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At the Edge: Negotiating Boundaries in Research with Children and Young People

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Abstract: A research study of children and young people affected by parental HIV in Scotland provides the vehicle for a discussion of some of the complex issues at the heart of qualitative research. The research team sought to conduct a study which would be inclusive and empowering for those children and young people and their parents who took part. But in carrying out research on such a secret and stigmatised subject, we found ourselves caught in the middle of competing requirements of confidentiality and openness, protection and autonomy, sponsorship and independence. We conclude that our study, by nature of its subject and subjectivities, illuminates dilemmas which cannot be resolved simply by constructing better protocols. They are central to the research process, and their partial resolution demands continuous negotiation between the researchers and the participants, and also the other stakeholders. In these complex circumstances the process of individual reflexivity can be usefully enhanced by a team approach.

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1. Introduction

This paper uses a case study of a research project with children and young people in Scotland to explore some of the complex practical issues at the heart of qualitative research. It does not aim to develop methodological theory: rather it focuses on how researchers consciously used a reflexive approach throughout the study and how that approach had an impact on the research process and the outcomes. [1]

The research project centred on exploring the experiences of children and young people with a parent or carer with HIV illness. HIV and AIDS remain a highly secretive and stigmatised subject (BOR & ELFORD 1998) and as a consequence, our research carried with it particular demands and constraints which had an impact throughout the research process. We will examine this in three stages: firstly, planning and preparation for the research interviews; secondly, the interviews with children and young people; and thirdly, dissemination of the research. At each of these stages researchers had to negotiate boundaries of talk and actions with participants and stakeholders and at each stage the process was considered "reflexively", that is, it was written up and discussed by the team: therefore analysis and interpretation of the "data" was an integral part of each stage: analysis did not constitute a separate stage and reflexivity was a team affair rather than an individualised exercise. Before discussing these three stages, however, we will outline the situation for children and young people affected by parental HIV in Scotland. [2]

2. Children and Young People Affected by Parental HIV in Scotland

Most recent estimates suggest that there are over 700 children and young people in Scotland who have a parent with HIV (INGLIS & MORTON 1996). HIV remains a potentially fatal disease. However, the introduction of combination therapies in the late 1990s has altered the course of HIV progression in the developed world, so that for many people, HIV has become a long-term chronic condition (BRASHERS et al. 1999). A significant consequence of this change is that the numbers of children living with parents affected by HIV is growing: parents with HIV are living longer; parents with HIV are having more children; and transmission rates are rising in the heterosexual population (SCIEH 2002). [3]

Our study developed out of a recognition that while there had been extensive research interest in the UK on children infected by HIV (e.g. BATTY 1993, HONIGSBAUM 1991, MELVIN & SHERR 1993), and on adults affected by a partner's HIV infection (e.g. NIVEN & KNUSSEN 1999, REYNOLDS & ALONZO 1998), there had been no research into whether and how HIV affected the lives of children and young people with a parent or carer with HIV. In discussion with practitioners, a research team was formed and it was decided that a Scottish study should be undertaken. Reflecting our interest in and commitment to child-centred research and children's rights, it was agreed that the study should focus on the views and perspectives of children and young people (ALDERSON 1995, PROUT & JAMES 1997). The 30-month research project funded part-time by the

Community Fund and jointly managed by Children in Scotland and the University of Edinburgh's Social Work Department began in 1999 with three aims: to explore the impact of living with a parent with HIV on children and young people; to find out what social supports these children and young people draw on; and to examine their perceptions of services they currently use or have used in the past (both adult-centred and child-centred services) to find out what (if anything) has made a positive difference in their lives. [4]

3. Stage One: Planning and Preparation for the Research Interviews

Because of the sensitive nature of the research, planning and preparation for the interviews with the children and young people was a much-discussed and deliberated process. As members of the research team we were conscious that we brought along our adult memories of personal childhood experiences of parental illness, and to acknowledge this reflexively and to make these experiences apparent to each other, we all wrote short personal histories describing our childhood memories of parental ill health, which we then shared and discussed. [5]

Having reviewed our own positionality in terms of past experience, our goal was to involve children and young people in the design and planning of the research but in order to achieve this, we found that first we had to negotiate with two groups of adults, the professional workers and the parents. In practice, two major factors outside our control affected our ability to make contact with children and young people affected by parental HIV: whether parents had told their children of their HIV diagnosis and whether the family used HIV support-services. The research team made the decision that we would only speak with children and young people who had been told of their parent's HIV illness, and were thus able to give what we deemed informed consent to an interview which related to parental HIV. This, however, led to another set of dilemmas: what had children and young people been told, how much did they know and how much did they understand? This problem lived with the team throughout the research. [6]

We also made contact with other professional researchers, particularly those experienced in carrying out research with children (THOMAS & BECKFORD 1999, THOMAS & O'KANE 1998), and developed a protocol which became the basis on which we could explain to ourselves, and others, why we were acting in certain ways. Experience has since shown us that although extremely useful, the guidance was not able to remove some of the tensions and ambiguities in the research, as we have explored in another paper (CREE, KAY, TISDALL & WALLACE 2002). Throughout the project we maintained contact with other researchers, measuring our interpretations against other people's findings, and interrogating the differences: where and how did our findings and interpretations differ? Were differences due to researchers' methodology or theoretical stance? Did we have evidence to justify our interpretation? [7]

3.1 Negotiating with the adults—professionals and parents

Building and maintaining relationships with professional workers in the HIV field was essential to the research project. It was clear from the outset that although this research study had grown out of concern shared by practitioners and researchers alike, we would nevertheless have to "sell" the research. We invested time in completing extensive forms to submit to Medical Research Ethics Committees, in the expectation that workers in the medical setting would be able to pass on the invitation to patients to participate in the research. We were required to show that we understood medical concerns and ethical perspectives within medicine: we also had to explain, and convince the members of the committees that we brought other ethical concerns and social perspectives to the work, and we had to demonstrate our particular expertise in working with children. Our identity as "researchers" was challenged and scrutinised—were we sufficiently professional people to be allowed to work with children? We were pressured into becoming "experts" despite our commitment to a more participatory style of working. [8]

We also had to convince the wider HIV field in Scotland that we were "bona fide" researchers with competence in, and a commitment to our research. There are particular issues associated with research into HIV in Scotland which inevitably exacerbate difficulties with access. Because the numbers of people infected by HIV overall in Scotland have been relatively small, and because HIV has centred on the intravenous drug-using community in central Scotland (ROBERTSON et al. 1986), there is a small group of people who have been researched over and over again, by successive generations of medical and social researchers since the 1980s. Some of the children and young people interviewed had been part of previous research and had certain expectations of the researchers and the research process. Moreover practitioners in the HIV field have become quite protective of the people with whom they work. They expressed a feeling of distaste for those who are seen "to parachute" into this area of work for short periods; and their regular challenges felt threatening to the researcher who was working on a short-term contract. [9]

As members of the researcher team, we consciously approached professional workers in different ways. Helen, who was new to HIV, worked to find out as much about HIV as possible from the people "on the ground" while exchanging with them her knowledge drawn from previous experience of research with children. She did not pretend to have knowledge about HIV which she did not have; she attended seminars, read widely and built good working relationships with people throughout the HIV field. She was then able to ask "naïve" questions. For Viviene, who had worked with families affected by HIV in the 1980s, it was necessary to build on existing contacts and remind others about her long-standing interest in this area. [10]

The research team sought to show that they were committed to working cooperatively with professionals and parents, by building up relationships of trust and demonstrating that the research findings should be of interest to those living and working with HIV. One key mechanism for this was the Research Advisory Group. In addition to attending regular meetings, members took an active role in supporting the work of the research team, and indeed were considered to be partners rather than simply advisers (BARTUNEK & LOUIS 1996): they read reports and questioned researchers where reports did not match up with their experience in the field. This sometimes showed that the researchers were too much influenced by their own experiences but at other times, it lead the researchers (and members of the advisory group) to new understandings. [11]

Having established lines of communication with professional workers, it was then possible for us to make contact with parents. We found that parents were more likely to be open to getting involved in the research project when a voluntary HIV worker was known to the family, and had worked with the child or young person, discussed the research with the family and introduced the researcher to the family (CREE et al. 2002). So any early presumption that we could distance ourselves from the agencies working with the families had to be discarded: the agencies became active partners in the project. This meant that the research team had to take on the responsibility to openly acknowledge that this relationship will have affected the findings from the project. [12]

3.2 Negotiating with the children and young people

Children and young people were encouraged to take an active part in deciding the arrangements for the research meeting: where it would take place and when, and who should be there; and this led to some unanticipated outcomes. Some children told the researcher that their social worker sometimes took them for a burger meal, and they asked if Helen would do likewise. Even though she had strong personal reservations about eating in multi-national fast-food chains, Helen did not feel it appropriate to bring this issue into the negotiation with the children and young people. In addition, some children noticed that Helen drove a brightly coloured convertible car. Although she had a self-imposed rule of never taking the hood down during working hours, the children and young people, of course, wanted the hood down, no matter the weather. So the route of the journey to and from the interview also became part of the negotiation for a few of the participants and the researcher was drawn into the children's enjoyment of the whole experience. The research team took responsibility to ensure that these arrangements were not used as inducements to children to participate in the research (SCOTT 2000). However we agreed to accept that, if our attempt to be more child-centred was to be well grounded, we would have to negotiate around issues that were seen as important by the children and young people. There is always a tension for the individual researcher in making the effort to enter into the subject's world and then deciding how far to step into that world: in this project that decision on how to balance these tensions was shared by the team. [13]

4. Stage Two: The Research Interviews

4.1 Environment

Most researchers have in their "mind's eye" the kind of environment that they would like for conducting an interview with the child. It will be warm but not too hot, light and airy with outside views, quiet without interruptions, be child centred and contain appropriately sized, comfortable chairs, a box of toys, posters or drawings by children, up-to-date children's magazines and relevant information leaflets written for children and young people (e.g. THOMAS & BECKFORD 1999, THOMAS & O'KANE 1998). [14]

In practice, although many interviews in this study were conducted in a pleasant office in a child-focused organisation, some interviews were conducted in far from ideal settings. Some children and young people chose to be interviewed at home, in their bedroom. Others chose to be interviewed in offices where they had been before, offices which were over-heated and adult-centred; and some had no windows and the doors let out onto noisy corridors. However in some noisy settings the children and young people were quite at ease whereas the researcher was uncomfortable. Helen felt an added responsibility when the interview took place in a playroom which the child was likely to use in the future: that room needed to remain a safe place for the child. [15]

But it is important to acknowledge that even the "pleasant office" threw up problematic issues. This was in the researcher's office building where she felt at home in the known environment (making her more relaxed) but this also increased her privileged position of authority in contrast with the child's. Moreover, this setting could have compromised the promise of confidentiality given to the child, as other staff in the organisation knew that the researcher worked solely on the project with children whose parent or carer was HIV positive. This research venue was also, significantly, a predominantly "adult space", even though in the context of a child-focused agency. So the setting for the interview had the potential to produce a series of complex affects on the interaction between the participants in the interview in the short term, and in the long term, both practically and on the potential for theory building. [16]

4.2 Interview beginnings

The researcher was careful to plan an introduction to the interview, going over with the child again the aims of the research, the importance of the child's view, the voluntary nature of participation and issues related to promises of confidentiality and anonymity, including its limitations under child protection legislation. In the initial stages of interviewing, the introduction seemed to the researcher to take up too much of the precious time available for the interview, and Helen was afraid that the children might become bored before they had a chance to speak. However children and young people did listen, and some used the time to assess how much they could trust the researcher to treat their views with respect. In reviewing the interviewer's concerns, the research team reinforced the commitment to this phase of the interview by agreeing that children should be invited to explain why they thought they were there. It was quickly apparent that where children were given time and encouragement to give feedback on their understanding of the purpose of the research, including the central aim to learn of children's and young people's experiences of living with a parent or carer who is HIV positive, the relationship between child and researcher felt more secure and the interview was better focused. [17]

To reinforce the message that participation was voluntary, Helen also spent time at the beginning of each interview showing the child how they could terminate the discussion or the recording at any time, by touching the card with the red "stop" sign or by pressing the stop button on the tape-recorder if they felt unable to say that they did not want to continue. None of the children used the "stop" card but one child switched off the tape-recorder to talk about a personal issue that she did not want recorded. Several children were fascinated by the red lights that flashed as the tape recorder registered the recording, and snapped their fingers to make it flash more. Others requested to listen to their recording for five to ten minutes at the end of the interview. (None asked for a copy of the recording and we did not offer one for fear that the confidentiality promised to the child might be broken if the tape fell into the wrong hands.) So the pressure of time was felt by the interviewer who was drawn into the children's enjoyment of a new experience but, at the same time, she was conscious that for the business of the project to be achieved, she had to achieve some time where the children were willing to talk about their experiences of parental HIV. [18]

4.3 Interview tools

The research team felt the pressure of their adult sensibilities when it came to a design for the research exchange that would allow a child's subjective experience to shine through the adult-designed encounter. We designed a topic list to guide the interview conversation. We also used several simple games as tools to facilitate communication. The interview plan incorporated some writing, some drawing, a simple game for younger children, a set of topic cards for older children, and a group of hand puppets, as we wanted to give participants some choice and control over how the interview was conducted (O'KANE 2000). On the whole, the younger the child, the more they enjoyed the change of pace between talking and doing. [19]

Younger children were invited to draw a picture of their family: this led children into a discussion with the researcher about who should be defined as 'family'. Many children declined to do a drawing; some said they were no good at drawing, others made it clear that their way of drawing took time and they could not see the point of doing that in the context of the interview. All the reactions were accepted by the researcher as the point of the drawing was not to produce images for interpretation but to facilitate communication about family issues. Children's drawings are acknowledged to be too complex and too inherently ambiguous to be reliable indicators of the emotional experiences of the children who drew them (THOMAS & JOLLY 1998, BACKETT-MILLBURN & MCKIE

1999). In the early interviews, the researcher asked children to cut up the drawings of the individual family members and rearrange the figures to represent closeness between family members, but this request was not repeated in later interviews as children said did not appreciate being asked to cut up their drawings. [20]

The researcher sought to be alert to children's reaction to the use of games. Some children were clear in their decisions to use or not use certain games: others were more tentative in their choices. The researcher felt confident to offer younger children the opportunity to draw and do games and to invite the older participants, who were more like young adults, to talk in a more formal 'research interview' style. It was more difficult, however, with young people in the 11 to 14 year old age-range, as they might be offended by games that were too childish but were equally put off by a formal "talk session" which touched too many painful subjects (SIEGEL & GOREY 1998). Other researchers have attempted to resolve this issue differently. In a similar study in South Africa, the researcher presented the children with pictures and vignettes which allowed them to make up a story based on their experiences, or to explicitly talk about the similarities between the scenario in the pictures and their own experience (STRODE & GRANT 2001). [21]

4.4 Acknowledging adult-child power relations in talking about issues

Children and young people are expected to answer questions posed by an adult: this is part of their daily experience (ALANEN 2001). As we wanted to avoid giving the impression that we expected answers to all our questions, we had to ensure that children and young people had sufficient space and time within the interview to decide whether to talk to the researcher about an issue or not. When a child or young person fell silent in response to a question, changed the subject abruptly or moved themselves to another part of the room, the researcher accepted that this was one way of showing their reluctance to discuss that particular issue. During the interview the researcher was not able to foretell how a child was going to react and so had to be prepared to react to the child's lead: this was a long way from the objectively administered questionnaire. [22]

Younger children tended to give shorter answers in response to questions and were happier talking about their activities at home and school, especially their activities with their friends. In comparison, young people in their late teens were more able to talk about parental HIV and how that affected their relationships and their activities. As we tried to give the children and young people some control over the interview and the issues discussed, each interview was different in terms of structure and content. Some interviews were short while others were long: generally the interviews with older participants were more detailed. Each interview was taped and most were transcribed by Helen to give her time to review and reflect not only on the content but also on the dynamics of the interview: Viviene also listened to the tapes. The transcripts were reviewed with other members of the research team and advisory group who provided feedback. Helen used some of these recommendations to improve the interview interaction, rejecting only those which would have moved the interview away from its research orientation toward a therapeutic intervention. [23]

4.5 Taboos and secrets

The researcher had to face up to the fact that if the team was to learn more about children's experiences and about whether current service provision was meeting their needs, the researcher had to ask children and young people a series of questions about their lives and invite them to tell us whether and to what extent their lives had been affected by parental HIV. As an adult putting these questions to a child, the researcher often felt uncomfortable, and it became important to analyse the data to ascertain whether there were good "objective" reasons for the researcher to be feeling discomfort which were indicative that she was breaching, rather than negotiating, a boundary. After reviewing initial interviews the researchers noted that we were asking the child to talk:

- about a third party,
- about their parents,
- about the effect of their parental ill health on their lives,
- about the effect of parental HIV on their lives. [24]

These questions seemed to break several taboos. We were asking children to talk about the impact of someone else's illness (and in this case their parents), and this could be interpreted as an invitation to disregard their feelings of loyalty to their family. We were also talking to them about the messy practicalities and difficult emotional responses of coping with chronic illness in the family, and not just any illness, but HIV illness. And in asking them to talk HIV, we were asking them to tell us about an illness which carries sexual connotations. So there were valid "objective" reasons for the researcher's feelings of discomfort. [25]

We needed to avoid any suggestion that we wanted the children to be disloyal, to "tell tales" about home life. Helen spent a great deal of time in the interviews talking with children about things that were important to them, because we wanted to set their experience of parental HIV within the context of their experience of life in general. We wanted to understand what was important to them as individuals; how they understood their world of family, school, friends and community; what meaning they placed on family life and how that fitted in with their life outside the home: we did not want to erase the ordinariness of their everyday lives (SANDBAEK 1999). We tried to tap into their subjective experiences as we anticipated that we would be better able to understand how the children coped with parental illness if first we had some understanding of their perspectives generally. Despite our focus on the child's perspective and the child's experience, the researcher continued to feel uncomfortable asking children and young people about the effects of parental ill health on their lives. But an analysis of the data showed that this discomfort of "talking" about parental HIV illness was a reflection of the feelings displayed in the children's narratives when they spoke about who had the right to talk about the parental illness

> "[He's] the person I cannae talk to cos I know it's him that's got it and that, so just in case I say something that he doesnae want me to say, so I don't talk to him aboot it at all." [26]

In our ongoing analysis of interview data it became obvious that we had to focus clearly on the fact that although the children and young people don't "own" the illness, they do "own" the experience of living with a parent or carer who is HIV positive. Many of the children spoke openly about the pain of learning that their parent had a life-threatening illness. Like other studies of children living with chronic illness, they spoke of the anxiety of living with uncertainty; living with a parent who can need urgent hospitalisation when they are least expecting this (ALTSCHULER 1997). Others spoke movingly about the deterioration in health and subsequent death of a parent. As has been reported in other studies (e.g. ALDRIDGE & BECKER 1993), the children and young people in this study did not define themselves as "carers", although most had to help out at home when a parent had a bout of illness. The researchers wanted to find out how much children helped in a practical way, how did this affect their other activities and how did it affect them emotionally. Responses to all these questions demand an assessment from the child about the trustworthiness of the interviewer: how is she likely to respond to their description of messy illness, of parent's distress, of the effect on younger siblings? The researcher has to decide whether the child's distress is due to the pain of experience or to the pain of discussing it. If the purpose of the interview had been therapeutic then working through the pain would be part of that process but in the research interview we had no such remit. Our purpose was to listen to the children's narrative and to try to understand their perspective of everyday life with their parent or carer who had HIV illness. However we were aware that by talking to the researcher, their emotions might become overwhelming after the interview was over: we made sure that all the participants in the study knew how to contact the specialist HIV workers, should they want help in coming to terms with the pain of their experiences of living with parental HIV. [27]

Throughout the time of the project and beyond we had to negotiate and re-negotiate research boundaries with participants and stakeholders. In the practice of communicating with the children and young people Helen had to decide what could be asked and what should be left unsaid. In dealing with the challenging issues associated with parental HIV, the members of the research team had to constantly explore and review whether Helen had, in negotiating with participants made too many decisions about the boundaries, collaborating in the construction and maintenance of an area of unsaid issues which were too important to ignore. In negotiating boundaries with children the task was made more difficult by the adult researcher's awareness that the children were still learning how to decide what can be said. Moreover only the adult researcher is aware of the process whereby the sayings of the children and young people will be objectified to be made public in the dissemination of research findings. [28]

The majority of children who participated in the research were aware that they may not talk about the issues around parental HIV in everyday life:

> "You have to watch who you speak, choose carefully who you speak to cos it's a more touchy subject, but it is hard for people to understand if you know what I mean. It's like they dinnae understand what you are trying to say to them. It's hard to explain, you're trying to explain them a bit but they dinnae understand it, if ye know what I mean. It's hard to speak to them aboot it because, it's like, they are scared of it, if ye ken what I mean. It's no they are scared of the actual thing, jist like they are scared of what you might tell them, if that makes sense." [29]

The stigma associated with HIV is unlike the stigma of other chronic illnesses. In asking children to talk about parental HIV, we considered that we might be breaking what is arguably the biggest taboo of all, because of the sexual connotations associated with HIV. It is known that children find it difficult to think of their parents as sexual beings; that they are brought up in the developed world to be "quarantined" from adult activities such as sexual behaviour (ENNEW 1986). There are hints in our study that children have some awareness of the complexity of sexual issues for parents. Some adolescent boys reported that they become enraged when others "slag" their HIV-positive mother and even get involved in fights to "protect her honour": some adolescent girls reported that they took a proactive role in rejecting their mother's new partner following the death of their father. However, in some cases it may be the researcher who is most aware of the adult taboos associated with a sexually transmitted disease whereas many children are much more aware of another kind of taboo—their need to keep the illness secret because of other children's fear of contact with anyone living in a family affected by HIV. Although HIV is known as a sexually transmitted disease, many fear that the infection can also be spread like other more common viruses, by contagion. So for many children and young people who participated in the research their fear of being ostracised by their peer group may be more real than their thoughts about their parent's sexuality. The identification of the taboos affecting the interaction between the children and young people and the researcher during the interviews was an early analytic task; using the strong feelings engendered by the interview experience Helen and Viviene explored how the interviewer's adult understanding of taboo was not necessarily shared by the children and young people. The analysis of our adult understandings had to be discussed and laid out; and then set against the tapes and transcribed words of the children and young people, taking account of the adult feelings engendered in and by the interview. [30]

So given the complex nature of adult attitudes and fears about HIV which the researchers brought to the project along with their professional concerns about working with children and young people, we began to realise that we needed to be extra careful in our attribution of meaning to pauses and disruptions in the flow of the research interview. Helen accepted that when a child did not answer a question that subject was closed, and it was our initial thinking that the reason for a child's silence was that the subject matter was too painful. But from an analysis of the texts it seems that there could be a variety of reasons for unanswered questions:

- They do not understand the question but do not want to appear stupid;
- They do not see the relevance of the question;
- They do not follow the interviewer's thinking but do not know how to say that;
- They may fear that they will not be believed sympathetically, especially if they have had previous bad experiences of talking about parental HIV;
- They do not want to disclose what is considered "private"
    - Things that might reflect badly on their family;
    - Things that might make them seem disloyal to the family;
    - Things that would expose their own confusion;
    - Feelings that they keep suppressed. [31]

Initial interpretation of interview data suggested to the research team that when children found a subject too painful to talk about they tended to change the subject abruptly. However further analysis suggested that sometimes the apparent change of subject may have reflected the reality of the child's experience. For example, one child who had been speaking about the final stages of her mother's illness apparently changed the subject to talk about a trip to the fair immediately after her mother's death. Initially the researcher interpreted this as an indication of the child's pain, but for the child this was how events unfolded as she did not take part in the funeral. Some of the pain during the interview was felt by the interviewer listening to the child's story and this may have been projected on to the child, thereby distorting the interpretation of the transcription data (BOURNE 1998). [32]

At other times during the interviews children responded to questions with "I don't know". Our analysis of interview data showed us that this response could have five meanings:

- I am not able to think about that issue,
- I am not able to talk about that issue,
- I am not willing to think about that issue,
- I am not willing to talk about that issue,
- I do not know the answer to that question. [33]

The research team decided that such responses would be accepted at face value during interviews—that the child would not be asked to give further explanation on that issue, nor would they be put under pressure by leaving them in silence, as previous studies have shown that young people find such tactics to be oppressive. Sometimes, however the child did follow up "I don't know" with an immediate response, and in this case "I don't know" meant that they had not thought about the subject but given a few moments to think about it they could give an answer. [34]

Given the sensitivity of all the issues it was essential to analyse and review both the interview "data" and the interviewer's ongoing interpretations from the start.

After a few interviews had been completed, two of the research team, Viviene and Helen, started to develop a conceptual tree to aid the analysis and their interpretation of the data. Much of the value of the analytic tree lay in the insights gained from the discussion and argument around the construction of the conceptual tree, which included discussions about how meanings could be derived from the interview data. We used the Nudist programme to assist the analysis: Helen and Viviene worked together to develop a coding frame and then coded words, phrases and sections of all the interviews. The coding process was not seen as a true or final categorisation of data; rather it was used as a tool by the researchers to mark the parameters of concepts, as each perceived them and to aid further discussion and interpretation. Given the limited number of interviews and the reticence of some children to talk freely about their experience of parental illness the analysis did not attempt to create typologies. [35]

Given the small sampling frame we were unable to seek out families where children's experience might be different, to explore for "negative" or extreme cases. Moreover we were unable to compare all issues across all interviews because some children did not discuss some issues. The transcription of each interview was carefully read by each member of the research team; and the words, phrases and sections were coded individually by Helen and Viviene who noted down questions and ideas which occurred as they undertook this process. Items in each category of coding were compared across relevant interviews, taking into account the whole context of the interview. [36]

4.6 Emotion work in the interview

Sometimes the children's very simple description of how they helped to care for a dying parent took away the researcher's capacity to respond: the very simplicity of the child's story made the loss feel more real and painful to the researcher. Some children had experienced multiple loss through the separation of parents, the death of parents or the estrangement of families and siblings and mixed into the narrative were stories of loss of toys or pet animals. Most children and young people did not want expressions of sympathy as a response: it seemed to be sufficient that the researcher listened to their narrative. [37]

At times the researcher found it difficult to make sense of the difference between the child's presentation as a "normal" child and the real difficulties being faced by the family, for example, the young competent girl with the bright cheerful bedroom in a household with a dark overheated sitting room where the mother sat quietly, having been discharged from hospital and the father contemplated his admission to hospital the following day. Where does the researcher stand in making sense of the contrasting realities? (LEE-TREWEEK 2000, HUBBARD, BACKETT-MILLBURN & KEMMER 2001) [38]

The pain of coping with HIV illness was sometimes near to the surface during the telling of a child's story but on one occasion the pragmatic resilience of the child sustained the momentum of the interview. This young person who had helped her mother to care for her father through his deteriorating illness and to cope with his death and funeral, was now coping with her mother's faltering powers to care for her younger siblings. The pain of human relationships portrayed in the interview had a disturbing effect on Helen's emotions: the vividness of the child's story lives on in her memory (COFFEY 1999). And here the support of colleagues on the research team was important to help Helen to acknowledge these strong feelings and use them to add insight to the analysis. [39]

On another occasion, the researcher was not fully alert to the dynamics of the interaction; for example, when a young person was describing her anxiety about her mother's prognosis following a spell in hospital, Helen took on board the expression of anxiety to such an extent that several times in the continuing interview she suggested to the young person that various other events "must have made her worried?" So despite professional training and experience the researcher was not always aware of the effects of her emotions on the interview dynamic. [40]

It was important that the process of reviewing and analysing the interview data was an integral part of the interview period: the team had to ensure that they took account of the influence of the interviewer on each interview. This ongoing analysis did affect the dynamics of subsequent interviews in terms of Helen's awareness; for example, it was Viviene who noted that in the early interviews it was not only the children that seemed to have difficulty saying the word "HIV"; their reticence might be a reflection of Helen's discomfort with the word. However reflexive the individual researcher tries to be, they still remain unaware of some of the affects of their appearance, their behaviour and their reactions on the dynamics of the interview. The benefits of working as a team, sharing ideas from the literature as well as from the analysis helped to keep us alive to the affects of the researchers on participants. [41]

5. Stage Three: Dissemination of the Research

The dissemination period was an integral part in the design of the study; it was not an "add-on" at the end of the research period. Resources in terms of both time and money were allocated to dissemination, so that almost one-third of the researcher's time was spent on dissemination of research findings. Dissemination, or re-presentation, took place at three different, but overlapping levels: feedback to research participants—children and young people and their parents/carers; feedback to professional workers; feedback to the general public. At all these stages the research team discussed and reflected on the likely affect of different methods of (re)presentation. [42]

5.1 Feedback to participants

The research team aimed to encourage participant involvement in the dissemination process: it was important that young participants and their parents should not feel excluded from dissemination of information about themselves and families in similar circumstances. An A4 summary of the research findings in easily accessible language was posted to all the children and young people, with a separate copy to their parents and carers. All were invited to comment on the document and their experience of participating in the research. [43]

In recognition that young people would not respond to an invitation to sit and listen to a "presentation of research findings", the researchers invited participants to a dance workshop led by a professional dancer where they were encouraged to act out some of the feelings that the research had thrown up for them. Another young person agreed to be filmed in discussion with Helen, exploring some of the issues previously raised in the research interview. This video was shown at a seminar for professional workers where the young person attended and took an active part but with the added support of a local social worker. So although they retained responsibility for the machinery of dissemination, the research team involved children and young people as much as possible in the review and (re)presentation of findings. [44]

5.2 Feedback to professional workers

We designed the dissemination to involve professional people in the process. The research team invited policy makers and practitioners from education, health and social work to seminars in which the researchers presented locally based findings and engaged the workers in a shared task of producing a set of good practice guidelines for practitioners. The researchers did not attempt to claim authority for their research findings; rather they offered to share the findings with practitioners, using evidence-based research and practice-based experience to co-produce knowledge. [45]

5.3 Feedback to the general public

One of the most pressing concerns in the last period of the research project was how we should disseminate the research findings into the wider public domain. We were committed to ensure that the project had some demonstrable benefits for all children and young people affected by parental HIV. We therefore wanted to alert the public to the issues faced by children and young people while at the same time avoiding any presentation which constructed them as "victims" in the context of parental illness. We had to remain "true" to the children's narratives: they had presented themselves as normal children, with normal parents who happened to have a serious illness. [46]

We debated for a long time how children and young people's voices should be heard at the national conference which marked the end of the research project. We were wary of exploiting the goodwill of those who had taken part in the study and felt protective about exposing them to what might be the prurient interest of others—especially the media. We had all previously attended conferences where children and young people had made a "token" contribution, and we felt that whatever was planned needed to be meaningful. We invited parents and a voluntary support worker to a lunch-time meeting to explore these issues and give us guidance based on their experiences. [47]

Thus the research team in setting up a dissemination process had to release control of some aspects of the research project to involve parents and other professionals. However this did not mean that they could maintain a distanced position as "the researchers" and let others take responsibility for the dissemination. Their position as priviledged knowers in relation to the family experience of HIV was managed into and through their positions as academics and salaried researchers to extend this knowledge for the benefit of the young participants. [48]

Members of the research team were conscious that they felt protective of the children and young people interviewed, none more so than the interviewer who had met the children and remembered their individual narratives. However the children and young people had told their story and it deserved to be heard. The research team sought the support of the advisory group as they struggled to work through their feelings of conflict engendered by a sense of responsibility to protect the research participants and a desire to encourage and support participants, to empower them, to present their own story. [49]

How could we use the press to inform a wide readership of the difficulties experienced by families affected by HIV without exposing them to more abuse? Where were the boundaries between protecting the anonymity of research participants but still empowering their parents to speak out? We had negotiated with children and young people who had confided their experiences to us: could we negotiate with the press to represent these issues fairly so as to bring about change for all children and young people affected by parental HIV? [50]

One member of the research team, Viviene had developed trust with a personal contact in the media by engaging in a series of discussions which started long before the project reached the "dissemination" phase: Viviene was confident that this journalist understood the issues as construed by the team. However this did not dispel major feelings of anxiety about boundaries, confidentiality and research ethics with regard to other members of the press. We discussed our own positions and consulted our institutional press officers; we negotiated with, and advised parents and consulted a specialist press officer experienced in work with children: we sought support from members of the advisory group: and agreed that the anxiety we felt could not be objectively interpreted as being due to an overstepping of the boundaries. We realised ultimately that if parents decided to be interviewed by the press we had no control over this, and their willingness to be "shown" in this way supported our overall claim that there needs to be less secrecy about HIV because stigma thrives in an atmosphere of secrecy and shame. In some circumstances the parent's individual family story had as good a claim to being "knowledge" as the research (re)presentation of the anonymised views from their children. [51]

6. Conclusion

We wrote at the outset of this paper that the nature of our research project, focused as it was on a highly secret and stigmatised topic, and carried out with children and young people, raised specific issues and difficulties for ourselves as researchers. We have shown that there can be little objectivity in discussing the emotional experience of children and young people living with parental HIV and AIDS, and we have tried to acknowledge our role as major players in the construction of the research findings. [52]

This article documents that reflexivity was not an intermittent process for the research team, more a state of mind which demanded reflexivity in all three forms—confessional, intertextual and theoretical (MARCUS 1998 as discussed by ST LOUIS & BARTON, 2002). Reflexivity did not start with the interpretation of data but at the start of the project, when we wrote down our personal histories of experiences of parental illness, to share and lay bare the baggage which we were each bringing to the topic and which we expected to influence our thinking, our perceptions and our interpretations at all stages of the research. Our starting point was an awareness that both our perceptions and our interactions with participants would be affected by our positionality bounded by factors such as age, gender and class. [53]

We have intended to show how we acknowledged that we cannot avoid our subjectivities, past, present and future. We bring our past experiences with us, and that influences how we see and interpret our interactions as they take place; and during the course of the project our perceptions influence the interaction, and are influenced by the negotiation and interaction with participants and stakeholders. Moreover our expectations of the future influence how we act as contract researchers and academics—even as I write I have to consider how what we write might affect our future career prospects: not only does the argument have to interest academics and researchers, it must also be seen to fit the current discourse. [54]

We have argued that the process of reflexivity was made more apparent by the process of working as a team. At stage one, preparing and planning, and at stage two, the conduct of interviews and their analysis, we showed how our positionality as adults affected our interactions with participants and stakeholders and how we worked together to analyse and make transparent our subjectivities which affected our perceptions and interpretations of those interactions. We checked out our findings based on our interpretation of the children's narratives with the children, with their parents and with other professional workers. At stage three we argue that another dimension of reflexivity, which we might call "transflexivity", is required to describe how we attempted to allow the voice of the children and young people, and their families to be heard above the noise created by the researchers' interactions and the expectations and perceptions of the audiences. Overall, we have tried to show how our perceptions and interpretations were refined and adjusted in the interaction with participants, stakeholders and each other, and at the heart of the process, in the negotiation of boundaries with the children and young people. [55]

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References

Alanen, Leena (2001). Explorations in generational analysis. In Leena Alanaen & Berry Mayall (Eds.), *Conceptualizing child-adult relations* (pp.11-22). London: Routledge Falmer.

Alderson, Pia (1995). *Listening to children: Children and social research ethics.* London: Barnardo's.

Aldridge, Jo & Becker, Saul (1993). *Children who care: inside the world of young carers.* Loughborough: Loughborough University.

Altschuler, Jenny (1997). *Working with chronic illness.* Basingstoke: Macmillan.

Backett-Millburn, Kathryn & McKie, Linda (1999). A Critical Appraisal of the Write and Draw Technique. *Health Education Research*, *14*(3), 387-398.

Bartunek, Jean M. & Louis, Margaret R. (1996). *Insider/outsider team research*. Thousand Oaks, CA: Sage.

Batty, Daphne (1993). *HIV infection and children in need.* London: BAAF.

Bor, Robert & Elford, Jonathan (1998). *The family and HIV today. Recent research and practice.* London: Cassell.

Bourne, Jill (1998). Researchers Experience Emotions Too. In Rosaline S. Barbour & Guro Huby (Eds.), *Meddling with mythology. AIDS and the social construction of knowledge* (pp.90-103) London: Routledge.

Brashers, D.E.; Neidig, J.L.; Cardillo, L.W.; Dobbs, L.K.; Russell, J.A. & Haas, S.M. (1999). "In an Important Way, I Did Die": Uncertainty and Revival in Persons Living with HIV or AIDS. *AIDS Care*, *11*(2), 201-219.

Coffey, Amanda (1999). *The ethnographic self. Fieldwork and the representation of identity.* Thousand Oaks, CA: Sage.

Cree, Viviene E.; Kay, Helen; Tisdall, Kay & Wallace, Jennifer (2002). Research with Children: Sharing the Dilemmas. *Child and Family Social Work, 7*(1), 47-56.

Ennew, Judith (1986). *The sexual exploitation of children*. Oxford: Basil Blackwell.

Hertz, Rosanna (Ed.) (1997). *Reflexivity and voice*. Thousand Oaks, CA: Sage.

Honigsbaum, Naomi (1991). *HIV, AIDS and children. A cause for concern.* London: National Children's Bureau.

Hubbard, Gill; Backett-Millburn, Kathryn & Kemmer, Debbie (2001). Working with Emotion: Issues for the Researcher in Fieldwork and Teamwork. *International Journal of Social Research Methodology, 4*(2), 119-137.

Inglis, Sheila & Morton, Sarah (1996). *Children affected by HIV in Dundee, Edinburgh and Glasgow.* Edinburgh: Children in Scotland.

Lee-Treweek, Geraldine (2000). The Insight of Emotional Danger: Research Experiences in a Home for Older People. In Geraldine Lee-Treweek & Stephanie Linkogle (Eds.), *Danger in the field. Risk and ethics in social research* (pp.114-131). London: Routledge.

Marcus, George (1998). *Ethnography through thick and thin.* Princeton, New Jersey: Princeton University Press

Melvin, Diane & Sherr, Lorraine (1993). The Child in the Family—Responding to AIDS and HIV. *AIDS Care*, 5 (1), 35-42.

Niven, C.A. & Knussen, C. (1999). Measuring the Stress Associated with Caring for Clients with HIV/AIDS. *AIDS Care, 11*(2), 171-218.

O'Kane, Claire (2000). The Development of Participatory Techniques. In Pia Christensen & Allison James (Eds.), *Research with children. Perspectives and practices* (pp.136-159). London: Falmer Press.

Prout, Alan & James, Allison (1997). A new Paradigm for the Sociology of Childhood? Provenance, Promise and Problems. In Allison James & Alan Prout (Eds.), *Constructing and reconstructing childhood* (pp.7-33) London: Falmer Press.

Reynolds, Nancy R. & Alonzo, Angelo A. (1998). HIV and Informal Caregiving: Emergent Conflict and Growth. *Research in Nursing and Health, 21*, 251-260.

Robertson, J.R.; Bucknall, A.B.V.; Welsby, P.D.; Roberts, J.J.K.; Inglis, J.M.; Peutherer, J.F. & Brettle, R.P. (1986). Epidemic of AIDS Related Virus (HTLV-III/LAV) Infection among Intravenous Drug Abusers. *British Medical Journal*, *292*, 527-529.

Sandbaek, Michael (1999). Children with Problems: Focusing on Everyday Life. *Children and Society*, *13*, 106-118.

SCIEH (2002). *HIV/AIDS quarterly report to 31st December 2001.* Edinburgh: Scottish Council on Infection and Environmental Health.

Scott, Jacqueline (2000). Children as Respondents. The Challenge for Quantitative Methods. In Pia Christensen & Allison James (Eds.), *Research with children: perspectives and practices* (pp.98-119). London: Falmer Press.

Siegel, Karolynn & Gorey, Eileen (1998). Childhood Bereavement due to Parental Death from Acquired Immunodeficiency Syndrome. In Robert Bor & Jonathan Elford (Eds.), *The family & HIV today* (pp.262-272). London: Cassell.

St. Louis, Kathleen & Calabrese Barton, Angela (2002, September). Tales from the Science Education Crypt: A Critical Reflection of Positionality, Subjectivity, and Reflexivity in Research [40 paragraphs]. *Forum Qualitative Sozialforschung / Forum: Qualitative Social Research* [On-line Journal], *3*(3). Available at: http://www.qualitative-research.net/fqs-texte/3-02/3-02stlouisbarton-e.htm.

Strode, Ann & Grant, Kitty Barrett (2001). *The Role of Sigma and Discrimination in the Increasing the Vulnerability of Children and Youth infected with and Affected by HIV/AIDS* Arcadia, South Africa: Save the Children. Available at: http://www.savethechildren.org.uk/hiv/pdfs/stigmav2.pdf.

Thomas, Caroline & Verna Beckford (1999). *Adopted children speaking.* London: BAAF.

Thomas, G. & Jolly, R. Drawing Conclusions: A Re-Examination of Empirical and Conceptual Bases for Psychological Evaluation of Children from their Drawings. *British Journal of Clinical Psychology*, *37*, 127-39.

Thomas, Nigel & O'Kane, Claire (1998). The Ethics of Participatory Research with Children. *Children and Society, 12*, 336-348.

Thorne, Claire; Newell, Marie-Louise & Peckham, Catherine S. (1999). Clinical and Psychosocial Service Needs of Children and Families Affected by Human Immunodeficiency Virus in Europe. *European Journal of Public Health*, *9*, 8-14.

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