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Dealing with chaos and complexity: The reality of interviewing parents and children in their own homes.

Abstract

Creating an environment which is conducive for meaningful conversation is essential for qualitative research. The setting in which data is collected is critical for the quality of information gained as participants are more likely to open up and communicate if they feel safe, comfortable and relaxed. Our recent experiences interviewing parents and their children with Cystic Fibrosis in their own homes, have led us to conclude however, that interviewing people in their own social setting is messy and competes with methodological purity. Limited attention or print space is paid to this issue as evidenced by a review of recent research papers e.g. “13 individual interviews were undertaken”, (Badlan 2006), or at best: “carers were interviewed in their own homes”, (Lowton 2002). Attention needs to be given to the challenges social researchers face when interviewing people ‘out in the field’ hence, we beg the question:

How can we as researchers ensure methodological and ethical rigour in both conduct and process during an interview with individuals, when the baby’s crying, the dog’s barking, the courting couple are needing the sofa back and the front door bell is ringing?

We present two case studies of families with a child with a chronic illness, both of which highlight ethical dilemmas relevant to building a rapport, consent, confidentiality, issues of power and control, and authenticity of the data - all of which threatened the credibility and integrity of the research process. 236

Introduction

Interviewing children and families from a qualitative perspective has until recent times been largely avoided. Reasons given for this are that children lack social competence because of underdeveloped capabilities to recall credible accounts of their experiences (Hill Laybourne and Borland (1996), Morrow & Richards (1996) *in woodgate*). Other reasons offered are that researchers feel uncomfortable and lacking in the skills and language needed to interview children (Harden et al 2000). Furthermore accessing children as research subjects means wading through many layers of gatekeepers ; Local authorities, teachers, parents, and once access is granted issues of privacy and protection of the child can be problematic (Mauthner (1997). According to Scott et al (1998) *in Harden* children in western cultures are viewed as a protected species and Harden et al (2000) contend that this view extends to researchers as well as predatory adults.

The purpose of this paper is to share some of the challenges we as neophyte researchers faced and the subsequent lessons we learned when interviewing children and parents in their homes. We contend that the theory around methodological procedures (i.e. what one reads in research papers) and the reality -(what actually happens when carrying out research with children and families can be very different). This is in keeping with Irwin’s (2005) view that these issues -which we will go on to discuss- are seldom addressed in scholarly articles, rather;

“they are sanitised and hide the unique situations, dilemmas and practical sticking points involved in collecting data from children” (Irwin 2005, p822).

Background

The research in question was an eighteen month qualitative study, which evaluated from four different perspectives the effects of befriending on young people with cystic fibrosis, (MacDonald & Goulbourne 2007).

We interviewed children and parents individually (or together) in their own homes, and in addition interviewed the befrienders via a focus group. Finally we undertook individual interviews with some other key personnel (play therapists, education liaison personnel) who worked closely with the young people.

Our expectations as researchers in terms of the process of collecting data, through question and answer technique in a calm quiet environment that was time limited for thirty minutes were very far from the reality of what happened in practice.

We were naïve, assuming that our collective experiences of working with children and families and undertaking qualitative research with adolescents and adults would be sufficient. How wrong we were, but we had nothing to draw on to challenge these assumptions in terms of theoretical know how from either experienced researchers in this field or accessible literature. Hence the reason for this discursive paper in which we give an in depth account of our experiences of interviewing children with their families in their own home.

We hope to raise awareness for other researchers as to the difficulties and challenges that arose for us illustrated through two typical case studies. These challenges included; multiple interruptions, building rapport, consent and confidentiality and power and control.

Case Study 1

Joe is a nine year boy with cystic fibrosis. He is very active and described by his mum Jean as “a real live wire”, he needs constant attention and can’t sit still. He has a very limited concentration span and gets bored easily. He keeps well and has been hospitalised twice in the past year for courses of intravenous antibiotics.

He lives at home with his older brother and two parents. He and his brother fight constantly and jealousy and competitiveness are features of their relationship. They have a dog who barks each time the doorbell rings and the doorbell rings often! Dad works full time, mum is the principle carer and works part time 1 night per week in the local hospital. Caring is therefore her full time occupation.

Joe had his first befriender for three months, (“it just sort of fizzled out”) and now has Jake who’s been his befriender for about three months.

Joe and his mum were interviewed twice in their own home, one year apart.

During the second interview with Joe and his mum, there was a half hour period of constant interruptions. After the first few minutes Joe’s dad entered the room and joined in the discussion while at the same time having a separate conversation with Joe. Thereafter Joe’s brother entered the room and began asking questions about why I was there and what I was doing. The doorbell rang at least three times in quick succession and

consequently made the dog bark. Each time someone arrived at the door, (granny, befriender, brother's friend), Joe's mum excused herself and got up.

The comings and goings of different people in the room added to the time pressure of interviewing mum and Joe before the befriender arrived to take Joe away. We were not aware that Joe had a planned befriender visit at the same time as the interview, therefore time to collect worthwhile data was precious but our perception was that time was being whittled away by all the interruptions.

Multiple interruptions

This case study illustrates the difficulties we as researchers faced in terms of hitting reality head on where we had to quickly adapt to an ever changing environment, and had no time or opportunity to control a situation in order to achieve a "squeaky clean" methodological process. Nunkoosing (2005) suggests that a good interview should not be hurried, that the interview for research purposes is not an interrogation. However, this is all very well in theory, and in many ways illustrates our point. Research guidance at times does not prepare researchers for the harsh reality of being out there in the field, and time constraints for the researcher are an ever pressing stressor especially when the interview process is not going according to plan.

We hadn't prepared ourselves for the ensuing chaos of other peoples' reality derived from multiple interruptions out with our control. However, in accordance with qualitative research principles, multiple interruptions are part of the complex social reality of other peoples' lives.

Irwin and Johnson (2005) argue that rather than trying to control the environment we should acknowledge that these events are a contextual part of the child's social world, and that by altering this environment we may also be hindering the process of finding the child's authentic voice.

Analysing this chaotic data was an interesting experience! However this background data together with our field notes helped contextualise our interpretation of events at the analysis stage. We can see in retrospect the importance of capturing the reality of this family's life and were relieved that we had left the tape running. However at the time because the interview process was out of our control, for technical reasons the recorder was left switched on. Ethically we wondered if it was right to keep the tape running. For us as researchers issues regarding consent, confidentiality, participant welfare, rigour of the research and timing were all competing for priority.

Reacting to so many things concurrently has been described by Warr (2004) as an "intellectually demanding" experience (584) and a normal facet of the data collection phase. As researchers we found this to be so, which was accentuated during periods of perceived chaos.

At the end of this draining interview the predominant thought was "What have I got....it feels like dross?". What qualitative research espouses is how integral "the dross" is for capturing authentic data (Irwin and Johnson 2005). In essence this is what we had achieved, but not necessarily by design.

When interviewing children or adults, the structure of the narrative does not form a linear sequence with a neat beginning, middle and end. It is peppered with tangents and often these are dismissed as irrelevant. Irwin and Johnson (2005) during analysis of interviews with children discovered that these tangents were core to the children's narratives and suggest that in order to find the truth behind the child's reality, these tangents should not be dismissed. Reflexivity therefore, is an essential skill for the researcher's kit bag. Next time we will be more confident to go with the flow and realise the importance of not placing a hierarchy on "data". We would not have gained such a rich understanding of the family in context had we opted for a "sanitised" version of data collection as is often described in the literature. We have learned that at the collection phase all data is relevant, but judgements on its quality and relevance of the data are part of the analytic process.

We have also learned the importance of debriefing by reflecting on what we think has just happened during the course of the interview and recording this as field notes. It helps to make sense of what happened, by capturing the whole experience-not just the spoken word but the context in all its complexity.

This is what qualitative research pertains to be about, but walking the talk is scary! For us it was important to be able to offload in order to maintain perspective and a sense of normality. Feeling emotional and drained after a researcher encounter is not a unique phenomenon (Dickson-Swift 2006). It is reported that researchers can feel exhausted and overwhelmed, especially when researching sensitive subjects (Gregory Russell and Phillips 1997, McCosker Barnard and Gerber 2001 – in Dickson-Swift), or in our case, when we felt as if the situation was way beyond our control . We were anxious that we had taken up precious time for these families, time which they had very little of and had volunteered willingly – not to mention our concern for the implications for the quality of the data collected.

Our experiences concurs with the literature in that researching can be an emotional burden and as such it is important to put this somewhere. Qualitative researchers should not expect to just walk away from a research interview unscathed and having someone else to off load to is as important for personal well-being as the quality of the final report.

Building rapport through chaos.

As researchers we were in a privileged position of being invited into the family home. We were in effect guests. Being a carer has many demands, not just the demands of caring for a child with a life threatening condition, but coupled with the demands of everyday life: occupation, household demands and other children- means that parents have very little time out, and in this case the family had difficulties with travel to a central point. This meant that interviews were by necessity done on an individual basis or, when interviewing young children, done with one or both parents present. At times this also included other family members, friends and anyone one else who happened to drop by!

In Joe's case it was entirely appropriate for Joe's mum to stay with him as she provided reassurance for him and we felt that his feeling secure was important and consequentially might encourage him to open up more, which he did. She helped to monitor his concentration and understanding, and know when he'd had enough.

Irwin and Johnson (2005) describe the contribution of a parent's presence at a child's interview as "scaffolding" which can add a richness to the child's narrative. For example using phrases such as "do you remember when", or "what did you say the other day about..."p827. Rather than leading the child they suggest that these scaffolding statements enhanced the child's story.

Additionally Joe's mum was able to keep him under control to a certain extent as at one point he was rolling around the floor and then proceeded to eat the cable of the tape recorder! Irwin and Johnson (2005) refer to this as "kinetic conversations"p826, which although challenging, enable the child to act naturally within their own environment.

Gilmartin (2002) and Irwin and Johnson (2005) experienced similar events during the course of their interviews. They contend that unlike adults, children rarely sit quietly and respond to the questions posed by the researcher.

Retrospectively we should not have been so worried about Joe's behaviour-this is a part of Joe which was revealed to us very quickly, and which also helped us to build a rapport in a short space of time. We might not have seen the "real Joe" if we had interviewed him anywhere else but in his real home.

In retrospect, deliberate use of distraction techniques may have helped provide a focus for Joe and enabled his level of concentration and conversation. For example painting, modelling, use of props and play are advocated in the literature (Harden et al) if this fits with the child's comfort zone. In future this is something we would bear in mind. Rapport with Joe *was* achieved however, through a personal line of questioning which on the face of it had nothing whatsoever to do with the focus of our enquiry but was essential in enabling Joe to feel safe and be himself; for example, favourite football teams, games, hobbies likes and dislikes. This personal knowledge of Joe was used deliberately in both interviews to encourage familiarity and increase his level of comfort. This worked well in this instance.

Observing Joe's level of activity allowed us to get a glimpse of what it must be like for his mum on a day to day basis. Lots of children of Joe's age are excitable but the rigour and demands of fitting a daily treatment regimen into Joe's day given the nature of his hyperactivity is especially draining for both him and his mum. Being there gave us an opportunity to see this first hand and develop a rapport through the use of an empathetic line of questioning.

"Being there" as researchers entails attending to what's going in the situation and responding with a line of enquiry pertinent to the participant's needs as well as the needs of the research (Asted-Kurki, Paavilainen, Lehti 2001). If we had gone in with a fixed line of enquiry and not taken cognisance of specifics, this would have impacted on developing a rapport as well as having implications for the authenticity of the data

Further ethical dilemmas which emerged during the multiple comings and goings of others were the issues of consent, confidentiality and power and control as illustrated in the second case study.

Case study 2

Gary is a sixteen year old adolescent with CF. He lives at home with his two parents and seven brothers and sisters and a menagerie of pets.

Neither parent is employed. Gary has just left school and is currently unemployed.

He was interviewed individually in his own home a few months into the study, and declined a second interview. He has had one befriender Pete, for over a year. Gary keeps well and was emphatic about his level of fitness and ability to keep up with his pals. His demeanour was typical in many ways of adolescent behaviour. He looked awkward and his non verbals were indicating he wanted to be anywhere else but in this room with this stranger – a woman who confessed to know ‘very little about CF’. The interview was conducted in the sitting room, which at the time of my arrival, was fully occupied by family, friends and pets. There was no where to sit and there was an awkwardness about the situation which Gary appeared to be unable to do anything about. The courting couple on the sofa eventually left the room of their own accord, while the little sister continued to hover round the door playing with marbles on a hard surface. The two cats slept peacefully on, but two of the dogs were highly excitable about my arrival. When eventually Gary and I managed to negotiate the sofa, one of the dogs proceeded to sit on my lap. Gary faced away from me, looking out of the window for the majority of the interview. During the latter stages of the interview, Gary’s mum arrived with an armful of washing and stood right in front of me listening intently to my line of questioning. It was at this moment I discovered that the courting couple had returned at some stage during the interview, and were sitting together on the arm chair behind me listening in. I had no idea how long they had been there.

Negotiating consent

The issue of consent was immediately apparent in this case, and the importance of reiterating the nature of the research and Gary’s voluntary part in it was established at the start. The dilemma for us was that while Gary’s verbal consent was apparent; his body language was saying the opposite. It was difficult to help Gary negotiate a way out of this, without making him feel worse about the situation. Tensions between the researcher’s needs – to get an interview – versus Gary’s needs – to articulate his concerns about the process raises ethical issues regarding consent which are not adequately addressed in the literature.

Informed consent has many more grey areas than assumed in the literature. Research Governance indicates the importance of obtaining consent and clearly constructed information sheets and consent forms are part and parcel of this process (ref). However, in many respects these benefit the researcher rather than the participant and could be construed as window dressing to ensure the essential aspects of the *conduct* of the research have been addressed for auditing purposes.

Gary's position on consent appeared to us to have shifted. Consent therefore could not be assumed, but enabling him to assert his rights was hard when we were meeting for the first time and we had no prior knowledge about his level of communication skills, change in circumstances since consenting or home situation. Glesne and Peskin (1992) are right to question the power imbalance in an interview that favours the interviewer. This is especially relevant when adults are interviewing children or any 'vulnerable' individuals and groups even though the setting for the research is in their own home.

Woodgate's (2001) assertions regarding gradual entry to 'the field' in order to build and maintain trusting relationships which would help to negate power imbalances, and in this case establish what consent may mean for Gary, is a sensible strategy – in theory. We had attempted to achieve gradual entry, and meet with all the families before the interviews to build rapport, establish consent and discuss areas such as space and privacy. This did not suit the families, as they had no time or opportunity for multiple meetings. Although we spoke on the telephone prior to meeting face to face, the delicate process of establishing consent and what this may mean in specific situations had to be negotiated 'cold' at the first meeting. This was not ideal. We contend that this is yet another example of the discord between espoused theoretical principles of research and the practical reality of conducting research in the real world.

Consent means more than just participation in the study for the individual, but access to space and privacy within the home. Vicarious consent from other family members is also imperative if multiple interruptions are to be kept to a minimum. This is often impractical to attain, but essential if interviews are to be confidential within a public domain.

Maintaining confidentiality

Negotiating space and privacy is a delicate matter, especially when disclosing sensitive issues which are confidential to the interviewee. Protecting interests of the child, other participants and the integrity of the research can at times be in competition.

An example of this was in respect to Joe's befriender (case study 1) entering the room unexpectedly. It felt ethically wrong to carry on a conversation about the befriending relationship with the befriender sitting there which is why the tape recorder was stopped as confidentiality for the child would have been severely compromised. Furthermore, consent to participate had not been negotiated with the befriender.

This is another example of the 'intellectual demands' (Warr 2004) placed on the researcher in an interview setting in terms of balancing an individual's rights with research responsibilities. Professional judgements at the time determine whose interests researchers should protect and indicates the importance of researchers being sensitive and tuned in to unexpected events as they emerge.

Pruit (2001) advocates for researchers to 'expect the unexpected'. In our case, the 'unexpected' included; others entering the room and although not consented to

participate, joining in the interview anyway and in Gary's situation, parents who may have been acting as gate keepers for their child, entering into the interview space in an attempt to control the process. The decision to continue was founded on cues from Gary as he appeared to be comfortable with the situation and conversation appeared to become more relaxed. However, the narrative did take a different slant as soon as his mum arrived and it appeared to us that he did not wish to disclose some information in front of her.

Mauthner (1997) recognised that finding a separate space at home or in school can be a sensitive issue, and argues that whilst parents or teachers see themselves as protectors they also need to recognise that children also have rights of privacy.

Woodgate (2001) asserts that as adults, researchers have an obligation to protect 'vulnerable' individuals (such as children) who may be at risk from exploitation and exposure and intervene when necessary. The nature of the research we were undertaking did not pose any unnecessary risks in our view, as the nature of the inquiry was not overly sensitive. Interviewing children and families from a qualitative perspective has until recent times been largely avoided. Reasons given for this are that children lack social competence because of underdeveloped capabilities to recall credible accounts of their experiences (Hill Laybourne and Borland (1996), Morrow & Richards (1996) *in woodgate*).

Morrow and Richards 1996 (cited Woodgate – p156) contest that while researchers need to be mindful of risks associated with research with children, they should not always be conceptualised as 'vulnerable' and in need of protection. If researchers hope to understand and analyse the child's experience, they should not underestimate the child's level of competency and their ability to participate in, engage with and control the direction of the research process.

Power and control

According to Scott et al (1998) *in Harden* children in western cultures are viewed as a protected species and Harden et al (2000) contend that this view puts researchers in a similar category as predatory adults. Woodgate (2001) asserts that our research culture exhibits an overly protective stance towards children as they should be shielded from difficult and emotional subjects. Woodgate (2001) contends that this perspective reduces children's potential to participate in research. In our experience, once we were able to access children through the gate keepers and the protectionists we found they were adequately equipped to determine for themselves the degree of disclosure and co-operation they were prepared to offer us.

We contest the plethora of arguments which assume that the power imbalance in research settings favours the researcher rather than the participant (Harden et al 2000, Glesne and Peshkin 1992, Oakley 1981). Children in our research had their own way of exerting control over the interview process and appeared to be able to use strategies deliberately to protect themselves from our 'predatory' interrogations in the quest of knowledge.

According to Charmaz (1995) interviewees, as holders of information, control what they choose to disclose or hide. Clarke (2006) experienced direct resistance to lines of questioning, where as for us, this resistance was more covert. For example, absenting themselves by hiding away, using parents to indicate when they were tired and had enough ... “When is she finished?” and appearing to be reluctant to talk, even when questions were closed and one word answers where required.

In the following example, we had to probe and potentially lead with our questions in order to elicit any response. emily
(EXAMPLE?)

This could be perceived as the child adopting devious ways of manipulating power and finding a way out of the interview by withdrawing consent. However, the literature (Wilson and Powell 2001 in Irwin and Johnson in particular) does indicate that one worded succinct responses are to be expected from some children in keeping with their developmental stage, as the open ended questions can be more tiring and frustrating. With this type of questioning, children have room to move and think, and their responses could require a degree of analytical thinking. This may be required but is beyond the capabilities of some children, and may not fit the line of inquiry.

Children’s use of language is not a deliberate ploy for gaining power in a research setting, but never the less can leave the researcher feeling powerless as the structure of the interview can appear to become derailed and leaves the researcher needing to find ways of getting back on track. Another example of how a child’s interpretation of a ‘simple’ question could throw one off course was with Joe (case study 1);

Researcher asking Joe about the attributes of his befriender:
“What’s she like?”
“She’s got brown hair”

Docherty and Sandelowski (1999) maintain that children do not always know what information interviewers want as interviewers assume that children will automatically know what they mean.

Responses such as these where children take a literal interpretation on what is required can test the competency of the researcher. It was important that these responses were acknowledged and probed further and seen as yet another way in which children’s interpretation of the world can differ from adults. These examples are illustrations of how children have power over researchers, but were not using power deliberately. Never the less we as researchers felt slightly insecure due to the unexpected nature of the children’s responses.

Feelings of researcher insecurity could be accentuated by the fact that the children and parents where experts of their own situation.

Equalising power relations – need for reflexivity and responsiveness open ended research goals.

Flexible approach to interview to tap into subjective experiences – Balance between asking too many questions and not enough – children to set the agenda around subject that are important to them. Did this work (Emily)

Over emphasis of the difference between children and adults results in underestimating the competency of children and overestimating the competency of adults and widens the power divide (Woodgate)

Concluding section – Woodgate

Importance of keeping context present when researching with children – immersed in their worlds and interact, communicate through others who contribute to their experiences (p154) Children and their contexts are interdependent. “An ecological and dynamic understanding of children’s experiences supports the need to study children in their natural settings to capture some of the complexity of the children’s world”

Pruitt - Anticipate as many factors as possible and plan for them. Expect the unexpected – key understanding of the population under study – realistic?

Conducting qualitative research is made to look deceptively easy and to seem that almost anyone can do qualitative research by reading a book, talking to someone, or taking a mini course on the subject – researchers need to accept that information seeking is in fact a reciprocal relationship and in accessing children’s thoughts the competency of the adult researcher must be a concern. Use theory to help guide understanding, but modify and maybe reject theories which do not fit the arena of practice – flexibility adaptability and a willingness to take risks in the field. Methodological purity? More than one way in which to achieve this – messiness embedded within the chaos is an essential feature of the complexity of qualitative research – knowing this empowering step towards reaching comprehensive understanding of the phenomena under study – children’s health and illness experiences.

Bits

Furthermore Harden, Backett-Milburn and Jackson(2000) contend that research that is child centred is often carried out in child centred locations, ie the classroom or playground, thus excluding the family from the child's world, which they suggest ignores the extent to which spaces for autonomous play are bound by adult control. However Warr (2004) argues that to develop a contextual understanding of the participants world, it is better to talk to them about it "on their own turf "p580. It could be argued that children have many "turfs"; including the home and the playground and therefore the nature of the research may decide the location of the interview. This is in keeping with Harden, Backett-Milburn and Jackson(2000) who suggest that there are multiple factors such as age, social differentiation, the situational contexts of interviews, and the subject area being explored which should be considered when interviewing children.

Making the methodology fit

When the research was first muted the proposed methodology was focus groups for the parents and this received ethical approval. It became apparent very early on in the study however, that attending a focus group would be almost impossible for these parents.. Quickly realising that continuing in this vane would result in no participants, we had to rethink our methodology. The change to individual interviews meant increased resource costs for the study: that of time to see participants, travel and the cost of transcribing individual interviews versus one focus group. However this has been a steep learning curve and would encourage us to do things differently next time. LIT here.

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