. While the overall direction was in favour of greater participation, control and equality, there were many times when they operated in a more traditional, dependent, non-competent role. For example, my notes of Session 4 record that

> *It was difficult to get a discussion going* [with the three oldest members]. *Gemma and Natalie said it would be easier if someone asked questions. I suggested one of them, but they felt it was easier if I did it. So we had a go.* *(Gillian - Video diary Session 4)*

Negative power

The construction of the concept of power needs to recognise both its positive and negative sides. It is more frequently framed in terms of the active exercise of power, but the passive withholding of consent, co-operation or activity can also be an exercise in power. Many of the project's participants demonstrated both straightforward and sophisticated use of negative power.

In Session 2, during some small group work, Laura D and Jack both resisted efforts to discuss their family situation and their own feelings. Laura used silence and occasional monosyllabic answers, while Jack was more vocal but swiftly turned the conversation to school and football, resisting efforts to talk about emotional issues. (S2 P2 onwards)

Laura's body language - no eye contact, guarded expression, gaze directed at her feet, powerfully reinforced her verbal message, *"I don't want to talk about it" (S2 P2 passim)* but this gave another opportunity to reinforce the message that we wanted the children to exercise power, and would respect that exercise of power, however negatively constructed:

> *Alison - If you don't want to say anything in that one minute, that's fine - it's your choice. (S2 VA 00.53)*

And during that minute when her peers tried to get her to talk, Alison intervened, exercising her power appropriately:

> *"It's all right, we've **agreed** to have a minute regardless"*

and at the end she affirmed Laura's choice by saying

> *"It's quite nice to sit in silence, isn't it?"*
>
> *Alison (S2 VA 5.10)*

In the same session, in the other small group, Ellis also demonstrated, somewhat less confrontationally, his own independence in the face of a more gentle adult pressure:

> Gillian, at the end of an informal discussion*, "Maybe you could say this in the interview?"*
> Ellis, (retaining control, very non-committal) - *"Maybe....."*
>
> (S2 VA 22.03)

Capacity-building

The session in which Megan led a discussion about painting their emotions demonstrates some of the issues around capacity building. Preparation is an important factor. Megan had been asked by one of the facilitators the previous week if she would be prepared to lead the discussion and brainstorm ideas and had readily agreed. Before Session Three one of the facilitators visited her at home by appointment to check out if she was still agreeable, to explore any ideas she had for leading the discussion, and to clarify where her responsibility ended and ours began. This meant that she came to the session clear about her role and more confident in her capacity to perform it. Then, at the beginning of the brainstorm, Megan's task was made easier for her by her sister acknowledging (humorously) a change in power dimensions.

> *Rachael "So you're going to be the teacher... Do we call you Miss or Megan*?" (Much laughter). *(S3 P3 19.00)*

Three minutes later, despite some contribution from the adults that might potentially have undermined Megan's position, the children are all directing their comments at Megan, and working well as a group, while the adults are by now merely observers. (S3 P3 22.10)

After the children had painted their emotions, they each had an opportunity to talk about their art. The facilitators made the initial suggestion that their co-researchers could question them further, and set an example by inviting the first question, but it was noticeable that thereafter, each child finished their explanation of their artwork with the words "Any questions?". They then demonstrated some confidence in answering queries from their peers and were able to further develop their interpretation of the painting. In one case, the process was reversed, with Laura C offering a sensitive and thoughtful interpretation of Jack's painting - one that he would have found difficult to articulate himself, but which he appeared to readily endorse by affirmative body language. (*S3 PC 20.00 onwards)*

At the very end of this session, Megan felt able to maintain her leadership role, at least among the children, by challenging the adults as to the future of the group and putting forward her own idea.

> *"I know this is for Gillian's research, but what about doing it again* [i.e. the group] *but not making the video....?"*
>
> *Megan (S3 P3 59.32)*

In turn, the facilitators also encouraged the children to identify actions they could initiate themselves.

> *"We may not be able to continue the group, but there is nothing to stop you emailing each other."*
>
> *Sue (S3 PC 20.11).*

For most of the children, the group gave them an opportunity to modify or strengthen aspects of their personalities, and perhaps to develop otherwise latent capacities. The twins provide a good example of this process.

An examination of the tapes of Session One reveals Gemma and Natalie to be reserved, self-contained, and apparently taking little active part in the proceedings. When it is their turn to draw a section for the comic strip, they each get down on the floor, draw their picture and then resume their seats. Others in the group had sprawled on the floor to draw and then stayed kneeling and looking over the shoulder of the next contributor, clearly feeling more confident than at the beginning of the session and possibly beginning to demonstrate some ownership of the space and the group.

However, in the painting session, a change was evident. Although both Natalie and Gemma struggled to express themselves with paint - and both used words more than pictures in their artwork - they came alive when it was their turn to explain their paintings. They spoke fluently and powerfully, graphically describing their emotions. Having done that - and responded confidently to their peers' questions - they each in turn put their painting neatly down, their hands in their laps and said almost nothing for the rest of the session. As one facilitator commented,

> *"They say so much, then they close up" (S3 Debrief tape 19.50).*

Nevertheless, over the weeks the tapes reveal a less constrained, more spontaneous side to them; they relaxed more and engaged more easily in debate. Perhaps most telling is Natalie's comment on the very last day;

> *"I've had a hilarious time".*

Disconfirmation and exceptions

It would be wrong to give the impression either that all the young people reacted similarly or that they were universally consistent in their behaviour and speech. For example, in Session 2, when asked what she liked, Becky responded:

> *"Getting filmed and I really enjoy it" (S2 VB 5.15).*

Yet her attendance (in contrast to her brother's) was sporadic and of all the participants, she appears least often in front of the camera and contributes the least in debates, discussion and brainstorming.

A notable exception was Laura D who, while committed to the project and active behind the scenes, avoided talking about her feelings. Most of her peers actively endorsed the concept of relieving stress by talking about what was happening; Laura simply said nothing. The one exception to this was during the Statements game, when, required to indicate agreement or otherwise with a statement to this effect, she became more fluent, explaining,

> *"But I don't like talking about it...but my Nan and my Grandad, they don't talk about it, so...*[that's why I like going there]"
>
> *Laura D (S7 F1 15.13)*

Another case in point was the video diaries; in Session Three Laura D appeared keen on doing one (S3 P3 14.25), but in fact she studiously avoided doing so.

Laura not only challenged the declared position of most of the rest of the young people but also the received wisdom in counselling and palliative care, that talking is preferable to silence. This assumption, together with notions of containment and denial, is considered further in the next chapter.

Richer, fuller perspectives of reality?

A claim of action research is that it captures a richer and fuller picture of the real world (Bradbury 2001) and the project provided some evidence for this.

Because the children were freed from the pressure to "get it right" that researcher-subject interviews may unwittingly generate, they spoke freely and fully in both small group and whole group discussions. Although in the early stages, they lost spontaneity and became self-conscious when being interviewed on camera, this faded with time and the participatory video activities and exercises enabled them to express themselves in some depth.

Much of the process footage captured debates about the same topics time after time, so that a many-layered, multi-perspectival understanding of, for example, 'truth-telling' was revealed.

Uncertainty, confusion, flexibility

The uncertainty inherent in this project - and at times a sense of chaos - was a noticeable feature, and I tried to acknowledge this with my co-facilitators:-

> *"I've also been re-reading "Human Inquiry in Action" -comfortingly down-to-earth about the difficulties of collaborative inquiry, and encouraging about staying with the chaos and uncertainty rather than going for the sterile safety of total control, power and pre-planning....The knack is getting the balance!"*
>
> *Gillian (Email to facilitators 2nd April)*

Session 4 was a particularly good example of this. The facilitators' roles had to be hastily reapportioned when it was learnt that Nick would be absent as his first child had just been born. On the day, there were other unexpected absences:

> *"No Megan - not quite clear why - no-one to be with her Mum while Dad took the children to the group? Others assured us that Jack and Becky definitely coming, but in the end only Jack came. Also a message that Laura wouldn't be coming - family friends from overseas visiting. So only 6 children.. "*
>
> *Gillian (video diary session 4)*

Nick's absence meant that we did not have the process camera, which was a further complication. Another camera was obtained, but with only three of us to manage the session's activities which were predicated on small group work, trying to operate two unfamiliar cameras was a challenge to which we did not rise.

Interpreting collaborative inquiry

Propositional knowing (knowing **about**) as in Reason and Heron's formulation of knowledge, is only one aspect. I had a reasonable grasp of propositional knowing, my adult colleagues a more limited one and our younger colleagues a yet different understanding. Experiential knowledge, for all the facilitators, came as we attempted to practise the theory, and was accompanied by some lively debate and good-natured teasing of each other. For example, my determination to be truly collaborative in almost every aspect meant that I constantly emailed my colleagues with my thinking and planning, in the hope that we would then share the responsibility for and ownership of the project. That this did not entirely hold good is demonstrated in the following exchange in Debrief 4;

> Alison*: ... so I didn't know about that..*
> Gillian*: Did you not get my email then, telling you?*
> Alison*: Oh, yes, sorry, I did and so I do* [know]
> Sue *(teasing): You mean you didn't memorise it, Alison?*
> Gillian *(laughing): Look, I'm trying really hard to make sure everyone knows everything...*

It was perhaps inevitable that we, the adult facilitators, should not always be in the same place, in terms of our understanding and practice of collaborative inquiry, any more than the individual children were. As the project progressed I was, however, able to be more confident:

> *"Nick's ideas worked well. Alison anxious for us to disappear completely* [out of the room], *Sue anxious that Nick should not think we were skiving, me not anxious about either - indeed not anxious much about anything. So different from some of the other sessions."*
>
> *Gillian (Video diary Session 5)*

Iteration, reflection

Much of the literature on action research emphasises the cyclical and iterative nature of the process. Action is followed by reflection, which informs further action and further reflection (Lewin 1948, Bryant 1996, Reason and Heron 2001). In our project these cycles were never as clear, neat or logical as these texts or Figure 7.1 suggest , possibly because while they all assume the co-researchers to be adult, the majority of ours were not. Equally, however, it may not be age or cognitive maturity that is the issue. The messiness of human experience at any age does not fit neatly into boxes, cycles or spirals. Nevertheless, those spaces that allow for reflection on earlier action impose or offer a considered level of iteration upon more chaotic, diverse and fragmentary moments. This section offers an account of these moments, while recognising that the process of writing the account adds yet another, more reflective layer or cycle.

The Reflexive Process

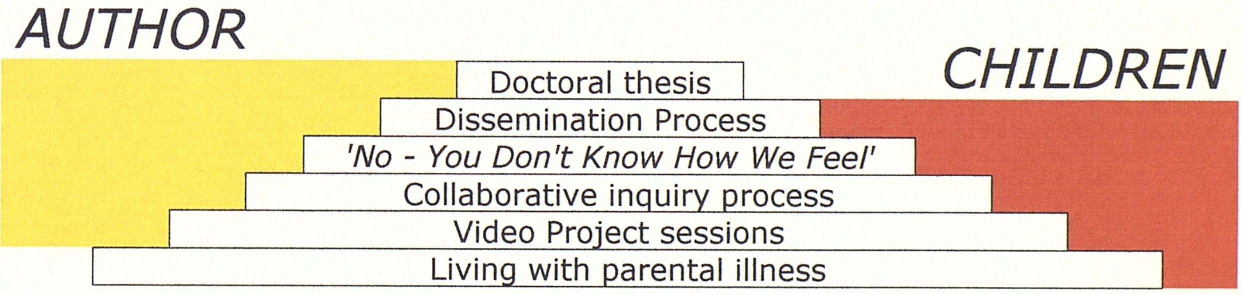


Figure 7.1

Note: I use iteration in its broader sense, to encompass revisiting, reviewing and reflecting upon action, thought and utterance.

In the extract below, both facilitators are reflecting on the tensions in the collaborative process, but reaching different conclusions:

> Sue: *I thought they responded quite well to our being directive*
> Alison (implying the opposite?): *There was no way Laura was going to introduce herself or say anything about her parent.*
>
> *(Debrief session 4)*

And:

> Gillian: *I am wondering if we should have a set plan-* (Interrupted by explosion of laughter from Alison, who says mockingly) - *So, we are being totally collaborative, then?*
> Gillian*: No, the content, themes -that's what comes from them but now maybe the time has come to say - we'll get this on camera..* ***We****'ll decide the context...*
> Alison: *We're changing the remit...?*

Later, we review the progress of group identity:

> Alison: *they're not grouping...the forming, storming...it's patchy...I wonder if it's because there are four of us?*
>
> *(Debrief 4)*

This issue of potential adult overload on group dynamics was one which we revisited and reflected upon at each stage of the project. Thus, one of us reflected that in the painting session the group was comfortable having all four of us around, and it was suggested that this was because they were active, occupied and busy with their paintings. A different dimension to the debate was introduced with my comment: *It's better (*the bonding*) in a smaller group... I was out of range.(Debrief 4)*

My being out of range had been a deliberate decision, based on reflection in action - I felt the small group was working well, had generated some good debate and could be left to develop its own momentum. The decision was made in a moment, inside my own mind, and acted upon without articulating it to either the child or adult co-researchers. But it then was added into the discussion about group processes that formed a diffuse but important iterative cycle.

A more deliberate iterative process was developed within the seven sessions by framing the core activities and the filming with an opening and closing period of reflection and discussion. In the opening slot, everyone had two coloured 'post-its' on which they were asked to write something good and something difficult about the previous week. This gave an opportunity to think quietly about the previous session (cycle of activity) from the perspective of a week on, and contribute a view, uninfluenced by other participants' opinions. Although the children resisted all our attempts to avoid pejorative language and cheerfully referred to the orange (Difficult) post-its as 'Bad Things', they interpreted this broadly and the range of comments - which were stuck up on a flip-chart sheet and then read out by a volunteer - generated yet further discussion that both refined and broadened the group's understanding of the experience. Often this discussion would then inform or influence the activities to follow. For example, 10 out of the 13 'Bad things' post-its about Session Five said *"Not enough time"*, *"Rushed"* or *"No time to do everything"* and in the remainder of Session Six there seemed to be a renewed sense of purpose and urgency.

Similarly, a criticism on a Session Four post-it, "Too much planning, not enough doing" prompted the adult facilitators to adjust the fifth session programme in favour of more activity and less talk. It also validated, in some measure, their belief that it was right for them to be more directive about the structure of the sessions, in order to free up the children to communicate their experience and concentrate on the content of the video.

Each session concluded with a similar slot, which offered an opportunity for adults and children alike to comment on what they had done and how they had felt, and discuss what to cover in the next week. In general, this was less successful, largely for very practical reasons. We were committed to finishing on time, for the sake of the parents who came to collect the children, as well as for reasons of good practice, and this meant that the last slot of the programme was often compromised. Secondly, while sitting quietly and reflecting worked well at the beginning of each session when the group was reassembling, it worked less well at the end of a busy, interactive two or three hours when their instincts seemed to be for distraction rather than introspection. Reflection is perhaps more of an adult norm: our experience was that they were well able to do this obliquely, in among other activities, but that the formal end slot was not the best time or place.

Another cycle of iteration occurred each time we reviewed film footage. Watching the film was itself a form of iteration; the children were immediately exposed to what they had done either earlier in the session, or in the previous week. Crucially, unlike memory, the playback was not distorted by time or emotion; it was a raw, uncensored, accurate, objective record of what they had said and how they had looked. The playback allowed them an opportunity to both see and process the experience, to evaluate and critique it, and sometimes to develop their thinking further. The pattern of continually offering playback also enabled them to move beyond the earlier self-conscious reactions to seeing themselves ("I hate the way I look/sound") to a point where they could critique the content for veracity, impact and relevance to purpose.

Editing and Dissemination

This was the aspect of the inquiry that was the least well done, and the responsibility for this lay largely with the lead researcher. The adult facilitators had recognised the need to set aside some time for this, but had no experience of the process. The PV expert had spoken at one stage of doing some preliminary editing during the fieldwork, in the days between each weekly session, but it became apparent that this was not happening. It was also obvious that the young people's interest was primarily in the filming itself and that editing was of less interest to them. While recognising that the editing of the film was a crucial stage and presented both an opportunity and a threat in terms of being faithful to the totality of the product of the children's research endeavours, practicalities dictated that they were less involved than we had wished.

Editing is a complex technical process and the equipment was set up in the PV facilitator's home, an hour's drive away from our meeting place. The facilitator was working on other projects at the same time and also experiencing a new role as father to a baby of a few weeks. It was therefore impracticable and inappropriate for the whole group to meet together in his study to share in the editing process. It was at this point that the adults deviated most from the principles they had tried so hard to espouse; they become more directive and, conscious of the pressures of time, the expectations not only of the children but of parents, their own teams and senior management, they moved into more traditional authoritarian roles. The process was as follows:-

In stage i) I identified a few clips from the process tapes, for possible inclusion in the finished film.

In stage ii) the four adult facilitators met to review all the 'public' footage (i.e. all the tapes to which the children had given formal consent) and to reach a broad consensus on what should be included. This was a lengthy and potentially difficult session, in which all four of us had shifted role, which brought accompanying tensions. As lead researcher, and project leader, I had a heavy investment in this stage. Meanwhile, Nick, as a PV expert, had an equally heavy investment and a claim not only to technical expertise in editing, but to aesthetic expertise in creating a 'good' video. And both Sue and Alison had their own personal conception of what the finished film should be like. We were no longer group facilitators, comfortable with and practised in our role and relations with each other - now we were uncertain of our role and competence and were jockeying, to an extent, for power and influence. I personally was very unsure of how much I should lead this stage, how much Nick would expect to do so, and how much Alison and Sue wanted to be involved. In earlier thinking about the project, I had assumed that they would be interested in the co-facilitation - in the running of the seven sessions of the project - but not the other practicalities of the project, which, I felt, lay more properly with the lead researcher as pertaining to the work of a doctoral student. This difficulty of disentangling the various threads of the work and distinguishing what should properly be done collaboratively as part of the inquiry and what should properly be done and owned by the doctoral student - since a PhD is an individual piece of work - was endemic in all four stages, and is discussed further in a later chapter.

Reflecting, as I now write, I think my responsibility lay in raising this issue so that all four adults could have then contributed to an open discussion and shared responsibility for agreeing a way forward. Instead, I avoided it and there was no common understanding of how to manage this stage. As a result, we watched and commented on more tapes than perhaps Nick felt necessary, but probably fewer than Alison or Sue had wanted.

We struggled to create a shape or narrative for the video, but did manage to agree on some areas and began to work towards a consensus as to what were the key themes. Later in the meeting we realised that we were in fact re-identifying the themes that our young co-researchers had so quickly and clearly identified during the brainstorm at the end of Session One.

Thus, although we were uncomfortably aware that we had shifted ground somewhat to a more traditional mode of working, we were reassured to see that, in a rather tortuous fashion, our own reflection and iterative process had led us back to decisions that mirrored those that might indeed have been reached if the process had been truly collaborative. And of course, the fact still remained that all the children had reviewed all the potential 'public' footage at least once, and much of it a second time in the last formal session.

Stage iii) was in no sense collaborative; this was the most lengthy and laborious stage, involving many hours in the editing suite for Nick. However, in stage iv) we reconvened in collaborative inquiry mode, with all 13 co-researchers present to view this first 'cut' and make suggestions.

Again, the practice did not match the theory. Although we had allowed time for (re) introductions, we had not sufficiently recognised that the children were in a different place emotionally and had not 'held' the inquiry in their minds in the same way as we had. Perhaps also their anxieties were even greater than ours, since it was, after all, themselves who would be most exposed in this film. Whatever the reason, they were restless, unsettled and apparently disengaged. There was almost no sense of their being a group.

> *"Quite some aggression...but also exercising more discipline - Laura D and Rachael quite assertive. GC and SB struggling to be heard..."*
> *Gillian (contemporaneous notes on Outline plan of meeting 14th May)*

Nevertheless, we were eventually able to show the film. Two aspects are noteworthy - first, their apparent lack of concentration, but, secondly, their ability to critique it.

The second was surprising in view of the first. They appeared distracted, munching crisps, getting up to get a drink, chatting or arguing with their neighbour, in fact appearing to concentrate very little on the visual images or sound so carefully crafted by Nick into a coherent whole. Whether this reflected a resentment at not being included sufficiently in the editing process or whether (my own assessment) watching and hearing themselves was difficult on a number of levels was not clear, but what became surprisingly clear was just how much they had absorbed and were ready to critique. Perhaps a mark of how successful we had become at breaking down some of the adult-child power relations was their brutal honesty in giving feedback.

> *"Too boring", "Not enough fun", "I wasn't in it very much", "I didn't like that bit with me in it."*

Ethical issues

It was important to ensure we had fully understood their criticisms, so the four adults worked hard to help them elaborate on their general comments. This established that there was little they had said that they wished to amend or withdraw, but it was the overall tone and particular visual aspects that concerned them

The ethical dimensions of this discussion were substantial. We had negotiated what might be described as a 'limited' and 'prospective' informed consent before the project began; this consent was itself part of an iterative process through out the project and became a fuller, continuing and retrospective consent as the children watched the playbacks immediately after filming, and then for a second time in the final session; and finally, it was a revised, considered and more complete consent when they had seen their various clips contextualised within the overall narrative of the film. It was essential that we obtained this final consent, since the content and meaning of each clip was mediated by its particular order, length and placing in the final film. While the camera may not lie, the editing process can dramatically distort the message and do considerable injustice to the participants.

In order to be sensitive to possible inhibitions on the part of some of the children, we invited them to see us privately at the end of the showing if there was something that they did not wish to discuss in front of the others. We recognised that there might be considerable pressure, real or imagined, to agree to something they were not happy about, because someone more vocal wanted that clip included. Two of the young people took advantage of this offer and spoke to one or other of the facilitators about specific sequences. For example, one of the twins was unhappy about a section in which she commented that, although he had meant well, her father had lied to her. A careful discussion established that she had no concerns with using the word "lied" but that she thought the rather inexpert camerawork (much jerky use of the zoom) spoilt the effect and detracted from the importance of what she was saying. In both hers and Rachael's case, Nick was able to reassure them that he could resolve this by using the verbal content as a voice-over with different visual images.

Technical concerns raised by the adults related to the quality of the sound, and some of the camera work. There was some disappointment that the video did not "say anything new" (personal communication from Alison June 03) but there was general agreement that it faithfully explored the key themes that we had worked on. There were, inevitably, issues that were either not represented, or never explored. The section on 'Absence as data' in Chapter Nine considers this further.

The fifth and final stage was the second edit, and this was extended somewhat. The three social workers met some days after the showing and discussed their reactions further and agreed some guidance for Nick. The lead researcher then negotiated an additional meeting with him in the editing suite, which proved fruitful. Working together on the second edit, felt slightly more collaborative and resulted in a number of small but important changes. This was a test of our commitment to genuine collaboration as we adults were reluctant to lose what we considered important verbal content in favour of 'pretty' footage of children under the cherry blossom. However, we needed to honour our promises, and meet the children's request to 'lighten up' the video. As I write, it is clear that our younger colleagues were the wiser; not only did that new footage lift the mood of the video but it effectively reinforced one of their key research findings - that children need to have fun and not grieve all the time.

The second-edit version was then shown to the children together with their parents. It seemed ethically right that the parents should have the opportunity to preview it before a public launch, but also ethically right that they should not exercise any censorship, since this would run counter to the avowed intention to give children a voice. We were aware that this could be problematic, if a parent were to be deeply unhappy about any part of the content, but we felt we needed to set this out as a principle.

> *"This was a collaborative effort. There may well be bits that you disagree with or are a bit uncomfortable about. But the decision as to what to include or leave out was the children's and we have respected that. And it was not a hasty decision - they have had several opportunities to change their minds."*
>
> *Gillian (notes of introductory speech at preview for parents 13th June 03)*

In the event, while all parents found some part of the video painful, they were unanimous in respecting the right of the children to express themselves freely. At the end of the evening, all the children were given a videotape containing all the 'out-takes' so that they each had a copy of all the footage to which they had given consent and in which they had appeared, regardless of whether it featured in the final public film. Naturally, they were all given their own copy of the finished video in due course.

This parental preview resulted in a third, very minor re-edit to correct some errors in the credit titles and some editing joins, and then the video was complete.

This section of the chapter has considered the third stage of the collaborative inquiry - the editing of the video, which itself is one output of the inquiry. This chapter's analysis of the process of collaborative inquiry, while drawing on the views of other colleagues, be they children or adults, is a singular one; it represents the considered views of the author alone. In that sense it is also an edit. And this chapter itself is an 'edited' version - the writing process is simultaneously a selective editing of a larger narrative.

Dissemination

Dissemination is clearly a key part of research, since by definition research is concerned with bringing knowledge into the public domain. There is general agreement that dissemination is often not integrated into the design and planning of a research project and is too frequently an afterthought (Powell 1997). In this project, I consciously considered this aspect of the research at the design stage and attempted to honour the collaborative principles in the dissemination phase. Thus, I had raised the issue with the young people of writing and speaking about the project before filming began. Once the video was complete, the opportunity to practise the principle became real.

Appendix Eight sets out the dissemination strategy for the 12 months following production of the video. This time period is necessarily arbitrary; while dissemination may have a clear beginning, it does not necessarily have an end. For the purposes of this thesis, I consider it in terms of formal dissemination through conference presentations, lectures and public writing - that is, opportunities chosen and controlled by the participants. Like all other research, collaborative inquiry has to recognise that once the research (in whatever format it may be) is in the public domain, it will be outwith the researchers' control. It will continue to be disseminated informally, often inaccurately, in prècis-ed, truncated and occasionally misleading versions, for purposes and contexts for which it was not originally intended.

One way of characterising the video is as an output of the research project. This thesis, in which this analysis of the dissemination of the two strands of research is embedded, is also an output, of a more traditional and academic style and will in turn form part of the dissemination process, but, as a work in progress it is beyond the scope of this section's timeframe. However, I return to this aspect of the thesis, as a further reflective layer, in Chapter Nine.

I turn now to the three key issues of dissemination; the target audience, the mode of dissemination, and the actors, in reverse order.

The actors

Although there may be considerable debate about the degree of participation or collaboration which justifies the claim of a piece of research to be genuinely collaborative or 'bottom-up' (see Methodology and Discussion chapter) there was indisputably considerable participation by the young people in the core research activity of the video project. I was therefore keen for the dissemination to be similar. As I write this in the first person, I see immediately that this was not a collaborative decision; the impetus did not come from the children or the other facilitators but from a personal conviction on my part that this would be appropriate, ethical and effective. Nevertheless, there appeared to be some genuine interest in this from the children themselves and at the video preview I offered an invitation to all of them to help at future events. As with all the other aspects of the project, the children self-selected, on a continuum from very enthusiastic to totally disinterested. Therefore, each time there was an opportunity to present our work, this information was emailed to the group, for those who wished to respond individually.

> *"We have been asked to give two presentations at conferences...We have about 20 minutes to speak and then a bit of time for questions. Please could you let me know if you are interested. The likely format is similar to previous ones -each of us takes a particular aspect of the project and talks about it, and we use clips from the video to illustrate our points. ...The three of us adults will be happy to help you with planning your presentation, if you want us to.*
> *Saying that you are interested (in helping) doesn't mean that you* ***have*** *to do it, just that you'd like to know more!"*
>
> *Gillian (email to the group April 2004)*

Over the period covered by the table, there have been ten child appearances. These have been shared among four of the children. Two of the nine were bereaved at the end of the filming and moved out of the county, and one moved abroad. Of the remaining six, three were bereaved during the dissemination period. One of these however participated in two presentations prior to the parent's death. In all the presentations, there was also one or more of the adult facilitators.

Since this research aimed at empowering children and giving them a voice, it seemed appropriate and ethical to enable that voice to be heard, unmediated by adults, in the dissemination process. We made it clear that each presenter was free to say exactly what they felt about the project and that we were happy for them to be critical about it. Nevertheless, it was the adult facilitators who suggested particular themes that the youngster might focus upon, they who wrote the initial abstract and they who designed the structure of the presentation. These were skills and expertise that only they possessed and the work was a legitimate part of their paid employment. For the children, abstract writing and presentation planning was unknown - and probably uninteresting - territory. Nor were they available to meet with us during the working day. The practicalities of collaborative presenting were thus quite daunting and militated against our developing the process further. Nevertheless, this limited inclusion of our younger co-researchers was a step in the right direction, and without doubt was effective. Their presentations were original, fresh and very direct, and audience feedback was very positive.

> *(Summary of a conference feedback; response to a request to highlight one aspect of the conference that made a particular impact)*
> *"User involvement session - the young people's video group"*
> *(Macmillan National Conference, Edinburgh 2003)*

Just as important, however, was the impact on the actors, the children themselves. The opportunity to present required them to reflect, at a greater distance, on the experience of collaborative inquiry, in a more measured and considered way. Thus:

> *"When I was asked to do this video I was a bit apprehensive, because I was the oldest there and I didn't know anyone but I realised that no-one knew anyone and we were all in a similar situation. After the sixth week these people I didn't know became my friends and people who I could relate to.*
> *This experience has affected my life as it made me realise that there are others in my unique situation and I hope other children and young adults will benefit from our own experiences as told through the video.*
> *Everyone spoke from their hearts....we addressed many issues across the board which we hope will help others.*
> *There were a lot of personal issues raised in this video and at first I was unsure but after watching the final video I realised how much it could help others and my concerns about* [it] *being released into the general public went* [disappeared].
> *Ellis (International Visual Sociology Conference, July 2003)*

In this short presentation Ellis highlights many of the issues this and other chapters have considered: the challenges of recruiting to and retaining the group; the impact of the project on his own life; the genuineness and expertise(experiential, presentational and propositional) of the children; the development of insight and understanding of the potential of collaborative inquiry and its output (the video) to achieve change.

The process of dissemination was in itself an iterative process, and a later presentation by the same colleague demonstrates a deeper and more detailed reflection on becoming a group member, and on the personal impact for his family;-

> *"At first I was very wary about doing the video. As a private person I wasn't sure how much or how little I was prepared to say. However, after meeting the group and talking with my Mum I decided to go ahead with the project.*
> *It* [the video] *gave me a chance to tell people, especially my Mum, of how I really felt about her cancer, I know my Mum found this really helped her to deal with it. When she was very low and tired we always tried to be there for each other."*
>
> *Ellis (Death, Dying and Bereavement Conference, June 2004)*

The themes of initial wariness and uncertainty, and growing trust and empowerment also featured in his peers' presentations:-

> *"At first I had a few worries (well I'm sure we all did!). I was slightly nervous of being in front of and speaking to the camera.... I wondered how much control we kids and teenagers had over the video. I was worried that the adults would put in a scene that I didn't want shown on the final version but it turned out that we were in charge and the adults did a lot of listening.*
> *We all worked really hard on this project, it was a team effort all the way through"*
>
> *Natalie (presentation to assessors, September 2003)*

> *"The adults didn't decide everything - the kids done some stuff too"*
>
> *Rachael (presentation to assessors, September 2003)*

The sense of empowerment is perhaps most explicit in Gemma's contribution:

> *"When I first started the video I was curious to find out how much freedom the young people had over what went in the video. I was pleased to know that we would have practically full control on what went in and what stayed out of the final version. I thought it was good that we had a lot of freedom*

> *because then we were not pressured to do or say anything we were not comfortable with. This created a relaxed atmosphere and it was easier to express our true feelings. Most of the decisions were up to us individually....Overall I feel that because the young adults had so much freedom the video gives a true picture of what we are going through."*

While the foregoing may demonstrate the extent to which the young people felt genuinely involved in the project, their capacity to reflect on the process and their ability to articulate this in public, it has to be acknowledged that they were not involved in the overall design of the presentations, or in the choice of audience. This selection was based on the interests of the facilitators and their employing agencies and an opportunity to involve the youngsters and discover what their preferred dissemination outlets might be was lost.

The same critique applies to a number of short articles about the project which have appeared in palliative care, bereavement and consumer research publications. In these, some of the children's comments and reflections have been incorporated, but the articles' conceptualisation and execution have been exclusively adult-driven. The most glaring example of both the demonstration and dilution of our collaborative ethos has been the chapter in a forthcoming book (Jarrett 2006) on users and the arts in palliative care. Having been commissioned to write the chapter, I consciously decided to mirror the video project and produce a collaboratively written account. My three co-facilitators agreed with varying degrees of enthusiasm to contribute a section each and I edited the resulting chapter. Regrettably, none of us reminded or urged the rest of us to invite our younger co-researchers to contribute. Some of us drew on their comments, but our writing perpetuated a power imbalance that we had previously worked so hard to challenge. While the reality was likely to be that none of them would have had the time or inclination to write to a tight brief and even tighter deadline, we simply made that assumption and never offered them that choice.

Maintaining the role of 'user'

Although dissemination is an ongoing process as acknowledged earlier, the continuing involvement of the young people has proved problematic for two reasons. First, the research focus was on living with a seriously ill parent and a key issue was the uncertainty that surrounded this. Eighteen months after the video was produced, five of the nine children no longer had a seriously ill parent; the uncertainty had gone, that parent had died and they were now bereaved children. (At the time of writing, seven of the nine are bereaved). Secondly, for the three young people whose sick parent was still alive, life had also changed, but in a different way. In each family, the parent had experienced further deterioration in health, and their children were in a different emotional place as a result. In a different sense, place was also problematic in that one had completed schooling and was now in employment which made participation in presentations even more difficult, while for the others forthcoming GCSE examinations were a barrier.

The way in which the changing career of the 'user' impacts on the continuing role of 'researcher' is considered further in the Chapter Nine.

Nevertheless, within those eighteen months it has been possible to demonstrate that the traditional model of dissemination, in which the verbal dominates the visual and presenters are overwhelmingly academic, adult and professional, can be effectively challenged by a more inclusive, ethical model which enables participants who are frequently marginalised - service users, children - to communicate their work directly to the wider public.

And although the active involvement of the children has effectively ceased, they continue to be present and part of the dissemination process every time a videoclip is used; technology brings the audience face to face with these young people in an immediate and engaging way.

Summary

This chapter has set out, as fully and openly as possible, the **process** of conducting the collaborative inquiry with the nine children. In contrast to conventional accounts, it has given equal weight to the planning, preparation, and dissemination stages as to the core 'investigative' stage. It then considers the key issues of power and capacity building that are central to any collaborative inquiry, before turning to an analysis of the diffuse, but constant process of iteration within the inquiry. In all these areas, the quality of the relationships and the need for ethical rigour are underscored, while there is transparency about the uncertainty, unpredictability, and inadequacies revealed in the process.

CHAPTER EIGHT: FINDINGS - THE EXPERIENCE OF LIVING WITH A SERIOUSLY ILL PARENT

"It changes everything"

Rachael

Introduction

This chapter presents the findings that arise from the data generated by the video project on the children's experience of living with a parent who had cancer. This chapter is largely, though not exclusively, based on the evidence the children gave to each other. As such , it does not make a formal distinction between the child as researcher or interviewee, since the young co-researchers occupied both roles contemporaneously and moved back and forth between each role with ease. However, where an adult co-researcher (who was of course not researching their own experience) contributed an opinion or raised a topic, this is clearly distinguished.

In writing this chapter I have been conscious of a tension between representing the children's findings faithfully by **presenting** the children's evidence, and **re-presenting** their work by interpreting the data in my role as academic researcher. Entries in my reflective diary attest to this dilemma.

> *.."am having a moral crisis...tension between collaborative approach...but no way I can use all the material"*
>
> *Reflective Diary July 05*

I was clearly uncomfortable with the apparent privileging of the adult academic researcher's voice over that of the non-adult, expert-in-life-experience of the children, which seemed to negate the principles of collaboration and democracy which we had all struggled so hard to practise in the research project.

In supervision, and in reflective conversations with colleagues in practice, with other doctoral students and within myself, I have come to a resolution of this dilemma that I characterise as 'good-enough' for the practical purposes of this work. This recognises that:

- The video "No - You **Don't** Know How We Feel" presents and represents the individual and consensual perspectives of the children, largely untainted by adult interpretation or re-presentation. It is faithful to the key themes that they themselves identified in the first meeting.
- The opportunity to involve the children in a more formal analysis of the data was never given. It seems unlikely that this would have had much appeal to them, or that it would have been at all practical in terms of time, competing commitments and their changing status from pre-bereaved to bereaved children. Nevertheless, the failure to offer this is evidence of attitudes and assumptions so ingrained in an adult that they were not even available for examination until too late.
- This chapter cannot and does not therefore claim to be other than a particularised and contextualised interpretation of the data. It is particularised in the sense that it is the interpretation of the data by one individual, a white, middle-class, female practitioner-researcher; it is contextualised by its location as part of an academic thesis, with its attendant culture and expectations, primary among these being the requirement that the work is that of the researcher alone.
- This chapter therefore **presents** an interpretation of the data that is mine alone, even though much of it may be endorsed by my co-researchers, both children and adults; it **re-presents** the experience of the children through an adult, academic lens.

With the above in mind, I present the findings within a framework that draws largely but not exclusively on Bronfenbrenner's ecological systems theory (see Figure 8.1) and constructs a 'nested' design, beginning with the children's perception of themselves and moving out into the wider world through relationships with family and friends, into the school setting and then beyond. Within each of these systems communication is a key theme, with sub-themes of talking, truth-telling, and trust dominant or implicit.

Bronfenbrenner's theory of ecological development

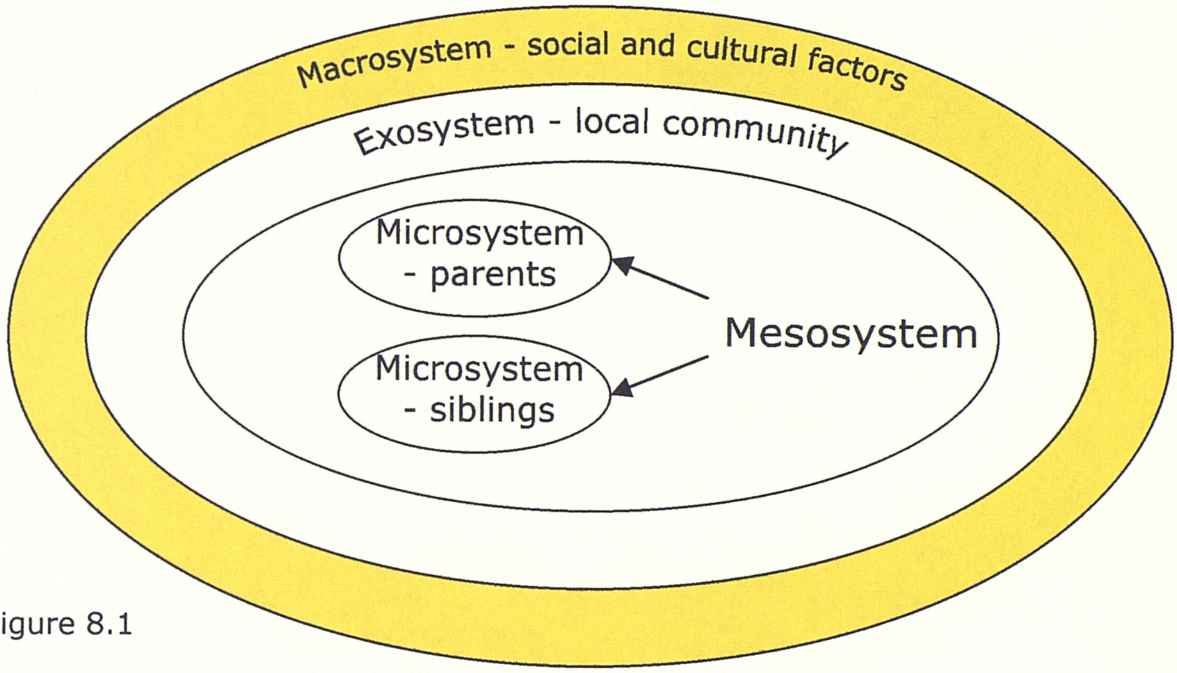


Figure 8.1

Each of these main themes and cross-sectional themes are illustrated - and occasionally challenged - by comments or reflections from the children themselves. I have drawn, in different sections, on the contributions of all nine of the young people. It is important to note that, at times, the same child articulates quite opposite views; while this may not provide the clarity of conclusion that researchers cherish, it does reflect the dynamic, contested and perspectival nature of their relationships and experience. It also reflects the uneven, lengthy and uncertain journey to empowerment (Warren 1997) based on Dunst's (1990) six key principles.

The video project was not uniformly successful in embracing all six; enhancing a sense of community, mobilising resources and support, and shared responsibility and collaboration sat comfortably both with collaborative inquiry's avowed aims and with palliative care social work principles, but the project did not set out to specifically address the remaining three principles of protecting family integrity, strengthening family function or embracing proactive human services practices. However, it could be argued that these were addressed indirectly.

The themes analysed in the following sections of this chapter emerged both during the active research phase (the video project) and subsequently during cycles of reflection, data analysis, writing, and redrafting - processes that overlapped, separated and reformed in different patterns. They are not static, and it is recognised that another researcher at another time might build the patterns differently. Using the nested design referred to above, this chapter moves from the micro system of the child to that of the family, then considers the meso-systems that are the negotiations between these microsystems, before moving further out into the child's social world to focus on the significant experience of school, a powerful exosystem, and finally to consider the equally but perhaps more subtly powerful macrosystem of contemporary British society.

The Microsystem - the Child Experiencing Cancer in the Family

(The reader is referred to Appendix 6 for a list of the child participants together with relevant background details.)

Impact of cancer

Creating and maintaining the self in relation to cancer was an ongoing challenge for the children. A basic, powerful and unresolved conflict was located in the tension between their own perception and presentation of themselves as competent, able individuals and their experience of cancer in the family as destructive of their ability and identity. So, the children generally saw themselves as capable individuals having something valuable to contribute to the project and to society. They wanted their abilities and expertise to be recognised, and were frustrated when that recognition was lacking. The claim of adults- or their peers - to know what it was like to live with parental illness was dismissed, often with irritation or anger:

> *"No- you don't! You **don't** know." (Ellis, Megan, passim)*

They were confident in their own experience and expertise and keen to use them to benefit others:

> *"My Mum's ill and I'm gonna help other people" Becky (S1 P1a 31.30)*

This was for all of them the underlying purpose of the project and a powerful and important reason for participating. This notion of capability as opposed to the more traditional emphasis of vulnerability in children is considered in relation to the process of collaborative inquiry with children in the preceding chapter. A further discussion of the issues implicit in this will be found in Chapter Nine.

Nevertheless, this sense of self, and confidence in self was seriously threatened by the advent of their parent's illness. The children characterised it as turning their world upside down, undermining both their abilities and their relationships. They found it harder to maintain their normal selves, and its disabling effects on their parent was mirrored in their own experience:-

> *"Cancer takes your real life away...takes your confidence away" Rachael (S2 VA 11.10)*

It was experienced as affecting their functioning on all levels, including the intellectual, because it was all-pervasive and inescapable, cluttering up the very pores of existence:

> *"When cancer clogs your life...your brain capacity gets clogged with pollution"*
>
> *Laura C (S6 VE 00.21)*

Despite, or perhaps because of their awareness of its destructive power, the children actively sought more information about it:

> *"It's good to know what's actually happening"..."just knowing more about it, treatment, chemotherapy"*
>
> *Ellis (S6 P6b 6.05 and 3.22)*

Most of the youngsters were well aware that cancer took many forms and some had a more sophisticated understanding of its nature. Megan and the twins highlighted its aggressive nature and its uncertainty, while other levels of awareness were more limited:

> *" cancer is - white cells, and the lump taken out"*
>
> *(Unidentified S6 VE 00.01)*

Although information is often equated with power, knowing some of the hard facts about cancer did not noticeably change the sense of its being uncontrollable, random and unfair. Laura C quoted the statistics (gleaned from a TV programme) that one in three people would get cancer, but then expressed her sense of helplessness:

> *"There are three in my house, why did it have to be her, why couldn't it be me?"*
>
> *Laura (S1 VA 11.15)*

Not knowing whether or when the cancer would return increased this sense of helplessness and several of the children spoke of their frustration and fear in living with this uncertainty; cancer, even when treated, was characterised as a ghost that continued to haunt their waking moments. On the other hand, although cancer was beyond their control, being made more helpless by the well-meaning actions of adults was taken very personally. Both Laura and Ellis experienced their parents' decision to delay telling them of the diagnosis as unhelpful, marginalising them in the family and undermining their perceptions of themselves as competent and significant.

Agency and empowerment

In the journey to empowerment, Warren (1997) supports Rappoport's analysis, which emphasises the importance of a strengths-based philosophy, ascribing difficulties less to the incompetence of the individual (child) and more to the institutional and societal structures which prevent the display or acquisition of competence and power. Our group's experience reflected this dilemma and revealed a number of strategies for managing this tension.

Once they knew about the diagnosis, the children demonstrated considerable agency in their choice of what they shared, with whom they shared, and when they shared both information and feelings. They adopted conscious strategies for managing their situation, preserving their sense of self and maintaining a sense of normality in the face of a disease that was often out of control, and a family life that had become chaotic, unpredictable and unsafe. The choice of whom to tell was based primarily on trust and intimacy, with most of the youngsters telling only their closest friends:

> *"I can talk about it to one person I can trust - Rachael".*
>
> *Becky (S2 VA 3.41)*

These selected friends could be trusted to handle the information sensitively and with respect, whereas others, though they might not laugh about it, might take it less seriously and, equally worryingly, spread it around the school. Clearly, it was important to the children to be able to retain some sort of control over the information, even though they knew they could not exercise control over the cancer itself.

Knowing what it was not safe to say led to other strategies for staying in control. For example, many of the children either did not trust well-meaning enquirers or did not trust themselves to stay in control of their feelings, and dealt with this by a strategy of dissembling:

> *"To get them off your back, say that she's fine"*
>
> *Rachael (S5 VD 22.20)*

Empowerment through not talking and telling

Just as the negative dimension of power is frequently under-acknowledged, so is the negative, or passive, dimension of speech - i.e. not talking. Putting on a smile, being non-committal and avoiding the subject of their sick parent were other ways of dissembling and allowing themselves to remain in control of both the conversation's content and their own emotions. It is a truism that what is not said speaks volumes, and Laura D, the middle of the three D siblings, avoided words wherever possible, but still conveyed some very clear messages in the process, as well as making a useful distinction between talking and telling, saying at one point: *"I talk to my friends"* but later making it clear that there was just one person for whom she broke her rule about **telling.**

> *"I've only told one friend"   Laura D (S2 VB 3.56)*

Clearly for her, talking with friends was helpful because it did **not** involve talking about cancer. Similarly, during the Statements Game Laura appeared to agree that *"Having brothers and sisters is good, because you can talk to them"* but this provoked an immediate reaction from her sister Rachael, her body language clearly implying disagreement (S7 VF1 11.45). Asked to comment, Rachael immediately said,

> *"She don't talk to nobody! Laura's like a closed bottle...Megan and me talk more about it".*

Asked by one of the adults if this was true, Laura did not talk(!) but nodded happily (S7 VF1 12.02). Another statement, about grandparents, gave her the opportunity to elaborate on her approach to talking:

> *"I don't like talking about my Mum's illness... I don't really like to..."*
> *(S7 VF1 15.13)*

Despite her reluctance to talk either on camera or off, Laura D challenged our assumed understandings of talking by her careful distinctions between 'talking to' (having friends), 'talking about' (discussing) and 'telling' (informing others about the illness).

> Adult: *"Do you talk to friends when you're stressed?"*
> Laura: *"Not really"*
> Adult: *"Is it easier to avoid (the subject)?*
> Laura nods *(S4 VA 23.07)*

Even the act of speaking the word 'Yes' is best avoided; she resorts to body language only. In this, she is remarkably consistent; earlier in the session, when invited to participate, in a small group of three, in an exercise that required each of them to speak for one minute about stress, she stated clearly, *"I'm not going to say anything at all"*.
Despite the well-meaning attempts of her peers she maintained a complete silence throughout her allotted one minute with the microphone (S2 VA 2.35 onwards) and in a later session she explained,
"I don't like drawing attention to myself" (S6 VE 5.50), a sentiment shared in part by Becky who also admitted that she didn't like talking *"in front of other people".* For them, it was not necessarily that cancer was difficult to talk about, but that it was difficult to talk in the public arena.

Megan also did not find it easy, but was able to talk about it (not finding it easy) more readily. Furthermore, she could acknowledge the value of talking to others undergoing the same experience:

> *"This project's very good...we're making new friends, talking to people going through the same situation...brilliant...having someone to talk to". (S6 VE 8.10)*

Ellis, the oldest of the co-researchers, tended to be economical with his words, but he made them count:

> *"I bottle everything up inside, then a couple of times a year it just overflows"* (sweeping gesture with his arms).
>
> *(S7 VF1 15.30).*

Both the palliative care and counselling literature have tended to assume that those who talk readily find it relatively easy, but this is not necessarily a safe assumption. Laura C commented in one of the later sessions that she preferred not to talk about someone dying because she feared it becoming a reality. To the challenge by an adult that she was often the first person to raise an issue, she explained:

> *"It's easy to talk about it here, 'cos we're all going through round about the same thing but talking to the actual person who is ill, that's hard". (S7 VF1 2.44)*

Here she exemplifies two other key principles highlighted by Dunst (1990) and endorsed by Warren (1997) - those of empowerment as a **process** or journey over time, and as **performance** - putting into practice what has been learnt in the process.

So, not talking might have several explanations - embarrassment, shy personality, magical thinking, or it might be dependent on to whom one was not talking. It was usually a deliberate, considered decision:

> *"If I want a teacher to know, I'll tell them." Ellis (S5 VD 17.04)*

The sometimes unwelcome pressure to talk came not only from teachers but also from parents, and the invitation to talk could be threatening to the young person's autonomy if their preference was to sort out their problems by themselves. The danger of this, as Chapter Two's review of the literature showed, was that adults tended to assume that if children did not talk they did not care or were not worried. However, this was emphatically not the case for our co-researchers:

> Laura C:[You can't ask your parent] *"Are you going to die, when are you going to die, how is it going to happen, will I be there?"*
> Alison: *"But these are things you'd quite like to talk about?"*
> Laura C: *"Well in a way, in a way, not"*
> Gillian: *"But they are things you are thinking about?"*
> Laura C: *"Yes!"*
>
> *(S7 VF1 12.34)*

Thinking, as opposed to talking, often reflected the ambivalence at which Laura hints in the above exchange. Holding two opposing thoughts in juxtaposition was a coping strategy, and the children often demonstrated a mature awareness of multiple and inconsistent positions:

> *"I didn't exactly expect him to get better, but I hoped he would"*
>
> *Gemma (S6 VE 2.15)*

And:

> *"You want to hide away, but you want someone to find you.."*
>
> *Laura C (S1 P1a 49.50)*

These quotations indicate their desire both to be seen as independent agents, realistic and competent, and their need for support and reassurance from an outside agent. Presenting themselves as active participants in their changed and challenging world was important to them, but it sometimes conflicted with their awareness of their own vulnerability and dependence.

Their ability to be self-aware was a consistent feature of the project and they did not hesitate to be critical of themselves on occasions, sometimes perhaps ascribing considerable power to themselves. One of the statements in a game they played in session 7 claimed that children could be 'horrible, cruel and vicious', but the response to this was to identify themselves as guilty rather than other children.

> Rachael: *"Oh, that is* ***so*** *me....they're horrible, then I'm horrible back, 'cos I think it's fair".*
> Adult: *"Are they horrible about your parent's illness?"*
> Rachael: *"Sometimes, and that's when I lose my temper badly"*
> *(S7 VF1 12.34)*

Most of her co-researchers agreed that they 'took it out' on other people unfairly; these people were sometimes siblings (Becky of Jack), more frequently 'mates', and occasionally the sick parent. This was a particular issue for one of the group, who expressed considerable anxiety and guilt about the parental-child friction in the home, a shifting sense of responsibility for this and an acknowledgement that it was unrealistic to shoulder all the blame themselves.

Living with a parent with cancer was clearly frequently stressful and managing the tension between their own sense of power and the conflicting sense of things being out of control led them all to identify stress as a major issue. Without exception, each session included some comments about this. In session one, this was an anonymous contribution to the worry box:

> *"I am really stressed. At the moment I am taking a lot of stress out on them. How can I stop? Help!"*

It was also a key theme generated in the brainstorm about topics with which the video should deal. (S1 P1a 50.30)

Megan's suggestions for relieving stress indicate the pressure experienced, but also demonstrate a capacity to initiate and exercise control, rather than be passive:

> *"We need a kids' Day Centre... a punch bag... a pillow.. a room for yourself, a room full of punchbags. Counsellors. And music."*
>
> *(S2 VA 9.30)*

A safe space - a place and a process of empowerment

Frequent reference was made by group members to the concept of 'space'. Advice to teachers, parents and friends was often about giving space, with an implicit sense that the children often felt crowded, pressured and directed, when what they wanted was freedom, distance and choice.

> *"We need space - if we've had an emotional evening, feeling down, then give us some space ... give us five or ten minutes outside, or to sit at the back of the class, or send friends to talk..."*
>
> *Gemma (S5 VD 16.08)*

However, this need for space was not always acknowledged by others and the children had to develop their own ways of achieving the necessary space. This could sometimes lay them open to criticism from others, who perceived them as uncommunicative. For example, while Laura D retreated to her bedroom without overt criticism, the outcome for Laura C was different:

> *"I get stressed....I go up to my room and ignore my Mum. Then I get grounded." Laura C (S5 VD 10.17)*

The Video Project, however, was accepted as beyond parental jurisdiction, and the young people quickly acknowledged the value of the group, highlighting the confidence it gave them, the relief from their erstwhile sense of isolation, and the sense of safety in having a space to share difficult things. They all spoke at different times of feeling isolated by the experience of being a child of a seriously ill parent. They were unaware of anyone else 'in the same boat' and felt that, however concerned friends were, they could not understand what it was like for them as they had not had the same experience, whereas the project provided both:

> *"We had people to talk to who were going through the same things as us, so that was good."*
>
> *Natalie (S7, VF1, 5.36)*

> *"I find this quite easy (the video project) but when we're not doing this, I sometimes worry about lots of things, but if you are doing it in a club then everyone else is going through nearly exactly the same and then you probably feel better. Here you feel secure, because everyone else knows what you're going through."*
>
> *Rachael (S3 VC 20.04)*

Within the safety of the project, small group work provided a further level of security, with several of the children highlighting how much easier it was to talk in a small group where they were better able to say personal things to people with whom they were developing a closer, more trusting relationship. Quite early on in the project, in Session Two, Megan, Ellis and Laura C had a lengthy discussion about cancer and its impact in which they shared precious personal information and feelings and demonstrated a sophisticated ability to respect and support each other.

An interesting aspect of this concept of a safe space was that the potential for sharing was equally as important as the execution. The knowledge that it was safe to talk and to share was not only a necessary but sometimes a sufficient fact:

> *Alison reported a conversation in which Rachael had said "This is like a club, you can talk here" to which she, Alison, had responded gently, "But you haven't really". "No, but it feels like we could" was the answer. (Video diary, Session 2)*

Thus, the implicit was sufficient to generate an actual experience of being in control and capable. Feeling empowered made for empowerment, as Freire (1972) had recognised, and it was the **process** that enabled them to **practise** it. It would seem that the project, in the shape of the seven sessions, provided containment for some of the uncertainty , anxiety and unhappiness that was concomitant with facing the possible death of a parent. Containing these difficult experiences gave them a sense of control, which gave them a feeling of empowerment and a stronger belief in themselves. It was a space wherein they could not only rest and recharge their batteries, but where they could also risk - risk raising difficult topics, risk revealing some of their inner fears and emotions - in a safe way. For much of their daily lives, they attempted to contain, or hold in, powerful feelings, but they recognised they could not do this all the time, and needed some opportunity for release.

> *"You're upset... you can't do* [everything] *and keep emotions in"*
>
> *Laura C (S4 VD 11.28)*

The majority finding of the co-researchers was that it was better to ventilate their feelings than to bottle them up.

> *"Everybody needs to get it out. If they feel strongly about something then they should make it heard, not keep it inside themselves - it makes it worse."*
>
> *Natalie (S7 VF1 33.00)*

Rachael, Ellis, Megan, Laura C and Gemma all expressed similar opinions, and used a range of methods - face-to-face, the telephone or texting. Ventilating feelings was not the only useful purpose of talking. Megan argued strongly that talking *about* what was happening could also aid the process of 'acceptance'

> *"Talking makes it easier. If you accept that it might happen at some point...it's not as much of a shock. It is a shock, but not such a shock because you've already prepared yourself for it."*
>
> *(S7 VF1 2.44)*

Choosing to whom they talked was another strategy by which the children could exercise some control over the cancer in their family. Thus, Megan was comfortable talking to Rachael, the middle sibling, but also found it supportive to talk to someone outside the family - Laura C. This was reciprocated by Laura C who, as highlighted elsewhere, felt her isolation, as an only child, keenly.

> *"You need someone to talk to. I'm an only child, no brothers or sisters. It's hard to talk to a camera"*
>
> *(S6 VE 5.30)*

Contrary to this assertion, made to camera, Laura was able to talk fluently and to good purpose to the camera to record her video diary. In it, she articulated the ambivalence about talking that has been noted elsewhere:

> *"You don't want to tell everyone your emotions - but then, in a way, you do."*
>
> *(S6 VE 4.20)*

Getting through

The group identified this theme at the very beginning of the project and it featured in video diaries, discussions and casual conversation. It was important to them all to carry on with life and they wanted to emphasise that their lives were not ones of unremitting gloom.

Staying positive

Quality of life is a well-established concept in palliative care, but usually related to and referred to by adults. However, the young co-researchers also addressed this issue, and were emphatic that there were many positive aspects to their lives and that it was important to maintain a balance. They were keen that the video should demonstrate this balance, which they sought to manage within their own lives.

Identifying and savouring all that was good or pleasurable in their lives was a conscious coping strategy that the close friends, Becky and Rachael, both endorsed. Becky expressed herself happy when her mother was happy; Rachael, whose mother was very seriously ill, and had lost her hair and put on considerable weight, commented on how good it was to have a mother and insisted that she was beautiful. She went on to say:

> *"Think of the good things, the good bits - eat them, eat them up, so many memories....If you think about the good things, you feel more happy, more secure."*
>
> *Rachael (S6 VE 3.29)*

Part of staying positive was having fun, and again the group insisted that the video demonstrated this. One of the ground rules suggested by them in session one was 'Have fun' (see Appendix Seven) and Natalie appeared to speak for them all when she pointed out that:

> *"You can't be sad all the time, otherwise it would just get to you"*
>
> *Natalie (S7 VF1 30.15)*

Their reaction to the first edit of the film was that it was too serious and boring (Reflective diary, 12/05/03). The second edit included shots of the group playing tag and a team game 'Samantha at the Circus' which met with greater approval.

These activities had been identified earlier in the project as providing possible footage:

> *"That was fun, we should put some of that in the film"*
>
> *Megan (S6 P6a 8.10)*

This notion of themselves as enjoying life was in contrast to that held by adults in other parts of the ecological system, who generally saw such children as tragic and to be pitied.

Other strategies

Other strategies varied according to age and inclination. Music was popular with most of the group and was perhaps another way of creating a containing space. For some, it was more of a distraction, draining away their troubles and calming them down, while for others it enabled them to release their emotions and cry. Most of the children moved between distraction and ventilation, but Jack appeared to use only the former - his comment entirely matched his preferred mode of behaviour throughout the project:

> *"I just play" Jack (S2 VA 22.54)*

Megan was the only co-researcher to articulate her deliberate choice of joking as a strategy, although several of the group displayed this behaviour. Her comments also underline the importance to the children of presentation of a particular self - usually that of being ordinary, normal and not needing special treatment:

> *"I tell jokes - it's like a defence thing, then they'll think I'm OK, which I want them to." (S6 VE 5.50)*

And Rachael identified writing as helpful - she kept a secret diary and the act of writing things down in it was a type of contained telling and communication that seemed therapeutic for her.

Containing and expressing emotions

A significant part of the construction of self, for these young people, was the concept of controlling emotions. This phrase is used in the sense of both being a powerful agent who could keep control of emotions and, conversely, of being controlled by powerful emotions. This tension was evident in the painting session that occurred at the mid-way point of the project.

Living with either the fear or the knowledge that your parent would die of cancer affected the young people's emotional state in both subtle and obvious ways. It was a topic to which they returned frequently and which they now addressed in paint. Depicting their emotions through art was something they embraced enthusiastically; their paintings were graphic, powerful and triggered some passionate but thoughtful exposition of their meaning.

> *(For ease of reading, individual references are only occasionally given here; the relevant section of videotape which contains the discussion, the painting activity and the exposition by the children is S3 P5 19.00 - 62.00.)*

Jealousy, being excluded, shyness and 'out of your head' (further translated as 'weird') were suggested in the brainstorm but not selected for illustration. The notion of exclusion is analysed in the section on 'not talking' but the others were not raised anywhere else in the project. In the paintings themselves, the children appeared to demonstrate two approaches - some focused clearly on one emotion as dominant, and others emphasised a mix of emotions.

Dominant emotions

Jack, aged 7, produced a single emotion painting, 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 (S3 P5 62.00).

Natalie also chose sadness; her painting showed a solitary pale blue tear drop and she spoke of her sense of isolation. Of course, it would be surprising if sadness did not feature frequently in the young people's conversation, but perhaps what is more interesting is the need for them to 'manage' or control the emotion.

> *"'Nobody can grieve all the time' (Statement) - Well, I* ***agree*** *with that. If you grieve all the time, you start becoming bitter"*
>
> *Ellis (S7 VF1 17.10)*

Implicit in this comment is some notion of choice and control on the part of the actor - that it is important, and feasible, to choose the amount of time that one emotion is permitted to dominate.

Ellis chose '**Frustration**' as his dominant emotion. He got down to work quickly and with evident pleasure. He used a mix of bright colours and whistled cheerfully as he painted. However, his demeanour on describing his painting to the group afterwards was more appropriate to its significance. He spoke with care, but appeared to struggle to find the right words.

> *"My painting is about* ***frustration.*** *A mix of emotions. Pain, sadness, anger.."*

Asked what made him most frustrated, he responded,

> *"Not knowing if my Mum will get better - and teachers!"*

The best example of the conscious control of emotions came from Laura D, who, in sharp contrast to the boys, and to everyone else, chose a positive emotion. In the discussion beforehand led by her sister Megan, she contributed the notions of 'excited' and 'happy'. During the painting session, when reminded that at the end they would each have the opportunity to be filmed talking about their painting, she stated firmly *"I've already thought about it - I know what I'm going to say".* When it came to her turn, however, she also struggled for words:
"Happy! - not... actually, excited!" and, in response to the question as to when she felt like this, *"Mostly."*

In response to a question from her sister about her choice of colours - bright, rainbow-like - she claimed that she chose them for their cheerfulness. When I asked, *"Is it hard to always be cheerful, Laura?"* (58.52) there was only silence. Our adult interpretation of this was that Laura chose consistently to ignore the pain of what was happening in the family. It was not that she denied it, for she was well aware that her mother was dying; she simply did not address it.

Most of her co-researchers addressed the whirlpool of their emotions very directly. For example, although Gemma apparently identified one emotion only, **'confusion',** her painting was a mind-map of unanswered questions such as *"What will happen to me?", "Will I get it?" "How can I help?", "What caused it?"* She spoke of the overwhelming sense of uncertainty that she faced,

> *"until it ends you just don't know...".*

In response to Laura C's question as to why she felt confused, Gemma explained: *"I haven't been in this situation before, I've no experience".*

Mixed emotions

Megan's and Rachael's paintings also expressed this 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 her colleagues to 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)"*
>
> *(S3 P3 54.15)*

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.

Guilt was an emotion that did not feature in the paintings themselves, but was raised in the earlier discussion, and won approval from Megan. However, it was Laura C who had most to say on the subject. As noted earlier, she worried about the disagreements that she obviously had from time to time with her mother and struggled with a sense of guilt:

> *"You kind of think, what have you done wrong...why do they deserve to die?" Laura C (S2 VA 13.20)*

and

> *"It's wrong to get angry with the sick person - it's wrong but it can be right"*
>
> *Laura C (S7 VF1 9.08)*

Although this last statement attests to Laura's ambivalence about the ethics of being angry, what is consistent is the sense of agency or responsibility - her ability to exercise power is taken for granted.

The emotion of **anger** was frequently acknowledged as a key issue, directed at both cancer in the abstract, and also at specific individuals, such as the sick parent and friends.

> *"I get angry at school...fights with friends, or if my Mum's not well, fight with my sisters."*
>
> *Rachael (S3 P3 52.10)*
>
> *"Dad left two days before Mum's diagnosis. I punched a hole through the door, I was so angry"*
>
> *Ellis (S2 VA 9.30)*
>
> *"Tempers get frayed"*
>
> *Twin (S6 P6c 5.54)*

Anxiety, in the sense of an almost all-pervading worry, was another feature of their emotional life.

> [Reading one of the statements] *"'Children worry'.. I think that's true, because children think they're doing things bad.. It can't be children's fault, no-one can control it."*
>
> *Rachael (S7 VF14.43)*
>
> *"I worry -I might have to change school, make new friends"*
>
> *Jack (S2 VB 6.56)*
>
> *"When I found out my Mum had cancer, I got worried, as she had had it so many times, I thought she might die, I was really scared"*
>
> *Rachael (S7 P7 9.08)*

However, advice from Ellis was:

> *"Don't worry about it too much" (S6 P6b 22.10)*

The Mesosystem - Negotiating with a Family Microsystem

Negotiating family life

As has already been highlighted, the child does not exist independently but alongside other micro-systems, of which the family is usually the most influential. Bronfenbrenner characterises the relationship and negotiation between different microsystems as a mesosystem, and this section considers this in the palliative care context.

Just as consistency is crucial to a person's sense of self, so a level of consistency in family life is recognised as essential. In palliative care situations this is often threatened. For all the co-researchers, maintaining normality and its obverse, the destruction of normality was significant. For example, birthdays, while special events, carried assumptions of normal behaviour and emotions. So, celebrating her own birthday in hospital because that was where her mother currently was admitted, was both an insistence on normality (that birthdays should be marked on the day) and an acknowledgement of abnormality (that hospital was not an appropriate place).

On balance, however, Rachael mourned the loss of normality:

> *"They don't act like your real parents no more. My Mum used to pick me up from school - now she can't do that. It changes everything, all my family get stressed, they don't act themselves anymore".*
>
> *Rachael (S7 P7 17.10)*

The children also protested at the injustice and unfairness of the family situation:

> *"They've done nothing wrong... all they've done was trying to help you"*
>
> *Rachael (S7 VF1 9.08)*

The changing balance in terms of dependent roles within the family was another marker of loss of conventional normality. As noted by a number of writers (Sheldon 1997, Chowns 2005) young people are quick to notice changes in their parents' behaviour, and the co-researchers gave several examples of this. Gemma and Natalie noted that while their father was, paradoxically, more often 'there' because he was off work and at home, he was simultaneously less 'there' because he could not give them either practical or moral support:

> *"(Because of the chemotherapy, he's) drowsy..... falls asleep...he can't help with homework...not being there for you"*
>
> *Natalie (S6 P6a 10.00)*

One consequence of this was that the young people took on more responsibility and became more independent. For some of them, this 'empowerment' was experienced as positive; others were ambivalent. Natalie and Gemma recognised both advantages and disadvantages in it:

> *"You have to do things your Mum and Dad can't do. Dad's slow, he can't do much so we get impatient, then it's easier to do it ourselves. A pressure on us to be independent"*
>
> *Twins, completing each other's sentences (S6 P6c 4.01)*
>
> *"It makes you more independent. You can't rely on both parents, you rely on yourself and the other parent"*
>
> *Gemma (S3 VC 16.00)*
>
> *"That's positive - that you're more independent - it's good when you're older, but not now..."*
>
> *Natalie (S6 P6b 4.06)*

For others, increased responsibility was both practical:

> *"I had to do it all...do the cooking - dodgy!"*
>
> *Ellis (S6 P6a 11.25)*

and emotional - feeling an increased responsibility for siblings. What emerged from the data was an important, though sometimes indirectly implied notion of reciprocity in family relations. This is often missing from the palliative care literature, but this sense of both children and parents reciprocating care and concern emerged clearly. They willingly accepted a responsibility as a family member to give as well as to take. Thus several of the youngsters demonstrated a protectiveness towards or sense of responsibility for their parents:

> *"you try to do the best..(if) you put pressure on them...that's bad"*
>
> *Natalie (S6 VE 3.12)*

and

> *"I wanted to tell my Mum that I didn't like what was happening, but I didn't want to upset her"*
>
> *Laura C (S1 VA 52.00)*
>
> *"When we're round our Dad, it's hard to forget, 'cos he does things a lot slower. You have to put up with it"*
>
> *Gemma (S7 VF1 30.15)*

However, there were occasions when the children felt that parental demands were unreasonable:

> *"Don't tell us to clean our room, because we live in it, not them"*
>
> *Rachael ('No- You don't Know how We Feel' 25.13)*

Nevertheless many of them tried not to irritate their parents, aware that stress was not helpful, and therefore tried to shield them from their own distress. They understood that when their parents withheld the truth from them, the underlying motives were both good and also potentially self-serving - but they were still critical:

> *"Parents don't want you to be upset - but you still need to know"*
>
> *Megan (S6 P6a 43.54)*

Siblings

Just as the co-researchers criticised parents for assuming limited capacity in their children to cope with the truth, so they in turn held strong beliefs about their siblings. Only two of the nine young people did not have siblings. There was one sibling set of three sisters, one of two sisters (twins) and one set of a brother and sister.

Older siblings generally felt a responsibility for their younger siblings, or made assumptions about them:

> *"My brother doesn't really understand"*
>
> *Becky, 11, of Jack aged 7 (S2 VA 3.41)*
>
> *"It's hardest (for me) - I'm the eldest. My sisters are 11, and 10, sometimes fighting, but then best buddies. It's hard for my sisters - they don't understand, but in a way they do, they understand too much - but I don't think they want to..."*
>
> *Megan (S6 VE 5.50)*

Each member of the group had an opinion on the merits and otherwise of being a sibling. They identified support from siblings as a key advantage, citing a sense of togetherness and shared experience, but, conversely, siblinghood also brought tensions. Megan captured both the dynamism and ambivalence inherent in the relationship:

> *"...having brothers and sisters is annoying, but they know what's happening. Can sometimes be worse - sometimes it's easier."*
>
> *Megan (S7 VF1 11.15)*

Where the sibling group is more than two, the dynamics can be even more complicated.

> *She came with me to get blankets to sit on and talked about how this sister had helped her and they get on together, and when there is three of them it doesn't work so well. Any two of them works well, but three is difficult.*
>
> *(Gillian's video diary, session 6)*

However, to have no siblings simply reinforced the sense of isolation already identified in an earlier section. Although a number of those who had siblings had expressed a sense of not knowing anyone else in the same situation , those who were only children felt this particularly keenly.

> *"...you're stuck in your own world...there's no-one to turn to...It's hard being by yourself"*
>
> *Laura C (S6 VE 5.21)*

The fact that Laura wanted to tell her Dad about her Mum's illness, but was forbidden to do so by her mother, added not only to her sense of isolation but also undermined her sense of self as an autonomous agent.

The assumption that having siblings meant that you would have someone to talk to was, however, simply that - an assumption. One of the statements used in the game in session seven, 'Having sisters is a good thing because you can talk to them' drew an assent from Laura D, the youngest of three, which was immediately challenged by her older siblings:

> Rachael: *"I disagree **TOTALLY**. She doesn't talk to none of us."*
> Megan: *"She doesn't talk to anybody."*
>
> *(S7 VF1 11.15)*

Laura D then confirmed that she preferred not to talk about her parent's illness, but it was noticeable to the facilitators that she was committed to organising the process of enabling **others** to talk, an aspect considered earlier in the preceding chapter.

Two other aspects of sibling communication, or otherwise, were noteworthy. First, siblings did not always share knowledge with each other. Becky and Jack's Mum died just a few days before the last session and during the opening reflection it became apparent that Megan was unaware of how ill she had been, whereas Rachael and Laura C were much better informed. Since Megan attended a different school from the one at which Becky, Rachael and Laura were pupils, this may suggest that awareness of the parental illness was contained within the exo-system of the school setting and did not cross the boundary into the micro-system of the family home.

Secondly, adults did not always share knowledge consistently with siblings. Megan found herself in a difficult position:

> *"My sisters were told she had 2 or 3 years left, I was told 6 months - confusing, I didn't know what to believe...and seven months later, Mum's still here"*
>
> *Megan (S6 P6b 12.10)*

This may reflect yet more parental assumptions about children's capacity to cope with difficult information, but it also demonstrates that these micro and meso systems are not rigid but permeable - Megan's parents, in this instance, appeared to be including her in their own 'more -adult' micro-system. While Bronfenbrenner's model has its uses, it perhaps does not adequately account for the shifting, dynamic patterns of family relationships. The data referred to above suggests that there were many mini-systems - mainly dyads - that dissolved and reformed as they crossed boundaries of age, experience and attachment.

Parents

The key source, for children, of information in the family was, unsurprisingly, their parents. All the co-researchers wanted their parents to give them as much information as possible, as early as possible. Regardless of what other supportive relationships might be available, parents were the preferred source for all the children, and had a duty to be honest:

> *"Parents (should) try and make us understand, by explaining about cancer."*
>
> *Natalie (S6 P6c 23.01)*
>
> *"Tell your kids everything that's going on - or they'll not know nothing"*
>
> *Megan (S6 VE 7.55)*

Both these quotations also refer back to the notions of reciprocity and agency, discussed earlier, while implying a lack of confidence in parental honesty. However, the children were able to reflect on why their parents' behaviour sometimes fell short, ascribe reasons for it, and make allowances (intellectually) for it.

> *"Why didn't she tell us? She didn't want to upset us...not sure herself, hoped he'd get better and she wouldn't have to tell us"*
>
> *Natalie (S7 VF1 33.01)*

This supports the findings in Barnes' paper (2000) that parents delayed communicating honestly with children in the hope that recovery from cancer would be possible.

The twins, however, did not feel that this justified the behaviour, and saw it as bringing more complications, marginalising them as 'not-knowing' family members who were perhaps less competent or important than other 'knowing' members. It also undermined trust in the parent and contributed to the uncertainty and insecurity that seemed to be endemic in the experience of cancer. Their sense of agency was undermined also - without information, it was more difficult to actively support their parent:

> *"You need information... it's quite important to understand their point of view - so you can be patient with them"*
>
> *Gemma (S7 VF1 32.15)*

Criticism of parents was tempered with an acknowledgement of the stress that they were under, and an acceptance that, like the children themselves, parents would sometimes be unreasonable:

> *"If they've had a bad day... and you do something little, they just tear you off a strip..."*
>
> *Ellis (S5 P5a 46.59)*

Living in a one-parent family, as Ellis, and Laura C each did, presented additional pressures. Both Ellis and Laura C seemed to feel a greater responsibility for their parent, although it is not possible to say whether it was the single-parent factor or the only-child factor - or the combination -that was most problematic. Laura C was clear, however, that having separated parents was a lesser evil than having cancer.

Equally, the prospect, for those with two parents, of one not being there, was still worrying.

Just as the children sought to understand their parent(s) and minimise their stress, so they hoped that this could be reciprocated - that parents would not 'take it out' on them unfairly, and would be more understanding of the stress that they, as children, experienced. For some of the children, for some of the time, these expectations were met. They were able to communicate honestly and frankly with the parent. Rachael suggested it was good to *"have a mother-*

daughter chat" (S2 VA 23.05) and was able to share her fears that her mother might die:

> *"I was really scared, so I actually told my Mum. Then it came true"*
>
> *(S7 VF1 9.08)*

And Ellis, as usual, expressed his views clearly:

> *"A good person to talk to is your parent who has it* [cancer]*"*
>
> *(S6 P6b 22.10)*

His mother and his grandmother (whose husband had died of cancer) had both been able to tell him about the cancer diagnosis and to talk to him about it (S6 P6b 4.50) and he in turn saw communication as an uncomplicated issue. Nevertheless, for all the young people there were times when communication was difficult. Consistently, however, they all emphasised the need to be told the truth.

Telling - the truth

Every member of the group wanted to be told the truth.

> *"Tell the truth"* *Becky (S5 VD 8.03)*
>
> *"'Children should always be told the truth' (quoting statement) - that's true*! *Unidentified (S7 VF1 1.23)*

Every member also wanted the whole truth.

> *"Tell us the truth, tell us everything. Don't hide it, it makes it worse, freaks you up. Tell us exactly what's going on."*
>
> *Twins (S5 VD 00.04)*

Knowing the truth was not easy but was clearly preferable to being kept in the dark:

> *"Tell your kids everything that's going on or they'll not know nothing. Supposing you go into hospital - then they'll not know nothing."*
>
> *Megan (S6 VE 7.55)*

Ellis summed up much of this discussion succinctly:

> *"Children should be told what they want to know. They should be told the truth and nothing but the truth". (S7 VF1 7.29)*

The twins, however, were a little less certain about whether and when children should be told the whole truth, and felt that age was a significant factor.

> *"If you tell them too much, they might get too worried, too confused...it's OK for our age (14) but maybe under 10....?*
> *It's harder, 'cos they don't understand the complications, to take all the information in....Just tell them the basics." (S7 VF1 26.09)*

This view was robustly challenged by a co-researcher. Or then modified?

> *"Children should be told the truth - yes, definitely....*
> *"the truth should be told - but maybe gradually, over a longer period - not all at once"*
> *"At what age?"* [adult asking] *"Any age?"*
> *"Yes, any age".*
> *"It doesn't matter what age?"* [Adult]
> *"No. If you don't tell it, they may not understand, they get the wrong idea." (S7 VF1 27.07 and 27.25)*

There was a general consensus - which contradicted some of the comments about withholding information from younger children - about the timeliness of telling. Everyone wanted to be told immediately, and cordially disliked delay and secrecy.

> *"If you're told late, you just feel you've done something wrong.."*
>
> *Rachael (S5 VD 7.56)*

> *"Mum was diagnosed on my birthday - she didn't tell me til the Saturday"*
> *Laura C (S1 VA 11.15)*

> *"Tell us straightaway, or we're more upset" Rachael (S7 VF1 9.07)*

> *"After a while we did get suspicious"*
> *Twin (S6 P6c 00.32)*

Implicit in all this is the preference for parents to initiate the conversation, but several of the group made clear that there was an option for them to take the initiative themselves, exercising power by challenging parental power.

> *"They just want to do the best for you, so they don't tell you, so you can just ask. You don't have to sit there.."*
> *Laura C (S7 VF1 7.08)*
>
> *"She didn't tell us exactly. 'Don't worry, it's not serious, he'll get better'. "Mum, it's more serious, he's getting worse, tell us".*
> *Natalie/Gemma (S7 VF1 34.00)*

Interestingly, they chose not to ask their Dad, the sick person, directly.

Fore-telling

Finally, telling, for some of the group, was also acknowledged as risky, because it might become foretelling. That is, saying out loud, or talking about whether someone might die, might 'make it happen'.

> Laura D: *"If you talk about dying, it might come true"*
> Laura C: *"Why?"*
> Rachael: *"I was speaking about it to my Mum and it did come true"*
> *(S7 VF1 1.23)*

Rachael's elder sister, Megan, had a more considered view:

> *"It depends - that's why it* [*the statement*] *should be in the middle".*

And Ellis disagreed with the premise entirely:

Adult: *"Does talking about it make it come true?"*
Ellis: *"No!" (S7 VF1 1.32)*

Grandparents

In our largely nuclear society, there is little research about the role and impact of grandparents. In addition, in contemporary society, the location of grandparents within the ecological system is contentious. Our researchers' experience reflected the extremes, with some grandparents being very much part of the family micro-system and others residing well beyond it, in the exosystem. In our group of young people there was no consensus, some children (the twins) feeling that grandparents were not much help, being too old to understand and failing to react appropriately, while others valued grandparents(Ellis). For Laura D they were a haven of normality, leaving her free from the pressure to confront the sick parent's situation:

> *"I like going to my Nan's... My Nan and my granddad, they don't talk about it, so... I don't know, I like it...."*
>
> *Laura D (S7 VF1 15.00 onwards)*

Friends - mesosystem and microsystem

Friends formed a connection between family and school, located in both places as an important but problematic part of both a support network and coping strategies. They thus could be a bridge between the children and the family, and between the family and the wider world of school and society. They were frequently referred to in interviews conducted by the youngsters with each other, in discussion groups and in general conversation. Comments fell into two opposing categories - friends as valuable support and friends as unhelpful.

Ellis, as an only child, valued his support network of friends

> *"My friends know what I'm going through...I do tell them a lot. If they ask, I'll answer."*
>
> *Ellis (S7 VF1 18.28)*

Megan, while drawing enormous support from Laura C, a co-researcher who attended the same school and was a close friend, found other friends who did not have a sick parent much more problematic.

> *"Mates are really nice - but also annoying. They say, 'Everything's OK' and 'we know how you feel'. NO, they don't."*
>
> *Megan (S6 VE 4.40)*
>
> *"They say things, and if you're having a bad day it winds you up."*
>
> *Megan (S3 VC 16.01)*

When Ellis challenges this by asking how people would know if she was having a bad day, if Megan doesn't like them asking, she indicates that the claims of intimacy carries an expectation of sensitivity or even intuition:

> *"If they know you well enough, they'd know." (S6 P6b 9.50)*

This desire for significant others to be able to 'know' their mood and behave appropriately without having to be told what was wanted, was common to most of the group; they wanted others to be able to read their mood and divine their need for distraction from or ventilation of distressing emotions without their having to articulate it. Although they were themselves not always capable of it in relation to their sick parent, they ascribed, or sought, a competence from their peers that those peers were able to demonstrate only infrequently. In part this may have been because the foundations of their friends' worlds had not been undermined by the realisation that a parent was vulnerable to, or imminently facing death, a prospect that today's society has largely made invisible. Megan, therefore, could acknowledge, intellectually, the gulf between her world and that of her peers, even while regretting their failure to understand hers.

Others in the group, such as Laura C, championed the cause of friends, and the broad consensus, while demonstrating some ambivalence, held them to be an important source of support, both in terms of distraction:

> *"When we're with our friends, we just go out and have fun"*
>
> *Natalie (S7 VF1 30.16)*

and in terms of sharing the pain:

> *"Friends, they're there for me - that counts. I need them there for me".*
>
> *Laura C (S6 VE 2.00)*

> *"'Adolescents receive better help from friends than parents'* [reading statement]. *I agree."*

Asked how they helped, Ellis answered:

> *"It's just company - having someone there." (S7 VF1 17.10)*

The Exosystem - School

> *"School is not the best place to be." Laura C (S2 VA 2.13)*

This topic generated some of the strongest feelings and substantial data. Although social work literature often suggests that the exosystem of school may be a more peaceful, consistent and supportive setting than the home, the data from the project belies this, suggesting that it was often a source of stress. The two main sources of stress identified by the children were homework and teachers, the latter because their assumptions, values and behaviours challenged both the children's construction of themselves as competent and their desire to be in control.

Homework

This was difficult to do well for a number of reasons. First, the extra practical demands on children in a home where one parent (sometimes the only parent) was unable to fulfil their duties adequately meant there was less time to physically give to homework and less intellectual and emotional energy:

> *"Homework, it's really hard to...once you've found out (about your parent's cancer) it's so hard to concentrate. You have loads on your mind."*
>
> *Rachael (S6 VE 1.43)*

A consequence of this was that homework might be either done late, or badly, or both. What the children wanted was some indication of understanding of the reasons, as highlighted above, for this:

> Ellis: *"...Be understanding if homework happens to be late."*
> Megan: *"Or crap" (S5 P5a 38.39)*

Though unstated, the implication may be that teachers work from a deficit model - they assume that poor or missing homework is indicative of idleness and incompetence, whereas the co-researchers wanted their teachers to credit them with maturity and competence - and understanding as to why, on that occasion, they did not appear to manage this.

Teachers

Teachers had a mixed press, with strong views on both sides. The major criticism levelled at teachers concerned their insincerity and their naive assumption that they could 'know' the children's experience. This assumption that the adults, who had not had the same experience as the children, could know exactly how they felt was, without exception, deeply resented by the young people.

"Teachers say 'We know your pain'. No, you don't! You haven't got a clue!"

Ellis (S2 VA 21.50)

Rachael expressed her criticisms forcefully:

> *"If they know (about the illness) it goes in through one ear and out the other and that's what they say, 'yeah, yeah', and they look out at space and they tell* ***you*** *to listen and then* ***they*** *don't listen, none of the teachers listen. They teach us not to listen, none listen - except one."*
>
> *Rachael (S5 VD 7.56)*

The failure to listen and genuinely care was one source of irritation, but the hypocrisy of claiming to be one thing and doing the opposite was equally annoying. Implicit in this was an expectation of standards of behaviour superior to that ascribed to children, and an ability to look beyond the immediate for a deeper meaning. Thus Laura C, describing a scenario where a child might have had an argument at home with a parent and therefore not be concentrating at school, felt that a resulting detention would be unfair, since *"it is not your fault, 'cos you're feeling guilty about the argument".* The implication was that the teacher should look behind the behaviour for an explanation of it that would take account of the home situation. This ascription of maturity and power to the adult was not, however, shared by all the youngsters; while some struggled with an unwelcome sense of passivity, others still saw themselves as actors, in control and exercising power within this macro-system. Ellis, for example, is clear that he remains in control. As far as teachers having information about the home situation is concerned, he is determined to hold the power:

> *"They should know what you tell them, not what they want to know. If I want a teacher to know, I'll tell them"*
>
> *Ellis (S5 P5a 53.55)*

The diversity of views was dynamic - not only did it range widely between group members, but it was not static, with the children quite capable of expressing very different opinions on different days.

Those who were sometimes critical of teachers were nevertheless able to give appreciation where due.

When Jack asked why teachers asked so many questions, it triggered a lively debate.

> Laura C: *"I think they care, they're trying to get involved"*
> Rachael: *"They don't really care"*
> Megan: *"They do, they care too much" (S5 VD 17.04 onwards)*

Several of the group singled out particular teachers. Laura C, who had earlier been critical of unthinking teachers, had this positive comment to offer:

> *"One of my teachers had breast cancer at sixteen, so she kind of knows how I feel... So that helps"*
>
> *Laura C (S5 VD 21.00)*

Megan found social workers and counsellors intrusive, but was comfortable with some of the school staff:

> *"My Head and Head of Year are helpful, I talk to them"*
>
> *Megan (S6 VE 5.41)*

And, during the Good/Difficult Reflection on Session Four, one of the anonymous contributions was: *"teachers are understanding"*.

Overall, advice for teachers was direct and critical - and sometimes conflicting. All the children wanted genuineness and understanding - as they had wished from their parents - and to feel supported. However, what was construed as supportive was variable and sometimes conflicting - as it had been in relation to their parents. For some, being left alone or given space was helpful, while for others, talking and being heard was supportive. Thus Megan's comments, while superficially contradictory, are in fact an expression of the *nature* of the support she would like.

> *"Just leave us alone, go easy" Megan (S6 VE 8.50)*
> *"Be more supportive" Megan (S5 VD 7.56)*

In summary, the data suggests that, just as they did with adults who were their parents, the children's expectations of adults who were teachers - that they should be consistent, mature, understanding and intuitive - were not always met. Nor did the teachers' expectations of children match the children's own, more positive, self-perceptions.

The Macrosystem - Living in the Wider World

As indicated in an earlier section, cancer was experienced as all pervasive; wherever they turned the children could not escape it. The macrosystem, society, reflected not only this, but also the general social view of children as less than competent. The children resented the patronising attempts of others to give false reassurance:

> *"If people say, 'It'll go away' - but it won't, you know it will always come back"*
>
> *Rachael (S6 VE 3.12)*

Nevertheless, there was a recognition by some of the value of speaking to people outside the family who had some expertise.

> *"Yes, get it off your chest - they can help, and comfort and sympathise. They have their own perspectives, different opinions, advice..."*
>
> *Gemma and Natalie (S6 P6b 9.50)*

These outsiders were universally described by the children as 'counsellors'

> *"I'm getting help, I've got a, I see a counsellor."*
>
> *Rachael (S2 VA 30.06)*

despite the fact that their own workers were ourselves (Gillian and Sue) and we were careful to always describe ourselves, correctly, as social workers. Attitudes were not entirely clear-cut, however:

> *"It's easier to tell someone outside the family - I find that easier because they're not involved...but they don't **know** the family ... sometimes it's worse 'cos they don't know what you're going through"*
>
> *Megan (S7 VF1 11.16)*

Elsewhere, she is more directly critical of the experience:

> *"Counsellors - they know, 'cos they're with other people going through the same thing. But they ask too many questions. You need someone to talk to, to listen, not ask questions"*

Once again, a young person demonstrates an ability to deconstruct the concept of 'talking' and to critique the supposedly competent adult's performance of counselling.

Overwhelmingly, the children did not want pity from anyone, outsiders or not, and they refused to see themselves as victims and were determined to convey a clear message in the video that one should not allow the possibility of death to dominate life. They felt it important to 'get on with life' and although it seemed as if it was sometimes hard to avoid the subject of cancer -TV adverts were singled out as difficult to avoid - they expressed a belief that they could control their own thinking and activities to counter this.

> *"If you take it (too) seriously, it will get to you. ....Try and get on with your life"*
>
> *Ellis (S6 P6b 22.10)*

The question as to whether there was a greater being or power that was in control of the world in general and of what was happening to their family was not one that they raised spontaneously but it was one which provoked a strong response, when it formed one of the sentences in the Statements game. Both Natalie and Gemma commented that parental illness rendered a belief in God more problematic, and further up the scale of disbelief and ambivalence came a more complex and confused opinion:

> *"I don't really believe in it* [God] *in the first place…. I completely lost it…how can you believe in God - I didn't believe it one per cent.*
> *If you believed in God, you think he does the best for everyone…- he made my Mum ill, but I don't believe in him, so it's mainly his fault. No-one's ever seen him, no-one's got any proof that he's real…so I don't really believe in him."*
>
> *Rachael (S7 VF1 14.10)*

Rachael both ascribes agency to, and simultaneously denies the existence of, this all-powerful but invisible being. The use of multiple tenses, emphatic statements, questions, conditional clauses ('if') and limiting adverbs ('really', 'mainly') suggest an internal debate that is not yet resolved.

For some of the co-researchers, it was the cancer itself that was personified as an all-powerful, unpredictable and malignant being.

> *"It kind of scares you, knowing it could come back…scary…you want it to go away."*
>
> *Laura (S6 VE 00.30)*

Summary

This chapter has explicated the key themes identified by the young co-researchers themselves and has located them within the (adapted) framework of Bronfenbrenner's ecological system (1979), and in the context of our understanding of the journey to empowerment (Warren 1997).

The children themselves live the contradictions inherent in a sense of self - as competent and controlling - that collides with the micro-, exo- and macro-systems that impinge on their life experience as offspring of parents with cancer. The findings reveal a layered and inconsistent picture, wherein the children attempt to negotiate their way through systems whose assumptions of their (in)competence and (vulner)ability do not match their own aspirations or self-perception.

The data reveal that the children exercise considerable agency and empowerment, albeit unevenly and sometimes unsuccessfully. A key finding is that the children demonstrate sophisticated communication strategies, distinguishing between talking, telling and foretelling, and making careful choices as to when and with whom to 'not-talk'. Another key strategy is to focus on the positives in life. A second finding is the importance of experiencing a safe place (co-created by the children and the adult co-researchers) as an essential ingredient in the process of becoming empowered. Within this safe space, as well as outside in the ecological systems, it is possible to both contain and release the strong emotions generated by the experience of living with a seriously ill parent.

The findings from the family system are less clear. Negotiations around family life were complex and shifting. Siblings were found to be both a source of support and of stress, as were grandparents and friends. However, the study found a unanimous desire from children that their parents should tell them the whole truth as early as possible. It also found a mature understanding of how and why parents failed to meet this need for openness and honesty - but which did not justify the parental failure.

The findings around friends echoed those that emerged from the consideration of the family micro-system. That is to say, friends occupied both ends of the support-stress continuum and most spaces in between. The one consistent finding was how much friends impacted on the children, which is perhaps not sufficiently recognised within the literature.

The data generated on the exo-system of school leads to a finding that challenges contemporary writings on the school as a safe haven for children in need. The clear finding from our study is that, in the palliative care context, school is usually an additional source of stress, even though individual members of staff may be experienced as highly supportive.

Finally, the chapter briefly considers Bronfenbrenner's macro-system, the wider society. It finds that, as with the micro and exo-systems, there is a continuing tension between the children's desire to be seen as competent and their experience of society as a denier of competence. This has parallels with their own ambivalence about the locus of power, illustrated by their sometimes ambivalent characterisations of God or cancer as all-powerful entities.

Chapter Nine draws together the findings from this and the preceding chapter to argue that this study demonstrates the need for a new understanding of children in contemporary society.

CHAPTER NINE: IMPLICATIONS OF THE RESEARCH FINDINGS

"The child is a myth, a fiction, an adult construct"

Gittings 1998 p2

Introduction

This chapter brings together the implications of the research findings from the two preceding chapters and links them with the earlier chapter which reviewed the literature on four key themes:-

- Counselling distressed children: the impact of cancer on families
- Childhood and children's rights
- Users in palliative care
- Researching children

It builds on these narratives to argue, in the light of this study, for a revisioning of our understanding and practice, in three key and interlinked areas - the concepts of childhood, power and agency, and voice. For the purpose of this study these will be considered separately, but it is important to realise that they do not stand alone but are intimately intertwined, each feeding into, and affected by, the others (see Figure 9.1 below).

For example, the discussion on notions of childhood will inevitably trespass on understandings of power and agency, and the concept of voice is both constrained and mediated through matters of agency and social constructions of childhood. The attempt both to impose a logic and contain some very permeable notions within defined boundaries can therefore only be partially successful; in practice it is often difficult to define where one begins and another ends. Within these three concepts, some parallels will also be drawn between some seminal palliative care concepts relating to the experience of living with a life-threatening illness, and their mirroring within the **process** of conducting a collaborative inquiry. In particular, the dual process model of bereavement (Stroebe and Schut 1999) and time limitations will be reviewed.

Key themes and Connections

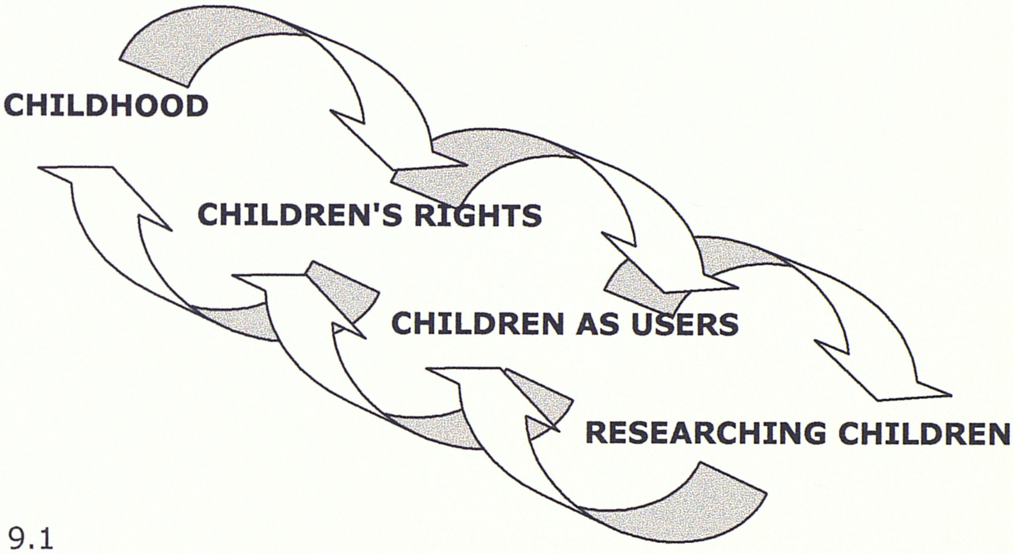


Figure 9.1

In the section on voice, the place of the (lead co-) researcher and author of the thesis is then discussed, with particular attention paid to issues of role-blurring and boundaries, and the contentious nature of reflexivity. This leads to a final section on the limitations of this study, which attempts both to locate the work within the three contemporary arenas of research methodology, palliative care, and social work with children; and also to chart a possible way ahead.

Conceptualising Childhood

This thesis began with an examination of the lack of literature on supporting children facing parental illness. It considered both the historical and cultural backgrounds to conceptualising childhood and children and traced the emergence of childhood as a specific construct, over the last few centuries. It considered four interrelated issues, current research on distressed children, children's rights, children as 'users' of palliative care services and the contemporary approaches to research on, for and with children. In considering these four areas, I inevitably wrote of them separately but it is axiomatic that they each link into the other; beliefs about children's rights will have been shaped by understanding of what it means to be a child, and will influence one's approach to researching children. In turn, the research conducted on or about children, whether or not it articulates its fundamental assumptions about the nature of childhood and the capacity of children, will reinforce, challenge or modify contemporary constructions of children as users. The iterative process continues beyond the fieldwork into the thesis itself.

Concepts, of course, do not change overnight; sudden, seismic shifts of understanding are rare and most concepts are in a continual state of dynamic but slow evolution. The passage of time allows us to see the changes and to write of stages; but in truth the stages may overlap and merge. So, though we may identify differing discourses of childhood over the last century, in one discipline they may be alive and well, where in another they may have effectively died out.

While the work of Aries (1973) and Cunningham (2005) debate the genesis of childhood as a construct, it is clear that it is now well-established and given formal recognition by the State. How it is constructed, as Chapter Two demonstrated, is more problematical, and it can be argued that more recent models have not succeeded in replacing some of the older, influential constructions. We have seen how the commodity model was discredited; children were no longer regarded as possessions of their parents, but were accorded a limited identity of their own. The possessiveness of parents was transmuted into the paternalism of the State, as a much more protectionist model, popular in the social welfare discourse, gained ground. Much work with distressed children, while predicated on the counselling literature which advocated empowering the adult client to find their own solution, nevertheless either failed to challenge or tacitly accepted the protectionist contexts of education and social services. In the quite separate world of health, the accepted model of childhood was a developmental and default model; children were largely defined by what they were not - not adult, not competent, not physically mature. The dominant factor was biology and this dictated the conceptualisation of the child; the biological processes were the focus of most research and underpinned the assumptions of childhood as a process towards maturation, incomplete rather than rich and valuable in itself. Both this developmental model and the protectionist model have been particularly influential in the research discourse; children were framed as inherently vulnerable and unreliable, and it was ethically unacceptable to subject them to interview when other, presumably more robust, individuals of integrity, such as parents, teachers and doctors were available to speak on their behalf. It is only in the latter decades of the twentieth century that there has been a grudging recognition that this approach to research is inadequate. In part, the challenge to the established ways of thinking came, appropriately, from those researchers inquiring into the nature of childhood who were open to a critical interrogation of the conventional beliefs. This both resonated with, and fed into, the growing emphasis on children's rights and the drive for more partnership, within the social care world, with clients of whatever age or disadvantage.

This more liberationist approach has not however gone unchallenged. The turn of the century has seen two further, and superficially similar, models of childhood compete for attention in the public domain. Both accord considerable power to children, but one seeks to limit it while the other attempts to maximise it. The containerist model emphasises the destructive and dangerous power of children (usually teenagers), rather than their competence, suggests they are out of control (the 'yob culture') and advocates a containing and ultimately punitive approach, which reduces their rights. The rapid rise in popularity of ASBOs (Anderson 2002), which abrogate the right to congregate in public space, is perhaps a testament to the influence this model has had on Government thinking about juvenile justice. Popular representations of this model can be found almost daily in the press, and not necessarily exclusively in the tabloids (Guardian 12.12.05).

Though it may lack academic respectability, the media, or the advertising media, is also a major source of the other model - that of the child as consumer. By the late twentieth century, children had become the target of retailers, manufacturers and advertisers to an unprecedented extent. They were seen as an important and influential sector of the market and were courted by the commercial world through television, magazines and in the shops. Some may see this as a cynical abuse of vulnerable and impressionable individuals, but others simply argue that it recognises the reality of economic power, both real and by proxy.

This brings me to the last and equally debatable model of childhood - that of the child as economic unit. In some senses, this model encapsulates three of the earlier ones - protectionist, developmental and commercial/consumer. In this model, childhood needs to be protected and enhanced, and the child valued not for what she is, but in order that she may *become* a unit of economic activity, a notion that embraces her as both consumer and producer - or in Alvin Toffler's terms (1981) - the 'prosumer'. This has been an increasing discourse of the New Labour government, with Tony Blair characterising children as '100% of our future' (policy speech 1999) and Gordon Brown frequently arguing the case for 'investment' in children. It has however, been challenged by children themselves; at the 2002 UN General Assembly one of the child representatives to the forum reminded world leaders, "You call us the future, but we are also the present". (Lister 2005)

It is perfectly possible to see the influence of all of these models in the Video Project for, as I have argued earlier, they are not static but shifting and dynamic. The previous chapter has illustrated this clearly. However, the study also makes a case for a revisioning of our understanding of children and childhood and Figure 9.2 (below) sets out a model that conceptualises the child as the Able Child-Citizen. This model incorporates many of the themes that shaped the older models but offers a less polarised construction of childhood. The other models, like the older discredited model of disability which categorised structural inequality as personal inadequacy, focus on the limitations and risks of childhood, whereas the Able Child-Citizen model may be considered as similar to the social model of disability; the problem lies in the way that others conceive the person (as disabled by being a child). Above all it is a strengths-based model, celebrating ability - capability and responsibility, rather than disability - vulnerability and unreliability.

The evidence from the Video Project, as outlined in the previous two chapters, is that children and young people are more capable and articulate than most adults give them credit for. It is not protection that our co-researchers asked for, but understanding and respect. They wanted their coping strategies to be acknowledged and respected. They wanted to be included and involved, as persons in their own right, not ignored and marginalised as 'not-yet' people who were too vulnerable. They wished to be counted, not as potential workers of the future or consumers of palliative care services and goods, but as supportive family members and as change agents and givers of knowledge to other families. They saw themselves not as passive victims but as active contributors to the good of others facing serious illness in the family. In this sense, they embodied the Able Child-Citizen model, exercising both rights and responsibilities, vulnerable to all the emotions and imperfections of children (and adults), but competent and capable of making choices and accepting the consequences.

Re-conceptualising childhood

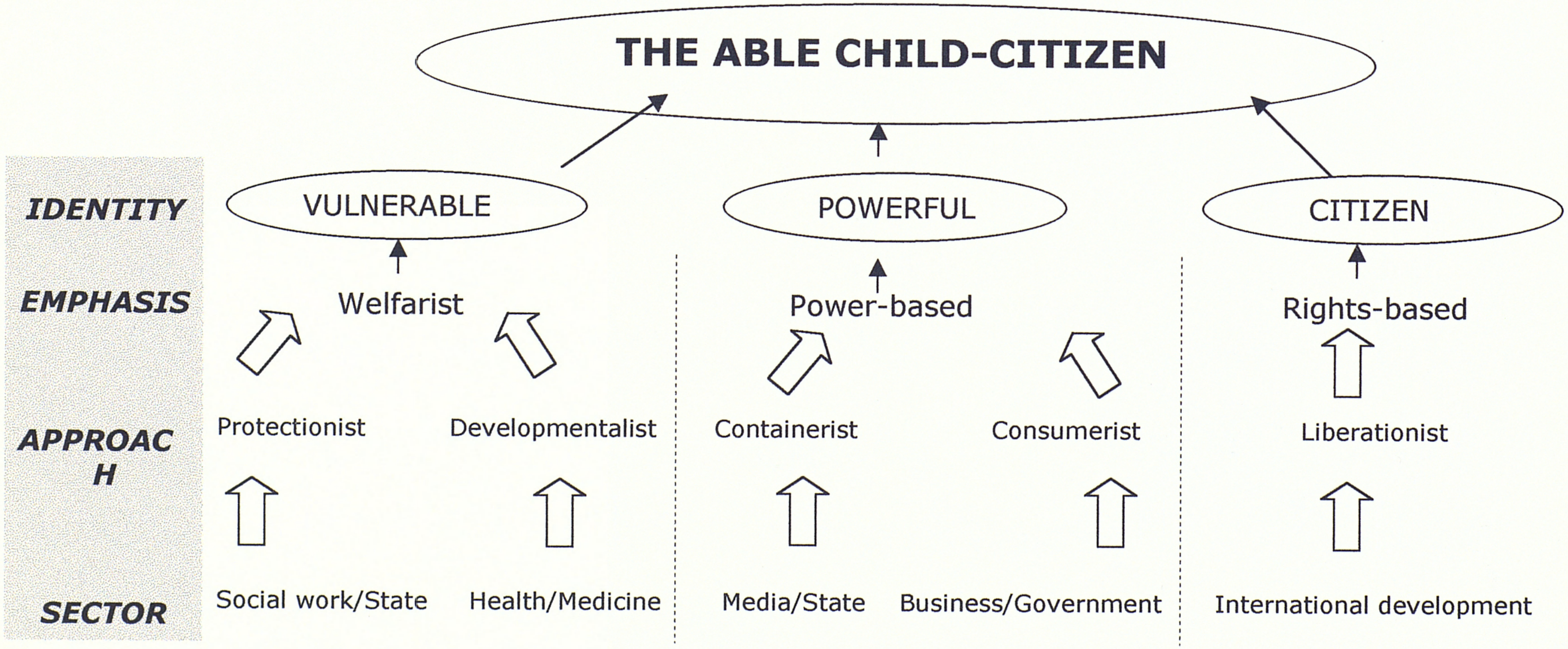


Figure 9.2

This model of childhood frames the child as more powerful than the protectionists and developmentalists would admit, but less powerful than the consumerist and containerist factions would claim. Its disposition of children's rights, parents' rights and the State's rights is more liberationist and may therefore be more controversial. The question of power in all these models, including this new one, is central and I now address this.

Power and agency

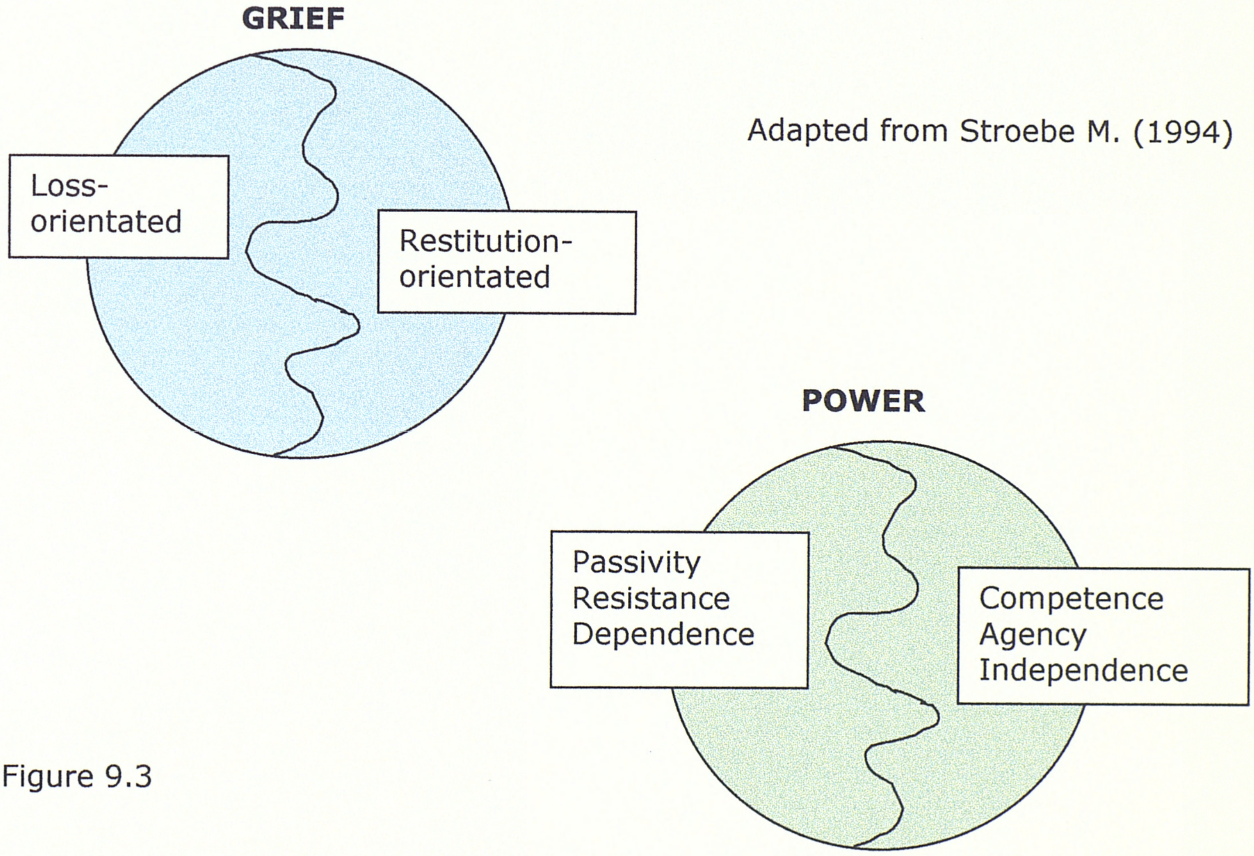
The ascription of power to children, as we have seen above, is not straightforward but remains contested. Chapter Two traced the gradual recognition within society that children were capable of making decisions for themselves. In time and in turn, the law, in recognising children's rights, conferred power upon children to exercise those rights, albeit in a limited way, over against those of adults, be they parents or professionals. Child abuse inquiries, the Gillick case, the UN Convention on the Rights of the Child(1989) and the Human Rights Act (1998) have all shifted the balance of power somewhat. Most recently, the High Court decision of 23rd January 2006 (Guardian 24.01.06) has reconfirmed the right of under-16's to confidential contraceptive advice. However, as indicated above , while some commentators focus on 'feral children' and 'teenage hooligans' and argue that children have too much power, there are many who categorise children's power as still limited, contested and contextual.

Both these approaches tend to assume that power is an oppositional exercise - that increased power for one group means a loss of power for the other group. I had been guilty of this assumption (see Chapter Four) when I made the decision to use the participatory video approach, as outlined by Nick, rather than a documentary style. Although I could see its strengths, I also felt that I would be handing over greater power to Nick; I would no longer be in control. However, the reality proved to be more subtle and rewarding; shared power begat reciprocity and increased collective power. During the ensuing weeks I, and probably both Nick and my two social work colleagues, came to see that the imagined losses were outweighed by the very real gains of **sharing** power. Our experience was that we, as facilitators, were more effective, and that we, as a 13-member collaborative inquiry group, were more effective than if we had not shared that power.

That the young people were 'empowered' has been demonstrated in the two previous chapters, but the strengths and limitations of that empowerment bear further reflection. Collaborative inquiry seeks to empower those whose expertise is often not recognised and validated as 'proper' knowledge. Our co-researchers, as children and as users of palliative care services, were located on the fringes of both society and research; and the espoused values of social work and collaborative inquiry had to compete with the normal, everyday experience of their lives as less-than-powerful people. Collaborative inquiry constructed them as 'knowers' and 'actors' and 'equals', and from the first open meeting to the last conference presentation we adults endeavoured to assert this in word and action. However, the children did not construct themselves in this way, at least initially - because the world did not construct them as holding this much power. They came from a world where they occupied positions of relative powerlessness, as dependants and as pupils - an adult-dominated world, in which, in their experience, adults controlled the agenda and, sadly, could not always be trusted to keep their promises. It was therefore unsurprising that our group did not accept our protestations of power-sharing with open arms. Indeed, one could argue that this was just one small way in which children learn to exercise some power and control - discounting adult promises enables you to survive better when those promises are inevitably broken. So, a review of the tapes of the first session show a group who are largely passive, wary, and apparently conforming. As one facilitator reflected, watching the tapes again some twenty months afterwards, "They're playing the game, aren't they, doing what they think we want...and making up their minds about us?" We adults held considerable power, simply by virtue of being adults, as well as by being either experts with a camera or in palliative care, but the children had their own, not inconsiderable, power as well. Their trust and collaboration was theirs to give or withhold, and they did not do either unthinkingly.

This negotiation of power was a continuous, dynamic process - an oscillation. Characterising it in this way draws parallels with the Dual Process model of bereavement (Stroebe 1994). It recognises that an individual does not make a steady ascent up a path from grief to contentment but may swing wildly from loss-oriented to restitution-oriented activity and thinking (see Figure 9.3). These swings may occur from one day to the next or from one moment to the next, but over time (varying according to personality, culture, and context) the pendulum will more often come to rest in the restitution area. Thus, a widow may decide to learn a new skill at evening class and feel pleased that she can contemplate doing something on her own (restitution-focus) and in the next moment be overwhelmed with sadness that there will be no one there when she returns home to ask her how she got on (loss-orientation).

Dual Process Model



Adapted from Stroebe M. (1994)

Figure 9.3

Similarly, the young people in the study oscillated, not only from session to session but also within each session, between power and powerless-orientations. For example, towards the end of Session One, when we adults invited them to brainstorm ideas for what should go into the video, the contributions came thick and fast, individuals endorsed or qualified others' contributions uninhibitedly and there was a palpable sense of energy and power within the circle of children that in some cases was physically translated into jumping up from the chair. Yet at other times in this first full meeting of the group, they had been very much in teacher-pupil mode despite our best efforts - in the way we had arranged the chairs (in a circle), ourselves (scattered among the children rather than grouped as leaders), and the programme (contributions from them as well as us, acting and filming as well as talking and listening) - to challenge these daily norms.

As the weeks went by, the children exercised their power more clearly and confidently. Their behaviour in Session One had already demonstrated a subtle ability to use negative power - to withhold trust or cooperation. In later sessions some were able to be more direct, deciding not to do something because it did not feel right for **them**, rather than as a simplistic assertion of child power versus adult. Gemma and Natalie, for example, had no wish to make a video diary and by Session Five had grown confident enough in themselves as unique and valuable members of the group to stand by this decision. Both they and Ellis had been slow to contribute verbally in the earlier sessions and exercised power through silence; in the later sessions they were more fluent, but their contributions made clear that they were always selective as to what and with whom they shared difficult things.

Chapter Seven supported the argument that collaborative inquiry facilitates a shift in the power dynamics between 'user' and 'academic', but challenged the notion that the methodology and method are sufficient in themselves. It went on to argue that it was in the day-to-day, or session to session, outworking of the project that the adults demonstrated and modelled the principles of collaboration, and thereby enabled the whole group to live those principles. It was possible to see that power balance shift considerably over the life of the project, but as highlighted earlier, it was not an even process. In Session Three Megan was able to take on the role of facilitator for the painting activity, and in Session Six Ellis raised the unexplored topic of advice for other children. The process tape (S6 P6) shows him working hard to generate a discussion with several of his co-researchers, and produce some tips, though with little success. However, in the same sessions, there were clear instances of children reverting to the less-powerful orientation, asking the adults to suggest questions, direct the interviews and generally take charge. In the asking, of course, they nevertheless demonstrated the use of both positive and negative power!

One partial explanation for the oscillation in power, or agency, may be the capacity for sustainability. Although the offer of shared, collaborative power was as consistent throughout the project as we adults could make it, its acceptance and use required considerable mental and emotional energy. At times, neither adults nor children were able to sustain this level of energy, and we each slipped back into more conventional modes-of-being. Thus, when we were filming a section on the theme of 'Information about cancer' and the adults were trying to stand back from the groups, one group managed happily with little adult input whilst the other one struggled to say anything and eventually asked a (reluctant) adult to intervene. It seemed as if they had simply run out of energy. Later in the same session, with a different group, one of the adults very much moved back into adult/professional mode, trying to organise the group and elicit views, with little success, although earlier in the day she had been able to maintain a much more collaborative style without difficulty.

There were times, also, when it could be argued that we adults failed to use our own legitimate power to empower the children. A notable example of this occurred during a discussion of how to cope with well-meaning questions from other children or adults about a parent's health. Several of the children suggested it was best to reply "She's fine" in the hope of shutting down the conversation. We adults simply acknowledged this, but another option might have been to encourage a discussion of alternative strategies that framed them less as victims avoiding difficulties and more as active managers of the situation. The response "She's fine" merely bought a little time for the anxious child and left her powerless to avoid a repeat question in the future. We adults could have encouraged the group to explore ways of explaining to others why this was a difficult question and not always welcome. This might have then enabled them to take control of and change a difficult situation. As it was, our failure to exercise an appropriate power disempowered the children and left them masking rather than controlling a problem.

A final aspect of power is the consideration of the children's power to select and present the self (or selves) by which they wish to be known. Although this study is only one study, and therefore only one story, it is also a composite story, drawn from nine different individuals. However, the story of each individual is only one of several possible stories, for we each create and build our own stories and our own *persona*. I consider the legitimacy of user stories later in this chapter; here I wish to acknowledge that the caveats relating to academic researchers (Fine 1997, Peshkin 1988, Shakespeare 1993) apply also to co-researchers and participants of any age. Every self is a selection and presentation of particular facets of a multiple self and the video project gave the children and the adults the space and opportunity to project particular selves. I do not mean to suggest that this was devious or dishonest in the least, merely to recognise that within the Video Project, as with any and all situations, the participants had the power to choose which parts of themselves to consciously expose or celebrate and which to rein back. It is not possible or necessarily helpful to debate how 'real' these *personae* were, but it is important to recognise agency in this - whether consciously exercised or not, the power to present their choice of story and self lay with the children alone. The fact that the group met over a period of several months and that all sessions were recorded on video meant that, despite the fears expressed by some adults (see below), these selves, which were consistently displayed, were less likely to be merely temporary, misleading or consciously manipulative presentations of self than might be the case with interviews. Television has taught us all that the rolling camera renders it much more difficult to maintain an invented *persona* consistently over any length of time within a dynamic group.

Capacity-building and competence

In drafting the original research proposal for this study, I had noticed the tendency of individuals and agencies with whom it had been discussed to think of the children as vulnerable subjects. Many of their queries presupposed vulnerability and unreliability. A typical view was that the project either would make too many demands on them or that the children would 'play up' to the camera. Either way, the common opinion was that, as a class of people, children were vulner-able rather than able.

My own position was much closer to the other end of the continuum. I recognised that they were as vulnerable as any other research participant or researcher, and that I therefore needed to be rigorous in my ethical approach (Farrel 2005), but in my role as practitioner I usually began with an assumption of ability rather than vulnerability. Thus, I always acknowledged at first meeting with a child that they had the ability to either make this the only and last meeting, or the beginning of some joint work. And I had a fundamental belief that it was possible to survive parental bereavement and that all children were capable of doing this. I brought these values to the research study and thus began with a bias in favour of capacity and confidence. Barnard (1999), Holland (2001) and Alderson (2000) all argue that adult assumptions of ability or incompetence will either enhance or diminish a child's actual performance, and there is a convincing case for distinguishing between children's relatively poor performance in research on hypothetical situations and their maturity when responding to research in areas of which they have had real-life experience (Alderson 2000). In this study, there was some evidence that living with life-threatening parental illness had given the young people a more mature approach to life than that shown by their peers. The youngsters themselves acknowledged this from time to time; Megan commented negatively on how childish and irritating her peers could sometimes be, while several of the group highlighted the need to support and protect their parents or siblings, and put their own preferences on hold (see previous chapter). Thus, one positive consequence of recognising the vulnerability of a parent with cancer was that the child's capacity for **other-centred** behaviour was increased, and in **practising** this other-centred behaviour their competence as participants or citizens of society also grew. Although they all wished for their parents to be more understanding of the stresses that they, as children, experienced, they saw this as an example of reciprocity - just as they were actively trying to support their parents, so they hoped their parents would actively support them. However, their support to their parents was already freely given and was not conditional upon it being extended in turn to them.

This capacity for a more mature outlook and behaviour, developed in response to the young people's situations, therefore pre-dated the Video Project but it is at least potentially possible that their participation as co-researchers in a collaborative inquiry further enhanced their capacity and competence. For example, after seven sessions in which they had been consistently told that it was their experience which mattered, their choices that would count, and their feedback on the previous sessions that needed to be heard, their capacity to critically appraise the first edit of the video was clearly demonstrated. Similarly, in Session Five there was a long, complex and animated debate about truth-telling (S5 P5) wherein several of the children demonstrated an impressive capacity to marshal their thoughts, construct an argument and respond respectfully but robustly to challenges, all on a difficult and semi-abstract topic. While not capable of being 'proved' in a conventionally scientific way, it is likely that the collaborative ethos of the project contributed to capacity-building, the expectation of competence inherent in the underpinning values of collaborative inquiry brought forth competence, and the constant sharing of power provided frequent opportunities to display and hone that competence.

However, this competence was not a static state, for it shifted and slipped, disappeared and re-formed, in response to many factors outwith the control of the study. Jack and Becky illustrate the dynamic nature of this competence in their attendance and involvement in the project. Superficially less focused than his co-researchers, Jack was nevertheless fully committed to the group and despite his mother's rapidly deteriorating health, the deepening uncertainty of his daily life, and his dependence on adults to honour his wishes, he attended every session and was never a presence that could be ignored. His sister Becky was equally competent at having her wishes honoured; her energies were focused on her dying mother and her attendance was sporadic and her contribution limited. Perhaps she was husbanding her resources and had none to spare for the project. What is less certain is whether the two siblings were as capable of getting their wishes met once the main phase of the study was completed. Neither attended the review of the first edit, nor the pre-launch showing to the parents, nor the formal public launch a few months later. It may be that this was entirely consonant with their own preferences, but it is not possible to be confident that the collaborative inquiry had **sufficiently** strengthened their capacity and competence to act out their own wishes. It is equally as likely that their subsequent non-participation reflected their father's views as much if not more than their own.

This highlights the limitations of what Robson (2002) calls 'real world research'. While this study sought, *inter alia*, to help children become effective inquirers, it could not impact so directly on the many other parts of the system that is society. The **output** of the study sought to enable other parts - teachers, families, professionals, peers and siblings - to become more enquiring, but this was a future impact; the research itself had very limited power to change the broader **context** in which the fieldwork took place. Competence was recognised and celebrated within the study, but in the outside world it ran the risk of being dismissed and devalued. Knowledge may be power, but if that knowledge is not respected or sanctioned as knowledge by those currently in power (adults) then it may yet not bring power.

Their own understandings of themselves as competent and capable were challenged by the reluctance of their social networks - parents, school and the wider community, all of whom appeared to be working to the older models - to acknowledge competence in children.

Voice

One of the avowed aims of this study was to give voice to a section of the palliative care population not usually heard - children of seriously ill parents. Such children are 'users' of palliative care services and I consider here the issues arising therefrom in the contemporary debate on user voice.

Chapter Three traced the growing drive, from the Government and elsewhere, towards involving users, and outlined the associated dilemmas. A number of these have been thrown into relief by this study.

The primary argument for involving users is that attention to their experience and expertise will bring improvements in services (Skillbeck 2004, Payne 2005) and this study shared that hope. However, while it is too early to say how much this user-centred research will change policy and practice, there is little evidence of any follow-up from agencies and institutions. Many practitioners have purchased the video, presumably on behalf of their organisations, but to date no organisation has invited any of the co-researchers to contribute to policy groups, working parties or similar. There have been some invitations - directed at the adult researchers only(!) - to speak at professional gatherings, but that is all. The project is therefore open to the criticism so frequently levelled by disillusioned users at professionals - that their voice may be heard but it is not then acted upon.

A secondary argument for involving users may be loosely constructed as the therapeutic or transformative one - that the very process of being involved is beneficial regardless of any more global outcome, and thereby justifies the activity. This study clearly supports that argument, for the majority of the children emphasised this not only throughout the sessions but also in the year of dissemination thereafter (see previous chapters). They grew in confidence, in understanding of the importance of their message, and of what they had achieved together, and the project reduced their sense of isolation, insecurity and confusion. All this, however, was, in Alderson's words (1995) a bonus; it was not the prime purpose of this study. Nevertheless, the video validated their experience and the dissemination year gave them a very public endorsement of their capabilities, confirming a shift in others' (and their own?) construction of them from vulnerable to capable.

Positive though the dissemination process has been, it raises two important and difficult questions about user involvement. The first relates to time. An earlier chapter has acknowledged that, one year after the launch of the video, the young people had ceased to be involved in presentations. That is, they had ceased to respond to the invitations to co-present; the reasons remain speculative, since it would have been ethically inappropriate to press them for explanations. The very real, practical difficulties have been adumbrated in the preceding chapters, but there is a broader ethical issue here. If users are important because of their active use of a service, at what point in their 'career' as a user does their experience and therefore their legitimacy as a user cease to count? And what responsibility do professionals and their organisations have for the use, and abuse, of users? The literature on users rightly highlights the difficulties of involving and retaining them (Skillbeck 2004) so it is not surprising that those few who are willing and effective speakers are widely used to provide 'the user perspective', sometimes long after the events that qualified them as a user. This has led to some criticism that user 'evidence' is taken at face value (Gutaratnam 2005, verbal communication, Payne 2005) and is less rigorously evaluated than professional contributions.

The temptation to use, and possibly, abuse, the young people in this study in this way was one of which I was mindful. However, the practical difficulties in the way of their participating in conferences or writing for publication appear to have effectively removed that temptation. It would seem that their identity and role as a 'user' was important in their lives, but it was not their defining identity. Indeed, it may be an exaggeration to give it this label, since they themselves never used the term. An illuminating conversation with Ellis after we co-presented on 'User Research' at a national conference in Edinburgh led me, in the steps of Hones (1998) to try and re-present his sentiments in poetry rather than prose.

I didn't know I was a User, no I didn't.
I knew I was a person, I knew my name was Ellis.
I knew my Mum had cancer.

I didn't know about the group,
I wasn't all that sure;
Mum made me go along, she said I ought to see...

I didn't know about the others,
The others in the group.
The girls got on my nerves, but I liked the bloke who helped.
I got to use the camera, so that was pretty cool.

I didn't know if it would work,
I mean about the personal stuff,
If filming it would change things,
Would make it different in the future.

I know a lot more now.
I know it's helped my Mum
It's helped us as a family
It's helped us understand...

I didn't know I was a User,

Not til I saw the Programme;
I came because I wanted to.
I'm a different person now.

Although the foregoing discussion supports some of the criticisms raised in Chapter Two about an unthinking endorsement of user involvement, I nevertheless support the need for greater user involvement in research and this project was a considered attempt to practise the principles I espoused, as outlined in the Methodology chapter (Chapter Four).

Notwithstanding this, the comments of Beresford and Evans (1999) concerning the roles and relations of research ring uncomfortably in my ears. This study is but a very modest attempt to change these; it is incremental rather than revolutionary, and it missed the opportunity to genuinely collaborate with the young people in the key phases of data analysis and interpretation. What I thought to be an exciting and radical vision, as I introduced the project to others, I now see to be a limited and tentative step on a much longer road to a much more challenging goal. It might even be argued that in the later chapters of this thesis I have turned back, guilty of Beresford and Evans' charge (1999) of legitimating, if not emasculating, user involvement in research by my privileged professional and academic interpretation of their lived experience.

I counterbalance this somewhat with the claim that I have at least avoided the pitfall of so much palliative care research - the use of proxies. The evidence base for palliative care is weaker than we might wish, in part because of the very real difficulties of research on, with or about the dying. Ethical concerns have often led researchers to ask not the dying but their carers - partners, relatives and professional carers. Thus, we know a great deal about what nurses, hospices, doctors and spouses think about pain, euthanasia, 'a good death' or the impact of cancer on the family; we know much less about what the person concerned thinks. This use of proxies is sometimes unavoidable, but often unjustifiable (Hopkinson, Wright and Corner 2005). The review of the literature on family experience of cancer in the opening chapter of this thesis highlighted the tendency to rely on proxies and the ensuing mismatch between the results and the reality of children's experience. This study can, as a minimum, claim to have avoided the danger of research through proxies, and to have given space to the voice of the child himself rather than the voice of a parent re-presenting (sometimes inadequately) the child.

Of course, it cannot claim to represent **every** child. It is subject to the same caveats as pertain to adult users. The reader, or perhaps the practitioner, must make their own judgement, taking from it that which resonates with their own professional experience. It is interesting to note, however, that at the time of writing, I am involved in facilitating another group of children with a seriously ill parent. This is a purely therapeutic group rather than a research project, but the same themes as identified in the Video Project dominate the discussions, and the reactions and sentiments are remarkably similar to those of our co-researchers. For me, this has provided further independent confirmation of the findings of the research project. So, while it may not be possible to generalise, in the pure sense of the word, it seems reasonable to claim the potential for transferablity.

A final aspect of user voice that needs debate is the ethics of consent and identity. I have discussed elsewhere my understanding of consent as a continuous, negotiated and retrospective process rather than a one-off event; here I simply want to acknowledge that the power issues analysed earlier in this chapter inevitably impacted on the consent process. The evidence, from the children's spontaneous comments during the project, their considered reflection articulated in conference presentations, their feedback sheets and their behaviour - all strongly suggest that they gave their consent freely. Nevertheless, it is important to at least recognise that other, unarticulated pressures or assumptions from surrounding contexts - family, school and society - may have limited their ability to dissent. As lead co-researcher, I did my best to create a research context in which consent could be withheld, but I could not change the overall cultural context.

While the principle of consent is universally accepted, it is important to challenge the conventional wisdom that anonymity should be guaranteed. Increasingly, it is argued (Simons 2004) that participants should have a choice. Anonymity may be construed as patronising and possessive - it may seem a dismissal or devaluing of the participant and their opinion, or as an appropriation by the academic of the participant's knowledge.

The use of video in this project instantly removed any option for anonymity and in so doing preempted the risks of patronage and appropriation to a large extent. Nevertheless, it brought with it the attendant risks of public recognition. As outlined in Chapter Five, this was thoroughly discussed with the young people, but it would appear that that their greatest anxieties were not about the reaction of the general public but of their parents. To date, they have not been subject to any unwelcome attention from the national media and the video has not impaired their ability to function normally at home or school or work.

The Voice of the Thesis Author

A discussion of voice would not be complete without a careful consideration of the voice of the author of this work - that is, my own voice. While there is both dispute and overlap in the many definitions of reflection and reflexivity (Burns and Bulman 2000, Coffey 2002, Lovelock , Lyons and Powell 2004) there is general agreement that it is both unethical and unsatisfactory (Simons 2004) to conduct research on, for, by or with others, without being prepared to shine the spotlight on oneself. This is not for narcissistic reasons but to analyse critically the impact of oneself on the research process, since the research output is inevitably shaped in part by the beliefs and values of the researcher (Fook 2001). Just as 'history is written by the winners' so this thesis, despite its collaborative methodology, is written by the lead researcher. In Chapter Four I traced the genesis of this research, outlining the formative influences and experiences of my professional and personal life that had brought me to the point of initiating this project. In this penultimate chapter I now consider the key issues relating to my 'voice' in this study. As I do so, I reiterate the earlier caveat - these issues are not detached, linear, and contained, but interlinked, permeable and all-pervading. For purely aesthetic reasons and ease of elucidation, they are here presented as separate issues; in reality they are facets of the one diamond of 'voice'.

Reflexivity

As I attempt to write this section, I realise that it is impossible to do so without in some ways misrepresenting the process; the act of writing imposes its own structure and somewhat spurious logic on a process that is continuous yet intermittent, that consciously attempts to articulate that which frequently takes place in the unconscious and subconscious, and which implies a commitment to honesty which suggests that there may be a final, purer 'truth' somewhere out there if only we can be sufficiently reflexive and transparent. Richardson (2000) has highlighted the fact that "writing is also a way of knowing" and a method of discussion and analysis in which form and content merge and blend, while Peshkin (1988) has demonstrated clearly that there is never the one reflexive 'I', but several 'I's, sometimes confirming, sometimes conflicting.

The contents of the reflective diary may be thought to be the most accessible and direct evidence of the reflexive 'I' and this was my assumption as I began the diary, very much aware that the research literature suggested that this was a significant part of the audit trail, enabling me to demonstrate transparency, reflexivity and critical subjectivity. However, as I engage in reflection-in-action (of thesis-writing), as I sit at the computer at this moment late in the writing-up process, I recognise that the doctoral student 'I' has been leaning over the shoulder of the lead co-researcher 'I' much of the time, urging that 'I' to bear in mind that anything she writes 'may be taken down and used in evidence'. To be fair, there have been other times, when the frustrated social work practitioner has elbowed the doctoral 'I' out of the way and I have written the diary in frustration, excitement or passion with no thought (or none that I can reach down into my unconscious and retrieve) of public scrutiny. The subjectivity has been at the forefront and the critical element has not been called into play - at the point of writing the diary. The critical element, in relation to those social worker 'I' passages, comes now as I write this section of this chapter.

Thus, I begin to see that reflexivity, essential though it is, will only ever be a partial, incomplete and diffuse process. It is cyclical, recursive and always capable of revision. For example, should I return in two years to reread this thesis, two things would surely happen. First, in the intervening period I would have reflected further and differently on the project and I would bring that thinking to my re-reading. Secondly, because of that, I would critically evaluate the thesis differently. I might conclude that I should emphasise some aspects more and others less, or, possibly, that I should write a quite different thesis. That is not to say that this thesis is 'wrong' or 'untrue', but simply to acknowledge that there are multiple perspectives and that reflexivity is a condition rather than an activity; it is ever-present. Like my younger co-researchers, whose understanding of the research process changed and deepened during the dissemination phase and whose critical subjectivity continued to develop, my perceptions continue to shift, even though the demands of academe require me to freeze them at a particular point in time.

It is those demands, encapsulated in the British construction of what a doctorate requires, that are foremost as I write, but which impinged on only one of a number of selves during the project. Previous chapters have referred to these various selves in passing, and now I review them, again with the same reminder as to the impossibility of fully separating them in action, in the way one does in writing of them.

The use of self in case study research (Simons 2004) the concept of the therapeutic use of self in social work (Gould and Baldwin 2004), and the notion of presence in palliative care (de Hennezel 1997, Saunders 2001,) have much in common. In all of these there is an important distinction made between the professional and the personal. Practitioners in all these areas acknowledge the need to be aware of these boundaries and to maintain them. Nevertheless, it is equally a truism that the personal is political, and that these selves are reciprocal. We may theoretically separate the personal and professional self, but the reality is that they elide and collide, the personal shaping the professional and the professional impacting on the personal. A brief example from the project illustrates this. One of my colleagues was often critical of the attention-seeking behaviour of one child, whom I had been and was still supporting through the parent's illness. Or to be more accurate, my colleague reported the criticisms of this child and her parent made by the Dodds family who had failed to come to the open meeting and then to the project sessions. This family knew the parent and child in question and were trenchant in their criticisms of them to their own social worker, my colleague in the project. She then added her own, reasonable assessment of this child, as very attention-seeking and often disruptive. For my part, I felt I had developed a good professional relationship with the family in general and the child in particular. I respected the child's honesty and ability to articulate concerns that the rest of the group then were able to identify with. Frequently, this led to very worthwhile debate, and excellent footage on tape. I worked hard to attend to my colleague's opinion, but found it unpalatable. It challenged me on every level. I recognised that I felt protective of 'my' child, disappointed that their role as catalyst within the group was not valued more highly by the other adults, and disconcerted by the thought that I had perhaps over-identified with this family, seeing elements of my own early life in theirs.

Interestingly, when we three social workers were reviewing all the tapes of the project some two years afterwards, I myself found her attention-seeking behaviour much more obvious on tape than it had been in real time, while my colleague simultaneously acknowledged that her own involvement with the non-participating family had inevitably coloured her views.

I have endeavoured to disentangle the various strands of 'self' - personal, professional, practitioner and researcher, that were at play in the situation described above, but they were all part of the one self that was me. Where one began and the other ended was rarely possible to discern at the time and in action. Hindsight, reflection, distance and the judgement of others may then enable a greater critical subjectivity and a partial unravelling of the selves.

Finally, I wish to acknowledge the influence of the process of writing for a doctorate on 'voice'. As Schwandt has so clearly stated, what the researcher does when she interprets the data generated by the participating voices (hers included) is to "construct a reading of those meanings; it is to offer the inquirer's construction of the construction of the actors one studies" (1988 p222). That mine was a collaborative inquiry where the actors studied themselves does not invalidate Schwandt's claim. In the context of this thesis, I, as sole author, am the inquirer; it is **my** construction of the construction of the actors that is offered. Writing in itself adds another layer of reflexivity (see Fig. 6(iv)) - I reflect, from a distance of many months, through doctoral student lenses, on the entire project, adding this layer of reflexivity to all the other layers that have built up like the mossy accretions on a weathering statue. This process is transformative in three respects. First, it transforms what was a collaborative but private and personal experience, through reflection and analysis, into a formal, public, professional presentation of knowledge. Secondly, it transforms **others'** experience, expertise and knowledge/truths into **my** theories, knowledge and 'truth'. Thirdly, I recognise that it has transformed parts at least of my self. Like the ancient mariner, 'a sadder and a wiser' woman, 'I woke the morrow morn', for at the end of this research I am (like my co-researchers) a different person, with a different understanding of research, of collaborative inquiry, of living with life-threatening parental illness, and of my own, multi-faceted self.

The voice with which I speak and write is still uniquely mine, still passionate, but more tempered and more tentative as a result of both the research and the reflexive process.

Limitations of the Study

The claim that this study has broken new ground in palliative care research has been argued in earlier chapters; this does not, however, obviate the need to examine critically its limitations, some of which were apparent from its inception, others emerging both in the course of the fieldwork and in this writing-up process.

I deal first with those limitations that spring primarily from the methodology of collaborative inquiry, and then consider those that relate more directly to the experience of living with life-threatening illness of a parent.

Collaborative inquiry

As argued elsewhere, collaborative, co-operative, or participative inquiry may legitimately take many forms. One of its strengths is its willingness to attend to the social and psychological contexts of its area of inquiry, and to genuinely invest power in non-professional participants. It recognises that inquiry that springs directly from the experience and interest of those living with or through the issues under investigation is more likely to meet the avowed aims of such inquiry - the flourishing of human persons (Reason 2005). In this study, however, 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 is indisputable, 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.

I have addressed the issues of power in an earlier section, so will merely acknowledge here that 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 fact that, after the fieldwork was over, several of them spoke at various presentations about their initial wariness and their pleasure at discovering how seriously they were being taken, suggests a modest level of success.

However, despite the success that we also enjoyed in involving the children in presentations, it has to be recognised that, radical though it appeared to many conference organisers, it was in reality a very limited step forward, on three counts.

First, as highlighted in Chapter Five, participation in dissemination 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. As I write this chapter I see more clearly just how modest were the innovations we achieved, and just how much further there is to go in dismantling the very significant barriers to genuine collaborative dissemination.

Perhaps even more significantly, my own vision of collaboration did not extend to a key stage of the study - the analysis. While it might possibly be argued that the children were involved in a limited form of analysis - in terms of their discussions as to what should be included in the finished film and what should be left on the cutting-room floor - I failed completely to even consider the possibility of involving them in the analysis and interpretation of the data. In part, of course, this was based on very pragmatic notions of time available, understandings of research processes and level of interest. Nevertheless, the fact remains that these were untested assumptions - I did not take the opportunity to check out whether the group as a whole or any individuals in it might be interested in working on the data. Instead I moved back into conventional researcher-mode and simply presumed that making the video was the main interest for them and in consequence I denied them the opportunity to collaborate on a key aspect of the research process. As I reflect on this failure - and acknowledge 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!

Living with the life-threatening illness of a parent

Of the studies which focus on the impact of cancer on families, the majority attempt to define key variables such as age, gender and family composition, and some, additionally, limit their studies to one diagnosis or a particular stage in the illness. The study under discussion does none of these, for reasons of both principle and pragmatism. To take the latter first, the pool of available participants was extremely limited. Cancer is largely a disease of the elderly and the number of younger patients with children under 18, at any one time, within the geographical area covered by our respective agencies was relatively small. The problem of recruiting to groups has been well documented elsewhere (Ward 1998, Doel and Sawdon 1999, Whittacker 2001,) and to attempt to achieve a particular balance in age, gender or family background was unrealistic. The key factor for inclusion in the research group was the experience of being in a family where a parent was seriously ill, and the purpose of the research was to illuminate and understand that experience rather than to seek to prove hypotheses around gender, age or developmental stage (Christ 2000). While it is important to acknowledge the justifiable criticisms of studies that take no account of such factors and therefore presuppose all children to be more alike than dissimilar, thus privileging childhood as a defining factor over gender, ability, health or any other of a multitude of significant states or experiences, it is nevertheless equally important to emphasise that this study was a piece of action research, temporally and contextually located in the real world as opposed to the controlled conditions of an experimental laboratory. It was not within our power to 'balance' the group according to positivistic notions of appropriate sampling. Nevertheless, the group managed to encompass a wide age range and a broad mix of family composition, class and education, as well as both genders, and one example of children of mixed heritage.

The issue of selecting on the basis of parental diagnosis and prognosis was, however, actively considered and a principled decision made to discount this. The type of cancer, its 'stage' and the likely prognosis have been significant factors in much of the American research (see Appendix 1) and figure largely in the thinking of many palliative care professionals. It is my practice experience, however, that children and families view things differently. They appear to make fewer distinctions between the different cancers, so that it is the diagnosis of cancer rather than, say, Parkinson's disease, that weighs most in their minds, and although prognosis is critically important their understanding of it is different from professionals. Thus professionals, and researchers, may make certain assumptions about the homogeneity of patients who are 'stage four' in their disease, or who are 'dying' as opposed to 'terminally ill' and design their research accordingly; families, be they patients, partners or children often have neither this mind-set nor this expertise. They have not travelled this road before, and everything is uncertain, for they do not have any maps or models with which to match their experience. The uniformity that researchers may impose on them by bracketing them into the same group is likely to be illusory. What is of greater significance is the undoubted sense of uncertainty - the state of not-knowing - that crosses diagnostic and prognostic boundaries, barriers of class and gender, site and severity of the disease.

Some writers and practitioners of palliative care (de Hennezal (1997), Sheldon (1997),Oliviere (2005)) have begun to recognise this 'not-knowing' as a key variable in the work, and even a welcome challenge to the solution-focused world of medicine. The willingness to acknowledge the reality of 'not-knowing' enables the practitioner to share, in small measure, in the vulnerability of the client and family, and to shed the cloak of omnipotence and expertise that often disguises uncertainty. This is also applicable to the collaborative inquiry process itself.

While the study acknowledges the variables in the composition of the group, it clearly cannot draw any conclusions about these self-same variables. What it did confirm was the practice experience of working with children and parents - that the fear of potential parental death bore no direct relation to its likely imminence. It was this criteria of living with uncertainty in the face of parental cancer which was key to inclusion in the group. The consequence of this has been to limit the conclusions to be drawn about many of the other variables, but it has enabled the lived lives of the children to remain central to the research.

A reflection on 'Never enough time' - dealing with a 'dead'line.

One final limitation, deserving of brief consideration, is that of time. Both strands of this study - the collaborative inquiry and the experience of living with life-threatening illness - were shaped by the same limitation of 'never enough time'. In palliative care, the sense of time running out is often palpable. Families realise that there will never be enough time left to fulfil their hopes and dreams. Professionals worry that there will not be enough time to 'prepare' the sick person or the family for the impending death - implicitly, a good death. Similarly, the researcher frequently experiences the limitations of time (Shakespeare *et al* 1993, Broad 1999). The focus group is halfway through its allotted sessions and has barely begun to consider the topics the researcher is investigating. The interview has overrun and must be concluded just as the interviewee has begun to speak more freely. The participant observer has only one more week in her research setting and has yet to be permitted to accompany a key staff member on home visits. All these situations are familiar to many researchers. In this study, the experience of running out of time that was so familiar for families (including children) experiencing palliative care was also mirrored in the experience of inquiring collaboratively. Action research of necessity has an open and fluid agenda and the research act is a continuous act of enquiry, where those engaged in it live with uncertainty, not knowing what lies ahead. In this respect, the researchers are no different from the families of the palliative care world; both struggle with the uncertainty and the not-knowing, and have to recognise that it is not possible to exercise full control. One can be alert to the challenges, but one cannot eliminate them all. My experience of conducting this inquiry was that we indeed ran out of time - the deadline arrived while there was still so much to do, just as death so often arrives before the family is quite ready. And however much extra time the researcher and the family might crave, it would still never be quite enough….

And perhaps research also echoes palliative care in one more way - the story does not end when the 'dead'-line has been reached - just as contemporary models of bereavement emphasise the continuing bonds (Klass, Silverman and Nickman 1996) between the bereaved and the dead person, so this research, complete and final in the artificial form of a thesis, may continue to live on in some small way in future research that may be conducted in palliative care.

Summary

This study sprang from a desire to better understand the experience of children living with a parent who was seriously ill with cancer. It expanded to include a case study of the process of collaborative inquiry with children and the findings from both these arenas have been set out in the previous chapters. In addition, the design, conduct and dissemination of this research have raised other, broader and overarching issues which have been the focus of this chapter. Foremost among these has been the way in which society in general and, more specifically, the research world of academia, constructs the notion of childhood. This chapter has argued for a revisioning of our understanding of what it means to be a child, and has repositioned the child as the Able Child-Citizen. This model, while not denying the limitations inherent in any human being of any age, foregrounds the capacities and competences of children and moves them from the margins of society to a position which acknowledges them to be citizens and actors in their own right.

The second, interrelated theme of power is then examined. The potential for collaborative inquiry to empower young people, both as researchers and as members of the human race, is critically analysed. Its transformative nature is acknowledged, but the social context in which the children live and in which the research is set (where the concept of the Able Child-Citizen is not dominant) prevent its reaching its full potential. The study also confirms that power is not static, but a dynamic, negotiated process in which both adults and children may exercise or avoid it.

The third key issue for discussion is the question of voice. This is considered in relation to both the young co-researchers, the users of palliative care services, and to the dominant voice in the thesis - the author, myself. The strengths and limitations of the user voice are addressed, and I then consider the imperative of the doctoral voice. Although fully supportive of the need to be critically subjective, reflective and reflexive, I register two reservations about the process.

First, the transparency of the reflexive researcher inevitably privileges her voice and may therefore undermine the principles that this study espoused -that of collaboration in order to give voice to those whose voices are less frequently heard, and to give weight to the knowledge and expertise of those seen as less capable and confident. Secondly, while aligning myself with those who assert the primacy of being fully reflexive (Peshkin 1988, Lovelock, Lyons and Powell 2004) I doubt the possibility of achieving it; it will always be partial and compromised by one's very awareness of it.

Finally, and perhaps ironically in the light of the foregoing, this chapter concludes with a reflection on a theme common to both strands of this study - the children's experience and the process of collaborative inquiry. This theme of limited time embraces the palliative care context - working against time with a life-limiting family illness - and that of collaborative inquiry - that it is a process which challenges conventional research notions of certainty, control and completeness. Collaborative inquiry, like palliative care, needs to cultivate the ability to live with 'not-knowing' and to trust in the transformative power of human interaction.

CHAPTER TEN: CONCLUSION

"The truth is rarely pure and never simple"
Oscar Wilde

Introduction

If the purpose of participative inquiry is not so much to establish agreed truths as to generate a consensus on how to create a world that is more respectful and enabling (Rorty 1999) then this chapter offers not a complete or immutable blueprint but simply some modest markers as one way into an understanding of some key issues in the theory and practice of social work, palliative care and qualitative research.

There is a sense also that this conclusion is artificial - an interruption in a continuing narrative that others will take up and take on in different directions in the future. The conclusions offered below represent the author's attempt to shape and claim the learning generated by this study; the other twelve participants would doubtless shape that learning in different ways.

Palliative Care

There are four key findings from this study in relation to palliative care.

- Children see themselves as central to the family, and as reciprocal and active contributors. That they are frustrated by parental inability to see them as central and active does not in itself invalidate their **capacity** to be reciprocal rather than dependent family members. This reciprocity was evident throughout the video project sessions, with almost all of the young people speaking of the way they cared about and for their sick parent and other family members. They actively demonstrated responsibility by reducing their own practical and emotional demands upon their parents and by offering practical and emotional support to their parents. They thus contributed positively to the family's well-being, both by containing their own anxieties and needs and giving of themselves to others.

- The children displayed quite sophisticated levels of awareness of (potential) dying (Glaser and Strauss 1965). An awareness of 'uncertainty' was fundamental to their understanding of their parent's illness. They could no longer take the future for granted. The risk that cancer might kill their parent was acknowledged; in the words of Laura *"it kind of haunts you"*. This living with 'not-knowing' took considerable skill and energy, as Christ acknowledges (2001). However, the children's experience was that this was not always recognised by their parents and rarely by their peers, their school environment or the wider society in which they lived.

- The children employed a wide range of coping strategies to deal with not only the uncertainty but also the gap between their own self-image and the more limited, protectionist-oriented perceptions of adults in the wider ecological systems. They actively managed the tensions inherent in the mismatch and consciously selected appropriate strategies. They aimed for 'quality of life', with four elements being essential - having fun, creating 'space' for themselves, containing emotions and talking things through.

- Poor or no communication was as much an issue for children as it has been shown to be for adult carers or patients. There was unanimous agreement from all the co-researchers on the need for truth-telling - as much and as early as possible. While 'truth' remains a contested concept, all the children disliked delay, dilution and deception. The consequence of these was then distrust - the children lost trust and confidence in the adult - and this bred further uncertainty, isolation and disempowerment. Disempowerment, as this thesis has argued, is both an intended and unintended feature of current models of childhood and despite the emphasis on holistic practice, client empowerment and quality of life, it is alive and well in palliative care.

Collaborative Inquiry

Collaborative inquiry attempts to challenge the disempowerment of users, subjects and participants in research.

It recognises users as central to the enterprise rather than eccentric, respects their capacity and competence, sees them as autonomous rather than dependent and as active (collaborators in the research endeavour) rather than passive (sources of data). The literature assumes that the inquiry members will be adults, but this thesis has demonstrated that the approach is transferable to children. Much of the previous research on the impact of cancer on families marginalised children. It was the adults - spouses, partners, relatives and carers - whose experience and assessment of family functioning was valued; children were secondary, and suspect, sources, whose opinions generally needed further validation by 'responsible' adults. The models of childhood which underpin most of this research clearly originate in the developmentalist-protectionist stable.

Three key findings have emerged from this study:

- It has demonstrated that collaborative inquiry is a feasible and effective method of conducting research with children on a particularly sensitive topic - the possible death of a parent. It has also highlighted the importance of age-appropriate tools and the effectiveness of video as a medium accessible to both child co-researchers and to the audience they wish to reach. It is this study's contention that it demonstrated that it is possible to conduct collaborative inquiry with children in an ethically sound manner, despite the fact that the use of video pre-empted the traditional safeguards of anonymity.

- Children have shown themselves to be capable co-researchers, contributing not only to the more traditional phase of fieldwork, but also to the key areas of design and dissemination. In this study, the co-researchers were responsible for identifying the key themes for investigation. They demonstrated a commendable consistency in following these through, over the seven video sessions and were no less or more committed and focused than most adult groups. Their latent capacity, which the collaborative inquiry paradigm assumes in principle and which we adult facilitators had previously experienced in our practice, was able to be realised through three key areas of principles, tools, and relationships. Much of the literature on action research is not explicit about the quality of the relationships between the actors. What this study demonstrated was that while collaborative inquiry in itself changes the dynamics of the research act, it is in the nuanced, hard-to-capture, day-to-day negotiations of that inquiry, in the developing trust between co-researchers, and in the iteration of cycles of reflexivity that collaboration finds a fertile soil in which to sprout and grow. The seed may be the principles of participative inquiry, but it is fed and watered by the lived relationships and reflections of the co-researchers.

- The findings from the two areas above both demonstrated that children are capable of being mature, competent, insightful individuals when adults relate to them in respectful, reciprocal and attentive ways; expectations of competence have generated demonstrably competent behaviour and articulation. The disparity between the research experience and the existing models of childhood has generated a new model. The model of the Able Child-Citizen challenges the prevailing single dimension perceptions of the child as needy - in need of protection, control or economic development - and offers a model that is fundamentally strengths-based and child-centred, recognising the child as an active, in-this-moment stakeholder in society.

What are the implications of the findings for the future of palliative care, for research and for society as a whole? It is to these aspects that I now turn.

Recommendations for Palliative Care Practice

The family is aspirationally characterised by WHO (2002) as the 'unit of care'. Our findings confirm that parental illness has a powerful but often unacknowledged effect on children in the family, and it is imperative that practitioners and policy makers develop new ways of engaging effectively with such children, in order both to provide for such support needs as cannot be immediately met within the family, and also to empower the children to negotiate a different set of family dynamics that more fully corresponds with their own perceptions of themselves as capable, active and reciprocal family members.

However, key papers and Government initiatives of the last few years have yet to embrace this. The NICE Supportive and Palliative Care Guidelines urge that 'people affected by cancer should be involved in developing cancer services' (NICE 2004) but there is nothing to indicate that children are recognised as 'people'. Similarly recommendation 18 argues for 'the development and implementation of services specifically focused on the needs of families and carers' without making clear that children are part of families. The evidence from the literature review in this thesis is that unless children are explicitly identified they will be unintentionally discounted. This has already been apparent in some of the relevant reports and legislation, although the Carers and Disabled Children's Act 2000 is a welcome exception in devoting a section to the needs of young (16-17 year old) carers. However, the Government's 'Commissioning a Patient-led NHS' (2000) discusses the role of users in the assumption that they are exclusively patients rather than carers or family members, such as children.

Similarly, other recent initiatives such as the Government's End of Life Initiative (2003) encompassing the Liverpool Care Pathway, the Gold Standards Framework and the Preferred Place of Care paper, make some reference to the family, but children themselves merit no attention. Since the preferred place to die for over half the population is the home, it could be argued that a significant opportunity has been missed to address the needs of (grand)children who are likely to see a (grand)parent die in the family home.

The National Service Frameworks for Children (2004) mark the Government's avowed intention to achieve a 'fundamental change in our way of thinking about children's health' but the urgent need, demonstrated by our study, to change our way of thinking about **children** is not acknowledged. The document 'Every Child Matters' is rather more encouraging, in that its targets include the need for children to make a positive contribution and it addresses the issue of participation by children in its plans, but there is no real evidence of a fundamental shift in thinking on the nature of childhood.

Finally, the National Council for Palliative Care's '20-20 Vision' (2005) appears to see user involvement only in terms of understanding patient needs and children exclusively in terms of sick children with life-limiting conditions.

There is therefore an urgent need for policy-makers to incorporate the lessons learned from this research into their future planning.

A second need is to equip not only palliative care professionals but also their education, health and social care colleagues with skills in direct work with children, so as to honour the reality of the child's experience by enabling their voice to be clearly heard, rather than distorted by overlays of adult censorship or interpretation. This will require practitioners to reclaim direct work with children as central to their practice, and to resist the temptation to work by proxy, through assuming that the perceptions of adults (parents and health, social care and education professionals) accurately and adequately represent those of the child.

A third recommendation focuses on the outer rings of Bronfenbrenner's ecology. If children are to be more centrally located in the family, then the settings in which palliative care is practised need also to reflect that. Out-patients' clinics, hospital wards, consultants' sessions, hospice admission procedures - all these, and more, will need to assume the presence and involvement of children, rather than assume their absence and inability. On the simplest of levels, a standard statement, "We know - from children - that cancer affects everyone in the family" and a standard question: "How will you tell your children?" could do much to shift the culture of discounting the child that is still prevalent. This might then lead to a culture that is genuinely family-focused, rather than the current adult-family-focused one.

Ultimately, however, what this study recommends is a fourth step - a significant shift in society's response to children - a response that is balanced, fair and flexible. The research findings do not argue that children are ***in***vulnerable; they do make the case that children are less vulnerable, more resilient and more reciprocal in their family relationships than adults have previously acknowledged. Respecting children's capacity and competence leads to a recognition of their importance not simply as future citizens but in themselves, as of now, as child-citizens and stakeholders of the present.

Recommendations on Researching Children

Traditional interviewing techniques, however loosely structured, reinforce the hierarchical power dynamics of expert-layperson, teacher-pupil, adult-child, to which the child is already heavily conditioned. Our study suggests that researchers may need to move away from these, and develop a range of strategies that allow children a genuine freedom to express themselves in ways that are appropriate to their age, understanding and interests.

A second, relatively new, tool in the research armoury is video recording. Researchers have been surprisingly slow to turn it to their advantage. Partial though it is - as are all data capture methods - its use in this project has revealed its significant strengths. The breadth and objectivity of its gaze (static camera) together with its flexibility (roving camera) make an effective combination for capturing both group and individual activity, but its greatest strength lies in its permanent immediacy. Much qualitative research, particularly with groups, relies heavily on the researcher's ability to record in writing or on tape what was observed at the time, but remembered and valued **after the event**. A process of selection, however unconscious, has already begun. With video (even more than with audiotape which does not capture body language, settings, movement or listeners' reactions) everything within the camera's gaze is recorded disinterestedly and, more significantly, the passage of time does not distort or dull the data. Two years on, the 'evidence' of the session is as fresh, complete and uncontaminated as on the day it happened. The researcher may, in that intervening period, have forgotten much or selected specific things to justify a view, but the videotape will re-present the entire event as it happened and not as it was remembered.

The potential for video to enhance the research endeavour is therefore considerable and while mindful of its limitations, the research community could usefully adopt it more widely.

Despite the progress that has been made, to which this study makes a significant contribution, there is an urgent need for more research with children to understand and illuminate their experiences related to living with life-threatening parental illness. Further research might usefully focus on children's experience of professional support workers and their agencies. An investigation into the interface between school and dying could build on some of the data from this study. In both these projects, there would be scope for a collaborative approach.

Yet another area of investigation suggested by this study might relate to the information needs of children. And a follow-up study to this research could critically evaluate the use and impact of the video 'No - You **don't** know how we feel' on families, in schools and in palliative care settings. More radically, we (adults) could refrain from suggesting a specific topic and simply invite the young people themselves to decide what it was that was most important to them to research.

Last words - the 'I' as one among many

As I come to the end of both this thesis and this research adventure, I offer a reflection and a challenge.

The reflection concerns the adventure, or as it is often described, the research journey. In looking back, I see how far I have come - and how much further I might have gone! I see how the journey has both differed from and confirmed my imaginings, and how so many other people have shaped the landscape through which I have travelled. I recognise that the journey has also shaped me, as it has shaped my twelve companions, and that we all have also shaped each other. Nevertheless, the story of this research is my story only, just one voice among many, even if some of the richness of this experience has been captured in the video tapes, and maybe even in this thesis.

However, a thesis is a very particular academic animal. It owes some of its construction to assumptions about the nature of research, the ownership of intellectual property and the primacy of the written word that may no longer hold good in a post-modern, multi-media world. The academic requirements of a thesis have, in some measure, run counter to the principles and practices of this collaborative inquiry. That which has been a shared endeavour - carefully planned but constantly changing, a shifting, challenging partnership in which everyone has contributed much and in which space has been created for every individual voice to be honoured - has been reduced to a single voice, a prescribed and linear exposition which filters out much of the chaos and complexity of collaborative inquiry. The challenge may therefore now be to interrogate the doctoral model in the light of both academic and technological developments, in order to create a more appropriate vehicle for effectively achieving the avowed aims of intellectual endeavour - to promote new learning in the public domain.

Conclusion

This study has re-positioned children in the heart of the family, as competent actors in the drama of life-threatening illness, and as capable citizens not of a future but of today's society. It has demonstrated that collaborative inquiry can work equally effectively with children as with adults, and that sensitive topics can be addressed ethically and in depth.

It is a small beginning; we have only just begun to explore the opportunities to do research with children that is meaningful and transformative of our society, agencies and ourselves. This study, limited and imperfect as it is, does not claim to be a blueprint, a protocol or a prescription. It does, however, claim to have made an important contribution to our understanding of the experience of children whose parent is seriously ill, and to have demonstrated a radical but rigorous approach to research which may have applications well beyond palliative care and social work.

Appendix One: Table of articles

ARTICLES

Author	Date	Title	Focus	Methods	Child age	Comments
Altschuler J. & Dale B *Clinical Child Psychology and Psychiatry*, Vol. 4(1), pp. 23-57	1999	On being an Ill parent	Role of sick parent	Transcripts of family therapy sessions	undefined	Discusses practice implications for therapists and families
Altschuler, J., Dale, B. & Sass-Booth, A. *Educational Psychology in Practice*, Vol. 15, No. 1, pp.25-32	1999	Supporting Children when a Parent is Physically Ill	School-based support	Project exploring teachers' views	Primary school	Teachers' perspective only
Armsden, G.C. & Lewis, F.M., *Patient Education and Counselling 22*, pp. 153-165	1993	The child's adaptation to parental medical illness: theory and clinical implications	Theoretical/discussion paper		6-11, 12 and older	Developmental focus. Not palliative
Armsden, G.C. & Lewis, F.M., *Oncology Nursing Forum*, Vol. 21, No. 1, pp. 39-45	1994	Behavioural Adjustment and Self-Esteem of School-Age Children of Women With Breast Cancer	Comparison of children of parents with breast cancer and those with diabetes/fibrocystic breast disease	Quantitative - self-reporting (mother; child) and observer based	6-12	Children of parents with breast cancer scored better for behavioural adjustment
Barnes, J., Kroll, L., Burke, O., Lee, J., Jones, A. & Stein, A., *British Medical Journal*, Vol. 321, pp.479-483	2000	Qualitative Interview Study of Communication between Parents and Children about Maternal Breast Cancer, Telling Children about a Parent's Cancer	Parental (maternal) communication with children	Qualitative - 32 mothers	'school-age'	Children not interviewed (nor fathers)

Beale E, Sivisend D, and Bruera E. *Palliative and Supportive Care, 2, pp 387-393*	2004	Parents dying of cancer and their children	Professional intervention	Qualitative	3-18	Children more distressed and more aware than usually recognised
Bentov, L., *Journal of Theory Construction & Testing*, Vol. 3, Iss. 2 pp.42-	1999	Toward a Theory of Adolescent Coping with Maternal Breast Cancer	Theoretical	Review of papers	Adolescents	Constructs a theory of adolescent coping with maternal breast cancer
Birenbaum, L., Yancey, D., Phillips, D., Chand, N. & Huster, G, *Oncology Nursing Forum,* Vol. 26, No. 10, pp. 1639-1645	1999	School-Age Children's and Adolescents' Adjustment When a Parent has Cancer,	Behavioural problems	Quantitative	6-10 11-18 NB 6-10 group not interviewed	More behavioural problems than normal population
Black, D, *Jounal Family Therapy,* pp.1-13		Life-Threatening Illness, Children and Family Therapy	Role of family therapist		undefined	Recommends psychotherapeutic interventions for all families
Black, P.K., Hyde C, *British Journal of Nursing*, Vol. 11, Iss. 10, pp, 679-683	2002	Parents with Colorectal Cancer: 'What do I tell the children?	Two case studies	Descriptive	under 10; 13 to 19	Telling is difficult at any age
Buchanan-Barrow, *Journal of Health Psychology 8(6),* pp. 660-670		Children's Understanding of Illness	Theoretical		undefined	Critical of Piaget; argues child can understand illness from early age
Buxbaum, L. & Brant, J.M., *Clinical Journal of Oncology Nursing*, Vol. 5, No. 4, pp. 135-140	2001	When a Parent Dies from Cancer	Practice-based - assessment and intervention		undefined	

Call, D.A., *Journal of Psychosocial Oncology,* Vol. 8(1) pp. 97-118	1990	School-Based Groups: A Valuable Support for Children of Cancer Patients	Group support in school settings	Descriptive; practice-based	Grades 6-12 (U.S.)	Offers guidance re running groups
Christ, G.H., Siegel, K. & Sperber, D., *American Journal of Orthopsychiatric Association,* pp. 604-613	1994	Impact of Parental Terminal Cancer on Adolescents	Part of the study on which the book is based (Christ 2000)	Qualitative	11-17	Most adolescents coped with stress without 'acting out'
Compas, B., Worsham, N., Epping-Jordan, J., Grant, K., Mireault, G., Howell, D. & Malcarne, V., , *Health Psychology,* Vol. 13, No. 6, pp. 507-515	1994	When Mom or Dad Has Cancer: Markers of Psychological Distress in Cancer Patients, Spouses and Children	Anxiety, depression and stress	Quantitative	undefined	Adolescent girls of sick mothers most at risk. Family member's distress independent of patient's distress
Compas, B.E., Worsham, N.L., Ey, S., Howell, D.C., *Health Psychology,* Vol. 15, No. 3 pp. 167-175	1996	When Mom or Dad has Cancer: II. Coping, Cognitive Appraisals, and Psychological Distress in Children of Cancer Patients	Focus on children - conducted shortly after diagnosis	Quantitative and qualitative -	6-10 11-18 18-32	Distinction between emotion-focused and problem - focused coping.
Dale, B. and Altschuler, J. *Journal of Family Therapy*, Vol. 21, No. 3, pp. 267-283	1999	"In sickness and in health: the development of alternative discourses in work with families with parental illness	Family therapy focus	Descriptive	undefined	Adult-oriented. Impact of gender, including therapists'.

Davey, M.P. and Askew, J. and Godette, K. *Families, Systems & Health*, Vol. 21, No. 3, pp. 245-258	2003	Parent and Adolescent Responses to Non-Terminal Parental Cancer: A Retrospective Multiple-Case Pilot Study	Retrospective and non-terminal	Qualitative	11-18	Children chose to be interviewed with parents. Parents underestimated children's sadness and stress. NB Non- palliative
Davis Kirsch, S., Brandt, P., Lewis, F.M., *Cancer Nursing*, Vol. 26, No. 1, pp. 47-54	2003	Making the Most of the Moment – When a Child's Mother has Breast Cancer	Parental perceptions of intervention effectiveness	Qualitative	8-12	Challenges idea that families need time to digest diagnosis before intervention
Dowdy, J.H., Kiev, C., Lathrop, D.L. & Winkle, M. *Journal of Rehabilitation,* Vol. 63, Iss. 2, pp. 22-25	1997	Facilitating Adjustment to Catastrophic Illness through Involving Children in Age-Appropriate Education	Practice -based		undefined	Suggests an educational programme for families
Fergusson, D.M. & Lynskey, M.T., *Journal of Child Psychology and Psychiatry,* Vol. 37, No. 3, pp. 281-292	1996	Adolescent Resiliency to Family Adversity	No focus on parental illness	Longitudinal study of 940 children	Up to 16	Identifies factors conducive to resilience
Ferrell, B., Ervin, K., Smith, S., Marek, T. & Melancon, C., *Cancer Practice*, Vol. 10, No. 6, pp. 269-276	2002	Family Perspectives of Ovarian Cancer	'Family' defined as adults only	Qualitative	N/A	Adults only

Fitch, M., Bunston, T. & Elliot, M., *Cancer Nursing*, 22(1), pp. 58-63	1999	All in the Family – When Mom's Sick: Changes in a mother's role and in the family after her diagnosis of cancer	Maternal role change	Qualitative	1-18	No child perspective
Forrest, G., Plumb, C., Ziebland, S., Stein, A. *British Medical Journal*	2006	Breast cancer in the family - children's perceptions	Early breast cancer - children and mothers'views	Qualitative	6-18	Specific support needed for parents and for children
Gates, M.F. & Lackey, N.R., *Image: Journal of Nursing Scholarship,* Vol. 30, No. 1 pp. 11-15	1998	Youngsters Caring for Adults with Cancer	Care-giving	Qualitative	10-19	Care-giving 'hard but gratifying'
Harris, T., Brown G.W. & Bifulco, A., *Psychological Medicine*,Vol. 16, Pt. 3, pp. 641-659	1986	Loss of Parent in Childhood and Adult Psychiatric Disorder: the role of lack of adequate parental care				
Heiney, S., Bryant, L., Walker, S., Parrish, R., Provenzano, F. & Kelly, K., *Oncology Nursing Forum,* Vol. 24, No. 4, pp. 655-661	1997	Impact of Parental Anxiety on Child Emotional Adjustment When a Parent has Cancer	Parental anxiety	Quantitative, postal and telephone questionnaires	5-17	Parents asked to assess child, child not asked to assess parent

Heiney, S.P. & Lesesne, C.A., *Cancer Practice*, Vol. 4, No. 6, pp. 324-329	1996	An Intervention Program for Children Whose Parent or Grandparent Has Cancer	Psychoeducational programme	Descriptive	5-18	Stand-alone session for children, exploring facts and feelings
Helseth, S. & Ulfsaet, N., *Cancer Nursing, Vol. 26, No. 5*, pp. 355-362	2003	Having a Parent With Cancer – Coping and Quality of Life of Children During Serious Illness in the Family	Patterns of reaction	Qualitative	7-12	Both parents and children interviewed. Children rarely initiated discussion re illness
Hilton, A., Gustavson, K., *Canadian Oncology Nursing Journal*, pp. 198-206	2002	Shielding and being Shielded: Children's perspectives on coping with their mother's cancer & chemotherapy.	Child's perspective of parental breast cancer	Qualitative - current and retrospective	7-21	Child-focused. Key concepts of shielding themselves and being shielded by others
Hoke, L., *Psycho-Oncology*, Vol. 10, pp. 361-369	2001	Psychosocial Adjustment in Children of Mothers with Breast Cancer	Comparison of child functioning between benign or malign breast biopsy mothers	Quantitative	8-16	No significant differences overall
Holland, C.M., , *Dissertation Abstracts International: Section B: the Sciences and Engineering*, Vol. 58(7-B)	1998	The Effects of a Parental Life-Threatening Illness on Children's Adjustment	Bone-marrow transplants	Quantitative - self-report scales	undefined	Older children more depressed than younger; no gender differences

Huizinga, G.A., van der Graaf, W.T.A., Visser, A., Dijkstra, J.S., Hoekstra-Weebers, J.E.H.M. *Cancer Nursing* 26(3) pp195-202	2003	Psychosocial consequences for for children of a parent with cancer	Comparison with normative sample	Qualitative and quantative	undefined	Parents reported more problems than children did; quantitative analysis contradicted this
Hymovich, D., , *Oncology Nursing Forum,* Vol. 20, No. 9, pp. 1355-1360	1993	Child-Rearing Concerns of Parents with Cancer	Parent-focused	Qualitative	9 weeks-20 years	No child perspective
Issel, M., Ersek, M., Lewis, F.M., *Oncology Nursing Forum,* Vol. 17, No. 3 pp. 5-13	1990	How Children Cope with Mother's Breast Cancer	Child interviewed	Qualitative	6-12 13-20	Acknowledges children's ability and reliability
King, P., *Oncology Nursing Forum,* Vol. 30, No. 5, pp. 797-800	2003	Listen to the Children and Honor Their Pain	Children's experience; group programmes	Reflection-practice-based	undefined	Significance of groups; capacity of children
Kroll, L., Barnes, J., Jones, A.L. & Stein, A., *British Medical Journal*, 316 (1998), pp. 880		Cancer in Parents: telling children	Editorial -reviews key papers		undefined	Poor communication increases risk of psychological disturbance
Lackey, N.R., Gates, M.F., *Journal of Advanced Nursing 34(3), pp.320-328*	2001	Adults' Recollections of their Experiences as Young Caregivers of Family Members with Chronic Physical Illnesses	Care-giving; retrospective	Qualitative	3-19 as carers, 19-68 at study	Not palliative; retrospective

Landry-Dattée, N. & Delaigue-Cossett, M.F., *European Journal of Palliative Care 8(3),* pp. 107-110	2001	Support Groups for Children	Open session	Descriptive	2- 23	Stand-alone information and discussion session
Lewis, F.M., *Oncology Nursing Forum,* Vol. 25, No. 8 pp.1377-1388	1998	Family-Level Services in Oncology Nursing: Facts, Fallacies, and Realities Revisited	Overview of research programme	Descriptive; findings and recommend-ations	undefined	Relationship between illness demands and coping behaviour was weak.
Lewis, F.M. *Oncology Nursing Forum*, Vol. 31, No. 2, pp. 288-291	2004	Family-Focused Oncology Nursing Research	Overview of research	Meta-analysis	undefined	No specific child focus. Challenges assumptions about family functioning.
Lewis, F.M., Anderson, K.H., Shands, M.E., Zahlis, E.H., Darby, E. & Sinsheimer, J.A. *Cancer and the Family, 2nd Edition*, pp. 201-221	2000	Blowing Away the Myths about the Child's Experience with the Mother's Breast Cancer	Deconstruction of alleged myths	Draws on findings from series of studies	undefined	Argues for data-based interventions for family members including children
Lewis, F.M., Hammond, M.A. *Family Relations 45,4; ProQuest Psychology Journals*, pp. 456-465	1996	The Father's, Mother's, and Adolescent's Functioning with Breast Cancer	Aim: to test a theoretical model		Adoles-cents up to 20+	May not be applicable to advanced cancer
Lewis, F.M., Zahlis, E.H., Shands, M.E., Sinsheimer, J.A. & Hammond, M.A. (, *Cancer Practice*, Vol.4, No. 1, pp. 15-24	1996	The Functioning of Single Women with Breast Cancer and Their School-Aged Children	Comparison of single women with partnered women (all with cancer)	Quantitative and qualitative	School-aged	Children of single parents more vulnerable. Younger children shoed poorer psychosocial functioning

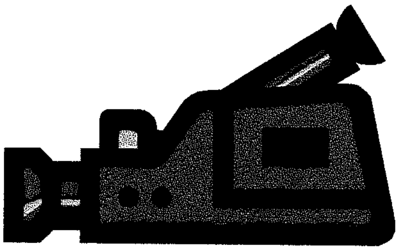
Lichtman, R., Taylor, S., Wood, J., Bluming A. Dosik, G. & Leibowitz R., *Journal of Psychosocial Oncology*, Vol. 2(3/4), pp.1-19	1984	Relations with Children After Breast Cancer: The Mother-Daughter Relationship at Risk	Mother's perspective; children mainly adult and living away from home	Qualitative	Mainly adult at time of study	Not palliative; maternal perspective only
McCue, K. & Bonn, R., , *Paediatric Nursing,* Vol. 1, Iss. 1, pp.47-51	2003	Helping Children through an Adult's Serious Illness: Roles of the Paediatric Nurse	Role of paediatric nurse; practice-based	Descriptive	undefined	Use of assessment skills to guide the parents
Naudi, T. *Global Perspective*, pp.159-161	2002	Family Support: A Summer Holiday Programme for Maltese Children	Summer activity programme	Despcriptive	4-14	Pre-bereaved and bereaved children
Nelson, E. & While, D., *Journal of Psychosocial Oncology*, Vol. 20(1), pp. 15-36	2002	Children's Adjustment During the First Year of a Parent's Cancer Diagnosis	Retrospective	Quantitative and qualitative. Child's adjustment assessed via child self-report, parent and school assessment	8-16	Mothers underestimate child anxiety; daughters more anxious than sons. Low self-esteem significant
Nelson, E., Sloper, P., Charlton, A., While, D., *Journal of Cancer Education*, pp. 30-36	1994	Children Who Have a Parent with Cancer: A Pilot Study	'cancer' not mentioned unless child used the term	Quantitative and qualitative	6-16 at diagnosis, 11-21 at interview	Retrospective

Northouse, L., Walker, J., Schafenacker, A., Mood, D., Mellon, S., Galvin, E., Harden, J. & Freeman-Gibb, L., *Oncology Nursing Forum,* Vol. 29, No. 10, pp. 1411-1419	2002	A Family-Based Program of Care for Women with Recurrent Breast Cancer and Their Family Members	Exclusively focused on adult family members	Quantitative - RCT	N/A	Children not includes as family members
Quinn-Beers, J., , *Journal of Psychosocial Oncology*, Vol. 19(1), pp. 35-48	2001	Attachment Needs of Adolescent Daughters of Women with Cancer	Attachment focus	Review of papers	Adoles-cent girls	Adolescent girls more at risk than other children?
Ranjan, R., *Social Work & Social Sciences Review 2(2)* pp. 109-121	1990	Consequences of Parental Illness on Children: A Review	Parental illness	Literature review -from positivistic position		Highly critical
Rauch, P.K., Muriel, A.C., & Cassem, N.H., *Journal of Clinical Oncology*, Vol. 20, No. 21 pp. 4399-4402	2002	Parents with Cancer: Who's Looking After the Children?	Practice-based; offers guiding principles		undefined	6-step programme
Rutter, M. *Journal of Family Therapy*, pp. 119-144	1999	Resilience Concepts and Findings: Implications for Family Therapy,	Interaction of different risk factors	Review of research	N/A	Multiplicity of factors; importance of process
Sargent, J., ,*Families, Systems and Health*, Vol. 21, Iss. 3, pp. 259-261	2003	Involving Children in the care of a parent with cancer	Case studies; not palliative		undefined	Highlights gender differences

Shands, M.E., Lewis, F.M. & Zahlis, E.H., *Oncology Nursing Forum,* Vol. 27, No. 1, pp. 77-85	2000	Mother and Child Interactions About the Mother's Breast Cancer: An Interview Study	Mothers' communication with child	Qualitative	7-12	Children not interviewed; mothers adopted teacher/educator role rather than expressive role.
Siegel, K., Karus, D., & Raveis, V.H., *J. Am. Acad. Child Adolesc. Psychiatry,* pp. 442-450	1996	Adjustment of Children Facing the Death of a Parent Due to Cancer	Comparison of pre- and post-death levels of depression and anxiety	Quantitative	7-16	Higher levels in pre-death children, compared with normal population. Retrospective
Siegel, K., Mesagno, F., Karus, D., Christ, G., Banks, K. & Moynihan, R., , *J.Am. Acad. Child Adolesc. Psychiatry,* pp. 327-333	1992	Psychosocial Adjustment of Children with a Terminally Ill Parent	Depression, anxiety and self-esteem	Quantitative	7-16	Children of parents with cancer more depressed, anxious, less social competence than control group
Siegel, K., Raveis, V.H., & Karus, D., *Cancer and the Family*, pp. 109-128	1996	Pattern of Communication with Children When a Parent has Cancer	Conducted after bereavement	Quantitative and qualitative	11 and under 12 and older	Communication strongly correlated with gender of well parent, and child's age (younger)
Spira, M. & Kenemore, E., *Clinical Social Work Journal,* Vol. 28, Issue 2, pp.183-195	2000	Adolescent Daughters of Mothers with Breast Cancer: Impact and Implications	Impact on adolescent girls	Qualitative - vignettes	12-19; girls	Young people demonstrate strength and resilience

Steck, B., Amsler, F., Kappos, L. & Burgin, D., *Psychopathology*, Vol. 34, pp. 236 -	2001	Gender-specific differences in the Process of Coping in Families with a Parent Affected by a Chronic Somatic Disease	Parental disease is MS	Quantitative and qualitative	3-26	Not palliative. Coping related to gender -daughters better than sons
Taylor-Brown, J., Acheson, A. & Farber, J.M., *Journal of Psychosocial Oncology*, Vol. 11(1) pp. 41-53	1993	Kids Can Cope: A Group Intervention for Children Whose Parents Have Cancer	Group support programme	Descriptive	5-18	Universality of experience; developmental themes
Welch, A., Wadsworth, M. & Compas B., *American Cancer Society*, pp 1409-1417	1996	Adjustment of Children and Adolescents to Parental Cancer	Parent and child perceptions	Quantitative	6-10 11-18	Parent and child perceptions of child distress conflicted. Adolescent girls of ill mothers at risk
Wellisch, D.K., ,*International Journal of Family Therapy, 1(3)*, pp. 230-241	1979	Adolescent Acting Out When a Parent Has Cancer	Practice-based - adolescents		13-18	Psychological (Freudian) approach
Zahlis, E.H. & Lewis F.M *Journal of Psychosocial Oncology*, Vol. 16(2) pp. 25-43	1998	Mothers' Stories of the School-Age Child's Experience with the Mother's Breast Cancer	Maternal perceptions of children	Qualitative	8-12	Mother's viewpoint only
Zahlis, E.H., *Oncology Nursing Forum*, Vol. 28, No. 6, pp. 1019-1025	2001	The Child's Worries About the Mother's Breast Cancer: Sources of Distress in School-Age Children	Retrospective	Qualitative, descriptive	8-12 at parental diagnosis; 11-18 at interview	Retrospective approach limits value. Reassurance not necessarily sufficient

Appendix Two: Information Sheet (child)



Information Sheet

My name is Gillian Chowns and I am a social worker with the East Berkshire Macmillan Team and I am also a University lecturer and researcher.

Because your Mum/Dad is ill, I am hoping you will be able to help. Together with some other adults I am helping a group of young people to make their own video about what it is like to have a parent who is ill, and what are the best ways for others to help the family. We are going to meet about 6 or 8 times and it will be up to you and the other young people to decide exactly what you want to go into the video. There will be lots of chances at each meeting to decide what to say and do, and what should be filmed.

When we have finished you will be able to watch all the tape that has been recorded, so that you can then decide what to keep in and what to destroy.

We will not keep in anything that you don't want shown in public.

Sometimes it can be upsetting to talk about difficult things, but many young people I have worked with also say that it can be a help to talk to someone outside the family – especially other young people in the same situation. We also hope that when other adults see the video and hear what you have to say, they will listen and take notice of your opinions. We are making the video especially for families like yours, where someone is ill, but anyone will be able to buy a copy. This means that other people will know your name and see you on the film, but they won't know your surname or where you live. We may take quite a lot of film, but we will only use the bits that you give us permission to use.

If you want to talk about this more, you can contact me on 01753 860441 and I will be happy to answer any questions.

It is up to you to choose; you don't have to join the video team. If you don't – or if you change your mind in the middle and want to leave – you can still get help if you want to talk about things with someone privately.

We will not tell your parents or anyone else what you say in the meetings – but of course, they will be able to see the finished video.

You will need some time to think about this – and to talk to your parents if you want to – so we will not ask for a decision for at least 3 days. If you do decide to be part of the project, please sign the form below.

We hope that there will be between 6 to 10 people in the Video Team. Our plan is to meet at King Edward VII Hospital, starting on Saturday 1st March and if you need help with transport, we will try to arrange that. It will not cost you anything.

At the end of the project, you will have your own copy of the video to keep.
I am working at the University of Southampton, which is supporting this research. It has also been approved by an Ethics Committee. The video will be shown to a variety of people including academics, social workers, nurses and teachers, but its most important audience will be other families facing similar situations to your own. We hope that it will help them to find good ways of helping each other – that is why we are doing this research.

Thank you very much for reading this. Please contact me if you want to know any more before making up your mind.

Gillian Chowns
Senior Social Worker
Macmillan Palliative Care Team

01753 860441 extension 6137

Appendix Three: Information sheet (parent)

"The Video Team" Research Project

My name is Gillian Chowns and I am a senior Social Worker with the East Berkshire Macmillan Palliative Care Team, and also a University lecturer and researcher.

As part of a research project towards a higher degree (Ph.D) I am helping a group of young people to make their own video about what it is like to have a parent who is ill, and what are the best ways for others to help the family. We are going to meet about 6 or 8 times and it will be up to the young people to decide exactly what they want to go into the video. There will be lots of chances at each meeting to decide what to say and do, and what should be filmed.

When we have finished they will be able to watch all the tape that has been recorded, so that they can then decide what to keep in and what to destroy. We will not keep in anything that any one of them do not want shown in public.

In view of your/your partner's illness, we would like to ask your child if he/she would like to take part in this research project and become a member of the Video Team. As your child is under 16 I am also asking for your consent to his/her participation.

You may be concerned that your child might find it upsetting to talk about difficult things, but in my thirty years' experience of working with children, many of them say that it can be a help to talk to someone outside the family - especially other young people in the same situation. We also hope that when other adults see the video and hear what they have to say, they will listen and take notice of their opinions. We are making the video especially for families like yours, where someone is ill, but anyone will be able to buy a copy. This means that other people will know your child's first name and see them on the film, but they will not know the surname or where you all live. We may take quite a lot of film, but we will only use the bits that the children give us permission to use.

If you would like to discuss this further, you can contact me on 01753 860441 and I will be happy to answer any questions.

It is up to your child to choose whether to join the video team. If they don't - or if they change their mind in the middle and want to leave - they can still get help if they want to talk about things with someone privately.

You will not be told anything about the meetings, as the full contents will remain private and confidential. However, you will, of course, be able to see the finished video, which will contain only the material that the young people are happy to make public.

As you may need some time to think about this we will not ask for a decision for at least 3 days. If you are willing to give your consent, please sign the form below.

We hope that there will be between 6 to 10 people in the Video Team. Our plan is to meet at King Edward VII Hospital and if your child needs help with transport, we will try to arrange that. It will not cost you anything.

At the end of the project, your child will have his/her own copy of the video to keep.
I am working at the University of Southampton, which is supporting this research. It has also been approved by an Ethics Committee. The video will be shown to a variety of people including academics, social workers, nurses and teachers, but its most important audience will be other families facing similar situations to your own. We hope that it will help them to find good ways of helping each other - that is why we are doing this research.

Thank you very much for reading this. Please contact me if you want to know any more before reaching a decision.

Gillian Chowns
Senior Social Worker
Macmillan Palliative Care Team

01753 860441 extension 6137

Appendix Four: Consent Form (child)

CONSENT FORM

I agree to take part in the Video Team research project.

I understand that I can change my mind at any time.

I also understand that I can refuse to have any film featuring me, that I do not like, included in the finished video.

I realize that when the video is shown in public there may be some people who will be able to identify me and my family.

Signed

Date

Appendix Five: Consent Form (parent)

CONSENT FORM

I give my consent for ….

to participate in the Video Team project.
I understand that the contents of the sessions will remain confidential and will not be discussed with me. However, I also understand that material from these sessions will appear in the final video, which will become available to the general public.

Signed: Date

Appendix Six: Co-researcher details

Name	*Gender and Age*	*Status*	*Sick parent*
Jack	Male 7	Sibling	Mother
Becky	Female 10	Sibling	Mother
Laura D	Female 10	Sibling	Mother
Rachael D	Female 11	Sibling	Mother
Megan D	Female 14	Sibling	Mother
Laura C	Female 11	Only child	Mother
Gemma	Female 14	Twin	Father
Natalie	Female 14	Twin	Father
Ellis	Male 15	Only child	Mother

Young people

Jack, aged 7; brother to Becky, aged 10. Father and mother separated. Jack is living with his seriously ill mother, but due to move to his father's home fifty miles away, to join father, step-mother and two step-siblings. Attends every session

Becky, aged 11; sister to Jack, aged 7. Also living with mother, but due to move to father and step-family. Attendance at project sporadic.

Laura D, aged 10; youngest of the D siblings. Lives with siblings and mother and father; mother seriously ill. Does not discuss her feelings but committed to the making of the video. Misses one session because of prior engagement.

Rachael D, aged 11; middle, but smallest, of the D siblings. Attends every session. Close friend of Becky.

Megan D, aged 14; eldest of the D siblings. Close friend of Laura C. Misses one session.

Laura C, aged 12; only child, living with ill mother. Parents separated, father in Australia, mother a New Zealander currently resident in UK. Close friend of Megan.

Gemma, aged 14; twin to Natalie. Living with parents. Father white British, mother Japanese. Father seriously ill. Missed one full session

Natalie, aged 14; twin to Gemma. Living with parents. Father white British, mother Japanese. Father seriously ill. Missed one full session

Ellis, aged 15; only child living with his ill mother. Father separated, but visiting. Attended every session.

Facilitators

Sue; specialist palliative care social worker in a multi-professional palliative care team (hospital and community). Social worker to three of the young people.

Gillian; specialist palliative care social worker in a multi-professional palliative care team (hospital and community). Senior Lecturer in palliative care. Project leader. Social worker to four of the young people.

Alison; social worker, counsellor and bereavement officer in a hospice.

Nick; participatory video expert.

Appendix Seven: Ground rules

Have fun!

Listen to each other – no interrupting!

Laugh with each other, not at each other

It's OK not to agree

Change groups each week

Confidentiality – don't tell anyone outside the group what anyone else inside the group has said

Respect each other

Have small groups –they can decide

Keep to time

Appendix Eight: Dissemination

DISSEMINATION

Event	***Activity***	***Scale***	***Participants***	
July 2003 International Visual Sociology Conference	Presentation - 20 mins	International	GC, AJ and Ellis	
Sept 2003 PQ course, Reading University	Presentation - 45 mins	Local	SB	
Sept 2003 Practice Development Unit Assessors, Ascot	Presentation - 30 mins	Local	GC, SB, AJ, Gemma, Natalie and Rachael	
Sept 2003 AHSPCSW conference	Presentation -30 mins	National	GC	
Nov 2003 Launch John Lister Postgraduate Centre, Slough	Presentation etc	Regional	GC,SB,AJ and Ellis, Rachael, Gemma and Natalie	
Nov 2003 Macmillan Conference	Presentation -20 mins x 2	National	GC,SB, and Ellis	
Nov 2003 Cancer Conference	Presentation - 30 mins	Local	AJ, GC	
Dec 2003 Reading University	Lecture - 75 mins	Local	GC	
Feb 2004 Oxford Brookes - R84	Lecture - 90 mins	National	GC	
Feb 2004 Oxford Brookes - 1812	Lecture - 1 hour	Regional	GC	
July 2004 Death, Dying and Bereavement Conference, Sheffield	Presentation	National	GC, AJ and Ellis	