

**PSYCHOTHERAPEUTIC WORK WITH FAMILIES
WITH LIFE-THREATENING MATERNAL ILLNESS**

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DECLARATION

This thesis represents my own research and original work. It cannot be attributed to any other person or persons.

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ABSTRACT

This exploratory research study describes a child and adolescent psychotherapeutic clinical service offered to children/adolescents and their families with mothers with a life-threatening illness. The clinical service itself was also exploratory in nature. The research objectives of the study were (i) to explore whether this form of clinical work could be beneficial for such families in relieving distress and supporting their development; (ii) to discover the factors at play within and between the family members using an adaptation of Grounded Theory research methodology; and (iii) to add to the knowledge base for adults – family members and professionals – relating to, and dealing with, such children and adolescents.

Descriptions and discussion of the therapeutic input and research study are given. Symptoms, which included emotional, behavioural, psychological, learning, and interpersonal difficulties, decreased in all the children/adolescents who were offered clinical treatment within an outpatient multidisciplinary Tier 3 Child and Adolescent Service (CAMHS). Six Themes were identified across the cases and these were named: Engagement, Parental Concern, Impact of Mother's Illness, Defences, Sustaining Factors and Feeling Different. These Themes are discussed in the light of relevant published research.

A literature review was undertaken and focuses on: epidemiological context; children's understanding of death; impact of parental bereavement in childhood; the mourning process; anticipatory grief; psychoanalysis: mourning and trauma; children's play and drawings as communication; and psychosocial therapeutic services.

The thesis has particular relevance for child and adolescent psychotherapists and other mental health professionals who work within hospital and hospice settings.

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CHAPTER 1: INTRODUCTION

This research developed out of my work as a child and adolescent psychotherapist. For many years, as one part of my clinical responsibilities, I saw children/adolescents who had been parentally bereaved or were facing the death of a parent. It seemed to me that it might be valuable to think systematically about this aspect of clinical work, especially as I found that little had been written on it in the child and adolescent psychotherapy field.

In this introduction, I will first describe my personal and professional background, and also describe the context of my work as a child and adolescent psychotherapist working in an outpatient multidisciplinary Child and Adolescent Mental Health Service (CAMHS) setting. I will explain how this work led me to an interest in this particular topic, and how this developed as a research project. I will then outline the research project and set out its principal objectives and research questions.

Personal and Professional Background

I was born and brought up as a Zoroastrian Parsee in Tanzania, and came to the United Kingdom to pursue further and higher education. After 'A' levels, I undertook a four-year first degree course in psychology at Brunel University which included three placements of six months each at an industrial rehabilitation unit, a psychiatric prison and an adult acute admissions ward of a psychiatric hospital. I received an Honours Degree in Psychology (2:1).

After two years of part-time preclinical training I started my four-year professional clinical training as a child and adolescent psychotherapist at the Institute of Child Psychology (ICP) which, for various reasons, closed down after my first year. The Association of Child Psychotherapists (ACP), our professional body, then took over the training of the students. The ACP arranged theoretical and practice-based seminars from across the professional schools in London with seminar leaders drawn from the Tavistock Centre (the Tavistock) (Kleinian), Anna Freud Centre and the Society of Analytical Psychology (SAP – Jungian). I received clinical supervision from across the theoretical spectrum and participated in

various seminars held at the Tavistock for their trainees. I qualified as a child and adolescent psychotherapist from the ICP Completion Course in 1982.

For my training psychoanalysis I started with an SAP psychoanalyst and then moved onto a Kleinian one for a longer period.

Since qualification I have worked as a child and adolescent psychotherapist in several outpatient CAMH services, mostly in south-west London but also for a short period in Surrey. I moved up the career ladder and became head of profession over five boroughs for an NHS Mental Health Trust.

In order to understand the complexities of the organisation in which I worked, I undertook a further part-time two-year Tavistock–University of East London MA course, Consultation and the Organisational Process, successfully completing this in 1998.

Whilst working in a senior capacity in CAMHS I supervised child and adolescent psychotherapy trainees on placement with us from the Tavistock, the British Association of Psychotherapists (BAP) and the Anna Freud training schools. Towards the end of my career I had professional and managerial responsibilities for staff within one borough of the NHS Trust, from disciplines including child and adolescent psychotherapy, clinical psychology, systemic family psychotherapy and music therapy.

In addition to working with abused, neglected and traumatised children in psychotherapy, I developed an interest in working with families where a parent had died via murder, suicide or illness. I also started seeing children and adolescents with parents with life-threatening illnesses.

I retired from full-time NHS work in September 2011 but continued offering some sessions on an honorary basis for a further two years in order to complete my longer-term psychotherapy and research cases.

In 2011 I had the opportunity to volunteer twice for an international women's development organisation called Feminenza which had secured funding from UN Women to offer education and mentoring to women leaders in Kenya working

towards conflict resolution in their communities in the aftermath of the post-election ethnic violence of 2007/2008. We offered training in understanding and managing fear, and in the need for forgiveness at a deep level within oneself and towards each other. We also offered media training to spread the word to out-of-reach areas. My experiences there as an educator, mentor and assessor of the impact of our programme affected me deeply. I saw the effects of trauma at a societal level and had to question and contemplate how and whether working in the UK as a child and adolescent psychotherapist had equipped me to work in such a different culture where both the best and the worst in tribal allegiances were at play. I was amazed and humbled to witness profound changes within most of the courageous and passionate women we worked with and the positive impact they had on some of the individuals in their communities.

My own personal history of being an immigrant, recent volunteering work in Kenya and my training and subsequent professional history have made me sensitive to change and loss. Change usually implies loss of some kind which can be painful at the time but can also be the spur towards a transformative process. Having lived all my life as part of a minority group – both in Africa and the UK – I have become aware of the importance of getting on with people from different backgrounds. It has also led me to value the creativity that the interplay between people from differing backgrounds can bring. In my professional life, for instance, I was able to support child and adolescent psychotherapy trainees from a range of training schools, and also clinicians from professional backgrounds different to my own. I have had to learn to adapt in my life to fit in with changing circumstances. In terms of this study, for instance, I was perhaps more able to offer therapeutic flexibility to the children/adolescents, and their families in order to fit in with their particular needs.

Outline and Principal Objectives and Research Questions

The death of a parent is a significant event in the life of a child and can have major repercussions, in the short, medium and long term. This exploratory qualitative research study focuses on children and adolescents who had been referred to an outpatient Tier 3 CAMHS in the context of one of their parents

having a life-threatening illness. At referral the children/adolescents who were aged between 5 and 16, were exhibiting a range of emotional, behavioural, psychological, learning and relationship difficulties and, in some cases, there was a risk of self-harm. There were three boys: Johnny (age 5), Andrew (age 15) and Elliot (age 16); and three girls: Gabby (age 6), Farah (age 8) and Sara (age 16). Two of the girls (Gabby and Farah) were sisters. The parents who were ill were all mothers. The youngest mother, who was in her early twenties, had had a malignant brain tumour and was being monitored by the hospital. The rest of the mothers had breast cancer: in two cases it was a recurrence, and in three cases it had become metastatic. All the mothers had had a range of treatments including radio and chemo therapies and surgery. The youngest mother with breast cancer was in her thirties and the rest were in their late forties or early fifties. In four of the cases the children lived with both parents. In the other two cases, the fathers lived separately but were in contact with their children. The maternal grandparents of the youngest child, Johnny, played an important part in his and his family's life.

The psychotherapeutic input in these cases included individual sessions with the children/adolescents, sessions with the parents, and family meetings. The types and frequency of sessions depended on need but were usually at least monthly. The last case was different in that I offered monthly sessions to the ill mother and her partner and participated in reviews with Andrew, his mother and her partner. These reviews were led by my consultant child and adolescent psychiatrist colleague under whose care Andrew remained. The length of my involvement depended on what was required and/or whether the family members wanted to continue attending. This differed from my input with Andrew's mother and her partner as it was time-limited due to my retirement. The length of time I was involved in the cases ranged from two years (intermittent) for Johnny; eleven months for Elliot; ten months (latterly via telephone contact) for Sara; ten months for the sisters Farah and Gabby; and eight months for Andrew's mother and her partner. I also liaised with schools and other professionals where appropriate, with the full knowledge of and agreement from the children/adolescents and their parents. All names have been changed to preserve anonymity.

In undertaking this research I adopted a qualitative methodology using an adaptation of Glaser and Strauss' (1967) Grounded Theory approach. The process notes from the clinical sessions were used as raw data to be coded and analysed.

The principal objectives of this study were:

1. To explore whether therapeutic work by a child and adolescent psychotherapist with families of a mother suffering with a life-threatening illness could be beneficial to them in relieving distress and supporting their development.
2. To discover the factors at play within and between the referred family members.
3. To add to the knowledge base for adults – family members and professionals, including those working in psychoanalytic psychotherapeutic practice – relating to and dealing with such children and adolescents.

The research questions were:

1. To what extent were anxieties diminished in the family members, and to what extent were the children/adolescents able to continue with their development (psychological, emotional, cognitive, social), having taken part in the psychotherapeutic process?
2. What impact does life-threatening maternal illness have on family members and what light does the research throw on this?
3. To what extent do the findings of this research add to the findings of previous studies in this field and enhance applied psychoanalytic child and adolescent psychotherapy practice?

It is recognised that research with a small number of clinical case studies cannot produce definitive answers to these questions. However, qualitative data of this kind can illuminate social interactions and their consequences, and can provide grounds for further comparative and empirical investigations of the hypotheses to which they may give rise.

The rest of this thesis includes chapters on the review of literature, methodology and findings, and ends with a chapter presenting conclusions and recommendations.

CHAPTER 2: REVIEW OF LITERATURE

Introduction

This review of literature provides the context within which the present research study lies. I have drawn on reviews of research studies as well as individual relevant journal articles and books. The reviews had the benefit of offering a wide angle lens and providing access to a broad spectrum of studies over time. The downside of using reviews, however, is the dependence on the reviewers' selection of appropriate studies and accuracy in reporting the information. To counterbalance this, I also considered individual journal articles and books that I thought to be most relevant to the present study, and accessed some information via relevant websites.

The review covers a range of relevant areas and topics as follows:

The epidemiological context: Prevalence data from relevant statistical studies is reviewed in order to set the epidemiological context to my research study.

Children's understanding of death: As children by definition are developing, I have included a section on children's understanding of death according to their cognitive, emotional and psychological development, taking into account their socio-cultural context.

The impact of parental bereavement: The death or prospective death of a parent is a very major event in the life of a developing child and I have therefore included studies that describe the many faceted impacts of parental bereavement on children/adolescents and their remaining parents.

The mourning process: Major contributions to the understanding of the mourning process are explored, along with literature on the effect on the surviving parent whose continued parenting capacities are so important for the grieving children's wellbeing.

Anticipatory grief: A section on anticipatory grief in adults and children is included as my study is about clinical input to the family before the death of the mothers with life-threatening illnesses.

Psychoanalysis: mourning and trauma: This section presents a selection of relevant psychoanalytical concepts from key figures as they informed my clinical practice for this research.

Children's play and drawings as communication: This section covers literature on the use of non-verbal means (play and drawings) used by children as a form of communication in the consulting room. This is part of my practice working psychotherapeutically with children, and non-verbal communication is deemed important in palliative care literature.

Psychosocial therapeutic services: The review of literature ends with a discussion of the variety of psychosocial services for bereaved children and their families, as well as palliative care literature – the arena in which my own clinical work and research lies.

The chapter finishes with a section presenting concluding thoughts on the implications of the literature for my study.

Epidemiological Context

The epidemiological context to my research study is provided by prevalence data for parentally bereaved children/adolescents and the survival rates of women with breast cancer and malignant brain tumours in the UK.

Parsons' (2011) study based on an analysis of data from the British Cohort Study (a longitudinal study of over 11,000 children born in 1970) reported that 5% (n=534) of participants had experienced the death of a parent by the time they were 16. Of these, 155 had experienced the death of their mother, 393 the death of their father, and 14 the death of both parents. In terms of gender, 5% of girls and 4% of boys had lost a parent.

Research cited by Cancer Research UK (2015) indicates that the survival rates for women suffering from breast cancer have been improving for 40 years due to earlier diagnosis, improved treatments, and national breast cancer awareness and screening programmes. Interestingly, the survival rates for women diagnosed in their fifties and sixties are better than those for younger or older women. It has been suggested that the lower survival rate for younger women is due to more aggressive types of breast cancers in pre-menopausal women as well as a lack of routine breast cancer screening (Cavallo, 2014). The five-year net survival rates in England for women diagnosed with breast cancer during 2007–2011 ranged from 64% for 80–99 year olds to 91% for 50–69 year olds; the survival rate for 15–39 year olds was 85%.

Net survival rates for women diagnosed with malignant brain tumours have also been improving over the past 30 years. The five-year net survival rate for women in England diagnosed during 2010–2011 ranged from 1% for 80–99 year olds to 60% for 15–39 year olds.

A USA-based study (Weaver et al., 2010), identified adult participants in the United States National Health Interview Survey (NHIS) between 2000 and 2007 with a history of cancer (n=13,385). The parents in the sample were identified as a biological, adoptive, step, or foster parent of a child. The authors reported that 14% of all survivors and 18.3% of survivors diagnosed within the previous two years lived with a minor child. Most of the survivors were female (78.9%), married (69.8%), and under 50 years of age (85.8%). There were 3,193 identified children of survivors.

A Norwegian study (Syse, Aas and Loge, 2012), based on a nationwide study as at 1 January 2008 found that, in 2007, 84,202 women and 67,554 men aged between 17 and 70 years had, or had previously had, cancer. A total of 2,075 families with 3,481 minor children experienced having a mother (56%) and/or a father (44%) diagnosed with cancer during 2007. A total of 2,272 families with 2,989 young adult children (19–25 years) were affected by parental cancer during 2007. The most common diagnoses in mothers were breast, cervical and skin cancers; and the most common in fathers were colorectal, skin, prostate and testicular cancers.

Discussion

Parsons' (2011) study analysed data from the longitudinal British Cohort Study on children having lost a parent before the age of 16, and offers a useful baseline for the UK. Although the proportion of parentally bereaved children (5%) is small compared to the wider population, we will see later (see *The Impact of Parental Bereavement in Childhood* below) that the impact on individual children, the remaining parent and the wider family is, on the whole, substantial, in the short, medium and long term.

Parsons' (2011) study found that more than twice as many fathers than mothers had died. This was reflected in my previous psychotherapeutic work with parentally bereaved children and their families. Over the years more children/adolescents were referred because of reactions to paternal death compared to maternal death. In comparison, more of the children/adolescents referred to CAMHS had a mother rather than a father with a life-threatening illness. One can only conjecture why that may be so. It is possible that mothers are more likely than fathers to seek referrals for their children, both when they are ill themselves and also if their spouse/partner has died. As will be seen below (see *The Impact of Parental Bereavement in Childhood*), mothers are more likely than fathers to be in touch with their children's emotional needs, and that could be one reason for the pattern of referrals.

Most of the mothers in this study had breast cancer and two were in the 50–69 year age range with a net five-year survival rate of 91% as shown above. Despite this more hopeful statistic, it is important to note that in this study breast cancer had recurred in two mothers (one within 5 years and one after 10 years) and one mother had bilateral breast cancer (cancer in both breasts). The one young mother (in her twenties) with a brain tumour fell within the 15–39 year age range with a five-year net survival rate of 60%. She also had a rare medical condition affecting her hips, back and feet. So it can be seen that the sample of mothers with life-threatening illness in this study was skewed towards complexity and severity, and it is therefore difficult to ascertain how long they would survive using the epidemiological data.

The USA (Weaver et al., 2010) and Norwegian (Syse, Aas and Loge, 2012) population-based studies are useful. There does not appear to be a similar UK population-based study of the number of children living with parents who are cancer survivors. Such a study would offer a baseline, helping with effective service planning and provision in the UK. Weaver et al.'s (2010) study usefully included all parents (biological, adoptive, step, or foster), and not just biological parents, as children can be affected by serious illness in all significant carers. The study by Syse, Aas and Loge (2012) included young people up to the age of 25 which is a useful extension as such individuals may still be dependent on their parents in a variety of ways (e.g., financially, emotionally).

Children's Understanding of Death

Children's understanding of death depends on their cognitive, emotional and psychological development, as well as their social and cultural environment.

Virginia Slaughter's (2005) overview of 50 years of research on children's understanding of death shows that research was initially carried out by those with a psychoanalytic perspective and this was followed by studies influenced by Piaget. These studies were augmented by those that looked at the effect of children's personal experiences and socio-cultural variables.

Slaughter (2005) mentions that the psychoanalytic researchers used descriptive methodology, using open-ended interview techniques and projective methods such as drawing or story-telling. These researchers found that death was emotionally charged and was characterised by feelings of sadness, anxiety and fear over separations, all found to be inherent when someone dies (Anthony, 1940; Nagy, 1948; Von Hug-Hellmuth, 1965). They found that, for children under the age of 10, separation at death was seen in terms of more familiar partings like going away to heaven or a place (the cemetery, the coffin), and the dead were understood to live in that other place (Nagy, 1948; Von Hug-Hellmuth, 1965). The children understood that the dead would not come back to life but rationalised this in terms of, for instance, heaven being too far away, or the coffin being nailed down. Some children saw death as a permanent sleep from which the person could not wake (Anthony, 1940; Nagy, 1948). To explain the causes

of death children often personified death ('the grim reaper', 'the bogey man'). Some children saw death as punishment for evil doing (Nagy, 1948; Von Hug-Hellmuth, 1965; White, Elsom and Prawar, 1978).

Slaughter (2005) summarises the findings of the psychoanalytic researchers thus:

“The psychoanalytic researchers concluded that young children’s capacity to understand and accept death was limited by their cognitive and emotional immaturity, and that children’s misapprehensions about death were likely to fuel their anxieties.” (p. 180)

According to Piaget (1963), very young children at the Pre-operational stage (2–7 years) do not understand the universality, permanence and non-functionality of death (i.e., cessation of all bodily functions such as breathing, feeling and eating) until they enter the Concrete Operational stage (7–11 years), at which point they recognise that death is irreversible. It is only when they reach the Formal Operational stage (11 years onwards) that children start holding an adult view of death as inevitable and universal for all living things, and as characterised by the cessation of all bodily functions.

According to Slaughter (2005), researchers following the Piagetian perspective and using structured interviews found a fairly consistent cognitive development pattern in children’s understanding of death, which had sub-components of universality (death happens to all living things), irreversibility (the dead do not come to life again), cessation (the understanding that death is caused by the breakdown of the body’s functions) and causality (different causes lead to death). They found that the sub-components of universality and irreversibility are acquired first, by the age of 5 or 6 (Kastenbaum, 1967; Koocher, 1973; Speece and Brent, 1992). The final sub-components to be mastered by children were those of cessation and causality (Koocher, 1973; Lazar and Torney-Purta, 1991; Orbach et al., 1985). This showed that the more concrete and clearly defined sub-components of death (death happens to everyone and once dead one cannot come back to life) were mastered before the more abstract and relatively more complex ones (death is caused by the breakdown of the body’s functions, and there are multiple causes of death).

Slaughter (2005) reports that the findings about individual differences in children's backgrounds and experiences affecting their understanding of death were contradictory, and that the bulk of the research showed that these individual differences, if they had an effect, only influenced specific and relevant sub-components (Kenyon, 2001; Speece and Brent, 1996). Some studies did show that children who have direct, personal experience of death show relatively advanced understanding, but only of the sub-component of universality (Jay et al., 1987; Kane, 1979; Cotton and Range, 1990; Townley and Thornburg, 1980). Other studies showed that children who had suffered longer-term illnesses and hospitalisations may have acquired the sub-components of irreversibility, cessation or causation, showing a relatively earlier understanding of the biological nature of death (Jay et al., 1987; O'Halloran and Altmaier, 1996; Spinetta, 1974).

According to Slaughter (2005), the socio-cultural aspects affecting children's understanding of death were centred on religious beliefs, but the findings were inconsistent. Some studies found that highly religious children showed a less mature understanding of the irreversibility of death compared to their peers (Candy-Gibbs, Sharp and Petrun, 1984); whilst other studies showed religiosity to have no effect (McIntire, Angle and Struppler, 1972).

Slaughter (2005) reports studies which showed that highly anxious children were more likely than their peers to deny the universality of death (Cotton and Range, 1990; Orbach et al., 1985), but this has been seen as a defence against anxiety rather than a misunderstanding about death happening to all living things (Kenyon, 2001; Orbach et al., 1985).

Slaughter (2005) concludes that, although there is evidence for children's understanding of the specific sub-components of death being influenced by their individual life experiences and socio-cultural factors, the bulk of the evidence points towards understanding being mostly influenced by their cognitive development.

A more recent study (Bonoti, Leondari and Mastora, 2013) showed that children's understanding of death varies according to their age and experience. Fifty-two

children aged 7, 9 and 11 from middle-income families were randomly selected from a school population in Volos, Greece. Half of the sample had personal experience of death and the other half did not. The researchers asked children to draw a picture reflecting the meaning of the word 'death' and also carried out a structured interview based on the 'Death Concept Questionnaire for Examination of Human and Animal Death'. This questionnaire had previously been used by Smilansky (1987) and was found to have high levels of validity and reliability (see Chapter 3: Methodology – Criticisms of the Case Study Research Method). The questionnaire helped to elicit sub-components of death which had been previously found in other studies. The children were also asked to draw "whatever the word *death* brought to mind" (p. 51). The researchers used drawing to complement the questionnaires as they hypothesised that it would help children express their feelings better and would also elicit more information.

The results showed that children with a personal death experience had a better understanding of death than their inexperienced peers, particularly in relation to the sub-components of human irreversibility and non-functionality (cessation). Children in both groups had a similar understanding about animal death in the sub-components of irreversibility and non-functionality. Analysis of the drawings showed that children with a personal death experience drew scenes depicting the dead person, the funeral, or the grave and none of them drew a violent death. About half the children without a death experience drew violent death scenes (e.g., shootings, murders or accidents). Most children in both groups included elements of the biological concept of death but few included psychological or metaphysical elements in their drawings. The researchers concluded that the drawings of the children with experience of death reflected their own personal experiences, and that those without a death experience probably used information from television or other media.

The researchers reported that the 11 year olds tended to give more immature answers on irreversibility and non-functionality. The researchers cite Brent et al. (1996) as follows:

"Brent et al. (1996) proposed that although children understand the basic components of the concept of death early, they revise their understanding of irreversibility and non-functionality during middle childhood by

abandoning scientific explanations in favor of non-naturalistic, spiritual ones.” (p. 57)

It is interesting to note that the above study was cross-cultural and the sample included Chinese and American children between the ages of 3 and 17.

This tendency has been reported in other research (Brent et al., 1996; Candy-Gibbs, Sharp and Petrun, 1984; Noppe and Noppe, 1997) and the researchers conclude:

“Thus, it seems that the concepts of irreversibility and non-functionality undergo ‘reconstruction’, which might represent a shift from rule-based categorical reasoning based upon biological imperatives, typical of younger children, to reasoning based on more socially based explanations, such as reincarnation, spiritual understanding, and energy continuation (Kenyon, 2001).” (p. 57)

Discussion

Research over the years has found that death is a complex subject for a developing child to understand. The discovery of the sub-components of this understanding and the conclusion that reaching an understanding of these sub-components is primarily influenced by the cognitive maturity of children is useful in helping adults (parents and professionals) to deal more appropriately with children/adolescents. These findings appear to remain consistent over many studies. However, there does appear to be an over-representation of studies dealing with cognitive development and fewer on how emotions may impact on children’s understanding of death. There is, though, some evidence of anxiety affecting cognitive understanding.

It is interesting to note how socio-cultural influences affect children as they get older. It seems that there is a personal search for meaning as children approach and enter adolescence, and they seem to become more prone to being influenced by social, spiritual and religious explanations of death, including the after-life. In my therapeutic work with parentally bereaved children, I have seen this wish to find some meaning in the experience of losing a parent, although this has tended to appear earlier, during the latency period.

There seems to be some evidence that the sub-components of the understanding of death appear cross-culturally (Brent et al., 1996) in the cognitive development of children. This may indicate that this is something that occurs mostly independently of individual life experiences or socio-cultural influences, as Slaughter (2005) concludes.

The research by Bonoti, Leondari and Mastora (2013) mentioned above used a questionnaire and drawings – two methods which complement each other. By using the questionnaire, which had a high degree of reliability and validity and which had been used previously, the researchers could compare their findings with those of other researchers with confidence. By using drawings the researchers could get to children's thoughts as well as emotions, and hence augment their findings.

The findings of this study showed that children with their own personal experience of death had a more mature understanding of death than those who did not have such an experience. This finding appears intuitively understandable. The researchers do not, however, mention what type of personal experiences of death the children had. This might have given us insights into whether there are differences in understanding depending on the closeness of the relationship between the dead person and the child.

The Impact of Parental Bereavement in Childhood

Akerman and Statham (2014) carried out an overview of the psychological and educational outcomes of children and young people bereaved of a parent or a sibling. This was produced by the Childhood Wellbeing Research Centre and funded by the Department of Education, and cites a number of studies as shown below.

Reviews of studies on parentally bereaved children show a wide range of emotional and behaviour responses to grief. Responses include anxiety, depressive symptoms, fears, angry outbursts, and regression to earlier developmental milestones (Dowdney, 2000; see below for more information); lower self-esteem and external locus of control (Haine et al., 2006); and

somatisation (Servaty and Hayslip, 2001). These reviews indicated that parents tended to report fewer symptoms and disorders in their children than the children themselves reported. The children tended to be anxious about further losses and the safety of their family members, and exhibited difficulties at separation.

Although the initial grief responses in children tended to decline over time, mental health and other problems could persist or even increase. These problems could fluctuate, and significant life events or changes over time could trigger delayed grief reactions (Christ, 2000), for example, when the remaining parent remarries or the bereaved children have their own child in adulthood.

Mack (2001) found no association between a child's age (or stage of cognitive or emotional development) and response to bereavement, so the evidence on age as a moderating factor was said to be inconclusive.

An ethnographic study (Brewer and Sparkes, 2011) found that young people identified having an area of competence (e.g., sport, music or academic achievement) as one of the factors which helped them live with parental grief. They also identified positive relationships with their surviving parent as a source of support, as well as the importance of maintaining an ongoing relationship with the parent who had died, through visual or auditory cues, by doing things to continue this relationship, or having a 'secret sense' that the dead parent was still 'around' and supporting them.

Friendships were seen to be important as a protecting factor for parentally bereaved children (Holland, 2001; Rask, Kaunonen and Paunonen-Ilmonen, 2002; Brewer and Sparkes, 2011). On the other hand, Servaty and Hayslip (2001) found parentally bereaved young people could feel different from their peers or worry about relationships. Parental bereavement could also lead the child to feel bullied by their peers (Cross, 2002).

Several studies highlight the surviving parent's ability to create a safe, secure and loving family base as an important factor. These studies indicated that higher levels of care-giver warmth and lower levels of care-giver mental health problems protected against negative outcomes from the death of the primary care-giver (Christ, 2000; Lin et al., 2004; Luecken et al., 2009; Haine et al., 2006).

There were gender differences in how the children reacted to parental bereavement. Abdelnoor and Hollins (2004) found that girls bereaved of mothers and boys bereaved of fathers were at increased risk. Linda Dowdney's review (2000) found that boys exhibited higher levels of emotional and behavioural difficulties following bereavement, and Haine et al.'s review (2008) found that boys displayed higher levels of externalising behaviour problems, whilst girls displayed more internalising problems.

There are variations in mortality rates in children and adults depending on social class, geography and locality, with young people living in deprived areas more likely to experience parental and sibling death (Ribbens McCarthy, 2006). Further, Parsons (2011) found bereavement by the age of 16 to have more negative implications for children and adolescents from more disadvantaged backgrounds, and Cerel et al. (2006) reported that higher family socio-economic status as well as lower levels of depressive symptoms in the surviving parent was associated with better outcomes for bereaved children.

Cultural factors were seen to be relevant and need to be taken into account in assessing the impact of bereavement in children. For example, in some cultures extended families play a significant role in the lives of children and therefore the death of someone who is not a first-degree relative could have a profound effect (Salloum, 2008).

Longitudinal studies have found that children who have experienced three or more stressful events (e.g., family bereavement, divorce, serious illness or the death of a close friend) are significantly more likely to develop mental health problems (Meltzer et al., 2003; Parry-Langdon, 2008).

Parsons' study (2011) based on an analysis of British Cohort Study data reported that 25% of girls and 16% of boys growing up in parentally bereaved families reported symptoms of depression at age 16. These figures were higher than those reported by young people in intact families (living with both natural or adoptive parents) or disrupted families (parents separated or divorced). In intact families, 17% of girls and 11% of boys reported symptoms of depression, whilst

in disrupted families 23% of girls and 10% of boys reported symptoms of depression at age 16.

The above study investigated the long-term effects of parental bereavement, controlling for family background characteristics, and found that men at age 30 who had suffered parental bereavement were less likely to be in employment. Women at age 30 who had grown up in bereaved families compared to intact families were less likely to have gained any qualifications or be in employment and reported more symptoms of depression and were more likely to be smoking cigarettes.

In the above study, parentally bereaved children were less likely than their peers to have had parents with experience of extended education or a father in a professional or managerial occupation, and more likely to have a father not in work.

The overview of outcomes for parentally bereaved children by Akerman and Statham (2014) mentions that there is relatively little evidence of a causal relationship between childhood bereavement and educational outcomes and, where there is, the studies are limited by the methodologies used (see Dowdney, 2000, below). Despite these limitations the authors mention reviews by Haine et al. (2008) and Dyregrov (2004).

The review by Haine et al. (2008) concluded that the balance of evidence suggests that parentally bereaved children are at risk of lower academic success. This review mentions a UK study (Abdelnoor and Hollins, 2004) which reported on the GCSE results of 73 pupils who had lost a parent and 24 who had lost a sibling. The authors found that parentally bereaved children underachieved significantly according to age, gender and parental employment history. The GCSE exam scores of children bereaved before the age of 5 or at the age of 12 were significantly more affected than the scores of those bereaved at other ages, although school attendance was not affected.

A review by Dyregrov (2004) found that traumatised and bereaved children were absent from school more often, on average, than other children; and that school performance could deteriorate after the event, especially in subjects requiring a

high level of attention. While the reasons for this deterioration are not fully known, the most likely factors were seen to be loss of motivation, attention being diverted to intrusive material and cognitive processing, and lowering of cognitive pace due to depression. It was also suggested that post-traumatic stress may lead to children perceiving a lack of support from parents, classmates and teachers, and may result in lower attainment at school.

In terms of social and educational adjustment of parentally bereaved children Dowdney (2000) says:

“Both clinical experience and research interviews indicate that some bereaved children determine to do better at school as a form of tribute to their dead parent. Others report more difficulty in concentration, and distress, particularly when memories of their dead parent are evoked in school (Silverman and Worden, 1992). Dowdney et al. (1999), using the Achenbach Teachers Report Form (Achenbach and Edelbrock, 1980), found that teachers of bereaved children rate them as being significantly less attentive than matched classroom controls.” (p. 822)

Dowdney (2000) mentions that studies of school performance share common methodological limitations which include retrospective parental recall of their children prior to the death and a reliance on indirect measures of educational attainment. She concludes that, combined with individual “differences in academic skills, competence, and response to parental death, these limitations mean that we can only conclude that outcomes will vary between children”. (p. 822)

Rolls and Payne (2007) carried out a study of children’s and parents’ experiences of the death of significant family members. They found that children communicated difficulties in expressing and managing their feelings (see Psychosocial Therapeutic Services on how these families experienced the UK bereavement services they attended), and reported that children’s “[f]eelings of anger and sadness were often overwhelming, sometimes accompanied with a sense of guilt or hopelessness.” (p. 290) Some children felt isolated at home and with peers; and some were being taunted and bullied at school. Children felt “...afraid about what was happening to them and their family, for the life of the remaining parent, and of telling their parent how they were feeling.” (p. 290) Part of this fear was that they may upset their parent by talking about the death and

“[t]his resulted in some feeling more responsible and...having to take on aspects of the dead parent’s role”. (p. 291)

Parents expressed difficulties in maintaining their parenting role as they struggled with their own bereavement and the changes in and disruptions to their circumstances. The main experiences reported by parents were that of feeling overwhelmed with “...exhaustion, stress, and the difficulties of coping”. (p. 291) The parents’ feelings included shock, anger and grief. Many parents reported that they kept going for their children and “[s]ome managed through what they described as their denial: trying to carry on as if everything was normal”. (p. 291) Some parents felt that they had neglected their children as life became chaotic, which added to their child’s and their own difficulties. Parents not only described their own feelings of grief, but also described “...the painful recognition of the impact the death was having on the family, the deep sorrow of watching their child struggle with painful feelings, and their own inability to help”. (p.291) Although some parents recognised that their child was trying to protect them by not talking about the dead parent, they also found it difficult to encourage their child to talk as they feared the child would get upset if they did so.

Parents struggled with what and how to tell their children about the death. They noticed different responses in their children and these included withdrawal, being tearful or ‘acting out’ difficulties. Some parents noticed that their child was becoming isolated and was being bullied; they also reported that their child’s school work was suffering.

I will now move on to an older longitudinal study with a robust methodology, the Harvard Child Bereavement Study, which published different findings for parentally bereaved children reported by different authors at different points after the death of the parent. Drawing on data from four-month and one-year timeframes, Silverman and Worden (1992) found little indication of serious dysfunctional behaviour in parentally bereaved children. However, Worden and Silverman (1996) found that at the two-year mark after parental death, there were higher levels of social withdrawal, anxiety and social problems, and lower levels of self-esteem and self-efficacy in the bereaved group compared to the control group. Twenty-one percent of the bereaved group showed serious problems two

years after the death. The authors underline the importance of this apparently delayed negative outcome in parentally bereaved children for those who provide support to this group.

Rebecca Abrams (2013), in her book written for teens and young adults, discusses various consequences for bereaved young people and their remaining parents, and these I cite next.

There are gender differences in how the remaining parent copes after the death of their spouse. Although gender stereotypes are slowly changing, parents usually take on differing roles in the family and when one of them dies then both roles will have to be filled by the remaining parent, which may not be easy for them to do. Mothers usually provide the emotional and practical support in families. When she dies there may be major changes in how the household is run.

Children who lose their mothers report difficulties in expressing their feelings in general as well as talking about their mother (Worden, 1996). Abrams (2013) notes that this may be due to the difficulty that many men have in expressing their own feelings; fathers may thus find it difficult to show and talk about their own feelings or to encourage their children to do so. Fathers may also struggle more in adjusting to day-to-day tasks and maintaining routines for their children. Fathers usually continue to work or even increase their work hours, ostensibly to go on providing for their children, but it means that they are not around for their children when they are most needed. Fathers may do this as a way of coping with their own bereavement (Worden, 1996).

Abrams (2013) goes on to underline the importance of continued stable routines, consistent discipline and boundary setting, and good communication for bereaved children, which many fathers find challenging to provide after mothers die.

Abrams (2013) mentions that the death of a father may leave both boys and girls without an important protector, guide, friend, or role model.

Abrams (2013) discusses the role reversals that may occur after the death of a parent. The remaining parent, caught up in their own grief, may need support themselves, and an older child may have to not only offer that but also take over day-to-day parental duties for younger siblings. This can detract from their own grieving process at the time and it is only later in life that the onset of depression may trigger their grief.

Dowdney et al. (1999) conducted a study of 45 families of parentally bereaved children aged 2 to 16 years from two adjacent London health authorities. Their findings showed high levels of psychological problems in both the children and the surviving parents three to twelve months after the death of the parent. Mothers showed more disturbance than fathers. Boys seemed to be affected more, mostly evidenced by acting out and aggressive behaviour. Parents with higher levels of psychiatric symptoms reported more symptoms in their children. Teacher ratings showed the parentally bereaved children to have significantly more widespread psychological difficulties than children in matched control groups. There was good agreement about the children's difficulties between parental reports and teacher ratings.

Dowdney (2000; see above on symptoms exhibited by parentally bereaved children) reviewed literature on childhood parental bereavement and concluded that parentally bereaved children expressed a wide range of emotional and behavioural difficulties. One in five of these children showed sufficient disturbance to be referred to specialist services. Parents reported fewer difficulties in their children than the children themselves.

Discussion

The above studies show that children react in many different ways to the loss of a parent – I encountered many of these reactions in my therapeutic work over the years.

One particular aspect of grieving children's behaviour which I have observed tended to puzzle the significant adults in their lives, and this does not seem to have been highlighted in the studies. The remaining parent, family members or

teachers at times reported that the child would cry or be upset but could also switch into laughter and play quite easily. I would explain to the adults that most children live more in the present moment compared to adults and switching into non-grieving mode was fine; it did not mean they were not grieving or remembering their dead parent.

Experiences in my clinical practice confirm the findings that parentally bereaved children tend to be anxious about further losses, and about the safety of other family members, and exhibit difficulties at separation. This was particularly marked in the children's anxieties about their remaining parent getting ill or even dying. This could lead to problems about separation. Examples of separation anxiety include not wishing to go to school, or not allowing their remaining parent to have a separate life.

Although there appear to be few methodologically sound studies looking at the diminishment of academic achievement in parentally bereaved children, I observed this in many of the children/adolescents that I worked with clinically over the years. Most of the children/adolescents in the present study were having difficulties at school with learning and, at times, with social relationships.

Dowdney et al.'s (1999) research was published in the *British Medical Journal* (*BMJ*), thus reaching general practitioners (GPs) who could be made more aware of the needs of bereaved children and the need for them to be referred to appropriate services. Their study also included the younger age range (2 to 16 years) which is useful as research tends to concentrate on children who are older, and does not often include the needs of the very young.

The Mourning Process

Elisabeth Kübler-Ross, a Swiss-born psychiatrist who moved to the USA, worked with the dying, both adults and children. She has also taught and written extensively about the subject. She postulated five stages of grief: stage 1: shock, denial and isolation; stage 2: rage and anger; stage 3: bargaining (with God or the doctors to be given more time to live); stage 4: depression; and, finally, stage 5: acceptance of the loss. She gave many vignettes from her clinical work with

the dying illustrating these stages (Kübler-Ross, 1981). She emphasised the importance of symbolic language and non-verbal communication when working with the dying and their families; for example, encouraging children to draw to express themselves. She also worked within the belief system that the death of the body was not the end and that people continue to live on spiritually. When explaining this to her patients she used the analogy of the dying person being in a cocoon, the body, and escaping free as a butterfly at death.

Colin Murray Parkes, a British psychiatrist, has worked with the dying and the bereaved and has done much research into bereavement. He has seen a pattern to the process of grieving starting with a state of numbness which moves onto pining for the departed, which then moves onto a period of disorganisation and despair, which in time declines as acceptance of the loss grows. People can move to and fro through these states and there are considerable differences in the way individual people do this. He too gives examples of these from his research and clinical work (Parkes and Prigerson, 2010).

Worden (1996), in discussing childhood parental death, differentiates between bereavement, mourning and grieving. Bereavement is defined as the process of adaptation to the loss, mourning is the process children go through towards this adaptation, and grief is seen as the child's personal experiences associated with the death. Worden postulates four tasks of mourning in children as follows:

- Task 1: To accept the reality of the loss.
- Task 2: To experience the pain or emotional aspects of the loss.
- Task 3: To adjust to an environment in which the deceased is missing.
- Task 4: To relocate the dead person within one's life and find ways to memorialize the person.

(Taken from Worden, 1996, pp. 11–16)

Abrams (2013) finds Worden's tasks of mourning (Worden, 1996) to be more helpful than phases or stages as she thinks the latter implies that successful grieving leads to giving up the dead person, relegating them to the past and moving on into the future. She thinks mourning is a lifelong process of adaptation,

and that the internal relationship with the dead person continues to develop and change as one goes through life.

Parkes and Prigerson (2010) mention an important contribution made by Stroebe and Schute (1999) to our understanding of grief via the dual process model of coping with bereavement. This model sees grief as having two orientations: a loss orientation and a restoration or change orientation. The loss orientation looks back on life to our attachments and the restoration orientation looks to changing our assumptions and habits of thought as we move forward. Bereaved people oscillate between the two orientations. This dual process model of coping with bereavement seems to resonate with Worden's tasks of mourning.

Parkes (Parkes and Prigerson, 2010) was influenced by John Bowlby's Attachment Theory (Bowlby, 1969, 1973, 1980) in his work on the part attachment plays in responding to the loss of the loved one. It can be seen at the beginning of bereavement in what he calls "the pangs of grief" and continues through "continuing bonds" (Klass, Silverman and Nickman, 1996), and this continued attachment to the dead person can either facilitate or hinder subsequent adjustment.

Parkes mentions the severe anxiety and psychological pain caused by pangs of grief as being a characteristic feature of grief. He compares this pining and searching for the loved one who has died with the infant's yearning when separated from his primary care-giver, usually the mother (Robertson and Bowlby, 1952). He equates pining and searching in the bereaved with separation anxiety in the young, and sees this behaviour as having survival value for the individual and the species.

The continuing attachment to the dead person, both adaptive and maladaptive, was further explored by Parkes and Prigerson (2010). The wish to find the person through a sense of the dead person being nearby or seeing them in dreams is usually experienced as comforting. In order to cushion the rawness of the loss, a bereaved person may slip into disbelief that the person has died; have feelings of numbness or blunting; have a sense of depersonalisation (people themselves

are unreal) or derealisation (the world is unreal); avoid thoughts of the loss; or remember the loved one with great clarity.

The bereaved person starts the task of building or putting together a new internal image of the dead person. This re-evaluation of the dead person may become selective as one wants to remember positive and happy memories and idealisation is common, and is encouraged by society.

Bowlby's former trainee Mary Ainsworth, an American psychologist, discovered patterns of attachment between infants and parents which arise in the first two years of life (Ainsworth et al., 1978). Ainsworth explored the effects of brief separation of infants from their mothers in the 'Strange Situation'. In this experiment a room with some toys and a chair was observed from a one-way mirror. The mother was instructed to stay with her infant for five minutes, leave the room for two minutes while a stranger entered, and then return for another five. This led to the identification of four patterns of reaction to separation. These Ainsworth called Secure and Insecure Attachment patterns. Insecure Attachment was sub-divided into Anxious/Ambivalent, Avoidant and Disorganised categories. Later research established that these patterns remained consistent throughout childhood and predicted future relationships. Parkes (Parkes and Prigerson, 2010) mapped these early attachment patterns on to his research into adult reactions to bereavement.

Parkes (2006) found that in both psychiatric and non-psychiatric samples, secure childhood attachments led to significantly less distress after bereavement in adult life compared to insecure attachments.

Parkes found that bereaved adults who scored highly in the Anxious/Ambivalent category during their childhood reacted to bereavement with prolonged grief and loneliness and a continued tendency to cling. These bereaved adults had highly dependent relationships and some had never separated from their parents and still returned to them when things went wrong.

Parkes found that the bereaved adults who had scored highly in the Avoidant Attachment category during childhood were intolerant of closeness in

relationships and found it difficult to acknowledge and express both affection and grief.

In carrying out further analysis to understand the Disorganised Attachment pattern, Mary Main (Main and Weston, 1982), Ainsworth's trainee, found that the mothers of children who had showed a Disorganised Attachment pattern in the 'Strange Situation' experiment had suffered loss or trauma at or around the time of birth of the infant and their ability to provide consistent parenting had been severely disrupted. The mother's own needs led to her either smothering the infant with unwarranted affection or being unable to respond to the infant's need for affection and attention. Other research showed that these infants were sometimes abused or rejected (Carlson et al., 1989).

Parkes found that bereaved adults in the psychiatric group displaying the Disorganised Attachment childhood attachment pattern would turn in on themselves in times of stress and not seek help. He saw this as a measure of helplessness which was predictive of anxiety, depression and alcohol abuse following bereavement.

Peter Fonagy (2001) points out that Ainsworth recognised that it was not the mother's physical absence in the 'Strange Situation' which led to the infant's reactions but how the infant appraised or evaluated her departure against what was normally expected of her in the context of their relationship.

Discussion

My own experiences and observations about the process of grieving fit in with what Parkes postulated. I have noticed that people move to and fro through different states and that there are variations between people. As different people may be feeling different things at different times, this can lead to difficulties in family relationships.

The research on the influence of childhood attachment patterns on adult grief reactions (Parkes and Prigerson, 2010) may indicate how a remaining parent might relate to their children after the death of a parent. This knowledge could be

used by health and social care professionals working with parentally bereaved families.

It is important to note that Kübler-Ross (1981) emphasised the use of symbolic language when talking with the dying (both adults and children), and the use of drawings as a means of expression for children.

Worden's (1996) tasks of mourning and the dual process of dealing with bereavement (Stroebe and Schute, 1999) are useful in understanding where a person may be in the mourning process. They show that there are steps towards the internalisation of the dead person and that there is the ability, in time, for the person to move on after the death of a loved one.

Anticipatory Grief

Anticipatory grief is the process that a person goes through before their own death or before the death of someone close to them.

Linda Reynolds and Derek Botha (2006) reviewed published research on the consequences of anticipatory grief in adults. The study's scope included the anticipatory grief of the dying person's close adult family members or significant others and their post-death bereavement adjustment. The authors found that in some studies anticipatory grief had helped the post-death adjustment of the bereaved while in other studies it had had a negative impact; in a third group of studies they did not find any relationship between anticipation and post-death grief. The authors reported that the inconsistent and contradictory findings were due to a range of methodological issues and recommended that they be taken into account for future research in this field.

I selected a few studies from Weaver et al. (2010) as particularly relevant, and these are cited below.

Northouse et al. (2008) reported that cancer and its treatment pose unique challenges to survivors living with minor children and may have a more negative impact on them and their children than on survivors without children or those with adult children. The negative impacts may include heightened distress in worrying

about not seeing their children grow up; an inability to perform usual parenting activities; the strain of multiple roles while being ill; and anger and resentment at many real and perceived losses, and the untimeliness of their illness. The well parent may experience distress related to taking on the ill parent's role whilst still performing his or her own role. Worries about family finances may lead to added stress. Many parents may also struggle with what to tell their children about their own or their spouse's ill health and the future.

Studies (Visser et al., 2004; Osborn, 2007) point to the negative impact on children of living with a parent with cancer. Problems experienced may include those related to emotional, social, cognitive, behavioural and physical functioning. The distress and functioning may vary depending on the child's age and gender, gender of the parent with cancer, nature of the illness and effects of treatment, degree of attachment to the ill parent, family dynamics, and whether the family is intact, divorced or separated. Problems may include regressive behaviour, anxiety, and difficulties in school and social settings. Adolescents show greater emotional difficulties than younger children, especially adolescent daughters of mothers with cancer (Gabiak, Bender and Puskar, 2007). Visser et al. (2004) reported increased somatic complaints amongst children of all ages living with a parent with cancer. Family disruptions appear to be greatest during the initial diagnosis period although health challenges and psychosocial concerns may persist well after the end of the treatment.

Prior work has shown parents to be unaware of the high levels of distress in children, both during and after cancer suffered by the parent (Welch, Wadsworth and Compas, 1996).

Syse, Aas and Loge (2012) cited studies which showed that the age and gender of children influence the type and degree of problems experienced (Thastum et al., 2009; Visser et al., 2005; Welch, Wadsworth and Compas, 1996). Other studies, however, have not reported significant adverse consequences for children (Schmitt et al., 2008; Lindqvist et al., 2007). The authors mention that younger children may be less affected emotionally compared to older and young adult children as they may not fully comprehend the significance of parental cancer (Visser et al., 2005). Older children may support each other but they may

also experience changes in their roles if they have to perform more household chores or assist with the care of the ill parent (Visser et al., 2006).

A Danish study by Buchwald, Delmar and Schantz-Laursen (2012) used interviews and video diaries kept by seven children/adolescents aged between 11 and 17 years of both genders who had a parent with a life-threatening illness. The authors found that “[w]hen children live in a family with a dying mother or father, they find that their home is transformed from a safe base into death’s waiting room”. (p. 234) The children’s anxieties became more acute at the time of diagnosis and when the parent’s condition deteriorated; the researchers found that it made “...no difference to the children’s thoughts and fears whether or not they are told about their parent’s risk of dying”. (p. 233) The children used a variety of coping strategies including using positive and magical thinking and resorting to statistical calculations of the likelihood of death. The authors stress the importance of talking openly to children who find themselves in this situation, and advocate enhanced training and supervision for nurses and teachers to help them be more able to counsel such children.

Deborah Hindle (1996) mentions a research study conducted by Rosenheim and Reicher (1985) focusing on families in which one parent had a terminal illness. The researchers noted that the parents, and especially the ill parent, underestimated the anxieties reported by the children themselves. The authors thought this may have been partly due to the children showing their anxieties in a covert, indirect or symbolic way and partly to do with the parents’ preoccupation with the illness and potential loss and their use of denial as a defence in managing their overwhelming anxieties.

The website of the Childhood Bereavement Network (2014) presents a list of selected literature on anticipatory grief in children and adolescents whose parents have a life-threatening illness. I will cite a few of these below.

Beale and Sivesind (2004) found that children of dying parents exhibited significant distress as well as more knowledge of their parents’ illness than was usually thought. The authors recommend that appropriate services from suitably competent health care professionals be put in place to help children cope with

the dying process of the parent and to ameliorate the future bereavement process.

Christ and Siegel (1994) found that, compared to younger children, adolescents' greater cognitive and empathic capacities allowed them to be more aware of the impending loss and the physical and emotional pain of their parents. There were conflicts around developmentally appropriate separation. Coping strategies included intellectual defences, searching for meaning and understanding, and seeking help. Most of the adolescents coped without resorting to severe acting out behaviour.

Kennedy and Lloyd-Williams (2009) found that children were distressed about their parents' diagnoses and were concerned about their parents' and their own health. Coping strategies in the children included distraction and maintaining normality. The most notable life changes were shown to be increased responsibility and decreased social activity. Parents did not recognise the degree of impact on their children as described by the children themselves, and used maintaining normality as a way of limiting the effect. Positive aspects of the experience were the strengthening of family relationships and increased valuing of family members and the important things in life.

Discussion

It is interesting to note that studies, both pre- and post-death of a parent, have found quite a few similarities in the impact on children/adolescents and their parents. This is not surprising for those of us working in CAMHS who see children/adolescents referred for a variety of reasons and who show their distress with symptoms which appear to be similar, although the causes may be different. This has been borne out in my psychotherapeutic work with both parentally bereaved children/adolescents and those living with a parent with a life-threatening illness.

An important finding, which has appeared in several studies mentioned in this chapter, is that parents are not very aware of the impact of parental life-threatening illness on their children. This may be due to the parents – ill and non-

ill – being preoccupied with the illness, and/or wishing not to know that their children may be suffering (i.e., denial). This has implications for how one conducts research into this area; that is, it highlights the importance of getting information directly from the children. It also points to the importance of therapists working separately with children/adolescents and the parents as well as working with the whole family together.

My own clinical work, both for this present study and over the years, confirms the findings about parental concerns for their children (Northouse et al., 2008). I have also found that parents (ill and well) are very concerned about the effect of the parental illness on their children, both in the present and for their future (see Chapter 4: Findings – sections on Parental Concern).

Buchwald, Delmar, and Schantz-Laursen (2012) found that it made no difference to the children's thoughts and fears whether or not they had been told about their ill parent's risk of dying, and this is important to note. It fits in with my observations that children pick up on anxieties in the family and may feel things are not right even though they may not have been informed of the details of the situation. It also corroborates the findings of reviews mentioned above (Dowdney, 2000; Servaty and Hayslip, 2001; Haine et al., 2006) (see The Impact of Parental Bereavement in Childhood) that parents reported fewer symptoms and disorders in their children than the children themselves reported.

Psychoanalysis: Mourning and Trauma

Sigmund Freud (1917) compares mourning to melancholia. The melancholic or depressed person exhibits a loss of interest in the outside world, a loss of ability to love and an inhibition in any kind of performance, and a diminishment of self-esteem which includes self-recriminations and a sense of worthlessness. The person who is mourning displays the same low mood, loss of interest in the outside world, and inability to choose any new love object, and is engrossed with the memory of the lost loved one. The work of mourning is to slowly and painfully sever the bonds with the external lost object and this is helped by reality testing, i.e., the acknowledgement that the person is no longer there. The mourning work is carried out 'piecemeal' over time with a great expenditure of energy. As the

ego is absorbed in the mourning work, the person turns away from external life and becomes apathetic. The loss of the external object is conscious, as opposed to in melancholia in which the loss may have become unconscious. In mourning, the world feels impoverished and empty, unlike in melancholia where the ego has become so. Mourning, as opposed to melancholia, is seen as a normal and non-pathological process.

Melanie Klein (Segal, 1978), through her clinical work with children and adults, postulated that, in early development, the infant is dominated by the paranoid-schizoid position for the first three to four months of life, with the depressive position becoming more prevalent from about six months onwards. She called them 'positions' rather than 'phases' or 'stages' of early life to emphasise that the terms described specific internal configurations of object relations, anxieties and defences which continue through life. In the paranoid-schizoid position the infant is unaware of the whole person and therefore relates to part-objects (e.g., the breast) and is subject to paranoid anxieties and splitting processes. The infant moves into the depressive position where there is a recognition of, and, therefore, a relationship with, the mother as a whole person. The depressive position is characterised by integration, ambivalence, depressive anxiety and guilt. The infant can now begin to both love and hate the good object – i.e., they can experience ambivalence. He or she feels guilt at having lost the good object through her/his own destructive internal attacks and starts to pine and mourn for its loss. This pain of mourning propels the infant into a reparative process to restore the good internal object and is seen to be the basis of sublimation and creativity.

Wilfred Bion (1967) described the mother's function for the infant in making tolerable catastrophic feelings of, for example, dying, by taking them in, transforming them through her thinking and making them available to the infant in a modified form. If the projection is not accepted by the mother, then the infant reintrojects it, unmodified, as a "nameless dread".

Caroline Garland (1998) notes that Bion (1967) linked this containing function of the mother for her infant with that of the therapist who contains the patient's overwhelming anxieties. Garland postulated that flashbacks after a traumatic

event are due to "...the loss of the container: the internalised place, or vessel, or space intimately connected with good early care, in which *thinking-about-something* can occur". (p.110) (author's italics)

Garland cites Hanna Segal's (1957) insight about the importance of a containing object for the development of symbolic thinking. After a traumatic event this capacity to symbolise may be damaged or lost and replaced by what Segal called "symbolic equation", a developmentally earlier version of symbolic thinking. In symbolic equation, the symbol does not stand for the thing symbolised.

Hindle (1996) quotes Pynoos (1992) thus: "...children seem particularly vulnerable to the dual demands of trauma and grief work". (p. 262) She discusses the difference in these "dual demands" between trauma and mourning by citing Garland (1991) who argued that symbolic thinking is lacking in the traumatised, and Freud (1917, above) who described the slow and painful work of mourning in letting go of the lost object and internalising some aspects of it.

Nicholas Temple (1998), a psychiatrist and psychoanalyst, discusses trauma as a consequence of separation and loss by citing earlier literature in this field. He cites Freud (1917; 1926) who mentioned people who could not come to terms with their loss and developed pathological melancholia. He continued with the understandings contributed by Klein (1935, 1952) who saw loss and mourning as part of normal development, as mentioned above, but also thought that not being able to mourn early losses could lead to disruptions in development and a return to a more paranoid way of functioning. Temple mentions Winnicott (1958) who discussed anti-social tendencies as a form of protest in efforts to get the environment to repair a trauma. He also cites Bowlby, Miller and Winnicott's letter to the *BMJ* (1939) on the long-term traumatic consequences of evacuating children from cities and separating them from their mothers during World War II.

Dorothy Judd (1994), in her discussion of life-threatening illness in adolescents as a form of psychic trauma, used the definition of trauma from Pynoos and Eth (1984) thus: "Trauma occurs when an individual is exposed to an overwhelming event that renders him or her helpless in the face of intolerable danger, anxiety, and instinctual arousal". (p. 88)

She continued that 'trauma' – meaning 'wound' in Greek – like the wound breaching the outer protective function of the skin, could be seen as the piercing of the psychic protective apparatus in the individual. She quoted Freud (1920) to illustrate this:

“We describe as ‘traumatic’ any excitations from outside which are powerful enough to break through the protective shield...the concept of trauma necessarily implies a connection of this kind with a breach in an otherwise efficacious barrier against stimuli.” (Judd, 1994, p. 88) (Freud, *Beyond the Pleasure Principle*, 2010, pp. 45–46)

Judd preferred to use the concept of 'protective *filter*' rather than 'protective *shield*' which implied something impermeable. She postulated that parents perform this function of being a protective filter for their children. This implies a permeability in which experiences can pass through both ways. So the parent filters not only what reaches the child from the outside world but also processes and communicates the child's distress back to others.

Roger Money-Kyrle (1978) mentions three types of innate or instinctive knowledge in people: "...the recognition of the breast as a supremely good object, the recognition of the parents' intercourse as a supremely creative act, and the recognition of the inevitability of time and ultimately death". (p. 442) The infant experiences the coming and going of the external breast and the loss of it permanently at weaning. If development is favourable, after painful mourning this leads to the internalisation of the first good object. As time moves on the young child discovers or recognises parental intercourse which arouses jealousy and the conflicts of the Oedipus complex, which leads to a period of mourning for the child–parent marriage that can never happen. Money-Kyrle mentions that the recognition of the inevitability of time and ultimately death was of a different order and he was not sure whether it was innately pre-determined. The fear of death can appear when a murderously competitive split-off part of the self threatens the self as persecutory anxiety or its loved objects as depressive anxiety. He postulated that the fear of death was not the same as the recognition of its inevitability, which is forced upon us by repeated experiences that demonstrate that nothing lasts forever (good or bad), a fact he thought we perhaps never fully accept.

Discussion

The dual demands of trauma and grief work mentioned above (Pynoos, 1992) are of particular importance for children facing the life-threatening illness of a parent. Advances in medical science have led to cancer patients being able to live longer, hence prolonging this dilemma. It is therefore no coincidence that unconscious defences, usually of denial, take hold of family members, as will be shown later in this present study (see Chapter 4: Findings – sections on Defences). Parents struggling with their own life-threatening illness may find it difficult to contain their children's anxieties (Garland, 1998; Bion, 1967) and the parental 'protective filter' (Judd, 1994) may well be affected too. The well parent may also find it difficult to fulfil these functions as they struggle with their own anxieties and the added responsibilities they take on due to the illness of their spouse/partner. These difficulties can be compounded if the ill parent is single or there are no other significant adults in a child's life.

Children's Play and Drawings as Communication

As child and adolescent psychotherapists we use non-verbal as well as verbal methods in therapy. The non-verbal methods include play and drawings which are usually used as a means of communication, mostly by younger and latency-age children, although adolescents also use them at times. Play and drawings can be seen as a form of free association, not unlike dreams in adult psychoanalysis. In this study I have included descriptions of play behaviour as well as the use of drawings in the overall process notes for the therapy sessions (see Chapter 3: Methodology – Data Collection).

Play

The medium of play has been used from early on in observations and understandings about children's internal world and in child psychotherapy.

Dr. Margaret Lowenfeld established the Children's Centre in 1928 which in 1933 developed into the ICP (Hood-Williams, 1974). Horne and Lanyado (2009)

mention Lowenfeld's contributions to this field by quoting Urwin and Hood-Williams (1988) thus:

“...Lowenfeld's wartime experience and research observations had already led her into the belief that, in addition to environmental considerations, there were processes inherent in children themselves which would enable them to find more adaptive solutions. For Lowenfeld the key to these possibilities was play.” (pp. 42–43) (Horne and Lanyado, 2009, p. 4)

Klein (1975a) describes her therapeutic interactions with children through play using small toys and how these led to her theoretical insights which informed her psychoanalytical work with children and adults (see Chapter 2: Review of Literature – Psychoanalysis: Mourning and Trauma). Klein (1975a) says:

“It has already been pointed out in the introduction to this paper that my attention from the beginning focussed on the child's anxieties and that it was by means of interpreting their contents that I found myself able to diminish anxiety. In order to do this, full use had to be made of the symbolic language of play which I recognized to be an essential part of the child's mode of expression.” (p. 137)

Winnicott (1971) describes the interplay between psychotherapy and play thus:

“Psychotherapy takes place in the overlap of two areas of playing, that of the patient and that of the therapist. Psychotherapy has to do with two people playing together. The corollary of this is that where playing is not possible then the work done by the therapist is directed towards bringing the patient from a state of not being able to play into a state of being able to play.” (p. 44) (author's italics)

He goes on to say that this applies to both adults and children in psychotherapy, although play appears mainly in verbal form in adults. Winnicott suggests that playing is universal and starts early between the baby and his/her mother; that it facilitates growth and therefore health and leads to relationships in groups; that it could be a form of communication in psychotherapy; and that “psychoanalysis has been developed as a highly specialized form of playing in the service of communication with oneself and others”. (p. 48)

Winnicott (1971) emphasises that play is a natural process and leads to self-healing. It is immensely exciting in its own right without instincts being involved

(e.g., sexuality, although this may at times appear in therapy). He mentions that the playground of play starts with “a potential space between the mother and the baby or joining mother and baby”. (p. 55) He suggests that in playing there is always “the precariousness of the interplay of personal psychic reality and the experience of control of actual objects”. (p. 55) This is originally found in the intimacy, reliability and sense of trust in the baby’s relationship with his or her mother. He goes on to say that if a patient cannot play, then the therapist has to attend to this as a major symptom.

Karlen Lyons-Ruth (2006) reviews the literature on play in infants and young children and discusses it within the context of psychodynamic child play therapy. She discusses the development of play in infants and young children as follows:

“...this gradual working out of collaborative strategies for the elaboration of shared meanings is a principal function of joint pretend play in early childhood, and this is one of the critical developmental functions addressed in psychodynamic play therapy”. (p. 142)

Likierman and Urban (2009) summarise the importance of play in child psychotherapy thus:

“What Anna Freud, Klein, Fordham [Society of Analytic Psychology – Jungian], and the schools which they inspired, all had in common was a strong belief in the importance of the child’s imaginative life as developed in the matrix of family relationships and as expressed symbolically through play.” (p. 25)

One could add the psychotherapeutic work and thinking of Lowenfeld and Winnicott, as mentioned before, to the above list.

Drawings

Psychoanalytic child and adolescent psychotherapists have used drawings extensively in their work, and they have been included illustratively in case studies.

The most well-known example of a published case study using drawings to illustrate the therapeutic process is that reported by Klein (1975b), based on her

work with Richard, a 10-year-old boy who she saw for child analysis. In this case study Klein describes the process of child psychoanalysis using Richard's play and drawings as well as their verbal interactions.

Another published case study is that by Sheldon Cashdan (1967), who used drawings to show the process of child psychotherapy. Cashdan (1967) saw an 8-year-old emotionally disturbed boy in a therapeutic residential setting in the USA. He illustrates his case study with drawings which mark the different phases in the 11 months over which he saw the boy in psychotherapy.

As has been mentioned earlier, Kübler-Ross emphasised the use of symbolic language when working with the dying and the use of drawings in working with dying children (see The Mourning Process above). Gregg M. Furth (1981, 1988), an American psychologist trained at the Jung Institute in Zurich, worked with the dying (children and adults) using drawings as a medium through which the unconscious showed itself in the therapeutic process.

Mary Sue Moore (1994), clinical psychologist, psychotherapist and educator, expounds the complexity of the meanings embedded in children's drawings when working with physically ill and, at times, traumatised and abused children. Using case vignettes illustrated by children's drawings, Moore describes how "[d]rawings communicate both conscious and unconscious experience of self and the environment (which includes significant people in relationships with the artist) – sometimes with graphic accuracy, sometimes in symbolic form". (p. 114)

Moore (1994) underlines the importance of being present when a child is drawing, as *how* the child draws may point to what is significant or important to her/him.

Moore (1994) gives examples of how some drawings become more understandable to the therapist once the child's history was taken into account. She gives an example of David, a 9-year-old boy with a rare degenerative genetic disease of the teeth and gums (passed on by the mother to male children). He made drawings of himself and his mother, but the figures did not have mouths. This could have been seen in terms of his medical condition but in the light of additional knowledge about the family history the drawings took on an added significance:

“On-going psychotherapeutic work with the family later revealed that David’s father, a high ranking member in a fundamentalist religious sect, habitually battered his wife and children, and had threatened each of them with terrible retribution *if any one of them were ever to talk about the physical abuse they experienced.*” (p. 128) (author’s italics)

Moore (1994) describes how “[a]n additional meaning may be ascribed to a small, circular sun when it is placed directly above a specific person in a drawing: it may represent the unmourned loss or bereavement of a significant person – often a parent – in that person’s or the child’s life”. (p. 136) She illustrates this with a case example of an 8-year-old girl whose parents had an acrimonious divorce leading to mother being granted custody, with father denied access. The girl made two drawings of her ‘families’ and in the second drawing depicted her father and named him “my dad who I can’t see anymore” (p. 137). Above the figure of her father the girl placed a small round sun. Moore went on to say that “[t]he content of the session was directly connected to the child’s sense of loss of her father – ‘almost like he died’”. (p. 137)

Julien Gross and Harlene Hayne (1998), psychologists in New Zealand, have conducted systematic research into information gathered through drawings. Their research sample consisted of 3–6 year olds of both genders who were predominantly New Zealanders of European descent from middle-income socio-economic backgrounds. The children were interviewed individually and split into two groups. The children in the ‘tell group’ were asked to give a narrative account of three emotional experiences (happy, sad, scared). The children in the ‘draw and tell’ group drew and described what they drew. They found that children asked to ‘draw and tell’ reported more than twice as much information about their emotional experiences as children who were asked to ‘tell’ only.

Gross and Hayne (1998) then conducted another experiment to see whether drawings influenced the accuracy of children’s verbal reports. In this second experiment, 5–6 year olds of both genders with similar racial and socio-economic backgrounds to the children in the first experiment went through a similar interview process about their emotional experiences, but this time they were asked to remember instances when they had been happy, sad, scared *and* angry. As before, the interviews were audio and video taped and transcribed verbatim.

To assess the accuracy of the reports, parents were interviewed about the content of their child's interview. The parents indicated a high level of accuracy in the descriptions of the emotional events provided by the children through their drawings and verbal reports. The authors concluded that drawings may facilitate children in talking about their emotional experiences in both legal and clinical contexts.

The authors put forward some possible explanations for the above results. They thought that drawing might decrease the social demands of the interview making children feel more comfortable; that pictorial representations might offer more effective retrieval cues; that it might offer children help in organising their verbal reports; and that, as drawing extended the duration of the interview, it might have allowed more time for information to be elicited.

Discussion

In psychotherapy the presence of an accepting and thoughtful person who is interested in what the child is depicting in their play adds an extra dimension to the self-healing process that Winnicott (1971) suggests play offers. Over time an understanding of shared meaning develops in the relationship between therapist and child as Lyons-Ruth (2006) mentions, facilitating the continuation of the therapy.

It is interesting to note the usefulness of non-verbal methods in working with the dying mentioned in the literature. For example, drawings were used by Kübler-Ross (1981) in her work with dying children. Furth (1981, 1988) used drawings with children and adults who were terminally ill. Macleod (2009) found the concepts from psychoanalysis and Attachment Theory and the non-verbal practice methods used in child psychotherapy in end-of-life care to be valuable (see Psychosocial Therapeutic Services below).

Moore (1994) aptly depicts the many-layered meanings of children's drawings when taken within the context of their lives. This is useful to the clinical practice of child psychotherapy.

The studies by Gross and Hayne (1998) show that the use of drawings to describe emotions can elicit more – and more accurate – information from children’s memories. In child psychotherapy the use of drawing is valued as a form of communication during the process. This study adds an empirically interesting slant to the subject.

Psychosocial Therapeutic Services

Akerman and Statham (2014) cite a 2010 survey about support services for bereaved children in England (Penny, 2010) revealing a variety of provision in local authority areas. Just over a third of the local authorities (LAs) and under a third of NHS Primary Care Trusts (PCTs) responded to the survey. Responses from either LAs or PCTs or both were received from 85 different areas, representing 56% of all local authority areas. Providers of support included community-based child bereavement services, child and adolescent mental health services, young people and school counselling services, hospices, hospitals, educational welfare and critical incident teams. The needs of bereaved children were also addressed through targeted mental health in schools programmes, healthy school initiatives and curriculum development. However, there were low levels of planning to meet bereaved children’s needs and little evidence of coordination of services. There appeared to be little consistency in whether children experiencing particular types of bereavements in particular localities would be offered appropriate supportive services, including basic information.

Kennedy et al. (2008a) conducted a review of key literature on current provision of support for children facing the death of a parent. They concluded that there was national and international recognition that the needs of bereaved children required careful assessment and that, although there was a complex range of services for children facing the death of a family member in the UK, provision was fragmented.

Kennedy et al. (2008b) conducted a study to elicit the views of children, parents and key stakeholders of a new bereavement service in Scotland for families with a parent dying from cancer. Six families (parents and children up to the age of

19) were recruited from the community palliative care service. Each case study comprised a family, a health professional and a family support worker. Six key stakeholders, including the manager of the palliative care service, the family support worker, a GP and Chair of the Cancer Network, a representative of the funding body (Macmillan Cancer Care), the lead palliative care consultant, and a previous user of the children and family support service, were also interviewed. A qualitative pre- and post-intervention evaluation design was used in order to explore the experiences of families with children facing the death of a parent and the expectations that they, and the stakeholders, had of the service.

The findings showed that children and families with complex and and/or enduring needs benefited from the specialist interventions offered by this service. The authors conclude that many families can be supported within the community drawing on their own social networks, and that risk assessment measures would identify need and ensure limited resources are directed appropriately. The research identified five themes which were: (1) Thrown into chaos – The impact of the life-threatening illness on the patient, partner and children's roles, and on relationships and family life; (2) Lost in the panic – The focus is wholly on the ill parent leading to children being protected or excluded and their needs not being met. Children may express disruptive behaviour and relationships may suffer; (3) Holding them steady – The family is the focus of care and assessment and agreement of a plan is conducted with the family; key interventions are with family members and resources are sought to support children and family; (4) Journeying together – The family support worker adapts to the needs and the pace of the family. There is shared understanding and mutual support and preservation of positive memories; involvement of the family in rites and rituals; and advocacy or brokering to reduce family tension; (5) The road ahead – The family support worker is there after the parent's death and can support the family during their grief; helping them to see positive aspects of past relationships; encouraging them to care for themselves and other family members; and offering support for the family to see and plan beyond tomorrow. It was found that long-term negative effects were reduced for those families receiving support.

A Norwegian study conducted by Bugge, Helseth and Darbyshire (2008, 2009) focused on a service for families with one parent who had incurable cancer. An

experienced nurse trained in talking to children in difficult situations conducted in-depth interviews with children (Bugge, Helseth and Darbyshire, 2008) and parents (ill, well, together and divorced) (Bugge, Helseth and Darbyshire, 2009) over a period of five or six weeks. Six families and 12 children (aged between 6 and 16) participated in the Family Support Program in three hospitals. The Family Support Program consisted of experienced health workers (four nurses, a sociologist and an art therapist) offering a combination of separate meetings with the family, the parents and the children individually.

In terms of the children, the researchers found:

“The program helped the children to feel more secure; increased their knowledge and understanding; helped them become aware of their own role, their family’s strengths, and whom they could approach for help; and helped them realize that it was good and helpful to talk about the illness situation. They needed to talk in private without having to think about other family members’ reactions, but they also needed to be in dialogue with other family members.” (Bugge, Helseth and Darbyshire, 2008, p. 426)

In terms of the parents the researchers reported:

“Parents described how the Family Support Program helped them gain greater insight into their children’s thoughts and reactions and into how the situation affected their daily living. Parents reported that conflicts were reduced, they could talk more openly about the situation in the family and that they were shown how to support their children’s coping.” (Bugge, Helseth and Darbyshire, 2009, p. 3480)

Rolls and Payne’s (2007) study (see *The Impact of Parental Bereavement in Childhood* on how children and parents experienced the death of significant family members) found that children and parents who participated in interventions offered by UK childhood bereavement services found them helpful in significant ways; this included “the benefit of speaking to someone who understood their experience”. (p. 281) Bereaved parents found the support helpful in taking care of their children, although some parents found it difficult to attend group interventions. The authors conclude that “[by] providing an ‘ecological niche’ for bereaved children, UK childhood bereavement services contribute to meeting outcomes identified in recent policy initiatives”. (p. 281) (These initiatives include

the Children Act (1989); the UK government ratification of the UN Convention on the Rights of the Child (1989) in 1991; and *Every Child Matters* (2003).)

Charitable organisations for bereaved children and young people have also grown over the last few years, offering support and counselling to children, young people and their families, both before and after the death of family members or significant people in their lives.

Winston's Wish (2015) offers practical support and guidance to bereaved children, their families and professionals. This includes face-to-face support services for families in certain areas of the UK; a national helpline; information via email; specialist support including individual work with bereaved children and adults when grief becomes complicated; practical and creative group activities for children aged 6 to 18; a six-week play and group support programme for children between 3 and 5 years; SWITCH – a community outreach bereavement support service for young people aged 8 to 14; and an interactive online service for young people. Winston's Wish has both paid and volunteer staff and offers consultancy and training to professionals. This is a Gloucestershire-based charity which also offers services in West Sussex and the north-west of England.

Child Bereavement UK (2015) offers a similar range of services, information and guidance. It also offers training tailored to meet the particular needs of organisations including hospices, schools, hospitals, local authorities and other charities UK-wide. They also offer e-learning to teachers, head teachers and support staff on supporting bereaved pupils. This Buckinghamshire-based charity offers support services in Buckinghamshire, Milton Keynes, west London, Newham, South Lakeland, Cheshire, Carlisle and Eden.

Hindle (1996), a child and adolescent psychotherapist, describes the process of both individual psychotherapeutic sessions she offered to two siblings (a girl aged 12 and her brother aged 14) and family therapy with the children and their mother, co-working with a hospital social worker. At the point of referral, just after their mother had been diagnosed with ovarian cancer, the children had been exhibiting risky, self-harming behaviour as well as psychosomatic anxieties. Their father had died of testicular cancer four years previously. Hindle described complex

traumatic reactions of family members as well as interactions within the family. The children missed and idealised their father and denigrated their mother who they saw as being ineffectual. The anger about their situation seemed to be acted out between the siblings. The uncertainty of their mother's survival was an important contributory factor. Hindle emphasised the crucial importance of the containing function carried out by the professional network for this family dealing with life and death issues. Hindle's model of therapeutic work in an outpatient setting is congruent, in many respects, to my clinical experience.

The following examples of child and adolescent psychotherapists working with very ill children and their parents in hospitals have relevance to my study as many of the issues described are similar to those I encountered in my clinical work. I have discussed the similarities and differences between their work and mine in the commentary below.

Judd, a child and adolescent psychotherapist, has worked extensively with dying children in hospitals. Judd (2014) describes her clinical work with a 7-year-old dying boy and his parents and related liaison work with other professionals. This book's subject – childhood death and the context within which it appears – is mentioned further in Chapter 3: Methodology – Introduction.

Ricky Emanuel and his child and adolescent psychotherapy colleagues (Emanuel, et al., 1990) offered individual psychoanalytic psychotherapy to 20 children and adolescents who were in hospital for chemotherapy and bone marrow transplantation. They provided this as a preventative measure to try to alleviate possible psychological damage arising from having treatment for a life-threatening illness. They described how they had to modify their technique to adapt to the particular circumstances the children found themselves in. They discussed how the issues that arose were to do with control, denial, isolation, dependency, contamination, abnormality, uncertainty and cultural differences.

In order to ascertain whether minor children are included in psychosocial services offered to adults with life-threatening illnesses I looked at the literature in adult palliative care which now follows. Although the mothers in the present study were not at risk of dying imminently and therefore not in need of end-of-life palliative

care, I have included the palliative care literature in my review as my clinical work, as well as the literature, shows that there is a continuum to how families experience parental life-threatening illness as the disease progresses, and that there is an impact on families at every stage of the illness.

Dame Cicely Saunders, who trained as a nurse, a medical social worker and a physician, founded St. Christopher's Hospice in 1967. This was the first hospice to offer palliative care for pain control and to see the dying person as a whole and offer care for their physical, spiritual and psychological wellbeing; the hospice is also involved in research and teaching. Since its establishment, hospices for both adults and children have spread worldwide (St Christopher's Hospice, 2014).

Frank Brennan (2014) discusses the recognition of and response to the inherent dignity of the human person as a unifying concept in human rights law and palliative care. A research study by Hack et al. (2004) gathered data to explicate the concept of dignity from the point of view of terminally ill cancer patients and found that the factors relating to dignity at the end of their lives were Pain, Intimate Dependency, Hopelessness/Depression, Informal Support Network, Formal Support Network, and Quality of Life. Forty-six per cent of the patients reported some loss of dignity and subsequent regression analyses found the final two factors of Hopelessness/Depression and Intimate Dependency had statistical significance. Jaiswal, Alici and Breitbart (2014) offer a comprehensive review of palliative care for patients with cancer, focusing on psychiatric, medical and psychotherapeutic aspects. Pringle, Johnston and Buchanan (2015) review studies which show the difficulties of providing dignity and patient-centred palliative care in hospital settings, compared to hospice or community care settings.

There is a wide array of types of interventions that can be offered to terminally ill adults which seem to be beneficial in alleviating psychosocial and spiritual distress. Chochinov et al. (2011) conducted a randomised controlled trial comparing terminally ill patients' experiences of dignity therapy, client-centred care or standard palliative care. They found no significant differences in distress levels before and after completion of the trial in the three groups. However, patients reported that dignity therapy was significantly more likely than the other

two interventions to have been helpful in improving quality of life, increasing sense of dignity, changing how their family saw and appreciated them, and to have been helpful to the family. Macleod (2009) discusses contributions from psychodynamic psychotherapy for end-of-life care and found concepts from psychoanalysis and Attachment Theory and non-verbal practice methods used in child psychotherapy to be useful. A study by Woolf and Fisher (2015) found the use of group dance and movement psychotherapy relieved holistic pain by enabling people with terminal illnesses to express a sense of who they were as a human being. Leow, Drury and Hong (2010) found the use of music therapy promoted communication and social interaction. A study by Selman, Williams and Simms (2012) found the use of group yoga and dance therapy (offered separately) improved social interactions, relaxation, mobility and breathing ability in terminally ill patients. Lo et al. (2014) found improvements in the alleviation of symptoms of depression and death anxiety, and an increase in spiritual wellbeing in patients with advanced cancer who were offered brief individual psychotherapy – Managing Cancer And Living Meaningfully (CALM) – which is based on relational, existential and attachment theories.

Beng et al. (2015) mention that Mindfulness Based Supportive Therapy with its five components of presence, listening, empathy, compassion, and boundary awareness is potentially a useful psychological intervention in palliative care, specifically designed to address psycho-existential suffering of terminally ill patients.

O'Brien et al. (2008) conducted a study of women with metastatic breast cancer who took part in supportive-expressive group therapy using both face-to-face and teleconferencing methods. They found that participants experienced significant improvement in mood and reduction in distress after 12 months in the group. The teleconferencing method reached participants living in rural areas around Brisbane, Australia, where the study was based.

Kraft (2012) reviewed the use of complementary and alternative medicine to relieve symptoms of depression, anxiety, grief and cancer-related fatigue. She concluded that some yoga techniques, acupuncture, some massage techniques, and aromatherapy may have short-lived positive effects on depression; that

anxiety may be treated successfully by some yoga techniques, music therapy, mindfulness-based stress reduction, acupuncture, some massage techniques, and aromatherapy; that fatigue may respond to acupuncture; that exercise was seen to be a valuable option but not for patients in advanced stages of disease; and that ginseng may even do harm.

Serfaty et al. (2012) conducted a randomised controlled trial to examine the clinical effectiveness of aromatherapy massage versus Cognitive Behaviour Therapy (CBT) for emotional distress in cancer patients in palliative care. They found that both interventions led to improvements in depression and anxiety; and that in the longer term CBT may be more effective for depression.

Some professions have reviewed the importance of their roles and the competencies needed in those roles in working within the palliative care setting. These include nursing (Dobrina, Tenze and Palese, 2014); social work (Cadell et al., 2010); and counselling and clinical psychology (Golijani-Moghaddam, 2014).

Amoah (2011) reviewed the literature on spirituality and pastoral care and demonstrated, both from the literature and his own experience as a chaplain, why spirituality should be considered on an equal footing with other key themes in palliative care. He defined spirituality by mentioning that “NICE (2004, p. 95) recognizes that ‘beliefs can be religious, philosophical or broadly spiritual’, and that spirituality as a concept ‘may not always be expressed in a religious way’”. (p. 354) The author concludes that: “[s]pirituality, whatever its shade and form, helps many of those facing terminal illness make sense of life during this challenging time”. (p. 357)

The above literature emphasises the need to work within interdisciplinary teams; for all professional staff to have attitudes and communication skills which are respectful and sensitive to the dying person, their autonomy and their cultural and spiritual needs; and for training in palliative care across the professions to be provided. The need for risk assessment is highlighted by some studies so that relevant services are offered to the most needy: for example, those who have complicated grief being offered specialist psychosocial services (Kennedy et al., 2008b; Schuler, Zaider and Kissane, 2012). The importance of including families

is highlighted in the approach of these professions, and a paper on family grief therapy (Schuler, Zaider and Kissane, 2012) discusses the use of this model before and after the death of the terminally ill patient and the importance of offering it in whatever setting is most appropriate (i.e., hospital, hospice or family homes).

Rodgers et al. (2005) came to the conclusion that psychosocial interventions showed beneficial effects in general psychological distress and emotional adjustment in patients with cancer. It was not clear how much these beneficial effects were due to the greater attention provided by the health care workers and how much it was specifically due to the psychosocial interventions. The effects of psychosocial interventions on anxiety and depression were not clear. There was a variation in findings for types of interventions (e.g., behavioural or non-behavioural) and these may have been due to inconsistencies in separating out the different interventions across the research studies. Results were also inconsistent for different types of interventions (e.g., individual versus group). Evidence for the effects of psychosocial interventions on physical outcomes (e.g., immune responses, survival) in cancer patients was relatively sparse and showed mixed results.

Discussion

A UK-based study (Scotland) that involved families with children (up to age 19) (Kennedy et al., 2008b) identified five themes to illustrate the journey of a family as the terminally ill parent's illness progresses; the findings of the study also note issues both within and between family members. It also shows the need for and usefulness of the same practitioner working with families before and after the parent's death. This model of therapeutic intervention fits the model I have developed. An example of this form of intervention – working with these types of families both before and after the parent's death – is described later (see Chapter 4: Findings – Lara). In this present study the ill mothers were still alive at the time of discharge when the symptoms in the children/adolescents had receded. It is important to make a distinction between the needs of these two groups of ill parents (i.e., parents facing impending death and those with a longer life

expectancy) as the services offered may have to be geared differently to best suit the needs of the families concerned.

Hindle (1996) mentions that there can be an increase in anxieties within family members when they are uncertain how long an ill parent will survive. She also mentions the role health professionals' networks can play in containing anxieties within the family. My liaison work with other professionals offered this form of containment to the family (see Chapter 4: Findings – Johnny). Work with the families in this study showed that there were anxieties in family members finding themselves in this situation but also defences against them.

There seem to be a range of services offered to bereaved children and their families and to families with parents with life-threatening illness, including valuable information and support services from the charitable sector, but these services are fragmented and uncoordinated across the UK (Kennedy, et al., 2008a; Penny, 2010).

Commentary

In this section I discuss the similarities and differences in the work done by child and adolescent psychotherapists working in hospital settings with terminally ill children (Judd, 2014; Emanuel et al., 1990) and my own therapeutic work with families where there is a parent who has a life-threatening illness.

The most important similarity is that we are working within a psychoanalytic framework, aware of unconscious as well as conscious communications. In both settings the main purpose is to allow the children and family members to communicate their feelings and thoughts about the situation they find themselves in, containing their anxieties and facilitating the grieving of the eventual loss of the dying child or parent, if that is the outcome. As child and adolescent psychotherapists we use both verbal and non-verbal methods of communication (e.g., play and drawings). Due to the nature of the illnesses, uncertainty about the future is common in both settings. Working flexibly to fit in with the needs of the family, and especially the ill person, seems common to both settings.

Another important similarity is the need to be aware of the defences in the people we are working with as these defences may be required at times to cope with the devastating situations very ill people and their families find themselves in. Working in the transference and being aware of one's own countertransference feelings and thoughts are other similarities in both settings. The highly emotionally charged situations that the families find themselves in could lead to the members trying to evacuate their unbearable feelings into the therapist and the ability of the therapist to stay contained and think about this rather than act out is important. Supervision and team discussions could help with this. In both settings close liaison with other professionals is vital and, at times, offering understandings and containment to the professional network seems to be an important part of the role too. This kind of work may be seen as applied child and adolescent psychotherapy. It may have to be offered at crisis times for families and have frequent disruptions and be of shorter duration than usual long-term psychotherapy.

The main difference is that I was working with a parent who had a life-threatening illness and not with a very ill child. Child and adolescent psychotherapists working with terminally ill children were mostly offering individual child or adolescent psychotherapy while I offered sessions to children/adolescents, parents and families. I saw the clients in a suitable consulting room within an outpatient CAMHS, away from the disruptions and distractions of a hospital ward. I could usually plan with the family how long I saw them and end cases appropriately. In hospital work the child patient may be too ill to be seen, may be undergoing a medical procedure, or may suddenly go home, sometimes without prior notice being given to the psychotherapist. I was not subject to the physical changes and needs of the patients which my hospital colleagues had to deal with. Although I was very aware of the physical changes in the ill parents and how these impacted on their lives, it was one removed, so to speak. I did not witness them in their night clothes in bed or surrounded by machines, or with medical and nursing staff administering to them. In the hospital setting the psychotherapists had to be mindful of the organisational defences which were acted out by the staff; in outpatient work this is not usually an issue to contend with. I had a mixed case load working in outpatients CAMHS and therefore was not inundated with such

cases at any given time. I wonder how my fellow child and adolescent psychotherapists working in hospitals manage this. It is possible that they work part time, and/or in other settings too, to offset the great emotional and psychological stress which is inherent in such work.

Concluding Thoughts

This literature review shows the context within which my research lies. There is a sizeable number of parentally bereaved children and adolescents and a growing body of literature on the multifaceted impact on them and the surviving parent. There is a growing body of literature on children's understanding of death as well as their individual experiences of death and the contexts they live in. There are also substantial understandings about the processes of grief. Research into anticipatory grief seems to have conflicting findings for adults close to the dying person and is relatively sparse for children and adolescents. There is a sizeable literature on psychoanalytical understandings of the internal development of the psychic apparatus of the child which takes into account the child's relationships with early internal and external objects or part-objects; and on Attachment Theory which focuses on the development of the child within the context of their relationships with the primary care-giver (usually the mother).

There are support and counselling services for children and young people and their families, both before and after the death of a parent, but these appear to be fragmented and not available consistently across the United Kingdom.

The growth of the hospice movement and better understandings about the need to treat a dying person holistically can only be lauded. There is a growing body of palliative care literature focusing on the psychosocial and spiritual needs of the dying patient and the importance of working within multidisciplinary teams.

Children communicate both verbally and non-verbally and a discussion about this was added to this literature review as descriptions of play and drawings in process notes formed part of the raw data in the present study. The literature also points to the value of using symbolic communication and non-verbal methods (especially drawings) when communicating with the dying.

There does not appear to be any published literature on research conducted by a child and adolescent psychotherapist working with children, adolescents and their families where one parent has a life-threatening illness.

CHAPTER 3: METHODOLOGY

Introduction

This research investigates whether child and adolescent psychotherapy with children and families where a parent (usually a mother) is suffering from a life-threatening illness can be helpful to them. I had already spent some years offering this form of input to such cases before deciding to research it more systematically for this doctorate programme.

The work was undertaken in a Tier 3 multidisciplinary outpatient CAMHS which at the start of the study was based within a physical health and mental health hospital setting close to an oncology hospital. During the latter period of the research study our clinic moved to a site a few miles away adjacent to primary health care and other outpatient mental health services. On both sites the clinic was self-contained.

The mental health Trust I worked in offered services over five London boroughs to children, adolescents, families, adults and older people. The research started while I was working full time in a senior capacity, professionally heading up the Trust's child and adolescent psychotherapy department across all the boroughs. Later, when the Trust adopted a borough-based structure, I headed up all the psychological therapies within the borough. These included child and adolescent psychotherapy, clinical psychology, systemic family psychotherapy and music therapy within CAMHS. I continued with some of my long-term psychotherapy cases as well as the cases included in this research on an honorary basis after my retirement from the NHS.

I had made connections with clinical psychology colleagues within the neighbouring oncology hospital over the years and a significant number of cases appropriate for this research were referred to me from there. These were cases which went beyond the Tier 2 uni-disciplinary brief of oncology clinical psychology and needed the expertise of our multidisciplinary service. These were usually complex cases with added risks attached: for example, self-harming.

In common with many other child and adolescent psychotherapists doing research for a Doctorate in Psychoanalytic Child and Adolescent Psychotherapy, I decided to make use of my clinical practice to provide data for my research. This type of clinical work usually comes under the umbrella of 'general' work within CAMHS, as opposed to the offering of a specific formal psychological therapy. It can also be called 'applied child and adolescent psychotherapy'. My practice was only slightly modified to make the research possible, in so far as I ensured that cases relevant to this particular clinical and research interest were made available to me. In the early years of my work with such cases, it happened that most of the mothers who were seen in fact died of their illnesses. Later, several mothers continued to survive, managing their illness (mostly cancer) though not being cured of it. This may reflect a general improvement in survival rates as a result of the implementation of government policy on early diagnosis for cancer as well as improvements in medical treatments which became available during this period of my work (1999 to 2013).¹

I undertook clinical work exactly as I would have done had no research been envisaged, with the wellbeing of the clients being my main consideration. The only difference the research made to my practice was that I was seeing several cases of the kind selected, and being supervised from the doctoral programme. My academic supervisor suggested that I complete the clinical work for each case before starting to analyse the material. This was a very useful piece of advice as it kept me free to interact with my clients as I would normally. The clinical supervision helped bring a deepening psychoanalytic perspective to my work. This, along with the accumulating experience of seeing such cases over the years, may have helped me in my clinical practice.

The research takes the form of a sequence of clinical case studies approached from the perspective of a child and adolescent psychotherapist. Much of the development of knowledge in child and adolescent psychotherapy has been achieved through clinical case studies, and in recent years the practice of reflecting on and comparing clusters of cases has become more common. There are methodological benefits in being able to compare cases, even when neither

¹ According to Cancer Research UK (2015) survival rates for breast cancer have been improving over the past 40 years with nine out of ten women now surviving beyond five years (2010–2011).

numbers nor patient selection (e.g., by randomisation, or by establishing a 'control group' for purposes of comparison) allow one to claim any 'representative' or 'typical' status for the cases in question. In one sense, all such work can hope to do is to establish hypotheses that could, in principle, be further tested by more formally designed studies. However, the furtherance of understanding that can be achieved through the use of clinical case studies, and being able to compare the features of several cases in depth, has in the past given rise to new discoveries which have then become accepted as widening knowledge in the field of psychoanalytic child and adolescent psychotherapy.

An example of clinical research in psychotherapy with severely deprived children within the care system was conducted by Hindle (2007). Her work focused on an assessment protocol for the placement of siblings in foster care and/or future adoption. Another study was that conducted by Janet Anderson (2003) to investigate the origin, structure and meaning of risk-taking and dangerous behaviour in children and adolescents. Yet another was conducted by Marguerite Reid (2007) who explored the area of perinatal death by focusing on the mother's experience in psychotherapy and how this impacted on the subsequent 'replacement' baby's sense of self and their relationship with the mother. All these research studies, which used clusters of similar case studies and were part of the Tavistock/University of East London Child and Adolescent Psychotherapy Doctoral Programme, have contributed to the knowledge base within the profession as well as in clinical practice. They have also offered insight into diverse and difficult areas to inform other professions, settings and organisations. For example, Hindle's study informs social work practice relating to the placement of siblings in the care system; and Reid's study offers insights for hospital staff dealing with perinatal death.

The seminal book by Judd (2014) about her psychotherapeutic work with children with life-threatening illnesses did most to establish the child and adolescent psychotherapy field in which my work with parents with life-limiting illnesses, their children and families lies. She described her work with dying children within historical, cultural, medical, professional and theoretical contexts. She included a sensitive, moving, honest and harrowing diarised account of providing psychotherapy input to a 7-year-old boy who she called Robert, who had been

diagnosed with acute myeloblastic leukaemia two-and-a-half years prior to her involvement, and who she saw in his hospital room on the paediatric ward over the last three months of his life. She also liaised and had discussions with his parents and the professional team looking after him. Her main findings and recommendations continue to be relevant to therapeutic work in this area. I have found these to be consistent with my own therapeutic work and discuss these earlier in this thesis (see Chapter 2: Review of Literature – Psychosocial Therapeutic Services – Commentary).

Margaret Rustin (1991) extended the idea of research in the consulting room to include group collaboration where cases could be discussed regularly by participating therapists. She described the usefulness of the model of the Tavistock's Practitioner Workshops as a way of developing new insights and techniques. She mentioned the weekly workshops focusing on work with severely deprived children. These were attended by a group of therapists with differing levels of expertise and from a variety of professions, who came from several child and adolescent mental health teams. Process notes were made by the therapists and discussed and minutes kept by the group. In all, 80 children were discussed over a period of time. If similar themes arose in discussion, they could be attributed to this group of children with their traumatic and neglectful histories. As well as offering much needed support for the therapists concerned, this form of group research could lead to advances in knowledge and practice.

There have been several other clinical workshops of this kind at the Tavistock which have been productive in advancing knowledge in the child and adolescent psychotherapy and psychoanalytic fields: for example, in the fields of autism (Alvarez and Reid, 1999); eating disorders (Williams et. al., 2003a, 2003b); and brief work with parents and under-5s (Emanuel and Bradley, 2008).

Although I was not part of a Tavistock clinical workshop, the fact that my therapeutic work for this research was with several similar or related cases and was supervised on a regular basis could be seen as providing some of the benefits of such a clinical workshop method.

Ethical Issues

My research project was approved on 5 June 2009 by my employer at the time, South West London and St George's Mental Health NHS Trust (Research and Development Department). All the relevant Trust managers were aware of my research and the local borough Trust Director signed it off. The CAMHS manager in particular was very supportive throughout the time I was in the Trust working with my research clients. I received ethical approval from the Wandsworth Research Ethics Committee on 14 December 2009. A letter from University of East London/The Tavistock and Portman NHS Foundation Trust's University Research Ethics Committee (UREC) dated 27 February 2014 confirmed their own retrospective approval. Copies of both these ethics approval letters appear in Appendix I.

I have carefully considered the ethical issues involved in this research, especially as my clients, where parents were suffering from such serious illnesses, were in such a difficult and stressful situation.

I mentioned my research to all my clients at an early stage of my involvement and explained carefully what would be involved in this study. I explained it in different ways so the younger members of the family understood it too. I offered written information, suited to different ages, and left them to think about it before signing consent at a later date. In the information sheets for adults, young people and professionals I had included details for my consultant psychiatrist colleague as an independent person they could talk to if they wished to discuss my research. At an appropriate later stage I asked them if they had read the information and whether they had any questions. Some clients did have questions and I answered them fully. I also said that they could withdraw from the research at any time and this was also written in the information sheets. I made it clear that they would be seen by me whether they signed consent for the research or not, and repeated this at every stage. I explained that the research findings would mainly help other children, parents, families and professionals in the future. I told my clients that I would work with them as I normally would, and that the only difference was that my session notes would be analysed to look for common themes. I explained that

their names or identifying details (e.g., dates of births, addresses) would not be used.

All clients agreed to take part in the research. Consent forms were signed by parents for themselves and for children under the age of 16. Andrew's mother's partner signed consent to be part of the research and the two teenagers (Sara and Elliot), who were 16 years old, signed the forms as well.

In previous cases where a parent was seriously ill, I had at times done clinical work jointly with professional colleagues from within and outside CAMHS and I had therefore included that option when asking for ethical permission. In the research sample there was only one case in which my team colleague, a consultant child and adolescent psychiatrist, continued to see the young person and I met with the mother and her partner to do parallel parent work.

I believe that in most cases my work was found to be helpful by my clients and that in no case did I have reason to believe that being part of this research caused distress to them. I was very aware that many of them found themselves in an extremely painful situation because of the mothers' severe illnesses and I proceeded very carefully in how and what I said. Although I formed a view of the meaning and value of this work for my clients, I did not attempt any formal evaluation of its 'treatment outcomes'. This was because designing appropriate measures would have been premature considering that this kind of clinical work was relatively untried in my Trust and, as far as I know, elsewhere. I also did not wish to ask any more of my clients than arose from my clinical responsibility for them.

Case Studies

Stake (1994) mentions that the case study research methodology allows us to focus in depth on the dynamics present within a setting. He described a case as a bounded system in which the object of the study is specific and unique. Data collection could be via archives, interviews, questionnaires and observations. The data collection could be qualitative or quantitative, or both. There could be various aims for conducting cases studies. These could include describing a process or

generating or testing a theory (Huberman and Miles, 2002). There is extensive literature which demonstrates the use of case studies in a variety of settings, including health, education, sociology, industry and information technology (Byrne and Ragin, 2013).

The case study method of research in psychoanalysis started with Freud. For example, Freud (1909) illustrated the concept of the Oedipus complex via the case study of Little Hans, a 5-year-old boy who was afraid of horses because they represented his father in his unconscious mind. And this method was continued by those who followed. For example, Klein (1975b) explored the psychoanalysis of Richard, a 10-year-old boy whose anxieties affected his internal and external worlds. This child analysis was done during the Second World War which had increased his anxieties. Klein mentioned that she wrote her book to illustrate her technique in child psychoanalysis as well as her theoretical concepts.

Anderson (2006), in her review of psychoanalytic research, mentions that psychoanalytic theory and practice has mainly progressed through research based on single case studies rather than collections of cases. Clinicians learned from experience in the consulting room rather than through formal research.

Michael Rustin (2003) argues that psychoanalytic theories and practice have developed over the years as a result of research both 'in and out of the consulting room' as follows:

“– in it, in the sense that this is where its facts or data came from, and out of it, in the sense that much reflection and thought took place outside, in the minds of analysts, in discussion with supervisors and colleagues, and in their solitary struggles to formulate ideas for the printed page.” (pp. 139–140)

He suggests that, from the early days of work in this field, psychoanalysts and child and adolescent psychotherapists have practised an effective method of research in working within the clinical consulting room which has generated new knowledge as well as new ways of working in practice. He argues that this form of psychoanalytic knowledge “has accumulated in logical and ‘accountable’ ways,

in the sense that successive advances in theories and techniques have been explicitly built on earlier discoveries”. (p.139)

Rustin (2003) also points out that the main subject of psychoanalysis is the understanding of the unconscious or the inner world of the patient and that the best way to elicit this in the consulting room is when it manifests itself spontaneously within the transference relationship. This is the nature of research in the consulting room and has been going on since the time of Freud.

Michael Rustin (2009) suggests that research methods need to fit the subject matter studied. Therefore, in the case of psychoanalytical research, as clinicians try to understand the complexities of individual patients, “...its findings have been best represented in case studies and monographs rather than in the codified style of a textbook or manual”. (p. 38)

Peter Fonagy and George Moran (1993) discuss single case studies in psychoanalytical research. They mention a number of advantages of studying empirical psychoanalytic data using an individual case study methodology. Firstly, the methodology shares techniques with other disciplines including psychology, linguistics and sociology. Secondly, the individual case study method helps communicate the benefits of psychoanalytical work to a wide range of non-scientific communities as well as to opinion leaders (e.g., psychiatrists, media commentators and judges). Thirdly, the method is a development of traditional case study methodology and may offer fresh insight into conscious and unconscious functioning. Fourthly, they state that:

“...the method is uniquely suited to psychoanalytic clinical practice in certain respects, including the relatively long term nature of psychoanalytical investigations,...the attention to events occurring during treatment...and the influence of specific features of history.” (p. 87)

And fifthly, they argue that “...this method is closer to psychoanalytic practice than other modes of systematic research...”. (p. 87)

In discussing the advantages of the qualitative case study the authors argue that it uses a more systematic approach to analytical material than is usually the case and that it is a well-established methodology within psychoanalysis. They

mention three principles to be taken into account which include the use of data from multiple sources to improve credibility (see discussion of 'triangulation' in Criticisms of the Case Study Research Method below); clear formulation of hypotheses to allow counter-examples to be identified; and the need to clarify the personal connection between the researcher and possible threats to objectivity (see Criticisms of the Case Study Research Method below).

One good example of a single case study is that reported by Moran and Fonagy (2009). The aim of this study was "to examine the association between diabetic control and the variation in the themes of psychoanalysis". (p. 88) Sally was a diabetic teenager who started five-times-a-week psychoanalysis at the age of 13. Her psychoanalysis lasted for three-and-a-half years. Process notes and weekly summaries were made by her therapist and the themes which emerged were independently rated. Diabetic control was assessed via weekly urine glucose content testing at home over the course of Sally's analytic treatment and the two years preceding, and the results were validated by random blood glucose measures taken in hospital. Her therapist was not aware of the content of these measures. The researchers carried out time-series analysis to examine diabetic control and psychological conflict. The findings showed that working through the psychic conflict could predict improvement in diabetic control, both in the short and long term. The findings showed that the presence of themes of conflict in analytical material tended to foreshadow improvements in diabetic control, and improved diabetic control seemed to increase manifest psychological symptomatology one to three weeks later. The authors explain this as follows:

"The increase in phobic avoidance and deliberate self-harm consequent upon improvement in diabetic control may be understood as a dynamically meaningful reaction, reflecting the patient's relative incapacity to tolerate states of well-being. We may assume that during certain phases of analysis, particularly during its early years, good blood glucose control could only be achieved through temporary inhibitions that exacerbated psychological conflict and led to a significant intensification of other psychological symptoms. A non-dynamic account of such a temporal association is difficult to formulate." (pp. 96–97)

Criticisms of the Case Study Research Method

Over the years there have been criticisms of the use of case studies as a method of advancing knowledge in psychoanalysis. Most influential perhaps were the arguments of Karl Popper (1962), a philosopher of science in the twentieth century, who rejected classical inductivist views of the scientific method, favouring empirical falsification. From Popper's point of view psychoanalysis could not be considered a science as its hypotheses or theories could not be falsified. Popper's critique was developed more extensively by Grunbaum (1984), who argued that evidence produced in psychoanalysis was 'contaminated'. Grunbaum held, as Michael Rustin (1991) puts it, that "the patient's unconscious appears in forms which are hopelessly subject to the influence and interpretation of the analyst". (p. 117)

The criticisms about using clinical case studies as a method of research fall, according to Midgley (2006), into three parts:

1. Reliability: that the data or basic observations within clinical case studies are unreliable.
2. Validity: that the analysis of data lacks validity; that is, it does not allow us to assess the truth or the accuracy of what is being observed.
3. Generalisability: that such results cannot be generalised beyond the case being studied.

In terms of reliability, it is maintained that the notes taken of a clinical session by the psychoanalyst or psychotherapist are subjective and rely on her/his memory and can be selective. Midgley cites Wallerstein and Sampson (1971) who argued that systematic studies of process notes in adult psychoanalysis had found a lot of variation and inaccuracy in what was recorded and how it was recorded, leading to concerns about how legitimate process notes were in providing accurate data for research.

One response to this difficulty would be to use audio or video recordings but clinicians have been reluctant to do this as they fear it would interfere with the process with their patients and would not capture the emotional atmosphere – the transference and countertransference information. However, the recent

experience of child and adolescent psychotherapists working with randomised controlled trials – for example, IMPACT (Improving Mood with Psychoanalytic and Cognitive Therapies) (IMPACT, 2015), a study comparing Cognitive Behavioural Therapy, Short Term Psychoanalytic Psychotherapy and routine ‘specialist clinical care’ with depressed adolescents may at least lessen anxieties about the effects of audio recordings.

Another option would be to use checklists or standard formats for separately recording verbal as well as non-verbal information, and the analyst’s own countertransference.

Midgley goes on to say that clinicians may be selective in the data they use in writing up case studies, leading to justification of the clinician’s own hypotheses or theory, rather than leaving room for an alternate view or understanding. This could lead to the analysis of data lacking validity.

The use of more systematic methods of data analysis could answer some of these criticisms. Midgley mentions several, including intensive qualitative case study analysis, content analysis, thematic analysis, discourse analysis, conversational analysis, narrative analysis and Grounded Theory analysis, the last of which is used within this study and will be discussed later in this chapter.

Midgley discusses both the difficulties of plausibly testing hypotheses in qualitative analysis of clinical case studies as well as ways to surmount these. He mentions procedures which could be used where the researcher-clinician makes explicit what hypothesis is being tested, separates observations from interpretations and discusses the evidence for accepting one particular hypothesis over another.

Another way to ensure reliability is via training in observation and recording of those observations. There is a strong emphasis in child and adolescent psychotherapy training at the Tavistock and elsewhere on close observation and on meticulous writing up of sessions. During this training, the presentation and review of detailed observational and clinical material is taken to supervision and clinical seminars. The training takes place over six years, starting with the Infant and Young Child Observations modules, theoretical seminars, and the

commencement of training psychoanalysis. This is then followed by clinical courses in child and adolescent psychotherapy supervised practice and the continuation of training psychoanalysis and further theoretical and practice-based modules. After qualification child and adolescent psychotherapists continue to write up detailed process notes to be taken to supervision. Hence the skills of careful observation and recording of session material are maintained.

Although audio or video recorded transcripts of sessions would be more accurate in terms of the actual words spoken and their sequence, there are some kinds of information which a recording will not contain, but which a clinician's write up from memory may well do. This is information related to the emotional atmosphere of a session, and what is gathered by a therapist in regard to transference and countertransference phenomena, which is central to psychoanalytic clinical practice and inquiry.

I believe that audio recording or video recording would not have been appropriate for this study for clinical reasons. The family members were extremely vulnerable and I did not wish to impose any additional burden of feeling observed or exposed, which recording might have caused.

One way to augment validity is to supplement the clinician's observations with information from several different sources. Anderson (2006) mentions Denzin (1970) who took the term 'triangulation' from surveying to express this and proposed equivalents to it in sociological research in order to enhance the validity of data.

One way of using triangulation in child and adolescent psychotherapy would be to use parents' and other professionals' observations and reports of how they perceive the child or adolescent as well as the clinician's notes. In this research study, with permission from my clients, I obtained access to reports and/or liaised with school staff and other professionals where appropriate. And, as I was dealing with parents as well, I asked for regular information from them about their children. This extra information added to, and at times confirmed, what I was observing myself.

Midgley (2006) also discusses the difficulties of generalising from evidence gathered from one case. One way round this would be to study and compare several similar cases but even here there are problems with 'statistical inference' lacking 'external validity' as the group of patients may not represent the wider relevant population. Another problem, if one gives a quantitative dimension to such comparisons, might be that by averaging scores one may lose sight of the differences between individuals. Such averaging may therefore not be helpful to clinicians in their everyday work.

Despite all the above mentioned difficulties in ensuring reliability, validity and generalisability in conducting psychoanalytic research, Michael Rustin (2009) has argued that child psychotherapy research has contributed to advances in theory and practice. Rustin's views on the development of knowledge and practice within child and adolescent psychotherapy can be summed up in his own words:

“My contention is that the established tradition of clinical research in child psychotherapy has been very productive in generating new knowledge. It has enhanced our understanding of child development and its various difficulties and disorders, and has evolved new clinical techniques in response to these. It is the links made between psychoanalytic concepts and theories, and phenomena encountered in clinical practice, which have enabled this knowledge base to be established.” (p. 43)

Grounded Theory

One way to answer the criticism levelled at psychoanalytic research based on single case studies is to use the 'constant comparative method of analysis' as espoused by Glaser and Strauss (1967). Their groundbreaking work, mainly in sociological research methodology, has been furthered by others including Kathy Charmaz (2014). Anderson (2006), a child and adolescent psychotherapist who used this methodology for her doctorate research at the Tavistock, has written a paper to show the well-suited partnership between Grounded Theory and psychoanalytic clinical research.

The Grounded Theory methodology has mostly been used in qualitative research in studying human behaviour. It uses inductive methods to generate theory rather than looking to test or validate already established theories. The researcher starts

with an open mind and therefore without prior hypotheses that she/he wants to prove or disprove. It is recommended that the researcher does not read all the relevant literature before gathering and processing the data. The raw qualitative data is analysed and coded to arrive at categories. The data can be 'fractured' in various ways to add to understandings of the categories and their inter-relationships. The categories and codes need to emerge from the data.

The recommendation of coming to the research with an open mind when using Grounded Theory cannot be easily adhered to by child and adolescent psychotherapists who have had years of experience, both theoretical and practice-based. Glaser (1978), who was aware of this, addresses this as follows:

"Most generally, the background experiences of one's education and training is used to *sensitize* the researcher to address certain kinds of broad questions. Thus, one's methodological orientation is broadly, rather than narrowly, based in one's scholarly discipline. Its sensitizing nature lacks specification of attributes, but forms guidelines and reference points which the researcher uses to deductively formulate questions which may then elicit data that leads to inductive concepts being formulated later." (p. 39) (author's italics)

Charmaz (2014) discusses this and mentions that researchers do have preconceptions. These may come from personal, cultural and theoretical standpoints, and she makes an important point about how the researcher could be biased without realising it by "...what the researcher *takes for granted* about self, situation, and the world". (p.160) (author's italics) It is therefore important, she suggests, to be self-reflective and make such preconceptions explicit.

Data Collection

The six cases which made up the sample in my study – Johnny, Sara, Farah, Gabby, Elliot and Andrew – were all referrals of children/adolescents to an outpatients CAMHS. The cases themselves had the level of complexity and/or risk sufficient to warrant referral to the multidisciplinary Tier 3 CAMHS. They were either referred by their GP or by the oncology clinical psychologist. The mothers of all the referred children/adolescents had a life-threatening illness. I was the main clinician apart from in Andrew's case. The psychiatrist working with Andrew

referred his mother and her partner to me to do time-limited parent work. I discussed this with my supervisors who suggested I include it in this research. The cases varied in family history and configuration and the children/adolescents showed their distress about their parents' life-threatening illnesses by displaying a variety of emotional, behavioural, psychological, learning and interpersonal difficulties.

A seventh case (Lara) has been included to illustrate my previous work with children/adolescents whose parents died and where therapeutic input had continued with the child/adolescent and the remaining parent (see Chapter 4: Findings – Lara). Although I obtained written consent from Lara and her current family when she was re-referred at 16, I did not use the session notes as raw data for analysis, as the family did not have a dying parent.

In order to meet the needs of my clients, the therapeutic work had to be flexible. This usually meant trying to see them when it would least disrupt their lives: for instance, taking account of their school, work and hospital attendances. It also depended on the children's/adolescents' and parents' abilities to sustain what I was offering clinically due to the emotional pain that it invariably invoked. Hence, there were more cancellations and non-attendances in these cases than was normal for my other cases. Despite this, I can say that the frequency of attendance was broadly comparable across the cases, although not exactly so. I also communicated with the clients on the telephone when necessary, especially if for some reason they could not attend the clinic. Wherever appropriate I liaised with school staff and other professionals, having first obtained permission from the child/adolescent and the parents. Again, this was not necessary for every case. The period I was involved with the families ranged from eight months to two years, depending on what was appropriate clinically or allowed by the members of the families. This client sample, therefore, imposed on me a particular obligation to adapt my clinical approach to the clients' needs, even if this meant some loss of 'standardisation' of the data.

The following table shows the duration of psychotherapy, number and type of sessions, and total number of sessions for each case.

Table 1: Number and types of sessions for each case

Case (age)	Duration (months)	Child/ Adolescent	Parents	Parent/ Child	Family	Total
Johnny (5)	24	1	0	18	5	24*
Sara (16)	10	3 + 2 phone	3 + 2 phone	0	1	11
Farah (8)	10	3	2**	2	4	11
Gabby (6)	10	2	2**	2	4	10
Elliot (16)	11	8	8	0	1	17
Andrew (15)	8	0	9	0	3***	12

* 3 school meetings not included.

** Same sessions with parents of the two sisters.

*** Reviews.

As can be seen, the time over which the family was seen by me was generally about 10 to 11 months, apart from Johnny (24 months) and Andrew (8 months). Each case was different, needing different types of sessions. Most of the sessions with Johnny were with his mother and the therapy, although appearing to have lasted the longest, had large gaps in treatment. This was the only case in which I mainly saw mother and child together. Sara's case was again different as she was reluctant to attend after the initial face-to-face meetings and I then had several short telephone sessions with her and her parents. Farah and Gabby (the sisters) had fewer individual sessions but more family ones – this included two sessions with the parents on their own, as well as parent–child sessions (each child with each parent). Elliot and his parents were mostly seen separately with just one family session at the beginning. I met with Andrew's mother and her partner monthly, and also took part in the CAMHS reviews for Andrew, where Andrew, his mother, her partner, my psychiatric colleague and I were all present.

I have explained the reasons for this flexibility in treatment above and I think, on the whole, it seems to have worked well for the clients, at least in terms of the children's symptoms receding. This, however, had implications for the research as the number, types and frequency of sessions, as well as the duration of the interventions, differed. So I was not comparing like for like although the cases were broadly similar. Hence the research design lacked standardisation in this respect.

There was a difference in engagement in therapy and attendance at sessions due to age. The teenagers were on the whole reluctant to engage and this was

most marked by Sara refusing to attend after the first few times; Elliot also did not take up all the sessions I offered.

I did not find any differences attributable to gender in terms of attendance, although it is possible that Elliot (16) may have found coming to see an older female psychotherapist more difficult. He may have engaged better with a younger or male therapist. I do not think Sara's difficulties in attending were attributable to gender and I discuss the possible reasons for this in Chapter 4: Findings – Sara. The younger children, both male and female (Johnny, Farah and Gabby), engaged well in therapy and did not show any reluctance to attend.

I wrote up detailed notes very soon after I had seen the clients. These were recorded electronically and later used by me for analysis. As a child and adolescent psychotherapist I was trained and have had many years of practice in writing up such process notes. What was also noted in the process notes were descriptions of play and drawings produced in the sessions with the children. If the children used the white or black boards I would copy the drawings on to paper, explaining to the child why I was doing so. It is common practice in child and adolescent psychotherapy to collect drawings in separate folders for each child and I would explain to the children that these, as well as the copies I made from the black or white boards, would help us understand things better as we continued. As mentioned above, I had earlier explained the nature of my research and what participation meant to all members of the families: that is, that I would write up notes of what we did, and also use what they drew when we met for my research.

These detailed case notes formed my raw data. These kinds of data arise in ethnographic fieldwork, for example, or process notes of sessions or reports in infant observation. Michael Rustin (1989) makes a comparison between infant observation and ethnographic methods in anthropology. Judy Shuttleworth (2010), a child and adolescent psychotherapist, has made recent use of such methods in an anthropological study of a religious congregation. These kinds of data are best suited to Grounded Theory as they are not pre-structured or pre-organised by protocols, such as would be the case for data gathered through experimental design or surveys based on questionnaires. Therefore, there was a

fit between the kind of data I collected and Grounded Theory, and they were thus 'well-suited partners' as Anderson (2006) puts it.

Apart from the process notes, the information I used in writing up the thesis also included referral letters, discussions with and reports from other professionals, and attendance at school meetings.

Data Analysis

My approach to data analysis was based on a good deal of prior knowledge and experience, both theoretical and practice-based. It was consistent with the Grounded Theory approach in that I allowed the data to 'speak for itself', and maintained an open mind, as far as I could, regarding the meaning of what I saw and heard. This is consistent with my open-ended clinical method too. The value of the detailed analysis of the material is that it enabled me to reflect on the clinical data very closely, to see what associations and ideas emerged from this close reflection, and to make use of these reflectively as the analysis proceeded.

As suggested by Charmaz (2014), I went over the analysis of the data several times. The first time was usually just after the end of the clinical work; the second time was some months later; and the third time some months later still. As the cases were not seen weekly and differed in the frequency and type of sessions (e.g., individual, parents, family) I decided to analyse all the sessions, including substantial telephone conversations, for all the cases. Common Themes emerged, enabling me to make comparisons across the cases. This led to my identifying six Themes which have been written up fully for each case (see Chapter 4: Findings). The Themes were:

1. *Engagement*: This is the ability of the client (child/adolescent, parent, parent's partner or other family members) to engage in the therapeutic process meaningfully. It includes verbal and non-verbal interactions in therapeutic sessions; being on time for appointments, keeping them regularly, and sending apologies for non-attendance; parents bringing themselves and younger children regularly to sessions and, in the case of adolescents, parents encouraging them to attend sessions.

2. *Parental Concern*: This is the concern (or lack of concern) showed by parents (both ill and well) for the wellbeing of their children. It includes observations by the psychotherapist of the verbal and non-verbal interactions within sessions between parents and their children; parents expressing their concerns in meetings and in telephone conversations with the psychotherapist; and reports about this given to the psychotherapist by school staff and other professionals.
3. *Impact of Mother's Illness*: This is how the life-threatening maternal illness affected all family members. It includes how this was observed by the psychotherapist in the clients' thinking, emotions, behaviour and relationships; and how it was reported by the clients themselves, as well as by school staff and other professionals who knew the child/adolescent well.
4. *Defences*: This is the unconscious defence mechanisms which individuals use to reduce anxiety (aversive inner states that individuals seek to avoid or escape). There are several types of defence mechanisms and the most commonly used by participants in this study were *repression* (preventing unpleasant thoughts and feelings from becoming conscious) leading to *denial* (that the unpleasant thoughts and feelings do not exist); and *displacement* (shifting the anxious feelings and thoughts to another object or situation from the one which is causing the anxiety).
5. *Sustaining Factors*: These are the factors which helped individuals in this study cope with or manage the difficult situations of life-threatening maternal illness that they found themselves in. These ranged from internal strengths (e.g., resilience) to external support from family, friends or professionals.
6. *Feeling Different*: This occurs when the individual feels and thinks that she/he is different to other people due to their mother having a life-threatening illness and are concerned about how others in their external lives saw and related to them. This includes the ill mothers themselves wanting to be seen and treated as they were before their illness.

Process of Data Analysis Leading Up to Final Themes

I will describe how the final Themes emerged by using one Theme, Impact of Mother's Illness, to illustrate the early stages of the process of data analysis. My

data comprised all my notes of sessions and phone discussions – these were typed and held in electronic format. I printed the notes on paper and highlighted meaningfully connected sequences of information. I did not carry out coding on a line-by-line basis. The process involved moving from the more concrete (the notes or raw data itself) to the more abstract. Similar meaningfully connected sequences, Examples, were listed. Some of these Examples had a connection and were therefore grouped together as Aspects. The Aspects could themselves be put under an umbrella heading or Strand. Several of these Strands emerged which could then be put under a Theme. Hence, taking, for example, Strand 1 for Johnny, the Examples show how Johnny had been affected by his mother's illness. These included his external behaviour (tantrums and challenging behaviour reported by his mother); his inner trauma as observed by me in his play sequences in therapy; and Johnny saying that his mother had been sad and he had felt sad and frightened when mother had been ill. These were grouped together under Aspects, and came under Strand 1: Emotional and behavioural effects on the child/adolescent (see below). Each child/adolescent expressed their distress in a different way, and this was recorded under Strand 1 of the Theme of Impact of Mother's Illness. As mentioned earlier, this was an iterative process: I went through coding and analysis several times before settling on the final Themes which appeared across the cases. It is important to note that the Themes are interrelated and I had to decide at times which Theme to put a particular sequence of a session under, as they could well have been added to more than one Theme.

Illustration of Data Analysis Process: Theme 3: Impact of Mother's Illness

Appendix II shows the results of following the process for the Theme of Impact of Mother's Illness for each of the six cases. The three columns are, left to right: Strands; Aspects; Examples. There were five Strands as shown below.

1. Emotional and behavioural effects on the child/adolescent
2. Child's/adolescent's difficulties at school
3. Physical illness affecting ill parent
4. Emotional effects on the well parent affecting his wellbeing

5. Relationship difficulties within the family

The table below shows the presence of the above Strands in each of the cases. 'Yes' means they were present and 'No' means they were not.

Table 2: Presence of Theme 3 Strands in each case

Case	Strand 1	Strand 2	Strand 3	Strand 4	Strand 5
Johnny	Yes	Yes	Yes	Yes	Yes
Sara	Yes	Yes	Yes	*	Yes
Farah	Yes	Yes	Yes	Yes	Yes
Gabby	Yes	No	Yes	Yes	Yes
Elliot	Yes	Yes	Yes	Yes	Yes
Andrew	Yes	Yes	Yes	Yes **	Yes

* Both of Sara's parents were ill – there was no well parent.

** Mother's partner as he was performing day-to-day parental function.

As can be seen in Table 2 above, all five Strands appeared in all the cases (except for Gabby in relation to Strand 2) for the Theme of Impact of Mother's Illness.

Conclusion

This chapter shows how I collected and analysed the information I gathered for the six cases using an adaptation of Grounded Theory methodology, putting it in the context of psychoanalytic and child and adolescent psychotherapy research. I have discussed the value of case study methods for this type of qualitative study as well as the criticisms. The analysis led to the discovery of six Themes across the cases.

CHAPTER 4: FINDINGS

Introduction

This chapter is split into two parts. Part 1 presents each of the six cases (Johnny, Sara, Farah, Gabby, Elliot and Andrew). The cases are described in terms of family and psychotherapy histories, the six Themes discovered through Grounded Theory analysis, the outcome of psychotherapeutic input and the implications the case material may point to. They appear in the order of my seeing the case for the first time. Johnny, Sara and Elliot were seen by me very soon after referral to CAMHS. Farah, Gabby and Andrew were seen following internal referral to me by my consultant psychiatrist colleague.

Material for each case study is structured under the following headings:

- Introduction
- Family History
- Psychotherapeutic Input
- Themes
- Outcome
- Implications of the Case

The six Themes are (see Chapter 3: Methodology – Data Analysis):

1. Engagement
2. Parental Concern
3. Impact of Mother's Illness
4. Defences
5. Sustaining Factors
6. Feeling Different

Part 1 also includes a summary of a seventh case (Lara) illustrating my previous experience of working with a family when the parent actually died. Lara was referred twice, once at age three-and-a-half when her mother was terminally ill, and again when she was 16. In this case I continued having sessions with Lara

and her father after the mother's death, and then had further sessions with Lara, her father, stepmother and stepbrother when she was between the ages of 16 and 18.

Part 2 of the chapter considers the six Themes across the cases, and includes a final section presenting concluding thoughts.

All names and identifying details have been changed to preserve anonymity. All ages of the children/adolescents are as at the time of referral.

PART 1: THE CASE STUDIES

JOHNNY (AGE 5)

Introduction

Johnny (age 5) was referred by a clinical psychologist working in an oncology hospital because of challenging behaviour at home and difficulties in social interactions at school. His mother who was in her mid twenties had been treated for a malignant brain tumour and was still being monitored medically. I met with Johnny and his mother for parent–child psychotherapy over a period of two years. Johnny, his younger brother (age 2) and his mother were supported by the maternal grandparents and moved in with them during my involvement. The children’s parents were separated and father saw the boys from time to time.

Family History

The following history was reported by mother and maternal grandmother.

Johnny’s birth had been traumatic as he had the cord twice around his neck and was not breathing. He had jaundice and had been diagnosed with streptococcus B. Johnny was said to be a non-demanding, placid baby who slept through the night. Johnny fed well on the breast for six weeks and was then bottle fed. He had become a fussy eater at age 2 and only wanted to eat certain things which had to be separate on the plate. He had had glue ear and had had grommets put in when he was three and this had affected his hearing and language development. He was under the care of an ear nose and throat (ENT) specialist and had received speech and language therapy. He was said to be about one year behind his age group in literacy.

Mother and maternal grandmother were very concerned about Johnny and wondered if he had an autistic spectrum disorder (ASD). They felt that something was not right with Johnny, that he was not like other children. They said that the school was concerned about his social relationships with his peers. For example,

there had been an incident in which Johnny was cross with another child and had sat with his head in his hands saying he could hear voices in his head.

The children's father had not been able to cope with mother's illness and had left the family home during the acute stage of her cancer but had since come back into the children's lives.

There was a history of cancer going up several generations on the maternal side and a history of mental ill health and alcoholism on the paternal side.

Maternal grandparents had been very worried that mother would die. Mother had decided to fight the disease once it was diagnosed. Maternal grandmother said that Johnny had looked at mother in a funny way when her appearance changed considerably while in hospital. Mother had lost her hair, her body had swelled up and she had been on drips. Johnny's behaviour had deteriorated since mother's illness. Mother and maternal grandmother both felt a great sense of guilt about how mother's illness had affected Johnny.

Mother suffered from short-term memory loss as a consequence of the brain tumour and medical procedures, which had included brain surgery and radio and chemo therapies. She also had a rare chronic disease which led to pains in her hips, back and feet, and found walking difficult. Johnny's mother continued to be monitored by the oncology department and was pronounced clear of cancer a year into my involvement. Nevertheless, she continued to exhibit many physical symptoms including headaches, sinus problems, hay fever, asthma, numb arm, and pains in the neck, back and hips which led to mobility difficulties; she also had difficulty hearing due to narrow ear canals. During the period of my involvement she had a couple of accidents injuring her foot and ribs, a cervical procedure, and a breast reduction operation to help her with the back and neck pains. Mother reported obsessive compulsive disorder (OCD) symptoms which led to a difficulty in tolerating messy play by her children.

There were other family health issues during my involvement. Maternal grandmother had an operation and maternal grandfather became ill with bronchitis. The children's father had a work-related accident injuring his foot. Johnny's younger brother had to have hospital investigations. At one point

Johnny had stomach pains and had to be taken to A&E. After tests he was given laxatives as he was said to be suffering from impacted faeces.

Psychotherapeutic Input

I decided to offer mother–child psychotherapy in response to the referral and my assessment, which indicated difficulties in Johnny’s relationship with his mother. Another option was to see Johnny individually for weekly psychotherapy but his mother indicated that she would find that difficult to maintain. The fortnightly sessions offered were rarely achieved as appointments were either forgotten or cancelled due to illness or childcare difficulties with the younger brother.

In the consulting room I talked to mother but at the same time attended to Johnny’s play and interactions with his mother and me.

With mother’s permission I liaised with Johnny’s head teacher and attended school meetings with mother and maternal grandmother. The head teacher in particular was very supportive of the therapy and found ways to help mother to attend CAMHS. For instance, she allowed the younger son to continue nursery school into the afternoon while Johnny and mother saw me.

The therapy was divided into phases with several breaks in between.

A first phase of therapy lasted four months and included the extended assessment. During the assessment I had meetings with mother and maternal grandmother; Johnny; Johnny and his mother; mother, Johnny, his younger brother and the maternal grandparents; mother, Johnny and maternal grandmother; and mother with her older sister. Mother’s main concerns were her relationship with Johnny, her worries about how her major illness had affected him, and the possibility of ASD affecting his relationships, particularly at school.

There was then a break of four months as the family faced various health issues including mother’s breast reduction operation and cervical procedure. Mother also forgot some sessions and had to cancel some due to a lack of childcare for the younger son. During this period I continued to be available to mother and maternal grandmother via the telephone. I had referred Johnny for a clinical

psychology assessment within my team and the psychologist ruled out ASD but confirmed problems with comprehension and suggested further speech and language input.

A second phase of therapy lasted eight months and consisted mostly of meetings with Johnny and his mother, with many cancellations and some forgotten sessions. On their return from the above break mother reported that her relationship with Johnny had improved, she was not as concerned about the effect of her major illness on Johnny and, to a lesser extent, her concerns about ASD had diminished. I attended school meetings. The family moved back to live with maternal grandparents. The family had lived with maternal grandparents during the acute stage of mother's illness. Father kept in touch with the boys.

Another break followed, this time of two months, due to family illnesses and mother forgetting sessions. The younger son became ill and was investigated medically.

The third phase of therapy lasted one month. On their return from the preceding break mother reported that her relationship with Johnny continued to be improved and her concerns about him being adversely affected by her major illness had receded significantly. Her concerns about Johnny's social and communication difficulties, although less acute than when she first came to see me, remained, especially about the effects of these on his future schooling.

The therapeutic input ended following a period of two months in which there were again cancellations for various reasons. The clinic had moved and mother told me it would be difficult for her to bring Johnny to the new site as it was further away. During this meeting, which turned out to be our last, we had another review. I said that, despite the difficulties in attending, Johnny seemed a much happier child, and suggested a planned ending with two more sessions to say goodbye. Although mother agreed she did not return. I tried to contact her by telephone but could not reach her. After liaising with the head teacher I closed the case.

Themes

1. Engagement

Johnny and mother demonstrated a friendly, warm relationship in the consulting room. Mother, at first, tended to direct Johnny's play and behaviour. I modelled a different way of interacting and explained that by letting Johnny express what was inside him through play we would be able to understand better what was going on. Mother began to emulate me, allowing Johnny to lead in play and interactions. At times, mother fussed with Johnny's appearance, especially when difficult issues were being portrayed. Mother found water play difficult and it was only much later that she explained she had OCD symptoms.

Johnny engaged well in therapy despite the breaks and made it very clear he loved coming to see me with his mother, as this example 17 months into my contact with the family demonstrates:

“At the end of a sequence of play with his mother where they had communicated over the hose phone (garden hose with wooden shaped hand-sets at either end), when I said it was time to finish, he said ‘I love coming here’.”

Johnny worked hard to engage his mother and me by initiating games which included us.

As one of my goals was to improve the mother–child relationship I suggested that mother find some time to play with Johnny between sessions. Mother did try to do this but it was difficult as she had a younger son too. Despite this, mother, who had found Johnny's behaviour very challenging, started reporting that things were much better at home. This seemed to indicate that something was happening therapeutically. Johnny's school too reported that he seemed a happier child.

Johnny and mother showed their love by teasing each other in play. For example:

“One of Johnny's regular kinds of play was making pretend drinks and food for mother, himself and me. The choice of colour for the cups and saucers was the source of the teasing. Mother supported Liverpool Football Club (red) and his father Chelsea (blue). Johnny persistently gave mother a blue

cup with her remonstrating in play, with Johnny laughing loudly at this response. I was usually given a neutral colour (yellow or green – was I a referee?). Mother had told me that Johnny, father and mother teased each other in this way at home.”

My hypothesis is that this was an acceptable family way of behaving for Johnny, both to join with mother but also showing her his angry, attacking feelings in a subtle way. Johnny may also have been playing out a dilemma of whose side to take – his mother’s or his father’s.

There was one memorable and moving occasion 16 months into my involvement in which there had been a lovely sequence of play which ended with Johnny whispering to mother via the hose phone that he loved her and she whispering back “I love you too”.

2. Maternal Concern

Mother showed her concern for Johnny and his wellbeing by bringing him to see me over a period of two years, despite many difficulties. As we have seen earlier, mother and maternal grandmother had been very aware of the effect of mother’s illness on Johnny and mother wanted Johnny to receive psychotherapeutic help to address this.

Mother’s concern for Johnny and his welfare also centred on the need to make sure he got all the services that would help him with his difficulties, especially at school. Johnny received various assessments (speech and language, educational psychology, clinical psychology) so that the right provisions could be made. Both mother and maternal grandmother repeated these concerns at our meetings, both in my consulting room and at school.

Education was important to mother and she did not want Johnny to miss school to attend sessions with me. The school was not concerned about Johnny missing lessons at his age. We managed to strike a compromise with mother bringing Johnny at two o’clock in the afternoon when she thought literacy and numeracy subjects would not be taught. As we have seen, the head teacher helped mother with childcare for her younger son so that she and Johnny could attend therapy.

I think there seemed to be a grandmotherly concern for mother and Johnny which was shared by mother's own mother, the head teacher and me. This was shown by the grandparents continuing to look after mother and her children. The head teacher had supported Johnny and mother during the acute stage of mother's illness and continued to do so during my involvement. With mother's knowledge and permission, the head teacher and I liaised regularly and shared our concerns about the difficulties mother had in bringing Johnny to therapy.

3. Impact of Mother's Illness

We have already seen above how mother's illness and other family illnesses impacted on the continuity of therapy.

The impact of mother's symptoms on her parenting was talked about in therapy a few times, as can be seen in the following two sequences. The first sequence took place two months into my contact when I was meeting Johnny, mother and maternal grandmother:

"I said I had talked to maternal grandmother earlier in the week on the telephone to arrange appointments and she had told me that Johnny seemed more settled. Mother replied that Johnny was fine when he was with her parents at weekends but she still found his behaviour challenging during the school week. She said that Johnny was being given quite a lot of homework and it was difficult for him to do it. Maternal grandmother thought mother got very tired due to the after-effects of radiotherapy (which mother had been told could last up to five years), and may not have as much patience at the end of the day in dealing with Johnny."

The second sequence is a year into my involvement when I was meeting Johnny and mother:

"Mother was telling me that the headaches had come back but she was not going to approach the hospital to bring forward the review in case it was something worrying as she wanted to have the family holiday first. Johnny had been listening to this and I asked whether he noticed when his mum was poorly and he shook his head side to side meaning 'no'. Mother said she shouted more when she was unwell if the children were making a lot of noise. I wondered if Johnny noticed and did he at times do kind things to help mother. Mother said when she had a headache and lay down Johnny brought her a pillow."

Mother's concern for Johnny was reciprocated by Johnny's concern for her. This appeared indirectly on several occasions when he would telephone her on the hose phone and ask if she was alright. He would feel reassured when she said she was. However, as she usually had a health problem that she had been talking about, I wonder how much of a reassurance that was for him.

I talked to Johnny and mother on several occasions about how they had felt at the time of her illness, an example of which follows:

“Four months into my involvement, when we were talking about the time mother was very ill and I had asked Johnny what he remembered about that time, he said that his mum had been sad, and he had felt sad and frightened.”

One of Johnny's persistent play themes involved catastrophes in which even the rescuers could not be rescued. An example of this can be shown in the following sequence a year into my involvement:

“Johnny came to me to fasten the apron so he could play in the sink with water. Emergency vehicles (police car, ambulances – air and land) were crashed into the water in the sink and he said ‘they are sinking’. Even the boat was upended. He threw into the water lots of people and cars and he told us they had sunk. Mother asked whether other people could rescue them. Rescuers arrived but they too sank. I talked of the time when mum was in hospital and Johnny may have felt that it was a total disaster, no one could be saved, not even the rescuers. Coming back to the present, I said there were some people and vehicles floating but Johnny pushed them down saying ‘they have sunk’. Concern appeared on mother's face. I talked about how Johnny may still be feeling inside himself that disasters continued.

Johnny said there was a volcano which was about to erupt in the water. I said that another disaster was about to happen and it would be dangerous. Johnny, pointing to the small barrel in the water, said there was acid in it and it would melt things. I said dangerous things were happening. This continued for a while with me describing what was happening. Johnny said ‘the volcano will happen and lava will come out and the water would go up’. I asked what would happen to the people and he said ‘they would get burnt’. I wondered how he felt about that and he said the water was getting hot (lava was in it). I said there were people (children, a woman, hospital lady, air ambulance pilot) and emergency vehicles still floating. There were some vehicles and a little girl who had sunk. Johnny scooped out the floating things and put them into the other dry sink (we had a double sink).

I wondered if Johnny was rescuing them from being burnt and he nodded 'yes'."

At our meeting 18 months into my involvement, this theme continued in the following sequence:

"Johnny wanted to play with water and came to me to help fasten the apron. He proceeded to crash the land and air ambulances. He put a sheep, a lamb, and some people into the water and mother talked to him about it. Johnny said 'they will die' and said there will be a fire which he would make. The moment Johnny said this, mother asked him to come near so she could check something on his school shirt. Johnny did not want to do this and mother assured him that she would not tickle him. He went to mother who said there was a food stain on his shirt. I said it seemed there was a disaster and everyone would die and that could be scary. It was hard to think about scary things."

I had a dilemma. I could understand how mother would find this sort of play particularly difficult to witness in her child who she knew had been adversely affected by her life-threatening illness. On the other hand, Johnny needed to work through these feelings of murderous rage. It might have been better if mother had not been in the room to allow Johnny to be freer but also to avoid overburdening her emotionally. On the other hand, sharing of this knowledge may also have been helpful. They now knew together how awful Johnny had felt – and still felt – about what had happened and that may have made mother more sympathetic towards Johnny and his predicament. Johnny, albeit unconsciously, may have felt relieved that mother witnessed the extent of his distress and also that there was someone else not involved in their drama who not only understood this distress, but was not afraid to put it into words. It was, perhaps, no longer a private thing that he alone was grappling with.

As we have seen, the effect of mother's illness on the extended family had been considerable. Mother's parents had been very worried about her wellbeing but had also taken on the major task of looking after mother and her children during the acute stage of her illness. This seemed to have continued as the family had gone back to live with them.

4. Defences

I experienced mother as rather brittle and vulnerable, despite her protestations that all was well. Mother may have had a need for this defence in order to not only continue living in hope herself but also to function as well as she could as a parent. Mother presented as someone who had decided that she was going to get better and did not wish to dwell on feelings to do with the critical illness she had had. She tended to minimise difficulties or even deny them. An example of this can be seen in a sequence when I met with Johnny, his younger brother, mother and maternal grandparents during the assessment stage:

“Mother appeared tired and when I asked how she was she said that in the preceding few weeks symptoms of headaches and her right arm going numb had come back. She was going for an MRI (magnetic resonance imaging) scan soon. When I wondered whether this was a scary time for them, mother made a dismissive gesture with her hand but her mother said it was.”

Mother found it difficult to acknowledge symbolic meaning of things in sessions when I talked about what Johnny was showing in his play. As mentioned earlier (see Chapter 2: Review of Literature – Psychoanalysis: Mourning and Trauma), Garland (1998) has discussed the diminishment of symbolic thinking in traumatised individuals. Mother had had a brain tumour which had to be surgically removed and this had been followed by radio and chemo therapies. This had led to short-term memory loss. It is possible that symbolic thinking had been affected in some way by the tumour and the subsequent surgical and medical treatments. Mother had experienced a major emotional and psychological trauma as well as actual physical trauma to the brain.

Despite the above, my working hypothesis had been that mother had found it emotionally difficult to deal with the possibly catastrophic nature of her illness, and that the only way she could deal with it was by not thinking about it. Therefore, in the room, when Johnny brought it up, she belittled or denied the significance of it. It is possible that not wishing to think about her illness had shut down the reflective part of her in some way too, making her more rigid than she might otherwise have been. It is possible that focusing her attention and feelings on

herself and her body (quite understandably) may have left little emotional space for anything or anyone else.

An example of mother's defences can be seen 17 months into my involvement:

“Mother told me that her father was ill with bronchitis and Johnny started playing with the big sponge on the edge of the sink, pressing it rhythmically with his thumbs. Mother was surprised and said Johnny was trying to get someone back to life, he was doing CPR. I said that we had, a few minutes ago, been talking about granddad being very ill and Johnny may be worried about him. Mother said he always did this. I said whenever I tried to bring meaning to what was happening mother tended to flick me off, it was difficult for her to think about meaning of things, especially difficult things like people being very ill or death. Mother said ‘uh uh’ and there was an awkward silence.”

It can be seen from the above example that mother was able to make a symbolic link between Johnny's play and what that may signify. It was only when I extended the meaning to include Johnny's worries about her father's illness and the possibility of death that the discussion seemed to enter a territory she did not wish to get into.

5. Sustaining Factors

Mother's life-threatening illness had been a catastrophe as Johnny was showing us in his play above, but it had been mitigated by several factors. These included the love from his mother and other adults in his extended family; his school being very supportive; the professionals involved working together well on behalf of the family; and my own involvement.

Despite the children's father leaving during the acute stage of mother's illness, he had returned and was in touch with the children. Although I did not meet father, his continued presence in the children's lives could be seen as a positive factor.

During the school reviews I explained Johnny's difficulties in the context of the trauma of his mother having been so ill. I explained that the young age at which Johnny experienced the trauma of seeing his mother so ill (he was 3 when she became ill) would have had an effect on how he understood what was happening.

This cognitive immaturity, as well as any specific difficulties in comprehension, would have made things even more confusing and scary for him. Also the great anxieties in the adults around him may have lessened *their* ability to contain Johnny's anxieties.

It was heartening to hear about the positive changes in Johnny reported by school staff and mother as therapy proceeded, despite the many interruptions. I would underline these positives to show change was possible – that he was actually a lovely little boy who had had to contend with very major things too early in his life. I think my presence and involvement helped contain the anxieties within the school and family network although concerns still remained about his social and communication difficulties and the effect on his learning as he continued his schooling.

6. Feeling Different

As we have seen earlier, mother, maternal grandmother and the school staff were all concerned about Johnny's difficulties, especially in the area of social communication.

Johnny, being aware of the adults' concerns about him, may have thought that there was something *really* wrong with him. For example, when I saw him on his own during assessment:

“He drew an alien, with many arms, legs and eyes. When I asked about this alien, he said he was scary. I asked how the alien felt and he said ‘he is happy’. I said people looking at the alien felt he was scary but the alien himself was happy.”

I wonder if Johnny felt that people saw him as a scary alien being although he himself felt happy. Was he really happy or did he think he was expected to be happy? After all, his mother did not want to think about scary things herself.

The following sequence is another example of Johnny feeling different, when I met Johnny with his mother a year into my involvement:

“Johnny drew and told us a story of an Evil Genius who experimented on people but who was nevertheless a goody. I wondered how an Evil Genius could be a goody. Johnny gave us a rather complicated explanation about the Evil Genius and his experimentation on people not being bad. In this story there was a character called Stitch who somehow escaped the clutches of the Evil Genius and was rescued by Lilo, a girl who looked after him. He repeated several times that Stitch was weird and when I asked how, he explained that he had four arms, but he was a goody but at times could do bad things. When I asked about what sort of bad things, mother said ‘naughty things’. I wondered if there was someone who was a goody but at times could be naughty and Johnny mentioned his younger brother’s name. I turned to mother and she agreed but also indicated by gesture towards Johnny, meaning he could be like that too. Johnny did not see the gesture as he had his back to her.”

I wonder if Johnny, being aware of the adults’ concerns about him, may have felt that he was ‘weird’ in some way and that this had come about magically by some evil genius experimenting on him – Johnny denied this as he did not really want to think of himself as ‘weird’.

My experience of Johnny in the consulting room was very different to how he had been described by family members. For instance, I had been told that he saw things in black and white and did not have a sense of humour. As has been seen above Johnny and mother interacted through teasing. Very often, Johnny and his mother exchanged jokes, with Johnny ending up in peals of laughter.

Outcome

By the end of my involvement Johnny appeared happy and confident in the consulting room. Mother reported that their relationship had improved markedly. Johnny was no longer exhibiting major challenging behaviour at home. School too reported that he seemed a happier child. However, mother and the school continued to be concerned about his social and communication difficulties and he was referred for further clinical psychology input to address this. Mother was told that she was clear of the malignant brain tumour but continued to be monitored by the hospital.

Implications of the Case

Despite the many interruptions in this mother–child psychotherapy, it seems the sessions provided a space for Johnny to feel supported in exploring his feelings, which led to mother reporting that he was much more manageable at home, and their relationship was therefore improving. It appears that some containment was offered to both of them, making it easier for them to not invade each other too much with their anxieties, and allowing their underlying mutual affection to find expression. Johnny’s mother and his head teacher appreciated my involvement with the professional and extended family network, including my ongoing liaison with the head teacher, and this too may have added to the sense of trust in me. The fact that I did not give up and carried on for two years despite the interruptions may have added to this sense that I was someone who had Johnny’s and mother’s best interests at heart, and therefore could be trusted.

Mother was able to learn by observing me in the consulting room and was able to play with Johnny which he absolutely adored. It was more difficult for her to see his preoccupations with death and dying. I do understand that I had years of experience witnessing such play as a child psychotherapist. Mother had not had such training or experience, and what was being portrayed by her own child was too personal and near the bone.

Mother often complained of all sorts of symptoms and it seemed her health had been compromised from very early on in life. She may have had to find a way to live as normally as possible, especially as she had responsibility for two small children, so her defences may have been very necessary.

My countertransference towards mother, at times, had been of irritation and frustration due to the interruptions in therapy. Looking at this now I realise how persistent mother’s efforts had been in trying to get to the sessions. Despite the many real external difficulties in attending regularly, mother continued over two years. This may have been due to her own positive transference and trust in me, as someone who had shown real commitment to Johnny and her, and also as someone who Johnny liked. It is possible that when mother’s guilt and anxiety became overwhelming – it all seemed too much to bear – she stayed away; and

when her positive transference was uppermost and she saw me as a helpful figure, she was able to bring herself to come, even though she knew that she would very likely be reminded of how her illness was still upsetting her son.

Johnny's play seemed to show that he was very aware and concerned about his mother's illness. His play also showed that his internal anxieties seemed to be catastrophic and little hope was left for anyone surviving disasters. I have often seen this sort of play in abused, traumatised and neglected children. Mother's life-threatening illness was no doubt a major trauma for all, including Johnny. Although mother and the school reported positive changes in Johnny, I remain concerned that these anxieties were not allowed to be fully worked through and Johnny may well continue to have difficulties in the future and need further therapeutic input.

Johnny also showed an underlying resilience and potential. He had been subject to very painful circumstances and almost unbearable anxieties, and it had understandably affected him emotionally. Despite this, after a rather disrupted therapeutic input, he seemed to have become happier and able to relate to his mother more positively.

Another important aspect of this therapeutic input was the containment of anxieties within the professional and family network. I had been concerned at the effect on Johnny of so many assessments. As we have seen earlier he may have felt he was 'weird' in some way due to the adults' concerns about him. I tried to explain Johnny's difficulties in the light of his mother's illness, his very young age when it happened, and the anxieties in the adults around him. Any specific difficulties in comprehension may have compounded his confusion and fears. Such attempts on my part may have led to the adults experiencing Johnny in a more positive light which may, in turn, have led to Johnny feeling that he was not so odd or 'weird'.

In his relationships and communications in the room with me and his mother it did not strike me that Johnny was on the autistic spectrum, although, at times, he struggled to express himself clearly. Mother and the school staff remained concerned about his social and communication difficulties and this seemed to be

borne out by assessments made by our clinical psychologist and the school speech and language therapist. Whether these difficulties were a consequence of the trauma and unmet emotional needs earlier in his life as a result of his mother's illness, or whether they preceded this one cannot say.

I think Johnny would have used individual psychotherapy very well and, given time, his internal world may well have improved further. As we have seen no such therapy took place as mother was not able to bring him regularly.

In conclusion, I think it was worth offering the psychotherapeutic input to Johnny and his mother as he certainly developed during our involvement into a much happier child and his mother reported a vastly better relationship with him. I hope the input helped him with his continued development.

SARA (AGE 16)

Introduction

Sara was referred by a clinical psychologist in an oncology hospital in the context of her mother's metastatic breast cancer because of difficulties in relationships with her parents; she was also self-harming. The presenting problems had started at the time of mother's second cancer diagnosis two years prior to the referral. Sara's father had a history of depression and had received psychiatric treatment. He also had cardiac problems resulting in hospitalisations around the time of the referral, leading to Sara's problems intensifying. I met Sara and her parents together and separately and continued with telephone contact over a period of 10 months.

Family History

Sara's parents, who were in their early fifties, gave me the following history. Sara was an only child. Just before the pregnancy mother had had a car accident and her own father had been very ill and died four months after Sara was born. Sara's birth was reported to be "horrendous" and mother had had to have an emergency caesarean section at full term. Sara was bottle fed as breast feeding was said not to have worked. She slept and fed well as a baby. Sara had good physical health. In her early school years she was described as learning well and being confident and sociable. Entry into high school coincided with her mother being diagnosed for a second time with breast cancer and her behaviour changed markedly. Sara was said to have become moody, aggressive, unpleasant and rude to all. Sara's interests included badminton, film club, karate (she had a black belt) and acting.

At the time of her referral to CAMHS she was depressed and had a history of self-harming by cutting. Sara was said to be bright but dyslexic and this impacted on her learning. A few months into my involvement Sara sustained an eye injury when a boy in class threw a scrunched up ball of foil. This led to Sara not being able to see properly for a while and added to her anxieties about doing revision for her exams.

There was a history of heart problems, dyslexia and self-harming on the paternal side of the family and a history of cancer and heart problems on the maternal side.

Mother had had breast cancer 10 years previous to the second diagnosis. After the first diagnosis she had a right breast mastectomy and reconstruction surgery which had gone badly and had had to be rectified. This second time she also had ovarian cancer and her ovaries were removed. Mother continued to receive chemotherapy for the metastatic breast cancer.

Psychotherapeutic Input

Psychotherapeutic input included face-to-face sessions with the family, Sara individually, and the parents together, and lasted for a period of four months, after which time Sara did not wish to attend sessions. As her parents remained concerned about her, I continued to keep in touch with Sara and her parents by telephone for another six months. Sara's relationship with her parents improved after the initial family meeting, and her depression receded very soon afterwards. She continued to maintain that she was no longer self-harming. She also did better in her GCSE exams than she had expected and was accepted in a college of her choice. After discussion with Sara and her parents over the telephone, we decided it was time I closed the case.

Themes

1. Engagement

Parents told me that Sara had not taken up offers of counselling from her school and mother's hospice before being referred to CAMHS, saying she had no problems. Although her parents and I managed to get her to CAMHS for a few sessions she dropped out of therapy fairly quickly.

At the first meeting I saw the family together, then Sara on her own, and her parents together on their own. Sara was open and forthcoming at her next individual session.

The following session she remained very closed as shown by the following:

“Sara kept her coat on and arms crossed throughout, saying she ‘had nothing to talk about today’. Her answers would either be ‘I don’t know’ or she would minimise or deny things. I said that I had noticed the two times I had seen her previously that she had come in closed but opened up as the session progressed. I said I had been told by her parents that there had been a marked shift in her behaviour for the better at home. Sara said she had not gone out of her way to be different. She said that on the scale of things in terms of world affairs what was happening to her was not a big deal. She did, however, agree that there had not been arguments at home recently, but then, she said, there had not been many before. I said that it seemed that the way she experienced things at home was different from her parents’ experience.

Sara said that her parents had told her that she was coming for family counselling and said that they had not mentioned her being seen on her own. I said I did a number of things and was flexible, seeing young people on their own, parents on their own and also meeting with families. We discussed what Sara would find helpful and she opted to be seen with her parents again. In fact she never came back.

Father had been in hospital again and there had been a delay in seeing Sara. I mentioned this and I wondered how she had felt about her dad going into hospital again, remembering that she had been very frightened when he had collapsed at badminton and had to be taken to hospital by ambulance. Sara did not have much to say about this.

I wondered about how things were at school as she and her parents had mentioned issues of not being given appropriate support for her dyslexia and her emotional needs. Sara did not have much to say about this either and did not want me to contact her school as she did not think that would help matters.

I asked about how depressed she felt and she rated herself 4/10 (0=not depressed to 10=very depressed). I said she had told me last time it was 7/10, and therefore she was now less depressed. I wondered what she thought had helped, but Sara could not think of anything, maintaining things had not been that bad in the first place.”

One can only speculate about why Sara seemed to have opened up so much in the previous session and then closed up. She may have felt safe enough to do so or may even have felt relief that she could talk to someone openly for the first time. But she closed off. What was that about? Was it, like with her mother, a way of coping with a very difficult situation, i.e., what is the use of thinking about such painful things, as it only makes you feel worse (see Defences section below). Or did coming to see me on her own account signify something was wrong with her? Or were there too many patients already in the home, so she had to remain strong and healthy?

In contrast, the parents were motivated to see me and were supportive of Sara attending. Despite their serious illnesses they managed to get to the clinic and also maintained contact with me via the telephone when that was not possible.

2. Parental Concern

Sara's parents came across as thoughtful and caring. They worried about Sara and her future. They felt that Sara did not have appropriate life skills, especially in her relationships with peers. They thought that she did not have friends although Sara disputed this. They were concerned that school was not offering an appropriate level of support for Sara as she had dyslexia and were also concerned that Sara may continue to self-harm. Father was concerned that Sara did not have a good sense of her own worth.

Parents helped Sara through her anxieties about GCSE exams and interviews with colleges in what appeared to be thoughtful ways. For instance, father coached Sara before she attended a performing arts college as she needed to do a monologue as part of her entrance interview. Mother took her to these interviews.

Mother's continued concerns about Sara and her future can be seen in the following sequence during my final meeting with the parents:

“Mother was able to say that she was worried about what would happen to Sara when she, mother, was no longer around. She wanted Sara to be 100% OK but knew that was unrealistic. Mother thought Sara would

survive. She thought that Sara had had a knock with mother's illness, but Sara's biggest challenges were still to come. Mother said Sara was not comfortable in her own skin and had insecurities. While recounting this, mother was in tears and it was very moving."

Father, on the whole, was very open about his feelings and was also sensitive to how Sara and his wife felt. For instance, he was first to mention his wife's worries about Sara. Both parents were very aware of the impact on Sara of both their illnesses and understandably worried about her present and future wellbeing.

3. Impact of Mother's Illness

In Sara's case both parents were ill and this is taken into account in this section.

As has been mentioned earlier Sara was described by her parents as a sociable, confident little girl at primary school until her mother's diagnosis when they had noticed a major change in her. At the time the medical team had told father that mother's cancer was very serious, especially as this was a recurrence of the disease. Father had decided to tell Sara that mother was seriously ill and that it could get worse and that mother could die. Sara seemed to have forgotten this as can be seen in the following sequence from the initial family meeting:

"Sara seemed surprised to hear how serious mother's illness had been, as if she had blocked out what father had told her previously. In addition to relationship difficulties with her parents, Sara herself said that at school her concentration and motivation had gone down. Sara said she had been trying to make more effort but she felt weighed down and fatigued."

Just prior to the referral Sara had been frightened on the badminton court (she and father went to badminton together, although they would both also play with other partners) when father had fainted and an ambulance had to be called. This was in relation to father's ongoing heart problems.

These major changes in mood and behaviour exhibited by Sara could be seen, not only in terms of her own anxieties about mother and the possibility of her dying, but also in terms of heightened anxieties within the family, impacting on Sara. This was also at a time when Sara was entering her teenage years and experiencing major changes in her internal and external lives. Puberty is often

felt by young people as a time of internal turmoil as they leave childhood and are at the threshold of adulthood. External changes include demands made in academic and relationship areas. It is a sensitive and vulnerable time for any young person. So, added to these 'normal' changes was the fact that Sara's mother was seriously ill. We also know that Sara's father had suffered from chronic depression and, more latterly, heart problems. So it seems understandable that Sara was showing her deep distress in this way. Her parents, even though they understood why she was being so awful, did at times lose patience and reacted by getting cross and thereby further escalating the family tensions.

At the initial meeting Sara had been surprised to hear that the cancer had spread to mother's lungs in addition to other organs, although her mother maintained that she had told Sara. So Sara, it seems, had again blocked this information from her consciousness. This was of particular importance as one of the main bones of contention was Sara smoking and coming home reeking of tobacco.

One can wonder about Sara's smoking. Was this an unconscious attack on her mother? And if so why? Was she very angry with mother for being so ill and possibly leaving her prematurely? Or was she unconsciously identifying with her sick mother and attacking her own lungs through smoking, to become ill like mother? Sara had told me in one of the meetings that she got on better with her father as he was less intense about things and they had similar interests (e.g., badminton). Was this an oedipal wish to get rid of her mother to be alone with father? It is very difficult to know as I had so few sessions with her.

Sara's parents had seen cut marks on her limbs and abdomen. Sara maintained she had only cut a few times and had stopped. Many teenagers who are referred to CAMHS self-harm, especially girls. We are usually told that the young person is experiencing intense feelings (usually of anger or frustration) which are discharged when they cut. When I asked about the cutting, Sara was not able to go into great depth about how she had felt at the time of cutting and what the triggers were.

One can speculate that, in cutting herself, Sara was unconsciously identifying with her mother's operations on her breast and ovaries. Mother had very female diseases and I wondered how that made Sara feel as she was a girl growing up to be a woman. This can be seen in the following sequence from the second individual meeting with Sara during which she had been very open and forthcoming:

“Sara told me that sometimes she worried about her own health. For instance, when there was a small ache, she wondered ‘is it cancer?’ Sara said that if in the future she did get cancer she would be like her mother, she would face it bravely. I said in a funny sort of way she was like her mother now too, by putting on a façade, hiding her sadness.” (See Defences section below.)

Sara's identification with her mother's bravery was very touching but also shows that she could identify with a strong mother.

Sara's parents gave me many examples of how the medical profession had let them both down. Parents described in great detail how their GP would not take their symptoms seriously, despite mother having had cancer before, and both times they had had to go to private doctors to have diagnoses and appropriate interventions.

They also gave many examples in which school staff appeared to be unhelpful and insensitive to Sara's needs.

Although I know these things do happen, I wonder how much this was a reflection of their own anger about their very tragic circumstances being projected onto the professionals. I had wondered if this would happen to me; that is, I would become the unhelpful professional. But it did not and we, at least the parents and I, ended on good terms. The parents were sad that Sara was not able to take up my offer of therapeutic help but understood I could not work with her without her presence and consent.

Mother felt tired due to her illness and she also felt stressed by father's negativity due to depression.

Father did not like to be in hospital as he needed privacy which he could not get. The first time he was hospitalised during my involvement he tried to discharge himself against medical advice and security had to be called to get him back onto the ward. Father did not want an operation just before Christmas as there had been several family deaths at that time of the year and the hospital acceded to his wishes by rescheduling the operation. Unfortunately the operation was then delayed by the hospital leading to further anxiety for father.

4. Defences

Mother wanted to carry on life normally and did not want to concentrate on her illness. For example, the sequence below is from the initial family meeting:

“Mother said she did not want to know too much about the details of her illness. She said ‘if I feel alright that’s good enough for me’. She did not wish to think about the prognosis, she just wanted to carry on living: she looked after herself, ate well, continued taking her medication and went to regular check-ups. She did not want her whole life to be dominated by cancer. She had been told that if the chemotherapy had not worked she would have had a few months to live. Although mother’s energy levels were low and she suffered the side effects of the medications, she thought she had a strong constitution and felt she would be around for a while. She had confidence in the doctors who were looking after her health and did not want to know about the results of her blood and other tests.”

One can understand mother’s point of view of wanting to live as best she could and not think too much about how long she was going to live, and to not be dominated by cancer. It can also be seen in the context of how much she supported both her husband and Sara. I think she felt that she needed to remain strong to continue in this role.

Sara, on her part, tried to hide her sadness in order to protect her parents from even more worries, as the following sequence from the second individual session shows:

“Sara told me that she did feel sad but did not show it. Since the time of mother’s second diagnosis, two years ago, she had felt this, every day, but had now got used to it. Sara said she found it hard to express what she was feeling, she was good at hiding her feelings. She said she put on a happy face and people thought she was OK. She said it was a ‘defence

mechanism', it had become natural now. She was worried that if she showed her sadness it would make her parents more worried."

It is possible that Sara's concern for her parents led to the major change in her attitude and behaviour towards her parents after our initial session. It is also possible that this 'retreat into health' was a necessary defence at a time when she was having to gear herself up to prepare for and sit her GCSE exams and was also going to college interviews.

5. Sustaining Factors

The main sustaining factors were Sara's own resilience and the parents' thoughtfulness and care, which I have mentioned earlier.

Despite the parents' concerns, Sara maintained she had friends and attended and enjoyed various activities. She seemed to have a sympathetic and supportive karate coach. After the initial meetings with me her mood changed for the better and it seemed to be maintained. She managed to get good GCSE results and was happily ensconced in the college of her choice at the time of discharge.

Although I heard reports from the family about Sara's school being unsupportive, on further questioning it seemed they had put in measures to help her: she was, for instance, allowed more time during exams. She was given an electronic device to type her notes in class although it did not have a screen so Sara could not see what she was typing. As Sara had not wanted me to speak to her school I had to rely on the family's reports.

6. Feeling Different

Sara felt that she was different from her peers and that they teased her as the following sequence from the second individual meeting shows:

"Sara said she found it hard to accept herself. An example was her appearance. She was very thin and other young people teased her calling her 'skinny' or 'fat'. She felt constantly being judged by other young people and felt they thought she was 'odd'. When I pursued this she said, for instance, she enjoyed films while they enjoyed other things. Although Sara

had several outside interests (films, badminton, karate) she said she would have liked to be able to play music but could not. She acknowledged though that she was good at badminton.”

Outcome

By the end of my involvement Sara and her parents reported that Sara had done better than she had expected in her GCSE exams and was delighted to get a place at a performing arts college. Her depression had lifted and her relationships with her parents had improved. Sara’s mother continued with pharmacological treatment at the hospital. Sara’s father continued being monitored medically for his heart disease.

Implications of the Case

There seemed to be a marked shift for the better in Sara’s behaviour and attitude towards her parents after the very first session. This continues to surprise me as I feel that I had only offered minimal help. One can only speculate why this may be so. One could argue that even this minimal contact may have acted as a ‘first aid’ intervention during this time of crisis for the family. This may have led to enough resilience surfacing in Sara to let her continue with her ordinary life.

Research on childhood depression (Trowell and Miles, 2011) has found the pattern of treatment outcomes to differ between the two types of therapeutic modalities: individual psychoanalytical child and adolescent psychotherapy and systemic family therapy. There was a more immediate reduction in the symptoms of depression in the young people involved in family therapy compared to those involved in individual psychotherapy, but the improvements in the latter group continued for longer, evidence perhaps of the ‘sleeper effect’ that has been seen in psychoanalytic treatment methods. It is possible that in the family therapy context relationships are explored and the young person feels she is only part of the problem and does not need to dwell on her own internal world as much as would be the case in individual psychotherapy. I had worked with the whole family and this could perhaps have been why Sara’s reported decrease in depression appeared to happen so quickly after our few meetings.

Sara had told me that she felt loved by both her parents and felt guilty at hurting them with her behaviour or words. So it is possible that when things were brought out into the open in the first family session, the more concerned part of her took over, and her behaviour towards her parents changed for the better.

Sara's parents came across as caring and thoughtful and were at a loss at Sara's ongoing oppositional behaviour towards them. I was able, gently, to point out that some of the behaviour they were concerned about seemed normal for a young person of Sara's age (e.g., not keeping her room tidy). It is possible that they felt their concerns had been understood by me and therefore felt supported. This would have taken some pressure off Sara. Sara had mentioned that after the first meeting her mother had been more cheery. Sara had maintained that her parents, especially her mother, overreacted. So it is possible that the parents' behaviour towards Sara had also changed for the better, allowing her to respond more positively.

Sara too, it seems, could be reflective in sessions, albeit for a short time. In her sessions with me she may have become more aware that she had more understanding than she thought she had. Although the situation itself had not changed, Sara may have discovered more resources within herself.

The fact that Sara had been referred in the context of her parents' illnesses meant she had not been referred for difficulties in her own right. That could have made it difficult for Sara to engage with me. She had not been keen to come in the first place but had agreed to come with her parents initially. If the therapeutic work had continued it would have been helpful to have someone else see the parents while I met with Sara.

There was a theme, with father in particular, of needing to be in charge when hospitalised. When one is ill one can feel at the mercy of the illness and also of the health professionals. By refusing to continue in therapy Sara was exercising her right to decide whether she needed help or not. It is also possible that by improving her behaviour she was able to ward off further therapeutic help and therefore not be defined as someone needing help. Sara may also have felt that

she needed to remain strong for all three of them. Coming to therapy may have implied weakness on her part which she could not allow in the circumstances.

It is also possible that, by containing some of the anxieties both in Sara and her parents, the anxieties got redistributed. They may have shifted enough for Sara to behave more acceptably at home. By sharing their concerns with me, the parents too may have felt understood and supported by an external adult. This may have led to more understanding and acceptance of Sara's feelings, thoughts and behaviours, and to different behaviour from them towards Sara.

Despite the brevity of the intervention, it seems, at least in the short run, that there was a beneficial effect for Sara. There was a lot of resilience in all members of this family. I agreed with Sara's parents that she was vulnerable and it would have been satisfying for me as a therapist to have been allowed to continue to work with her. One can only hope that, should she need and want it in the future, Sara would have access to appropriate therapeutic input.

FARAH (AGE 8) and GABBY (AGE 6)

Introduction

Farah (age 8) and her younger sister Gabby (age 6) were referred to our service as they were reacting to their mother's second bout of breast cancer. I met them and their parents in various combinations over a period of 10 months.

The family doctor referred Farah as she was banging her head and appeared upset. My consultant psychiatrist colleague conducted the initial assessment and she was told that Farah, on one occasion when she had been very upset and angry, had pointed scissors to her forehead and tried to cut her hair. Farah told my colleague that, although she was very upset and angry at the time, she had not thought of seriously harming herself. She felt bullied by a boy in her school who she had previously been friends with. Farah said that she was doing much better since mother was not on chemotherapy anymore but only had injections. She said that she liked it when mother wore a wig. She remembered two dreams: one in which mother had come into the school without wearing her wig (Dream 1); and another, just before the scissors episode, in which something was telling her it would be a good thing if she "punished herself" (Dream 2). She realised that what the dream told her was not right, and that her parents preferred her to talk about her worries rather than use scissors. My colleague liaised with the school and requested information about cancer from the oncology hospital which could be offered to Farah and Gabby by the school staff. School had arranged for the children to meet a teaching assistant every week for support.

Parallel to the above, the oncology clinical psychologist had met with the family and contacted me as she had referred cases to me previously. My psychiatrist colleague, the oncology clinical psychologist and I liaised and it was decided that my colleague would attend a meeting with the clinical psychologist and the family for a handover to CAMHS. During this meeting Farah's younger sister, Gabby, said she was worried that mother would die. After discussion my colleague and I decided the case would be transferred to me and that she would also refer Gabby.

At the time of the referral the parents had filled out a questionnaire about Farah. They said that at home she seemed to show self-loathing, sullenness, and frustration towards her younger sister and she was occasionally angry with her mother. She had tried to self-harm (see above). At school she showed low self-esteem, fragility, sadness, a sense of worthlessness and unsettled relationships. She was reported to have rapid, frequent and unproductive mood swings. She seemed to want to prove herself constantly and needed to win. The problems had started four to five months prior to the referral. Her parents wanted help to enable Farah to understand what was going on inside her, and to enable the family to understand Farah's frustrations and concerns; they also wanted advice on how to deal with Farah at school and at home.

Gabby's referral came on the back of Farah's. Neither the parents nor the school staff reported any changes in Gabby in response to her mother's life-threatening illness. Despite this, she verbalised in the handover family meeting with the oncology clinical psychologist and my psychiatrist colleague that she was worried that her mother would die (see above). Hence it was decided that she too would be referred to CAMHS.

Family History

The family and children's histories were given by the parents, who were both in their late thirties. Mother had had breast cancer five years previously, and had had a mastectomy of the right breast and reconstructive surgery. The cancer had recurred four years later in the same breast, and the reconstruction was removed. This was a year before the referral to CAMHS. She had had radiotherapy and chemotherapy, and continued to be on medication. She was due to have further reconstructive surgery. The children saw their mother naked and called the breasts 'hard' and 'soft' boobies. They had seen her without hair on her head (she had lost her hair as a side effect of chemotherapy).

Farah

Farah was a forceps delivery as she had been stuck high up in the womb and had to be revived by a paediatrician at birth. She breast fed for six months, and

was then bottle fed by day, and breast fed morning and evening. She was said to continue to love her food at the time of my involvement. She was looked after by a nanny from 6 months, grizzled when separated from her mother, but was said then to be fine.

Farah struggled with large groups of peers but was fine with a smaller circle. She was very bossy and therefore peers tended to keep their distance. She had stuck up for a girl who had enuresis and peers called 'smelly'. Farah thought that was wrong as the girl, who had a medical condition, could not help it. Farah doted on children under two. She also tended to have better relationships with adults.

Farah had a love–hate relationship with her younger sister Gabby. The two sisters would play together nicely but Farah tended to boss and even hurt her sister at times. Farah would nevertheless defend her sister with peers.

Mother said her relationship with Farah had been great when she was little, but thought that as she had grown older Farah had become more of a 'daddy's girl'. However, when hurt, Farah would go to her mother for comfort and also asked for 'mummy time'. Father said his relationship with Farah was good. She asked him questions and they had discussions, looked up information, experimented in the garden and did simulations (for example, of Galileo's Leaning Tower of Pisa gravity experiment). Father made things for his children. Farah was learning to play the violin; she swam and rode her bicycle.

Gabby

Gabby had been induced at birth and breast fed well until 11 months. From 5 months she had bronchitis, and had to spend one week in an oxygen tent with a feeding tube. There had been multiple trips to A&E. Finally, she was diagnosed with a collapsed middle lobe of her right lung and pneumonia. Her diaphragm did not work on the right side which was a rare and lifelong condition. She had been seen at a specialist lung hospital over the years, especially when she had infections. She had been discharged from hospital earlier in the year prior to her referral to us. It was difficult for her to get rid of infections. She was unwell in the first two years of her life, but had been better in the three years preceding the referral and had not been back in hospital as an inpatient. Her parents described

her as a jolly, happy baby. She was looked after by a nanny from one to two-and-a-half years and went to nursery school between three and four years of age. She had been very clingy when her mother left her at nursery. At school she was very sociable and well liked. Mother thought Gabby being pretty helped. She had lots of friends, both boys and girls. She was of average learning ability and was said to be a 'scatter brain'. She found it difficult if lots of instructions were given at once. She loved dance, ballet and swimming.

Psychotherapeutic Input

I met with the two girls separately, the parents on their own, the family together, and – after mother's operation – each child with each parent. My 10 month involvement fell into three phases with two gaps.

Phase 1 focused on working with the family about mother's life-threatening illness and lasted two months. This included a handover meeting with my psychiatrist colleague with the family present, and an extended assessment with one parental meeting and individual meetings with each child. There was then a gap in therapy of one month due to family holidays and cancellations.

Phase 2 coincided with preparation for mother's second reconstructive surgery and lasted two months. This included a meeting with parents, family meetings and individual meetings with the girls.

Phase 3 lasted for three months and involved meetings after mother's operation. This phase consisted of individual meetings with the girls; meetings with each child with each parent; and a meeting with parents. Another gap in therapy followed, this time of a month, while I tried to meet the parents on their own but there were several cancellations.

The last meeting was meant to be with the parents but father had arrived with the children instead. After this session, I made several attempts to meet with the parents but appointments were cancelled or were not kept. I finally sent an opt-in letter offering a family meeting to say goodbye but parents did not respond, so I closed the case.

Themes

1. Engagement

Considering that the family had been handed over twice professionally before I got involved (oncology psychologist to psychiatrist to me), the family engaged with me quite well. There were several cancellations and a number of muddles about appointment times. Despite this, the parents worked hard to get the children to see me.

The children engaged well in the therapeutic process and were able to talk freely and confidently with me. They also used drawing, and at times play, as a medium of expression and discussion during all our sessions (individual, family, parent-child). They were well used to talking with their parents at home and this no doubt helped. The parents interacted with the children and me well in the meetings with their children.

The parents were happy to be involved when dealing with concerns about their children but less so in discussing their own relationship, as will be shown later.

2. Parental Concern

The parents came across as caring and wishing to do the best for their children. They had initiated the referrals for the children.

The loving relationships between both parents and their children were very evident in the consulting room. The parents had told the children it was good to talk about their worries. This was shown in the consulting room with the children freely discussing things with their parents and me.

3. Impact of Mother's Illness

Farah

Farah seemed to be particularly affected by her mother's illness which showed up in the symptoms mentioned at referral. This was apparent in my first meeting with Farah, as seen in the sequence below:

“Farah said she felt sad and worried about her mother. She said she was worried that mum would die. She told me she worried when mum was ill, when she remained in bed, or she could hear noises from the bathroom when mum could not go (to the toilet). Farah sat nearby on a small chair and looked at me and away intermittently. It seemed talking about her worries about her mother dying was too much, and could not be looked in the eye so to speak (at least in the reflected eye of the beholder).”

There was evidence that Farah blamed herself for her mother's illness. For instance, in Dream 2 above, something was telling her to punish herself, and it was just before this dream that she was seen with scissors in her hand pointing to her forehead and trying to cut her hair. This raised a question in my mind: did she unconsciously think that she had damaged or destroyed her mother's breast, the very thing that had given her sustenance as a baby?

I was told by Farah that mother had long hair before the illness and now she had to wear a wig with short hair. Farah herself had long hair. Farah told me she did not like to see mother without the wig, with no hair. Dream 1 above shows mother coming into school without her wig. Again, I conjectured about this. Was she doing penance by trying to cut off her own hair, identifying with the sick mother? Did she unconsciously think she had made her mother ill?

The answer to my last question was provided when I met Farah and mother together after mother's second reconstructive surgery, as can be seen in the following sequence:

“Mother said that Farah had told her that she had been worried that she had caused her mother's cancer. Mother reminded Farah of their talk. Farah said that when she had visited mum in hospital last time (i.e., during the previous operation) she had seen all the tubes coming out of her (she uses her own body to show us this and makes sounds of disgust). She had cried afterwards. Mother said she had not caused her illness.”

But I wonder how much this reassurance had convinced Farah.

There was also a possible oedipal theme in Farah's guilt. As we have seen earlier mother had told me that as Farah grew older she had become 'daddy's girl'. Father had agreed that he had a good relationship with Farah. This was very evident in the consulting room when I saw them. Farah very often tried to get father's attention and sat on his lap whenever she could. The two children vied for father's attention and the rivalry was very marked. Farah told me, and father agreed, that she spent more time with father when mother was at work as he came home earlier. Farah helped her father with cooking meals and enjoyed talking to him. One can conjecture that Farah may have unconsciously wanted to oust mother in father's affections but she also loved her mother. So, it is possible that a part of Farah may have felt triumphant about mother's illness and the possible total removal (i.e., death) of mother, as then she would have father to herself (of course, Gabby would still be there, but, try as she might, Gabby did not appear to be first with father).

At my second meeting with Farah she recounted her current worries to do with her peers at school, as shown in the following sequence:

"She told me that she had been accused of spying on others. She gave me an example when she had been accused of sitting on the toilet and listening to what the girls were saying outside the cubicle. Her best friend was cross with her although Farah denied she had been doing this. She also told me that a lot of spying went on in school. Farah told me that she listened from under a gap at the bottom of the door at home when her parents wanted to have a private talk with each other in the kitchen. She remembered doing this when her parents were talking about telling the children about mother having cancer. She thought there should not be secrets – they needed to know about mum's cancer. I said that listening to someone's private conversation could be seen as spying – Farah laughed and agreed."

This 'spying' could be seen as Farah trying to control the very uncertain world which their mother's illness had created. In this last example with the parents Farah could have felt left out, so the oedipal theme could be present too.

The children used the term 'soft' for mother's healthy left breast and 'hard' for the right breast which had been removed and reconstructed. One can wonder about

the emotional/psychological effect of the destruction (cutting away) of a maternal breast on the baby that had fed from it. During a family meeting just prior to mother's second reconstructive surgery, mother told us in great detail what would happen, and explaining that the nipple would not be put in at this stage so the two breasts would look different.

My conjecture is that the 'hard' booby, the reconstruction, was really a sham as a feeding device: it did not hold milk nor did it have a nipple from which the baby could suckle. So, although attempts were made to make good the destruction externally, it was cosmetic, which it was meant to be. Did Farah unconsciously think that the damage she had caused had not been rectified properly externally, and was this stopping her repair it within herself? And would that have caused her guilt to continue? These are hypothetical questions as the answers did not appear in her sessions.

Farah identified with her mother in several ways. An example of this can be seen in the family meeting just before mother's operation:

“Farah drew and wrote on the blackboard and Gabby drew and wrote on the whiteboard on the opposite wall in the room [see below under Gabby]. Farah drew the hospital room where mother was going to be, including everything in detail (bed, buttons which mother could use to call people, cupboard with clothes, a nurse) and wrote 'My life so far' and signed her name under that.”

It seems Farah felt that her whole life was dominated by her mother's illness. She may have felt that her mother's experience and her experience were the same, one defining the other. It seems that Farah had been taken over so powerfully by the catastrophe of her mother's serious illness that nothing else existed in her life.

When I met with Farah and her mother after the operation there was a theme of soft and hard behaviour: Farah had been kind and helpful (with a child who needed help in the playground) but had also been rough when she played football. One may possibly relate this to the 'hard' and 'soft' boobies of her mother. Was she identifying with both aspects of the maternal function? Soft and caring but also firm, with the latter transformed into hardness. I had been told by the parents that Farah could be very controlling with peers and her sister and this

could be seen as the hard part. It is also possible that the controlling was a defence as her life had been pitched into so much uncertainty by her mother's two bouts of cancer.

The parents had said that they were very open with the children about mother's illness. The parents were trying to allay the children's anxieties by being very open but the policy of 'no confidentiality' was a process which could leave the children cruelly exposed to too much knowledge.

Gabby

Gabby's mixed feelings about her mother's illness can be seen in the following sequence which appeared in her first individual session:

"Gabby told me that she felt sad and happy about her mum. She felt sad when she felt that mum was poorly. She could not at first say why she felt happy. I wondered whether it was to do with mum feeling better now and she agreed. Gabby said she could not tell when mum was poorly but her sister Farah could. Her sister would tell her that mum was in bed and they must not disturb her."

In this session Gabby did a drawing of her mother in hospital, as described below:

"The picture was drawn in black felt tip outlines. Mother was lying down wearing a black nightdress, eyes shut and mouth turned down, a tube coming out of her nose and going into a machine. Gabby did not know what that was and felt confused about it. Mother had very short hair and Gabby said that when dad had cut mum's hair off she had been shocked. She had not known then that it was because of the chemotherapy. There was a vertical curtain drawn as a black line, separating mother from the family and the nurse. They all stood on the other side of the curtain in a line. Nearest to the curtain was Gabby and then Farah, both with long hair and mouths turned down (meaning sad). Next came the lady who looked after mum (nurse) with an uplifted mouth, and then father with his mouth straight (meaning serious). Father and the nurse wore grey. There were black curtains on the small window behind mother and a black outline of a door going out of the room on the right beyond the standing family and nurse. Gabby had a pink dress and Farah a blue one, both girls had red mouths. The most striking bit of colour was the yellow light bulb under a big yellow shade pointing down from the middle of the ceiling. The light seemed to illuminate the stark and sombre situation that mother and the family were in." (See copy of the drawing in Appendix III.)

I think that seeing mother in hospital looking so poorly must have been confusing and sad, as Gabby said, but also quite frightening.

Gabby continued to have mixed feelings about mother before her reconstructive surgery, as seen in the following sequence during the family meeting before mother's operation (see above under Farah):

"Gabby wrote and drew on the whiteboard opposite to Farah at the blackboard. Gabby went through a process, with my acknowledging what she was conveying in words. Gabby wrote 'Mum' and circled it in red. Coming out of this circle were several lines leading to phrases: 'having surgery, is ok'; 'Gabby is vere (sic) sad with mum'; 'Mum is OK. Alive'. And underneath all this she wrote in blue, red and green lettering 'Love, Gabby', and drew three faces in blue, red and green, in a row going downwards, all with straight mouths (i.e., serious)."

After the above session when I met with Gabby on her own, she seemed to keep at bay any signs of sadness as shown in the sequence below:

"She drew a picture of herself with long hair and a green dress next to her mother with shorter hair, dressed in a black dress with blue dots which were hardly visible. Both of them had upturned mouths and were standing outside their blue front door in the front garden, giving each other a thumbs-up sign. This drawing was titled 'When mum comes out of hospital'. I said she is hoping that the operation would go well and mum would be OK, and she said 'yes'."

Gabby then drew the same picture on the whiteboard. It seemed she was trying to convince herself that all would be well with mother.

Gabby may have felt supported by the presence of her older sister in terms of their mother's illness. Parents had told me that the girls had a love-hate relationship, but if anything ever happened to Gabby, Farah would be there to help. Farah too showed her concern for her sister. This can be seen below in my very first individual meeting with Farah:

"Farah told me how, when she was two, her sister Gabby was born and Gabby had problems with her lungs, and she could not breathe properly. Farah said that, although Gabby was not still ill, when she heard her sister coughing due to dust, she remembered the time she had been very ill. She added that she was not really worried about that but Farah coughed, to

show me how her sister made the noise, implying that she was very aware of this still.”

As mentioned above, Gabby relied on her sister to tell her when mother may be feeling poorly and how to behave so as not to disturb mother. Although one may wonder about the burden that Farah was carrying as a result of her mother’s illness, her presence may have acted as a buffer for Gabby. Gabby, being the younger child, was not as aware as Farah, and this may have lessened the impact of her mother’s illness on her to some degree.

Gabby seemed to be keen to show me her individuality in the sessions and this is shown in the following two sequences:

“In the initial family meeting she wanted to draw her own name badge just like the one her father was wearing with his name. Father suggested that she drew her name badge on paper, cut it out, and he would then lend his magnetic badge so her badge could stick to her dress. In this meeting, Gabby also wrote her name in large letters using different colours for the letters.”

“In a meeting after mother’s operation she drew a picture of herself on the whiteboard in a pink dotted dress and wrote ‘This is Gabby’.”

I wonder whether as a younger child she was trying to stamp her individuality onto my consciousness: that is, she was herself and different to others. I wonder further whether this had become more important to her due to the circumstances she found herself in: that is, she needed us to pay attention to how *she* was feeling about things.

4. Defences

Farah

After the initial expression of her worries about her mother, Farah retreated into denial of them, as demonstrated, at the second individual meeting:

“She told me that she was no longer worried as dad had explained that mum would not get cancer again – if she became ill she would have an ordinary illness like everyone else.”

I would think that, deep down, that would not have convinced Farah, or her father for that matter: after all, mother had become ill again. Father had made a worry box for Farah and this was in her room. If she had a worry she would write it out and put it into this box. Parents would check the box and then they would discuss the worries. This had happened recently and Farah had been reassured by father as mentioned above. I think the use of the worry box is useful as a means of communication between children and parents, but it seems a worry box can also be used defensively: put the worry in the box, get it explained away, and it is no longer a worry. But on the other hand father was right, as the cancer had gone away. And, after all, defences are there for a purpose, especially in a family facing yet another operation which would inevitably spark off more worries.

At the family meeting just before mother's operation (mentioned above under Impact of Mother's Illness), Farah continued with ruminations about life and death:

"As she had filled up the blackboard, Farah went over to the whiteboard where Gabby was drawing and writing. Farah found some space on the right and wrote: 'Why do people live in this world? Why do they not live in another world like Mars or Venus? That is my question'. Gabby responded by adding 'Alive' to her whiteboard ruminations [see above in Impact of Mother's Illness]. I talked about the hidden question within Farah's questions. Was she wondering where people can live? That is, at present we were all alive in this room. But soon mum was going to go to have a very long operation and she had just told us what would happen, that she would be 'specialised', that is a nurse would be with her all the time to make sure that the blood supply to the reconstruction would be maintained. If not she would have to have the reconstruction again. So when mum would be in a different place, the hospital, things could go wrong. I was wondering whether Farah was telling us about her worries about mum living or dying.

Farah was sitting on father's lap at this point and both she and father looked scared. Farah whispered something to father and he told me that Farah said she was just writing out things in her mind. I said it was all very difficult to talk like this with mum sitting here. We all did not want to talk about death and wanted to protect mum. Farah wanted to wipe the black and white boards clean. I asked her not to as I wanted to sketch the drawings and writings on paper when they left. Farah again whispered something to dad and he said Farah wanted me to know that what she had written was not what I was saying. I turned gently to Farah who was now sitting on my right and thanked her for letting me know."

It can be quite difficult to know what to do in terms of timing, and I wondered if I had got it wrong in saying what I had said. The family had come that day especially to prepare the children for mother's operation. I was being shown things by them and I felt I needed to voice them. But at the same time I realised that everyone needed to remain strong in the face of the impending operation.

In the individual session with Farah two weeks later, Farah brought this up again:

“Farah had her legs crossed and sat opposite me and spoke throughout the session in a grown-up way. She explained that what she had written on the whiteboard last time was nothing to do with her mum going into hospital. She had wondered and wanted us to discuss why there was no life on Mars and Venus, why it was only on our planet. She did not think it was fair. She thought life should be everywhere.

I acknowledged what she told me and decided not to say what I thought at this stage as she needed to be strong in the face of her mother going into hospital. In my mind this was to do with life and death and she was wondering why some people lived and some died, and the unfairness of it all.”

Gabby

At the end of the first individual meeting with Gabby, I asked her whether she would like to come back to see me again. She replied that it was a difficult question as she did not know how life was going to be. Although I did not say this at the time it seems Gabby was verbalising how her life was very uncertain in terms of her mother's illness.

One way Gabby may have managed living with such uncertainties was by retreating into her imaginary world. This can be seen in the following two sequences when Gabby mentioned imaginary friends:

“At the initial meeting with the family, Gabby sat on her mother's lap wearing a tiara and a grey dress. She said that when she wore this dress she was 'Lucy', an alter ego. Mother acknowledged this smiling.”

“When I met with Gabby and her mother after mother's operation, Gabby mentioned five imaginary friends, boys and girls, all benign. Her mother had heard about some of them and was interested in the new ones.”

It seemed that these friendly companions acted as a link with her mother, allowing the two of them to share something of Gabby's private world. I had been told by the parents that Gabby was a very popular girl and it seemed that she needed to continue friendly interactions with others when her friends were not there physically. It is possible she felt alone in dealing with the major issue of her mother being ill and the uncertainties involved in that, and was trying to gain as much comfort as she could from her interactions with her imaginary friends. Although it appears age-appropriate for Gabby to have imaginary friends, I wonder whether they were fulfilling a deeper function in her situation.

Parents

Father was able to articulate his great anxiety about his wife's illness. This can be seen in the following sequence at the meeting with Farah and father just after mother had returned home from hospital:

“Father told me that he had developed shingles on the left side of his face so could not visit mother in hospital. Father made a link with the shingles and the stress he had felt about mother going into hospital, i.e., his body had somatised the worries.”

In contrast to this, mother had a very matter of fact way of looking at her illness. This can be seen in the sequence below from the parents' meeting after the operation:

“I said mother had been uncertain about the success of the operation and wondered how they had felt about that. Mother said the operation would have been either successful or not, so she knew what was going to happen either way. She felt that one can have fear if things were unknown. I asked father about the shingles and he said he still had pain on the left side of his face from time to time. I said he had told me that he thought it was due to his anxiety about his wife's operation and he agreed. I wondered about communication between parents about mother's ill health. Father said it was because mother knew so much about the illness that he could not talk to her. He preferred to ask questions and was able to see things from different points of view.”

The issue of emotional pain and how to deal with it is here. Mother tends to stay with the 'facts' and seems to not want to look at the emotional aspects of her

condition. Father is aware of the stress he is under and how it is coming out somatically but cannot talk to his wife as she seems to have embargoed this.

At the same parents' meeting father continued as shown below:

“Father said that he was a realist and did not agree with being over-optimistic about things. He could see both the seriousness of the health situation but weighed it up against the positives.”

Father acknowledged that he had anxieties, and now he was using my presence to say to mother in a gentle way that she was not out of the woods yet. It seems that mother used her expert knowledge about her condition to not feel and think. This was a vivid example of flight – flight into theoretical knowledge – to avoid the emotional suffering of not knowing.

In this type of work I have to constantly remind myself that the mother and the family are facing very frightening things. Mother was using these defences in order to be able to continue to function normally in life and in her maternal role.

5. Sustaining Factors

The love and care of the parents was a major sustaining factor for the girls. This was shown in many different ways. For example, the parents did not want the girls to miss much schooling. I could not always offer after-school times so we compromised and I saw them during their lunch period with mother making sure they had packed lunches which they ate before their sessions.

The children too had a lot of resilience. This was shown by how quickly they seemed to recover after mother's operation, with the parents reporting that both children were doing well at home and at school. I also witnessed them to be happier and freer in themselves.

The school had put in extra help for the girls in the form of a teaching assistant who they met weekly before I got involved. My psychiatrist colleague had visited the school and consulted with the staff, even providing them with information from the hospital about how to deal with children when a parent had cancer.

The oncology psychologist, my psychiatrist colleague and I tried to ensure smooth handovers for the family. I had worked with my colleagues on other cases and this helped in the liaison and handover arrangements. So, the professional network did all it could in helping these children during this very difficult time in their lives.

6. Feeling Different

There was one clear example of how Farah felt about being a child with a very sick mother and other children's reactions at school, as shown below:

“In the very first session with me Farah told me that recently a boy at school had told her ‘your mum is very ill’. Farah was very upset and she said her eyes were red with crying and she did not go to assembly. She told a friend's mother who came into school to help the class with reading. This lady read her a cheerful story to try and console her. Farah told me that she had told two of her girl friends about her mother's illness but she did not know how this boy knew about it but he had got into trouble for saying this.”

There was also an indirect suggestion of how Farah may have felt about this in the dream she recounted to my psychiatrist colleague (Dream 1 about mother going into school without her wig). This may have shown her unconscious anxiety about it all coming out in the open with everyone at school noticing her mother with no hair, leading to questions of why that may be so. And this could have led to teasing or even being bullied by other children. I have been told by many children and adolescents how this could happen, if their circumstances were different to others in any way. It seemed Farah experienced our meeting room as a safe place where her anxieties could be aired and processed. This was one place where such ‘dangerous’ knowledge could be shared safely without stigma being attached.

Outcome

By the end of my involvement both girls appeared happy and confident in the consulting room. Both they and their parents confirmed improvements in how they were in themselves and how things were at home and at school. Mother's

reconstructive surgery was successful and she continued with pharmacological treatment.

Implications of the Case

Parents reported changes for the better in Farah and Gabby very soon after I started seeing them. I think the symptoms receded as the sessions with me had allowed them to express what they felt and thought in a containing environment.

As mother's operation came nearer, the defences set in. This was understandable as the children and the parents did not really wish to think or feel anxious about what could go wrong. They needed to hold onto the hope that mother *would* get better. Father, though, was aware that he was very stressed and that it was coming out somatically.

I met with the family in different combinations depending on what was needed at a particular time. This was an example of working flexibly to suit my clients' needs.

I think seeing the children with their parents helped forge understandings between family members which may not have been there before.

This family had been experiencing serious illnesses in both mother and Gabby for quite some time. For the children, especially Gabby, this had been for most of their lives. I did not pick this up and discuss it with the parents and I am wondering why. It is possible that, in the context of mother going into hospital for yet another operation, I too got caught up in the defences. There was enough to think and worry about without looking at what had happened before. But it is interesting that I had not picked it up and it points to the importance and value of supervision.

In this case I tried to continue working with the parents after mother's operation, but this was not what they wanted. They showed this by cancelling sessions offered to them and in the end they stopped communicating. The parents had come for help for their children and were satisfied with the results when the children seemed to be happier at home and school. In retrospect I think it would have been better to have complied with their wishes not to pursue further

therapeutic work with the parents so that we could have ended our contact with a family goodbye session.

ELLIOT (AGE 16)

Introduction

Elliot was referred by his family doctor for depression and inability to concentrate and motivate himself to do school work, although he was a high achiever. He was feeling very sad and tired but his appetite was said to be maintained and he had no suicidal thoughts. His mother had metastatic carcinoma of the breast. She was under the care of a specialist cancer hospital and was attending a local hospice. Elliot had a brother two years older than him who I did not meet as he was away at university. I met Elliot and his parents together initially and then separately over a period of 11 months.

Family History

The following family history was given to me by both parents who were in their late forties.

There was a history of cancer in the maternal family. Mother's parents had both died within three months of each other, six months prior to my involvement. There was a history of cancer and heart problems in the paternal family.

Mother's pregnancy had been fine and Elliot's birth had been quick. He was breast fed for a few weeks and then went onto the bottle and had fed well. He used to be a fussy eater but this had become less so as he got older. Sleep was very good as a baby. At the time of referral both parents and Elliot reported that he took a long time to fall asleep and that he had always been a light sleeper. His physical health was good.

Mother had had metastatic breast cancer for three years which was affecting her spine and hips, and she walked with a stick. She had had radio and chemo therapies but no surgery. At the time of my involvement she was receiving pharmacological treatment. Mother had been told by her medical team that she had terminal cancer and that it was treatable but not curable.

Psychotherapeutic Input

After the initial meeting with Elliot and his parents, I met with Elliot individually and with his parents as a couple, at monthly intervals over a period of 11 months. With Elliot's and his parents' permission I liaised with his school at the beginning of my contact. Elliot had started sixth form and I offered him fortnightly appointments to fit in with his school timetable. Elliot was not able to take up this offer as he was involved in after-school activities including orchestra and chess club. The meetings, thus, depended not only on his school timetable but also his after-school activities. By the end of my involvement Elliot was about to turn 18, the upper limit of the CAMHS age range. At Elliot's and his parents' request I referred him on to a service which offered CBT as he continued to demonstrate negative thought patterns to do with school work.

Themes

1. Engagement

Although Elliot came to see me over a period of nearly a year, I do not think he engaged with the therapeutic process in any meaningful way. As has been noted above, he did not take up all the sessions I offered. In a way being involved in things other than school work was good for his continuing recovery. He usually arrived on time or even a bit early and always looked rather sombre, if not miserable, when I went to fetch him from the waiting room. Once in the consulting room I had to do a lot of questioning to find out how things were with him. He did not agree with me that the depression which was affecting his concentration and motivation at school had anything to do with his mother's illness or the recent bereavements of his grandparents.

Why then did he come at all? It was clear that when he first arrived he very much wanted things to change inside him so that he could carry on with his school work at the very high level that he was used to. His parents maintained that he had always set himself very high standards which he felt he did not live up to. This wish to be 'perfect' may have become exacerbated as he found himself struggling

to do his school work. He had just entered sixth form and was due to sit his 'AS' levels (Advanced Subsidiary level exams are the first part of 'A' level exam qualifications) in a few months' time, so this made it even more crucial for him to be able to work at his peak.

Another reason for Elliot continuing coming to therapy may have been that his self-reports indicated a gradual lowering of depression which had been middling to start with. Elliot also reported that he was enjoying things in his life and his parents started mentioning that he appeared lighter and was even smiling again. So, despite appearing not to be engaged in therapy, he may have thought, albeit unconsciously, that it was achieving something positive.

I carefully arranged the parents' sessions in between mother's three-weekly hospital treatments as she told me she got very tired during the week after treatment. Father took time off work to come to appointments in the middle of the day. Parents attended regularly and came on time. Whereas father was quite forthcoming in discussing how he felt and thought, mother was less so. She did not think there was any point in worrying about her illness. Mother did not say that her illness had no impact on her son (as he himself said), but she reiterated that Elliot's main problems stemmed from the very high expectations he had for himself. Although father did not specifically agree with the link I was making between Elliot's low mood and his mother's illness, he did not deny it either. Despite any possible misgivings the parents may have had about the usefulness of the therapeutic input I was offering, they, and mother in particular, encouraged Elliot to attend sessions.

2. Parental Concern

The family came across as a cohesive unit and there seemed to be genuine care and concern between the members. Parents were very concerned about Elliot and his difficulties and tried to let him know that what mattered was his wellbeing and that he did the best he could in his school work. Although I did not meet the older brother, he seemed to be offering Elliot support and advice about his learning, and parents reported that Elliot looked up to him.

3. Impact of Mother's Illness

At the initial assessment meeting I met Elliot and his parents together and also, briefly, Elliot and parents separately. Elliot's low mood at the time of my initial involvement can be seen in the following sequence:

“In the family meeting I asked Elliot to rate the low mood he felt from 0 meaning not depressed to 10 meaning very depressed, and he gave himself 5/10 or 6/10. He said his main worry was that he lacked motivation and concentration at school. Elliot felt that he was not achieving at school since the beginning of his sixth form (six months prior to this meeting). His parents mentioned that Elliot had not been going out much and they had encouraged him to do so and he was going out a bit more. Elliot told me that his concentration was up and down and he continued to worry about the forthcoming exams.”

With permission from Elliot and his parents I contacted the year head of his school. She thought Elliot was doing reasonably well with his work; she also said that the school had suggested Elliot drop one subject so he could concentrate on the ones he really wanted to do.

In the brief initial meeting with Elliot I went through a mental checklist for risk as we normally did, as shown in the following sequence:

“He told me he did not smoke tobacco or take any substances. He had not self-harmed in any way and he had not thought about overdosing or cutting himself.”

In this meeting the following sequence shows how Elliot was feeling about his mother's illness and the recent deaths of his grandparents:

“Elliot said that he had been feeling a lingering sense of sadness since he started his sixth form. When I asked how he felt about his mum's illness, he said that he felt upset for mum but did not feel upset about it himself. When I wondered about the possibility of his mum dying he said he felt sad about that. He also felt sad after his maternal grandfather had died at the start of his sixth form year; but not so much after his maternal grandmother's death three months previous to that. He had been closer to his granddad.”

During the second individual meeting with Elliot I went through the 'Mood and Feelings Questionnaire' (Angold and Costello, 1987),² both as a form of assessing the level of depression and risk, and as a way of eliciting things youngsters may not usually tell us. The following sequence from this meeting shows Elliot's mixed feelings about his mother's illness and my contention that his depression was a consequence of her life-threatening illness as well as the multiple family losses:

"Elliot told me that he had cried a bit recently when he was returning home on the bus as he felt that his mum may not see him better. When I asked whether he meant that she would die before then, he said 'yes'. But he added that he did not know, mum seemed to be getting better. I wondered if it was a worry and he said it was a bit. I wondered if it was only a bit and he acknowledged it was in fact a big worry. But then he said it may not happen at all, she may live longer. He said he did not think about this normally. I said it was true we did not know how long his mum would live but she had a very serious illness. I said added to this he had lost his grandparents one after another and his older brother had left for university, all in the space of three months. It was during this time that his depression had started. I thought he may not want to think about mum's illness because it brought up all sorts of feelings he may not want to feel, like sadness, which were painful to cope with."

The difficulties of living with the uncertainty of how long mother was going to survive can be seen in the following sequence, at a meeting with Elliot four months into my involvement:

"Elliot was recounting how he had done in his exams and thought he had done well in physics but had found one particular exam in maths difficult. When I asked why, he explained that the questions were ambiguous and therefore difficult to answer. I talked about ambiguity and how not knowing how things really were could be difficult. For instance, knowing that his mum had a serious illness but not knowing what was going to happen. He said she looked well. I said that was the ambiguity, she looked well but he also knew that she had a serious illness. He said at times he thought about it and felt sad. When I explored this he alluded to his mother's possible early death."

² Mood and Feelings Questionnaire: Long Version – Child Self Report is a questionnaire to ascertain the level of depression in children/adolescents. It can be used as part of a clinical assessment by child and adolescent mental health professionals.

The parents' concerns about Elliot can be seen in the following sequence at my second meeting with them:

“Elliot’s parents told me that Elliot had not been interested in much since being told about the terminal nature of mother’s illness during the previous summer holidays. It was when Elliot entered the sixth form about a month later that they became more aware of his depression as he had difficulties concentrating. Parents again said that Elliot always set very high standards for himself. Father said that Elliot felt that he was ‘not quite good enough’ and that ‘he was rubbish’. He would say this when he played sports, for instance. Father said Elliot would take things hard and was self-critical. He could also be casually cutting when dealing with others. Mother thought that Elliot expected so much from himself as his own standards were very high. Father said that Elliot tended to switch off and was continuing to suffer from problems in concentration and memory.”

I was told by both Elliot and his parents that he had become withdrawn at home and spent a lot of time in his room listening to music. He interacted more with his mother as she was at home more, compared to his father who spent long hours at work.

As my involvement continued, both Elliot and his parents reported that he was beginning to feel better. This was reflected in his exam results and in his external life, as shown in the following sequence, six months into my involvement during the summer holidays:

“Elliot looked relaxed and had a sparkle in his eyes and was more forthcoming in discussing himself. Elliot had received his ‘AS’ level results the previous week. He had done 10 subjects and got mostly A grades with a few B grades. He felt disappointed that he did not get better marks. I pointed out how well he had done despite not being able to work for long periods of time in the past year. Self-reported depression levels were slightly up from the previous month from 2/10 to 3/10. Elliot said that he was eating more fruit. He was also running five kilometres every day as he wanted to be healthy. I said it seemed he was trying to lead a more healthy life and was also quite busy going out and enjoying himself. Elliot said he felt sad that he had not done all this before. I wondered whether he wanted to be a more rounded person, that is, not just concentrating on being a top academic performer. Elliot became thoughtful and said maybe that was so.”

At a meeting two days later with Elliot's parents, they reported their pleasure at how well he had done in his exams but also their continued concerns, as shown below:

“Elliot's parents said that they were pleased at how well Elliot had done in his 'AS' exams but were concerned about the following academic year, his final 'A' level year. Mother was concerned Elliot would be like the previous year when he got very anxious if he was not able to concentrate on his school work. Despite this, the parents agreed with me that there seemed to be a vast improvement in Elliot's mood compared to a year previously.”

In terms of the impact of mother's illness on herself, she told me that she felt tired and got help with housework but did the cooking. She attended the hospice and did art with others present. Mother said she tried to cope by treating everything as normal.

At the parents' meeting five months into my involvement, mother's physical wellbeing continued to be maintained through medical treatment, as can be seen in the following sequence:

“Mother looked well and I commented on it. She said she felt well. She was continuing with the three-weekly medication drip regime in hospital. She added this would continue until it stopped working. I said medical treatments had really improved a lot in the past few years.”

It seemed I, too, was trying to hold onto the hope that she would not die too soon.

Father felt surprised at how well his wife was coping. He said he managed by continuing to work hard. He said he felt guilty for not spending much time with the family and was trying to remedy this by going out more with the boys.

4. Defences

Elliot would at times admit to worrying about his mother's health and feeling sad, but he would either minimise this or quickly refute that it was a serious situation. For instance, in the same session in which he reported feeling sad (see above under Impact of Mother's Illness), he said later on that he did not think his depression was due to his mother's illness.

Elliot's difficulties in linking his depression with his mother's life-threatening illness can be seen in the following sequence:

"A month into my involvement Elliot had come in looking rather sombre and depressed. I said I had a hypothesis about why he may be feeling the way he did, i.e., not able to concentrate and having memory problems to do with his school work. I said from what I had heard from him, his parents and school, he was very bright. The centre of gravity seemed to be in his head. I had been told he started feeling depressed during the summer holidays after his mum told his brother and him that the doctors had said they could not cure the cancer but could treat it. My hypothesis was that all the feelings and thoughts about this which were underneath, unconscious were sending a message via the symptoms, saying 'we are here'. The problem was the very thing which was strong in him, i.e., his intellect, was being attacked at a time he needed it most as he was about to do his exams. I said the feelings and thoughts – they could be anger, sadness, fear, protection towards mum – had not been processed. They could only be processed if allowed out. Elliot listened to me with a soft vulnerable look on his face. Elliot talked about his worries about the coming exams and whether I had strategies about how to do them, since he could not concentrate or motivate himself to do any work. I said one way he kept away from feelings about his mum's illness was by concentrating on his worries about his school work; he kept the spotlight on them rather than letting himself think and feel about his mum's situation. I said he had the strategies and he could ask his teachers, but until the process of how he felt about mum's illness was addressed, the symptoms would continue. I said there may be underlying, unconscious thoughts in his mind. For instance, what does not being cured mean? And, how long did mum have to live? As I was talking I saw Elliot's eyes move over and beyond my right shoulder and I wondered what was happening. He said he was looking at the blind mechanism to see how it worked. I said that by concentrating on how the blind worked, he got away from what I had been saying about his mum's illness, as it was too painful to think about."

I am now wondering what the symbolic meaning of this was. The blind was a curtain to stop too much light coming in: it stopped people being blinded with glare when the sun was shining. It was also used when it was dark and the lights were on to prevent people from outside looking in, i.e., to preserve confidentiality. So, in this situation, was I shining too much light onto a dark area of Elliot's life, and did he want to switch this light off?

Mother's view that it was better to remain positive rather than dwell upon painful feelings and thoughts can be seen in the following sequence:

“When I met the parents one month into my involvement, mother kept her arms folded through the session and father did the same most of the time. Mother said they had just returned with the family from the north where she had met her siblings and their families and scattered their parents’ ashes in the countryside where they used to visit. She said it was a joyful occasion and they enjoyed it. I wondered how mother had felt about scattering the ashes and she said she had been fine.”

So, it seemed, if mother had had any other feelings about her parents’ death, they were either not conscious or not being reported.

In the same meeting, this theme continued thus:

“I said Elliot was finding it difficult to link his depression with mother’s illness. I said in my experience, when someone was seriously ill, all family members had feelings and thoughts about it. It affected everyone. Mother said that her view was that it was pointless worrying about it and it was better to have a positive attitude. I said it was good to have a positive attitude but usually there were other feelings and thoughts too, and in Elliot’s case they were appearing in the symptoms. I said people coped differently and families too. In their case it seemed that they did not want to think about unpleasant and frightening things.

Mother said Elliot had always been like this, thus implying that she did not agree with what I was saying about the impact of her illness on Elliot’s mood. She said he expected too much of himself and then got anxious when things did not meet his high standards. I said Elliot may have a predilection for being like that but he had not lost concentration, motivation or memory to do with school work before being told about the terminal nature of her illness, so that indicated something more was at play. Mother said at a recent mock exam Elliot had only answered two questions as his mind was on his worries and she was concerned that might happen with his coming exams. I said Elliot may not do as well as he could as the exams were very near and he had not yet started processing his feelings about her illness. Both mother and father then asked if I could give Elliot some strategies to help with the exams. I said he could get them from his teachers. I was here to help him with his mental health and psychotherapeutic input usually took time to work. I said Elliot was very bright and would be able to catch up at school. When I had talked to Elliot’s year head, she had thought so too.”

At this same meeting father too showed that he preferred not to worry about mother’s illness, thus:

“I wondered how father coped. He said he coped by being busy at his work which he found interesting. He said that it was so uncertain (i.e., mother’s

cancer prognosis), so he had decided not to worry about it. I said uncertainty itself could be difficult to manage, and some people may feel anxious. Mother said she did not.”

5. Sustaining Factors

The family came across as quiet and reported good relationships all round at home. They went out together to the theatre and father and the boys went to rugby and football.

Both the parents and Elliot’s school were supportive, as has been mentioned above. Elliot was able to ask for help from his older brother with his school work and with the choice of universities he was applying to.

Mother found her friends supportive. They took her out which she enjoyed. She also did art at the hospice. When I asked if the art group talked about their situations, she said they did not. Mother also enjoyed reading.

As has been seen, father found going to work helpful as he found it interesting and it kept him busy.

6. Feeling Different

Elliot voiced his concerns about not being liked by others only once, as shown below:

“Four months into my involvement, Elliot told me that he felt people may not like him as he had such a serious face. He liked being with friends, they chatted about school and other things, and that made him feel good. He said that he wanted people to think that he was nice but he had such a serious face, he feared that they may think he was moody, which he was not. He said that people who knew him knew he was nice. I asked how he felt about himself. He said that he felt likeable inside himself. He helped people with chess and when I asked how he felt about that, he said that he thought those people he helped may see him as nice. I talked about his wish to be liked and his concern of not being liked if people saw his habitual serious face. I said that he came across to me as being likeable. His face lit up.”

I could understand his concerns as he had a serious face which may put people off on first meeting him. I had also seen, at times, his face light up when he smiled, and he seemed more approachable then. I do understand that our relationship was different to Elliot's relationship with his friends and he probably was more light-hearted with them than he was with me.

Outcome

Elliot and his parents reported that Elliot's depression improved gradually during my involvement although he remained concerned about the diminution in his academic abilities. Despite this he entered the second year of sixth form and by the end of my involvement was applying for university. He was referred on to a different service for CBT. His mother continued with pharmacological treatment.

Implications of the Case

It seems that a relatively short period of therapeutic work did alleviate Elliot's depression. Although he and his mother, and possibly his father, did not consciously agree with my linking of his depression to his mother's illness, it seemed some changes for the better did happen, despite that fact.

It is possible that the main 'therapeutic agent' in lessening Elliot's depression was me listening to him. So this may have been more to do with the containment of anxiety and distress than with any specific kinds of understanding brought about through interpretation, although I did speak to him quite directly about what I thought was happening (i.e., the displacement of his anxiety about mother on to his school work). Elliot was a high achiever and it was understandable that he was worried about school work. Nevertheless, the level of displacement of his worries was quite marked. It seemed that worrying about school work was less frightening and painful than thinking about mother's illness and possible early death.

Elliot came from a high-achieving family with several close members, including his father and older brother, having attended prestigious universities. But being a

high achiever does not necessarily mean being a perfectionist, as Elliot appeared to be. While discussing this with his parents I was told that the paternal side of the family was competitive but that the maternal side was not. His parents had conveyed to him that he just needed to do the best he could in his academic work. So this feeling that he was never good enough whatever he did seemed to reside in him. I just do not have enough information about his early life to come to any understandings about why he may have felt this way.

Elliot's mother's wish not to think about her illness and to carry on as normal may have set the tone in the family, with Elliot's own defences being reinforced by mother's attitude to her illness. Father, it seemed, was more self-reflective, but he too seemed to go along with the view that it was best not to worry about things and to carry on with life as normally as possible.

As has been mentioned, Elliot continued to be worried about not performing as well as he used to academically and his parents continued to be concerned about his ongoing negative thinking about himself. Therefore, with Elliot's and his parents' agreement I referred him to a service which offered CBT. I hoped Elliot would be able to make more use of that form of therapy than the therapy that I had attempted to offer.

ANDREW (AGE 15)

Introduction

Andrew (age 15) had Asperger's Syndrome, and had been suffering from depression and anxiety. Andrew had become suicidal and had been in an adolescent inpatient psychiatric unit just before I became involved. He attended a specialist educational unit and was about to do his GCSEs. Andrew lived with his mother and older sister (age 20) and an older brother (age 19) who lived in a shared-care arrangement with the family and a foster family. Andrew's parents had separated a few years prior to my involvement but father kept in touch with the children. Mother and her partner had known each other for several years. Mother's partner lived separately but had moved in with mother and her family during the acute stage of her illness.

Andrew was already under the care of my consultant child and adolescent psychiatrist colleague when his mother was diagnosed with cancer in both breasts, eight months prior to my involvement. Following a request from my colleague we agreed (my colleague, mother, her partner and I) that I would offer time-limited parental therapeutic work until my retirement, so, over an eight month period, I met with Andrew's mother and her partner and participated in Andrew's reviews.

Family History

The family history was given to me by Andrew's mother, who was in her early fifties.

Mother told me that her own mother died of a rare medical condition when mother was in her late teens. Mother was depressed for a few years after the death of her mother and finally recovered from this in her twenties. She had three ill/disabled children: a girl of 20 who had Asperger's Syndrome but managed to work in a supermarket; a boy of 19 who had severe learning and physical disabilities – he lived in shared-care between a foster home and his home at the

time of my involvement but was about to be placed in his own flat with carers coming to visit daily; and Andrew (age 15).

Mother had been diagnosed with bilateral breast cancer, different types in each breast, eight months prior to my involvement. She had had a mastectomy of her right breast and a lumpectomy on her left. She had had chemotherapy and during the time of my involvement she received radiotherapy. After the end of radiotherapy, a couple of lesions had been found on her spine: one was still cancerous but not active; the other one was arthritic.

Psychotherapeutic Input

I met with mother and her partner over a period of eight months on a monthly basis and also participated in regular reviews for Andrew. Mother was being seen in a cancer hospital where she and her partner met a clinical psychologist for supportive therapeutic help. We discussed the difference between that input and the input I would be offering: mother would be going to the clinical psychologist in her own right as a patient and would be coming to me as a parent. Having said that, there would be overlap as she would be talking in both settings about her feelings and thoughts about her condition, as well as the impact of her condition on her three children.

I took this request for time-limited work to my supervisors as it was different to the other cases. They suggested that I could include this case in my research if mother and partner agreed to be involved.

Themes

1. Engagement

Mother and her partner were intelligent and thoughtful people and engaged well in the process. They came regularly for their monthly sessions, apart from once when the middle child was very ill in hospital. They appreciated the space to think through issues to do with mother's illness, and its impact on her, her children and the couple's relationship.

Mother seemed to be a person who made opportunities or took up opportunities in her life. Six months into my involvement, mother gave me two examples of this, as shown below:

“Mother said that she had been invited to talk about her needle phobia at a conference for professionals and, going by the questions the audience asked her at the end, she felt that they had had a better understanding about this subject due to her talk. She felt pleased that she could help professionals in understanding the patient’s point of view better.”

And later on in the same session:

“Mother was also very excited to be contacted by a doctor to be part of research into radio surgery, a non-invasive alternative to conventional surgery. Although this was subject to ethical permission and funding, she was hoping the research would lead to better treatments for patients in due course.”

It is possible that mother felt that coming to see me and agreeing to be part of my research project was another way of helping to advance knowledge and therefore help people in similar circumstances to her in the future.

Five months into my involvement, mother told me that she had been writing an online blog about her experiences as a cancer patient, as show below:

“Mother told me that from the time of her cancer diagnosis, she had started writing an online blog about her experiences. People from all over the world started contacting her. One person from another country had sent her a card which she brought in to show me. She said she could be quite humorous on the blog and that was quite evident in the sessions. She felt that by the feedback she got online, her sense of humour not only uplifted her but also others in similar situations. This was another way she felt she could help others.”

She continued to say that the blog had been turned into a play:

“Mother and her children were part of a local amateur dramatics theatre group. She had agreed to the leader of this group converting her blog into a play. She, her partner and her daughter took part, with other players. They performed at a fringe event in another part of the country and also locally. She said the audiences were very moved during the performances. She had also been interviewed by the local radio and appeared in the local paper about this play.”

I admired mother in the way she was conducting herself during this very difficult period. I think mother basked in these admirations from people. And I tend to think, why not? She seemed to have had a rotten deal in life so why not have some warmth back? I think there was an unspoken invitation from mother to me to attend her play locally (she gave me all the details of the performances) but I resisted this to maintain a boundary in my therapeutic role. I did, at times, feel that I was part of her audience during our sessions.

I think the attention mother invited made her feel that her life had had some meaning, that it had been of some account. She said several times that she did not want to be seen just as a cancer patient – she was the same person before and after the illness took hold. I think she wanted to be remembered as the vibrant person that she really was.

In our penultimate meeting mother and her partner said they had appreciated coming to see me, as shown below:

“Mother said that she had found coming to see me really helpful, it was like coming to an oasis of calm where there was space for mother and her partner to reflect. She felt that usually her life was going at 1,000 miles an hour and this was a chance to come and unravel some thoughts and make sense of them. Her partner agreed and said that he had learned quite a few things in the sessions.”

As has been shown above, mother seemed to be very good at engaging others, including me.

2. Parental Concern

Mother was concerned about her three children’s wellbeing, not only for the present while she was still alive but also for the future when she was no longer there. This was particularly so as her three children had quite substantial difficulties. Social services were involved with her sons and all the children had had CAMHS input over the years.

Mother told me that she had been a carer all her adult life. When her own mother died when mother was 19 she had looked after her 13-year-old sister, and she

had continued this role with her own children. An example of this role can be seen below:

“At our initial meeting mother said that as she understood her children and their needs so very well, who would look after them in that way if she died? She had put her affairs in order as much as she could by making a will where she had put down four close friends, including her partner, as trustees, and had got agreement from the children's father about this. Social services knew about this plan.”

How well the adults she was entrusting her children's welfare to could and would look after their very particular needs, one can only speculate.

An example of how mother continued to do what she thought was the right thing by her children is shown in the following example in a session eight months into my involvement:

“Mother told me that the middle boy became very ill and went into hospital for three weeks as he was breathing in faecal matter. Mother was very worried but had told me on the telephone that she had seen him like this before and in the past he had pulled through. Mother and her partner took turns to be with him 24 hours a day and they spent alternate nights in hospital with him. Someone had to be with him all the time as he would take the intravenous drip off if no one was there. He was very dehydrated and needed the drip intact. She told me that she thought she was stronger than she had thought as at one point she was with her son for 41 hours non-stop, day and night. That was when her partner had got ill. The night nurse told her that when she was not there her son would ask for ‘mum’. The son communicated with a few words and hand signs.”

It seems that, during this very critical time, mother had kept going for the love of her son, while the partner had collapsed.

Mother was most worried about this middle child as he was now 19 and his shared-care arrangement – living between foster carers and the family home – was due to stop soon. Social services were planning for him to go into a flat with carers coming in daily. She was discussing with social services the right kind of accommodation and support for him as she did not think he could manage to live on his own with carers visiting. She really wanted this to be in place before she died.

Mother continued talking about her concerns for her middle son during his recuperation period, as shown below eight months into my involvement:

“Mother felt that this son loved living at home and showed and communicated this to her. She had decided that he could live with them on more days a week than previously during his recuperation after his illness. She could not cope for a longer period, as her own energy levels were so low and he had such major needs. When he was due to be discharged from hospital he had made the sign for home (hands in a steeple shape to show a roof), meaning he wanted to come home. Mother felt this inability to look after him herself was heart-rending when her son seemed so happy living at home.”

Although during this time mother was preoccupied with her middle son’s illness, she kept Andrew’s needs in mind, as shown in this example, also from eight months into my involvement:

“Mother had made arrangements for Andrew not to be left alone for long periods of time. Andrew visited his father for a week and his girlfriend popped in during the daytime as she worked nearby. During night time either she or her partner would be there.”

Andrew could get very depressed and suicidal and mother was constantly on high alert for this as can be seen in the following two examples:

“In my first meeting with mother and her partner, mother told me that it had been Andrew’s girlfriend who had alerted mother one evening that he was actively suicidal after receiving text messages from him. Mother got the ambulance and he was subsequently admitted to the adolescent psychiatric unit.”

Three months into my involvement, mother recounted the following:

“One evening recently, mother had found Andrew sitting and rocking on his bed not able to tell her what was happening to him. She woke her older daughter and they sat with him for several hours. Mother remembered something she had read and swaddled Andrew in his duvet and that seemed to calm him down and mother decided not to call the ambulance.”

Mother’s daughter had Asperger’s Syndrome and worked in a supermarket. Eight months into my involvement mother told me that, just before her middle son had gone into hospital, her daughter had left home for an au pair job:

“Mother told me that her daughter had travelled to Italy to work as an au pair. Her daughter was emotionally quite distant when she was at home, but since going to Italy she had been in daily contact via texting and telephone calls with her mother. Mother loved this frequent contact. It seemed that the daughter too needed to be close to her mother, asking her for her thoughts and advice, as she attempted to fledge the nest. Mother was pleased that her daughter had found a way to do something she was enjoying, that is, being an au pair. Mother had cried at the airport as the daughter left for Italy and Andrew had comforted her by putting his arms round her saying she would soon come home – a rare sign of concern and warmth from Andrew which she had enjoyed.”

Sometimes, in her wish to help her children, mother made decisions which were not in her own best interests as a very unwell person. For instance, she decided to give Andrew a puppy after she had noticed that he had laughed for the first time in months watching a puppy being walked by a woman on the road. He was on one of his weekend visits home from the inpatient adolescent unit. The puppy arrived and it soon became evident that mother was the main carer, feeding him and clearing up his mess. Andrew half-heartedly cleared up after the puppy to start with but soon stopped. The daughter played with the puppy but refused to do the dirty work. When the puppy was old enough to be taken for walks, it was mother's partner who did this twice a day. Mother hired two different behaviourists, one after another, to help the family train the dog. The advice from the first one did not go far enough and she found another who seemed to understand the situation better. The advice did help to make things less chaotic at home but she felt she was still doing far too much for the puppy. So, after getting Andrew to decide whether he would help out with the dog or not, it was agreed that the best course of action for all concerned, including the dog, was to re-home him. Here again mother showed her maternal concern. It was she who phoned around the various charities with huge waiting lists to get the dog rehomed. It was she who accompanied her partner and the dog to the Dogs Trust kennels several hours' drive away. In the event Dogs Trust pulled out all the stops and got a suitable new home for the dog.

Six months into my involvement, mother made a comparison between services for dogs and children in need of appropriate provision, as follows:

“Mother said angrily that she felt upset that there was all this money and volunteers who went in for an hour and a half every day to give dogs cuddles but there was no such help for her middle son.”

It was ironic that mother worked very hard to re-home the dog so he had a good future but was not in the position to do the same for her own children. Her energies were low and time was running out. She was doing the best she could for her middle son by liaising with social services but she had two other vulnerable children. What would happen to her children when she died? This was a conundrum, almost unbearable to think about and with no easy answers.

It seemed that mother’s wish to care for her children took over despite the frailness of her condition.

3. Impact of Mother’s Illness

Mother told me that she had been a very active person and found it annoying that she could not do the things she used to do as her energy levels – both mental and physical – had gone down so much. For example, mother told me the following, six months into my involvement:

“Mother told me that she did not have as much stamina as she used to have. She was doing up the utility room at that time and could only work 10 minutes at a time. In the past she could work for 14 hours at a stretch. Her partner said, rather forcibly, that had not been good, going to bed at three in the morning and getting up again at seven. I mentioned something about pacing herself and her partner took that up and reinforced it.”

Mother’s mobility difficulties showed from the beginning of my contact as she slowly walked from the waiting room to the consulting room. The whole clinic was on the ground floor and she did not have far to walk within the clinic. Although they lived very close to the clinic her partner would bring mother in the car and leave her at the front door before going round the corner to park. Mother also mentioned several times – and I could see this too – that the worst thing was when she sat down for a while and needed to get up: she said that it felt like her joints had seized up and it hurt to stand up.

Another physical impact on mother was the loss of her hair. She arrived for the first few sessions with a hat on and kept it on during our meetings. The following shows mother's feelings about the re-growth of her hair after chemotherapy:

“Six months into our contact, she arrived with very short hair, and when I commented on this, she said it had turned out like this. She said this in a surprised way, the tone implying that she was not happy at the way it looked. It was dark hair, about an inch and a bit long and sticking straight up. I asked how it had been before the chemotherapy and she said she had had fine hair.”

Mother also explained her decision not to have reconstructive surgery, four months into my involvement, thus:

“In terms of the right breast which had been removed, mother had decided not to have reconstructive surgery as she was still under treatment. She said she felt quite comfortable as she was and she did not think her partner minded either. The partner agreed with her. Mother said this in a defiant way not inviting further exploration at that stage and I therefore did not pursue this major attack on her body and self-image as a woman.”

At times mother would cough and she usually brought in some water from the waiting room which she sipped through the session. There were a couple of times when the water ran out and I went to get her some more. She told me that her illness affected her immunity and she tended to get colds.

Although the amateur dramatics and the blog writing gave mother an uplift as she got so much positive feedback, it is quite remarkable that she did them given her condition.

Mother's feelings of having been cheated out of a longer life can be seen in the following:

“At the session six months into my involvement mother said she felt that she had ‘carer fatigue’. She said that now she was going to die she felt she had been robbed of her selfish years, did I understand that? Now that the children were growing up and did not need her care so much, she finally had the opportunity to look at her own needs and not just others’ needs.”

I was very moved by this heart-rending cry from a lady who still had so much to offer the world.

Mother's partner came across as thoughtful, supportive and devoted to mother and her family. He tended to hear the positives about her condition at hospital appointments and found it difficult to accept that she may not live for a long time. This could be seen, for example, at our second meeting:

“While mother was talking about her condition, her partner started looking uncomfortable, touching his eyes, with slight movements of his body. I picked this up and asked what he felt about what we were talking about. He said he knew [mother's name] was not going to die. Mother looked at him and wondered whether he was in denial. Her partner said he had heard the doctor say that.”

Another example, near the end of a meeting six months into my involvement, is shown below:

“I asked if they had anything else they wanted to talk about. Mother's partner said that normally he knew what he was going to talk about but today he had not known what to say. Usually he had felt energised after our meetings as I usually offered him things to think about. But today he felt flat. I said that mother was doing all the talking as she normally did and I wondered how did one live with someone who was dying? Mother's partner said that when he had been in the play it had brought things home to him. Being in the play had made things clearer to him: suddenly he realised [mother's name] would not live for another 20 years, she may not be there for that long. And it was this same feeling which had started coming back when we talked about the play today. I said the flat feeling he was talking about was a form of defence, in order not to feel that pain of the knowledge of her impending death. I said this would happen, the going in and out between the knowledge of mother's shorter life span and the wish to not know about it. For example, they may feel sadness, anger, frustration, ‘why me, I'm only 52’, and all other feelings about dying, and then defend against this by doing lots of things or thinking it is not going to happen. That was OK, we all needed our defences. Mother's partner said he did not want to be aware of [mother's name] dying so soon. Mother said that people in the audience were crying during the play. Mother's partner said he had not noticed it.”

As for Andrew, I can only report what mother told me about how her illness affected him. In the reviews he said he did not know what he felt or thought about his mother's illness. In our initial meeting mother told me the following about the impact of her illness on Andrew:

“Mother said that at first Andrew had been very jokey about the diagnosis of cancer. Then he overheard her speaking to a friend on the telephone soon after the diagnosis and he had come downstairs from his room and accused her of lying to him. He had overheard that she may die. Mother said that she had told him she would do all she could to get better. After that episode, Andrew was very angry with her for six months up to the time of being admitted to the adolescent inpatient psychiatric unit. Since his discharge and return home he had been lovely to her, saying things like ‘love you mum’ in passing.”

So it does seem that the knowledge of mother’s impending death had had a profound effect on Andrew leading up to him being actively suicidal and needing hospitalisation.

In my last meeting with mother and her partner, eight months into my involvement, mother told me that Andrew’s girlfriend was expecting a baby. After the initial shock – as both children were only 16 with major problems of their own – the two families rallied and told their children they would stand by them and their baby. One can speculate whether Andrew’s girlfriend’s pregnancy was an unconscious plan on Andrew’s part to line up another family to look after him after mother died. And was his girlfriend colluding with him in this? I had been told by mother that both Andrew and his girlfriend knew about contraceptives.

When mother found out that she had lesions on her spine she kept Andrew and his sister informed and I was told that both of them had initially appeared rather non-responsive. But after she and her partner had returned from a subsequent hospital appointment Andrew appeared very anxious and asked whether it was cancer and whether she only had one year to live.

As for the middle son, mother told me he had very little understanding of the situation, apart from the fact that mother was poorly. For instance, looking at the scar where the right breast had been he had been upset. She had then had a prosthetic fitted and, looking at mother’s clothed figure, he had communicated that the breast had come back.

Mother told me at the beginning that she did not know how her daughter felt about her illness. As we have seen earlier, since going away from home to work as an au pair, the daughter had been in daily contact which had pleased mother a lot.

One can only speculate why this was so. Was it the daughter's way of still getting support and care from her mother, as she always had, in an alien setting? Or, was this the result of the knowledge of mother being very ill and her way of keeping in touch, making sure mum was still alive? Although this was a temporary move away from home, was this the daughter's way of practising living without her mother?

Mother had an elderly father who she looked after in her own home for a while during the time I knew them, as he was recuperating from an operation. At one of our latter sessions mother had talked about preparing a meal for her father, his partner and her younger sister. I had wondered about this in terms of her own energy levels and she had said that her family always expected her to cook. Her partner would suggest bringing in take-aways for these gatherings. Her family did know how unwell she was. So, again, one could only speculate as to why mother acted in this way. Mother came across as bright and competent whenever I saw her and we knew she had been in a caring role for various members of her family for years. Was this her way of showing that she was still strong and healthy enough to feed them? And was the family colluding with this, allowing her to continue in this role, and perhaps also shielding themselves from the truth of the situation?

Although mother kept her daughter and Andrew factually updated about her condition, it seems that the possibility of her death was not discussed by her directly with the family. This may have led to the children getting very anxious and showing their anxiety in different ways. Externalisation of her experiences as a person living with cancer via the blog and play seemed to have been cathartic for mother. But it could also be seen as a way of publicly acknowledging her condition and, more importantly, of communicating this to her children. From what I was told by mother there was a lot of humour in her blog and the play. It seems the only way to communicate the bitter pill of the fact she had a life-threatening illness was to coat it with the sugar of humour and distance herself from it by using these public portrayals.

The theme of premature endings was quite marked in this family's case. Mother's own mother had died when mother was 19. Andrew became clinically depressed

and suicidal – that is, wishing to die before the natural time of dying for him. The daughter left the family home for a while. Mother told me that the very disabled middle son had defied death many times. One can only speculate that this young person knew, at some level, that there were big changes afoot. Not only were there plans for him to live more independently but mother too may not be around. Was his most recent life-threatening illness and subsequent hospitalisation and pulling the drips off an unconscious wish to die? I have been told by people who have family members with severe disabilities or who work with very disabled people that such individuals are aware of more than we may think.

And it seemed I too was playing out this theme by offering to work with mother for a limited time. Had I had more time I would have worked with this family in the normal way and ended contact when it felt like the right time to do so. I would have met with the children on their own and also with the family together. We would have discussed, over time, the fact of mother's eventual death. But my brief was limited as I was leaving. As will be seen in the Defences section below, it was hard enough for mother to think about the fact of her impending death let alone feel strong enough to discuss it with her children. I think this was a crucial limitation in the therapeutic work that I offered to this family.

4. Defences

From the beginning of my involvement mother had said that she usually tried to remain upbeat and had the view that anyone could die at any time. One could, for instance, walk out of the door and be hit by a car. On the whole she tried to maintain this state of mind but she was also very aware of how short her life was going to be due to her illness.

For example, six months into my involvement, mother talked about her impending death thus:

“As we were talking about how her energies were so low, mother said she was very mindful that she did not have much longer now and wanted to do more. Did I understand that? I said I did. I said she was balancing in her mind all the time the knowledge of perhaps not living as long as she could have and wanting to live life to the full. Mother said that after leaving the dog behind she cried for a whole day. It opened doors to all the sadness.

But this was very rare. I said that in a way she was saying goodbye to so many things in her life and not just people, to seeing, hearing, experiencing everyday things that we take for granted. Mother said as long as she knew she was not going to die tomorrow she was philosophical about it, there was no point in worrying about it. She was going to fight it. She knew her life was going to be significantly shorter, so she was going to live in the now and enjoy it. She said that each night when she went to bed she asked herself about what had happened during the day and she would list all the good things. I said that she was saying she was more alive to be living her life now that she knew it was going to be shorter than expected. Mother said she had always been a 'glass-half-full' person. She said that she was incredibly aware that the cancer would kill her if she went into depression, it would drain her energy. She said that she had a vision of the cancer inside her just waiting to get at her."

Mother could flip from being aware of the reality of her situation into defending against it. For example, this can be seen later on in the same session:

"When I asked how she was physically, mother said she had received a letter from the hospital saying that the lesion on her spine had not been cured despite chemo and radio therapies. When she and her partner had told me the previous time about their consultation with the hospital oncologist mother had heard her say that she had a lesion on her spine which had survived the treatments, although her partner had heard the opposite. In this session I took this up, that it seemed that previously she had heard the doctor correctly and her partner had not. Mother said that they had mistaken 'being treated' for 'being cured' – this meant that although mother had various treatments, that did not mean she had been cured of cancer. She immediately then told me of an 'exciting' development. A hospital consultant had contacted her to see if she would be willing to take part in a research study into non-invasive radio surgery which could remove the lesion more effectively."

Mother's ability to mask how she really felt can be seen near the end of this same session:

"Mother's partner said that people said that mother put on a bright face but he thought she may be feeling something different inside. Mother said she had probably put on a bright face for years looking after her sick children and it had become second nature. When she was miserable, when it broke through, everybody knew about it. She got cross with people."

One could see mother's online blog and theatrical performances as a way of keeping the sad or angry feelings at distance but one could also think of them as

creative ways of keeping going in a positive frame of mind in what was a very frightening and painful situation.

The family seemed to lurch from one crisis to another. These included mother's diagnosis; Andrew becoming suicidal and spending some time in an inpatient unit; mother's father's operation and recuperation in her home; the puppy's arrival and departure; the news that mother's treatments had not quite got rid of the cancer; the middle son's three-week hospitalisation; the daughter flying off to Italy to be an au pair; and, finally, Andrew's girlfriend becoming pregnant. It is possible that this was the way this family usually operated. But these apparently sudden events, happening at this time, may have also served a function of getting the family's minds off mother's life-threatening illness.

5. Sustaining Factors

The things that helped mother cope with the illness included her own attitude, values and beliefs, support from her partner and friends, and her blog writing and theatrical activities, as well as support from the various services involved.

As we have seen, mother believed in remaining up beat as she feared descending into depression would rob her of what little energies she had and would also bring her death nearer.

Mother had told me that her religious belief also sustained her. She had been a Catholic but had become an Anglican after the Anglican hospital vicar had been lovely to the family when her middle child was born with multiple difficulties. She believed in life after death, and heaven and hell, and hoped to go to heaven; she jokingly said her mother would tell her off there about all the things she had done wrong in the past 30 years.

I have mentioned how mother's partner appeared very devoted to her and there was evidence that he did many things to ease mother's life. Examples included the partner accompanying mother to various medical appointments including coming to see me at CAMHS, and taking the dog out twice a day when that was

needed. He had also agreed, with several of mother's friends, to look after the children after she had died.

I have mentioned how mother's blog writing and theatrical activities helped her express her feelings and thoughts about her illness and hence acted as cathartic activities. She had got a lot of warmth and good feelings from other people around the world who wrote to her, as well as from the reactions of live audiences.

The family had had many services involved over the years and my hypothesis is that that had become part of their lives and how this family functioned. And now, at this critical time of her life, they were still there.

6. Feeling Different

Mother wanted everyone to treat her as a person in her own right and not just as a cancer patient. She went to great lengths to achieve this. She remained upbeat and cheerful, she started writing her blog to let the world know, and she appeared in the play based on her own story.

In my very first session with mother and her partner, mother told me that she tried to remain positive, as shown below:

“When mother was diagnosed with cancer she talked to her sister, brother and father (who is at present living in the family home as he is recovering after a prostate cancer operation) whether they could have done more when her own mum was dying. I said did she immediately think she would die? Mother said that she usually tries to remain upbeat and has the view that anyone can die at any time. She said that anyone could go out onto the street and get run over.”

This view of trying to normalise her predicament was mentioned by mother on several occasions in our sessions.

Five months into my involvement, mother told me that she had been writing an online blog:

“Mother said that she had started the blog just after she had been diagnosed with cancer as a way of keeping her friends up to date with her situation. She said she could be quite funny. She gave an example of a

woman who emailed her to say that she had been frightened as she was about to have a mastectomy. When this woman read mother's blog she had laughed a lot and it had helped her to go on to have her operation."

Mother continued in this session as follows:

"Mother, her daughter, Andrew and mother's partner belonged to a local drama club. The woman who ran this club had got permission from mother for five or six episodes from the blog to be turned into a play. Mother, her daughter and her partner, with others, appeared in this play. They were about to do the play at a fringe event at a seaside town this coming Saturday. After that they would appear in the local theatre."

Mother told me several times that she was the same person now as she had been before she got cancer and wanted to be seen as [her name] and not only as a cancer patient.

But there was more than this: mother wanted to feel her life had been of some account and that people would remember that. For example, six months into my involvement, mother gave me the following account:

"Mother remembered that when she was in hospital with her second son who was 3 years old at the time, she and parents of seven other very sick children had spent eight months together and had formed close bonds. She said she was the only one who had brought her child home. She remembered hugging the mother of another child who had initially responded well to open heart surgery but then died of an infection. The baby had only lived for four months but she thought he had had his lifetime and had made an impact on others. I said that whatever the lifetime was, it was important and did matter, and had an impact on others in the world."

It can be seen from the above that mother wanted not be seen as 'just a cancer patient'. She wanted to continue what remained of her life by projecting a larger-than-life persona which, paradoxically, could be seen as being 'different'.

Outcome

Although I did not see Andrew on his own for therapy, I did see him at a review near the end of my involvement and he appeared happier and more relaxed. He had not done as well as he had expected in his GCSE exams due to missing a

lot of schooling as a consequence of his psychiatric problems, but was still hoping to apply to go to college. The two families were going to support their children and the new baby. Mother continued with pharmacological treatment.

Implications of the Case

This is the story of an engaging middle-aged woman who had spent most of her adult life being a carer to her family and was now battling with cancer and the knowledge of an early death. It is the story of a bright, caring lady who was doing all she could to remain upbeat and continue to do things to help herself, her family and others. She wanted her life to be seen to be important: that is, that it had been meaningful and of some account.

This case was rather unusual as I only did parenting work and it was time-limited. This was in contrast to most of the other cases where I had done all the clinical work. As I have mentioned before the offer of my intervention was thought through beforehand by all concerned including mother, her partner, my psychiatrist colleague, my supervisors and myself.

So, one conclusion that can be drawn is that discrete bits of therapeutic work can be done, as long as there is good liaison between the professionals. But it has its limitations. The crucial limitation in this case was that I did not have the opportunity to work with the children, on their own and with their mother, to help prepare them for their mother's death.

I think part of the value of this work was that our sessions created a space in which mother could say things that mattered to her and such things could be understood. After all, mother herself had called our sessions 'an oasis of calm', where reflection could take place, away from the hurly-burly of life.

One can conjecture about mother's need to be so busy all the time. She had told me that she had suffered from depression for several years after her own mother had died. She also felt she could not allow herself to be depressed now as the cancer would then get an upper hand and she would die sooner. So the defensive busyness had a purpose for her. But, by slowing down in the sessions, she

allowed herself and her partner the opportunity to reflect on things as they really were and to see that she did not fall apart catastrophically as she may have feared.

My greatest regret was that I could only offer this space for a time-limited period as I was retiring. I had already offered honorary sessions for two years after retirement to complete long-term psychotherapy and research cases. I did try to get mother and her partner to think about finding reflective time for themselves on a regular basis when our sessions ended. Whether that would happen remained to be seen.

LARA (AGE 16)

I had an unexpected opportunity to work with Lara, a 16-year-old girl who I had been involved with previously during her mother's terminal illness when she had been referred by her health visitor at the age of three-and-a-half. I worked with Lara and her parents, Lara on her own, and the parents together. Lara's mother died when Lara had just turned 5. I continued working with Lara and her father for two more years as father struggled being a lone parent while they were both grieving. After discharge father had kept in touch, letting me know how he and Lara were doing.

When Lara turned 16, her father got in touch again to refer her to me at CAMHS as she seemed uninterested in school work and there were major difficulties between Lara and his new wife and their 2-year-old son. At this stage I was able to obtain consent from Lara, her father and stepmother to be included in this research project as one of the cases to be studied. Over a two-year period I met with Lara on her own, the parents on their own, and the family. In the family sessions we explored the current family relationship difficulties. I also offered father and his current wife a few sessions to explore issues to do with being a parent and a step-parent.

Lara was suffering from bouts of unexplained anger and depression. In her individual sessions we explored the untimely death of her mother and the possible effects which may be surfacing now. I could remember her mother and that seemed to be an important factor in Lara being able to come back to see me. She did remember meeting with me with her father and doing drawings but not much else. Lara found it difficult to be reflective about her feelings and tended to want to say things she thought I, or her father, wanted to hear. The bouts of anger and depression receded very quickly but her ability to accept her new stepmother did not shift. She had spent years being with her father on her own and she felt shocked that he had brought a new woman into the family and also that they had had another child.

Lara did not want psychotherapy and we continued with family sessions interspersed with meetings with her on her own. Her relationship with her father had been both loving and tumultuous and this did change to become calmer. Father was able to let her live her own life without wanting to micromanage it. Lara went to art college which she enjoyed and father started to accept that she had her own ways of doing her college work. She had a circle of friends and interestingly got on better with boys than girls or women. In her sessions I had taken up the issue of trusting women, and me in particular. She countered by saying that, in fact, it had been easier coming back to see me as she had known me before. As we said goodbye she gave me a card with a poignant picture of a single empty armchair in a tastefully appointed living room, and these words: "Just want to thank you for all the support you have given me. I feel like I'm in a much better place now. Best wishes in your retirement. Thank you for everything. Lara".

Although I think coming to see me before and after her mother's death and more recently with her current family did help Lara, it still does not answer the question of how she would have fared if there had not been any therapeutic interventions. Nor does it tell us whether the therapeutic interventions would act as a buffer against future negative life events. And, of course, it cannot tell us about outcomes of different types of therapeutic interventions using different theoretical and practice-based models. In other words, it cannot tell us whether interventions offered by a psychoanalytic child and adolescent psychotherapist would have led to different outcomes compared to other therapeutic models. For example, Kennedy et al. (2008b) reported benefits to families who were seen by a family support worker with expertise in working with families recruited from a palliative care setting. The family support worker also liaised with other agencies. This was a model of therapeutic service similar to that which I had been offering.

Lara's case confirms some of the research findings mentioned earlier (see Chapter 2: Review of Literature – The Impact of Parental Bereavement in Childhood). One such finding is that, although initial grief responses in children tend to decline over time, mental health and other problems could persist or even increase. These problems could fluctuate and significant life events or changes over time could trigger delayed grief reactions (Christ, 2000) – for example, when

the remaining parent remarries or the bereaved child has their own child in adulthood. Lara had had more than one significant stressor in her life (the death of her mother, her father's remarriage and the birth of a half-brother) and longitudinal studies have found that children who have experienced three or more stressful events (e.g., family bereavement, divorce, serious illness or the death of a close friend) are significantly more likely to develop mental health problems (Meltzer et al., 2003; Parry-Langdon, 2008). Lara's depression at age 16 is also in line with findings from Parsons' analysis of data from the British Cohort Study (Parsons, 2011) which reported 25% of girls and 16% of boys growing up in parentally bereaved families as having symptoms of depression at age 16. These figures were higher than those reported by young people in intact families (living with both natural or adoptive parents) or disrupted families (parents separated or divorced). The long-term effects reported in the above study showed that, controlling for family background characteristics, at age 30, women who grew up in bereaved families compared to intact families were less likely to have gained any qualifications or be in employment and reported more symptoms of depression and were more likely to be smoking cigarettes. At this stage we do not know how Lara's future will turn out. My hope is that as Lara had found the therapeutic interventions offered during her early and adolescent life helpful, she may be able to seek future psychotherapeutic help should the need arise.

I have included Lara's case as it allows us to see how psychoanalytically informed therapeutic interventions could be used with children/adolescents dealing with life-threatening maternal illness, leading up to and following bereavement. I had seen Lara at three different stages: I saw Lara and her parents in the last year and a half of her mother's life; I continued to see Lara and her father for two years after that; and I then saw her again with her family for a couple of years from age 16. The other cases in this study only had interventions at the earlier stage and not up to their mothers' deaths or afterwards. Lara's case gives us a rare glimpse of how things could turn out, but I would be cautious to generalise from it.

PART 2: SUMMARY OF THEMES ACROSS THE CASES

Part 1 of this chapter presented each of the case studies, with material considered under the six Themes. This part of the chapter reflects on each Theme, drawing together key points from the individual case studies and offering some insights from the literature.

1. Engagement

The wish and ability to engage in a meaningful way in the therapeutic process varied between individuals. At times there was a variance between individuals within the same family:

Johnny was very engaged, he used words and play to show what was going on inside him and he loved to come to the sessions. His mother, on the other hand, found the whole process more difficult.

In the case of **Sara**, it was she who did not wish to engage, while her parents were very open to coming and discussing their concerns.

The two young sisters, **Farah** and **Gabby**, used their sessions well, both when I saw them on their own or with their parents or in family meetings. Their parents were engaged in so far as they tried very hard to get the children to see me and also participated in the sessions with their children, but they did not wish to pursue things in sessions offered to them on their own as parents.

Elliot found it difficult to be self-reflective and denied that his depression had anything to do with his mother's life-threatening illness. His parents attended their sessions but his mother believed in the importance of getting on with life and not worrying. Her husband followed her lead, although he was reflective about how he managed his anxieties by spending long hours working.

Andrew's mother and her partner used their time-limited sessions well and appreciated the reflective space that the therapy had provided.

It seems the younger children appreciated the space to express their concerns. The two teenagers were less open to discussing their concerns and tended to project their worries on to school issues. They were both doing exams so that became a convenient receptacle to project their anxieties into. The mothers on the whole wanted to not think very much about their illnesses. One could see this as an adaptive defence against being overwhelmed by unbearable anxieties. In contrast, the fathers seemed more able to think about their concerns and were able to express them. The mother and partner I saw were able to engage well although there was a split between the partner who remained over-optimistic and the mother who was more realistic about the outcome of her illness, although she too moved in and out of being hopeful about new procedures prolonging her life and the knowledge that she had a much shortened life span.

Most professionals working within the therapeutic field are aware that it can be difficult to engage with clients at times, but this research suggests that this may be even more difficult with parents with life-threatening illnesses and teenage children of cancer survivors, and this needs to be taken into account when planning and providing services for this client group and their families.

2. Parental Concern

All the parents demonstrated concern for their children and this showed up in various ways:

Despite many difficulties in getting to appointments, **Johnny's** mother managed to bring him to see me over a period of two years. At times she really was feeling very unwell but she still managed to drive to the clinic. Johnny's mother and maternal grandmother were very concerned about the impact of mother's illness on Johnny and had told me that they felt very guilty about that. They were also very concerned about his social and communication difficulties and the implications of this for his future schooling. They, therefore, accessed all the services they could for this, as described earlier in the chapter (see Part 1 – Johnny).

Sara's parents too, despite being very unwell themselves, encouraged her to keep appointments with me and kept in touch via the telephone if they could not attend the clinic. They were concerned about Sara's reactions to her parents' illnesses and worried about her future. They were particularly concerned about her low self-worth, relationship difficulties with peers, and the impact of dyslexia on her learning and exam results. They were able to support and help Sara through the period coming up to her GCSE exams and with interviews for colleges.

Farah and **Gabby's** parents brought the children to see me despite work commitments and mother going into hospital for reconstructive breast surgery. They were concerned about the impact of mother's illness on their children, especially as the breast cancer had reappeared and yet another operation was planned. They were able to communicate to their children the importance of talking about their feelings and encouraged them to do so, both at home and in our sessions.

Elliot's parents encouraged him to attend his sessions with me despite mother's reservations about my linking Elliot's depression to her life-threatening illness. They kept their own monthly sessions with me, with father taking time off work during the day and mother not feeling well at all at times. They were concerned about Elliot's low mood and communicated to him that what mattered was his wellbeing and that he tried to do his best in his exams, rather than whether he came top of the class as he had done previously.

Andrew's mother was very concerned about her three children who all had major difficulties. As has been shown above, she had to be very active in the care she provided. She was on high alert because of Andrew's suicide risk and acted appropriately when needed. For example, she took Andrew to A&E which led to him being hospitalised in an adolescent psychiatric unit. She was particularly worried about her middle son who had severe physical and learning disabilities. She was in an ongoing dialogue with social services to make sure his housing needs were met appropriately as he was about to be moved on from a shared-care

arrangement involving foster carers and home. She had found it heart-breaking that she could no longer look after her middle son for long periods of time as her energy levels were so low, despite the fact that he loved to be at home. She continued to support her daughter with Asperger's Syndrome who was out of the country working as an au pair by keeping in touch with her via daily texts and telephone conversations. Despite her reservations about how her daughter would manage in a foreign country, she was pleased she was taking steps towards becoming more independent.

The above concerns expressed by the ill mothers are supported by Northouse et al.'s (2008) study (see Chapter 2: Review of Literature – Anticipatory Grief) which reported that parents who are cancer survivors may feel heightened distress in worrying about not seeing their children grow up.

3. Impact of Mother's Illness

It is important to note that all the mothers had complex health issues and therefore the impact of their illness on them and their families may have been greater than if that had not been the case.

The parents reported diminishment of energies in the ill mothers which necessitated additional help in the household and with other activities. Sara's and Andrew's mothers verbalised their worries about not being around to look after their children when they died. Andrew's mother articulated her anger at the shortening of her life. Sara's parents had felt let down by the medical profession for not taking their concerns seriously resulting in delayed diagnoses and appropriate treatments not being offered in a timely fashion.

Northouse et al. (2008) reported that the concerns of parents may include heightened distress about not seeing their children grow up, an inability to perform usual parenting activities, the strain of multiple roles while being ill, and anger and resentment at many real and perceived losses, and the untimeliness of their illness.

As we have seen from the epidemiological data mentioned in Chapter 2: Review of Literature, the net survival rates for people with brain tumours and younger women with breast cancer are lower than for breast cancer sufferers in their fifties and sixties. The sample of the present research study had two younger mothers, one who had had a malignant brain tumour and one who had had a second bout of breast cancer. The three older mothers' breast cancers had become metastatic. We need to be careful about translating the epidemiological data to individuals, as each person is unique with a whole range of factors in their lives (e.g., genetics, personal resilience, support systems, medical history and care) which may affect how long they would go on living.

All the children and adolescents had been affected in different ways and hence the referrals to CAMHS:

Johnny, through his play, showed how traumatised he had been by his mother's illness. At referral his mother reported major temper tantrums and very challenging behaviour at home. The adults in his life (home and school) reported that he had difficulties in understanding things and in social interactions, especially with his peers.

Sara had been referred as her parents were concerned about her challenging behaviour and her self-harming. At assessment, Sara herself reported being depressed but denied that she was continuing to self-harm.

Farah had shown her worries about her mother falling ill again by becoming upset, sad and angry and had made an attempt at self-harm. Her sister **Gabby**, although appearing not to have been affected as much as Farah, had nevertheless voiced her worry that her mother would die.

Elliot had been referred for depression and inability to concentrate at school after being told of the terminal nature of his mother's illness. The situation was compounded as both his maternal grandparents had died within three months of each other around this time. He had very high expectations of himself and had just entered sixth form which made his worries about the lack of motivation and concentration to do his school work even more difficult to deal with.

I had been told by **Andrew**'s mother and his psychiatrist that he had high-functioning Asperger's Syndrome, long-term depression, and anxiety, and had made previous attempts at suicide. Andrew's mother reported that Andrew had at first appeared to be jokey about mother's illness but, subsequent to overhearing her on the telephone say that she may die, he had become very angry for six months and was admitted into an adolescent psychiatric unit as he had become suicidal. So it seems in Andrew's case that the difficulties he had had prior to his mother's diagnosis had been exacerbated.

The above negative impacts on children/adolescents living with parents with life-threatening illnesses are congruent with the findings of studies of parentally bereaved children and children living with a parent who is a cancer survivor (see Chapter 2: Review of Literature – The Impact of Parental Bereavement in Childhood; Anticipatory Grief). As has been noted earlier there are similarities in the impacts on children/adolescents and their parents in both of these groups.

My experience has shown that many of the symptoms exhibited by children/adolescents who have lost a parent and children/adolescents who are living with a parent with a life-threatening illness are similar. I have, therefore, drawn on literature relating to both groups.

Dowdney's (2000) review of the impact on parentally bereaved children concluded that such children expressed a wide range of emotional and behavioural difficulties: one in five of these children showed sufficient disturbance to be referred to specialist services with symptoms including anxiety, depression, fears, angry outbursts, and regression in developmental milestones.

Studies of children/adolescents living with a parent with cancer suggest that they experience emotional, social, cognitive, behavioural and physical functioning problems (Visser et al., 2004; Osborn, 2007).

I would like to mention a couple of studies which deal with gender and age. Grabiak, Bender and Puskar (2007) reported that adolescents showed greater emotional difficulties than younger children, especially adolescent daughters of mothers with cancer. So, in this study Elliot and Sara would fall into this group,

Sara doubly so due to her gender. Visser et al. (2005) reported that younger children may be less affected emotionally as they may not fully comprehend the significance of parental cancer compared to older and young adult children. We did see that Gabby seemed to be less affected than her older sister Farah.

4. Defences

The defences of the individuals varied in terms of intensity and timing, as summarised below:

Johnny did not appear to be reluctant to portray what was going on in him. His mother on the other hand held the view that she was going to get better and did not wish to dwell on the critical illness she had had. She tended to minimise difficulties or even deny them. She found it difficult witnessing the painful and traumatic material that Johnny portrayed in his play and its symbolic meaning which I verbalised.

Sara's mother also wanted not to think too much about her illness. She wanted to live as best as she could and did not want to be dominated by the cancer. Sara offered me a glimpse of her concerns and then retreated into not wanting to continue in therapy as she maintained that she did not have a problem. This was at a time when she was busy preparing for her GCSE exams and worried about how she would fare in these, especially because of her dyslexia.

Farah and **Gabby** were able to show me, at first, their worries about their mother as she was about to have a second reconstructive surgery of the breast. They then retreated into hoping all would be well although there were signs that they were still very concerned. As mother's surgery was successful this confirmed their hopes. The children's mother was matter of fact about the operation and thought that fear was a result of not knowing about things. She knew that the operation was either going to be successful or not. She had made sure that the best doctor would operate on her and therefore she had not worried about it. Their father, on the other

hand, was aware of his anxieties as the operation loomed and was able to talk about them.

Elliot at times admitted worrying about his mother's health and feeling sad but he would either minimise it or quickly assert that it was not a serious situation. On the whole Elliot found it difficult to link his mother's terminal illness and his depression. His mother's view was that it was pointless to worry about her illness and that it was better to have a positive attitude. Elliot's father seemed to take a cue from his wife and said that as there was so much uncertainty as to how his wife's illness would progress he had decided not to worry about it.

Andrew's mother, although realistic about the seriousness of her situation, moved in and out of worrying about it. She tried very hard to keep her mood upbeat as she feared that if she became depressed the cancer would kill her. Her partner, on the other hand, tended to be over-optimistic and even misheard things the doctors told them in terms of her prognosis.

These defences are understandable in the light of the seriousness of the mothers' illnesses. In some cases, however, they may have delayed the full impact of what was happening getting through consciously to the individuals and further therapeutic input may be needed in the future.

5. Sustaining Factors

People's own inner strengths and defences helped them keep on going. Other factors included work/activities and support from family members, spouses, friends, school staff and other professionals:

Johnny and his mother continued to be supported by his mother's parents and older sister. The family moved back to live with the grandparents, and the maternal grandmother attended reviews at school. Johnny loved his granddad who was a very important person in his life. The head teacher of Johnny's school was particularly supportive of the family and the therapy.

Sara's mother appeared to be a very strong person who not only had to deal with the consequences of her own serious illness but had to also support her ill husband and her daughter. Sara's father was able to guide and support Sara. Sara enjoyed external activities like karate, film club and badminton.

Farah and **Gabby's** parents were very committed to their daughters' wellbeing and were able to convey to them that they could talk about their worries. Both parents demonstrated warm relationships with their children. Their mother worked very hard which contributed to her feelings of continued competence and usefulness. There were indications that Gabby felt supported and guided by her older sister in terms of their mother's illness.

Elliot and his parents reported good relationships within the family. Elliot's parents tried not to put added pressure on Elliot with his schooling and told him to do the best he could. Elliot's school was supportive and suggested that he drop a subject for 'A' level to help him manage his work better. Elliot enjoyed playing chess and the violin. He felt supported by his older brother who guided him with his school work and university applications. Elliot's mother felt supported by her friends who took her out and she also enjoyed reading. Elliot's father continued to work hard which helped him to cope with the situation.

The things which seemed to help **Andrew's** mother cope with her illness included her positive attitude, values and beliefs; support from her partner and friends; her blog writing and theatrical activities; and help and support from the various professionals and services involved.

As has been shown in Chapter 2: Review of Literature – The Impact of Parental Bereavement in Childhood, young people identified an area of competence (e.g., sport, music or academic achievement) as one of the factors which helped them live with parental grief. They also reported that a positive relationship with their surviving parent was a source of support (Brewer and Sparkes, 2011). In the present study, for instance, the fathers on the whole seemed to be supportive

and caring of the family needs which somehow alleviated the stresses felt by their children and ill wives. Similarly, the two adolescents in this study had many areas of competence which seemed to add to their sense of worth and ability to continue, albeit with difficulty at times. Elliot, for example, played chess at school and also played the violin in the school orchestra, while Sara enjoyed badminton, karate and film club. The study by Visser et al. (2006) reported earlier showed that older children may support each other. As we have seen Elliot felt supported by his older brother and Gabby may have appreciated the presence of Farah who was acutely aware of how their mother felt and what she needed.

6. Feeling Different

There was evidence of the children/adolescents in the study feeling different in a range of ways:

There were indications that **Johnny** may have picked up the adults' concerns about him, as indicated in his drawings and play and he may have felt he was 'weird' in some way.

Sara reported that she could not accept herself as she was and felt that her peers thought she was 'odd' as she was very thin and had interests which were different to theirs.

Farah was concerned about her peers at school knowing about her mother being ill. For example, she told me that she had become very upset when a boy at school told her that her mother was very ill. **Gabby** did not appear to show concerns on this front although she may have had concerns which she did not communicate, or may have communicated them so subtly that the adults had failed to pick them up.

Elliot reported that he felt people may not like him as he had a serious face which might make people think he was moody. He wanted to be regarded as nice, and the people who knew him well knew he was nice.

Andrew's mother wanted people to treat her as a person in her own right and not just as a cancer patient.

Some of the above feelings and thoughts seem to be directly linked with the mothers' illnesses. In other cases it is not so clear: the feelings may have existed prior to the diagnoses, and may or may not have been exacerbated by the illnesses.

There is evidence in the literature that parentally bereaved children may feel they are different and may worry about their relationships (Servaty and Hayslip, 2001) and that this could lead to them feeling bullied by their peers (Cross, 2002; Rolls and Payne, 2007).

Concluding Thoughts

In the present study the mothers' life-threatening illnesses impacted significantly on all members of the families. The families continued to live as best as they could, given the circumstances, and in most cases they showed a lot of resilience.

These were relatively short-term cases and the therapeutic work seemed to benefit both the children/adolescents and their parents. In all the cases (apart from Andrew as I only met with his mother and her partner), there appeared to be a diminishment in the symptoms that the children and adolescents had displayed at referral. All the parents wanted their children to be seen and, to a greater or lesser extent, appreciated the therapeutic input.

I used a variety of therapeutic interventions including individual sessions with children/adolescents, sessions with parents, family meetings and, in the case of Johnny and his mother, parent-child psychotherapy. This was in keeping with trying to offer what was most appropriate at the time to best fit the needs of the individual child/adolescent and their family.

A psychoanalytic child and adolescent psychotherapist, with long and comprehensive training and subsequent experience, is well placed to understand children's communications and is therefore able to offer insights and understandings to their parents.

I met with the parents in all the cases and this input was used to a lesser or greater extent by the parents. Margaret Rustin (2009) offers a useful discussion

of parent work done by child and adolescent psychotherapists and she concludes thus:

“Child psychotherapists bring some special capacities to work with parents. The place of infant observation and the broad study of child development in their training, together with their own analysis, put them in touch with the changing pressures on parents as their children grow and change, and the intensity with which parents’ own infantile difficulties are stirred up by their children’s emotional lives. This knowledge and sensitivity can be used well in responding to parental anxieties, but it can also be a source of trouble. A degree of competition, jealousy and envy is likely to be evoked by professionals who try to help when parents feel themselves to have failed. Tact, humility and a real belief in the shared nature of the task are essential. The direct use of transference and countertransference and interpretation are only appropriate when there has been explicit agreement that parents wish to become patients in their own right. However, the understanding available through observation of the relationship made with the therapist can inform other kinds of conversation which have therapeutic potential. It is the capacity to empathise with both parental and child perspectives which is valuable.” (p. 218)

I also met with the whole family, to a greater or lesser degree, and that allowed family members to listen to each other and hopefully hear their differing perspectives. Although not trained in family therapy, I have worked alongside systemic family psychotherapists whose knowledge of family systems and ability to facilitate communication between individual family members, often during acrimonious exchanges, has influenced my practice in working with families. I also used my own psychoanalytically informed knowledge and experience in working with families.

This therapeutic model thus combined aspects of individual psychoanalytic psychotherapy, work with parents and family work.

The psychotherapist’s ability to contain anxieties is important for all CAMHS clients but I think it is of particular importance for families who are living in the shadow of parental death. Bion (1967) links the containing function that a mother provides for her infant with the role of the therapist who contains the patient’s overwhelming anxieties (see Chapter 2: Review of Literature – Psychoanalysis: Mourning and Trauma).

Winnicott (1979) makes a connection between the holding environment offered by the mother to the infant and the ability of the psychoanalyst to offer a similar level of holding and containment to patients by attending carefully to the transference and countertransference phenomena.

Monica Lanyado (1996) compares Winnicott's ideas about maternal care and the therapeutic holding environment thus:

“For Winnicott, the provision of maternal care, or the provision of a therapeutic setting resulted in a tailor-made, active adaptation of the carer's or the therapist's mind to the needs of the individual infant or patient which was highly responsive to communication between the baby and the mother, patient and therapist. In infant care, this was seen in the attention to detail that the mother gave her infant – in the way she held, fed, soothed and protected her baby from unnecessary interruptions in his or her state of being. By implication, the setting, and the establishment of any piece of clinical work, therefore aimed at providing a parallel kind of environment within which significant growth and communication could safely be explored and experienced. In other words, the therapist needed actively to adapt his or her mind, the setting and form of psychoanalytic treatment to the patient, rather than the patient having to adapt to the classical psychoanalytic model.” (p. 428)

My contention is that unconscious infantile anxieties may resurface in family members at critical times and therefore the containing function of the psychotherapist is of paramount importance. This containing function includes dealing sensitively with what is being presented within sessions, but also includes containing anxieties within the wider professional network. This latter has been shown, for example, in liaison work with the professional and school systems for Johnny.

My experience over the years in working with families with a parent with a life-threatening illness has shown that flexibility in *how* I offer the psychotherapeutic treatment – i.e., primarily in response to the circumstances and needs of the family – is also important. For example, appointments are offered to fit in with the families' medical, work and school commitments. This also gives some form of autonomy to the families whose lives have been turned upside down due to the parental illness. I have been told by very ill parents that they feel they have lost control over their lives, and the ability to choose when and how often they attend sessions is therefore important. There is a challenge in trying to offer flexibility as

what may suit one member of the family may not suit another. This was shown in Johnny's case where *he* welcomed and used the psychotherapeutic space well but his mother was not able to maintain regular contact for a variety of reasons.

Lanyado (1996) makes the point that “[n]on-intensive or brief psychoanalytic work can be of value to many patients, and should not be viewed as ‘diluted’ intensive work but a therapeutic discipline in its own right”. (p. 441) Lanyado offers two examples of such work: a case involving a family who had lost a child through an accident; and a case involving a sexually abused and abusing adolescent boy. She states that these clinical examples:

“...deal with the impact of trauma, which Winnicott saw as a massive impingements on the individual's sense of ‘going-on-being’. Part of the task of therapy could be described as helping the patients rediscover developmental and creative pathways in their lives, having been swept off course by the overwhelming events they had experienced.” (p. 429)

One could say that the overwhelming events were continuing for the families in this study and that coming to see me, albeit for a relatively short time, led to some containment of anxieties and hopefully put the children and adolescents onto a ‘normal’ developmental pathway.

CHAPTER 5: CONCLUSION AND RECOMMENDATIONS

Introduction

This thesis reports on a qualitative research exploration of the nature and effectiveness of the provision of a clinical service offered to families of mothers suffering from a life-threatening illness.

This chapter opens with a review of the principal objectives and research questions and how they were addressed in the study. This is followed by a discussion of the therapeutic input and the research study, and ends with some suggestions for training and service provision in this field.

The Principal Objectives and Research Questions

As stated in Chapter 1: Introduction, the principal objectives of the study were:

Objective 1: To explore whether therapeutic work by a child and adolescent psychotherapist with families of a mother suffering with a life-threatening illness could be beneficial to them in relieving distress and supporting their development.

Objective 2: To discover the factors at play within and between the referred family members.

Objective 3: To add to the knowledge base for adults – family members and professionals, including those working in psychoanalytic psychotherapeutic practice – relating to and dealing with such children and adolescents.

The research questions were:

Research Question 1: To what extent were anxieties diminished in the family members, and to what extent were the children/adolescents able to

continue with their development (psychological, emotional, cognitive, social), having taken part in the psychotherapeutic process?

Research Question 2: What impact does life-threatening maternal illness have on family members and what light does the research throw on this?

Research Question 3: To what extent do the findings of this research add to the findings of previous studies in this field and enhance applied psychoanalytic child and adolescent psychotherapy practice?

Objective 1 and Research Question 1: Therapeutic Outcomes

In all cases the children/adolescents (apart from Andrew who I did not see therapeutically) and their parents reported a decrease in the symptoms of the children and adolescents. Symptoms included emotional, psychological, behavioural, learning and interpersonal difficulties.

One could say that the therapeutic process offered a containing environment in which the family members could explore, to a greater or lesser extent, their concerns, and the children's/adolescents' anxieties thus diminished as shown by the decrease in symptoms. The improvement in the children's/adolescent's wellbeing was reported by them as well as by their parents and in some cases by other adults who knew the children well (e.g., teachers). My own observations in the consulting room also concurred with these reports. In all cases (apart from that of Andrew where I only met with his mother and her partner on a time-limited basis) it appeared that the children/adolescents were able to continue with their lives reasonably well by the end of the therapeutic process. One could also say that the parents, to a greater or lesser extent, found support and understanding about how their children were feeling or thinking by coming to see me.

I cannot, though, ascertain whether these improvements in the children/adolescents would continue and what the long-term sequelae of their experience of living with a parent with a life-threatening illness would be. That would require long-term follow-up which was not part of the present research. It is possible that the children/adolescents would get anxious and exhibit further

symptoms leading up to and after their mothers' deaths, if that was going to be the outcome.

In summary, one could say that the children/adolescents in this study benefited from the psychotherapeutic interventions in terms of symptom reduction in the short term but it would be difficult to predict whether these benefits would be sustained in the longer term (Objective 1 and Research Question 1).

Objective 2 and Research Question 2: Research Findings

Six Themes emerged via the coding and analysis of the data (session notes which included descriptions of the children's play and drawings and telephone contacts) using an adapted Grounded Theory methodology. They were:

1. Engagement
2. Parental Concern
3. Impact of Mother's Illness
4. Defences
5. Sustaining Factors
6. Feeling Different

The Themes within each case and across the cases are discussed in Chapter 4: Findings.

Although six Themes emerged from the data they were uneven in strength in that some had more evidence to support them than others. Theme 3 (Impact of Mother's Illness) and Theme 4 (Defences) were the strongest. These were followed by Theme 1 (Engagement), Theme 2 (Parental Concern) and Theme 5 (Sustaining Factors). Theme 6 (Feeling Different) had the least evidence to support it. The two teenagers' feelings about themselves may have been there before their mothers' illnesses commenced, but these feelings (Sara feeling that peers saw her as 'odd', and Elliot feeling that people may not like him because he had a serious-looking face) could have become exacerbated due to their mothers' illnesses. Johnny's feelings about himself as being 'weird' in some way,

as shown through his play and drawings, may be related to the adults' (mother, maternal grandmother and aunt; school staff) concerns about his communication and social interaction difficulties which may have become more pronounced due to anxieties about his mother's ill health. Farah's concerns about her peers at school knowing about her mother's illness were the most clearly related to her mother's illness. Her younger sister, Gabby, did not appear to have these concerns. All the ill mothers wanted to go on with life as normally as possible and this could be seen to be an attempt not to feel different or to be seen as being different. So, on balance, although there was not as much evidence for Theme 6 (Feeling Different), I have retained it.

Was this discrepancy in strength in Themes related to my relative inexperience in using a form of Grounded Theory methodology? Or was it due to researcher bias? I think both factors were probably at play. Although I had tried to adhere to what was written on Grounded Theory (Glaser and Strauss, 1967; Glaser, 1978; Charmaz, 2014), this was the first time I had used this form of data analysis and I was learning as I went along. As I was an experienced clinician before I undertook the research, this may have informed my choice of Themes. We always see a child within the context of their family in CAMHS and therefore this affected how I offered the psychotherapeutic input (to children, their parents and families). Again in CAMHS we had learned over many years that by supporting parents we can help them in their parental role and through that can help their child. It is possible that Theme 2 (Parental Concern) and Theme 5 (Sustaining Factors) may have been products of this emphasis on the family context and may not have appeared as Themes if someone else without such a background had done this research. My experience of what children/adolescents say about being treated differently by peers due to something about themselves or their circumstances (e.g., disability, illness, ethnicity, gender, social-economic status, culture, sexual orientation, academic ability, being fostered or adopted) certainly has had a strong influence on me. This may have led to Theme 6 (Feeling Different) being chosen, to emphasise how much children suffer due to being different in some way. As noted in Chapter 3: Methodology – Grounded Theory, these 'sensitizing' factors which stem from the educational and training backgrounds of professionals were acknowledged by Glaser (1978). Charmaz

(2014) also discusses the preconceptions that researchers may have due to personal, cultural and theoretical standpoints and emphasises the importance of self-reflection and making such preconceptions explicit.

All the children/adolescents as well as their parents and other adults in the family (partners and extended family members) were reacting to the situation they found themselves in. We have earlier seen research which supports this finding. What this present study offered was an insight into the complexities involved when families find themselves in this type of a crisis or traumatic situation; for example, the ability to take this fact on board emotionally and to think about it varied between family members and fluctuated over time.

In summary, one could say that the six Themes, although varying in strength, reflected the factors at play within and between the referred family members (Objective 2) and the quite significant impact that life-threatening maternal illness had on all family members, and in many ways confirmed previous research findings (Research Question 2).

Objective 3 and Research Question 3: Increasing the Knowledge Base

The present study's findings concur with some previous research findings and add to them, especially in understanding the nature of unconscious defences.

In the following discussion I will use studies on parentally bereaved children as well as anticipatory grief as my previous experience and the studies themselves show that the symptoms can be very similar.

Client engagement is an issue experienced by all professionals but there may have been extra resistance amongst my clients due to the nature of the work itself and therefore consideration of Theme 1: Engagement may increase understanding about this. This is of particular relevance in working with adolescents who are going through major internal changes to do with separation and individuation, and who therefore have a dilemma on their hands. How can they protest to show their growing individuality when one of their major attachment figures is dying and a permanent separation is therefore likely (c.f.

Sara)? How can they continue to excel academically to cement their identity when the depression they feel diminishes concentration (c.f. Elliot)? There is evidence that parentally bereaved children are at risk of lower academic success (Rolls and Payne, 2007; Haine et al., 2008).

Parents in my study reported being worried about their children, both in the short and long term, and the ill parent was particularly worried about when they would no longer be there to care for their children (Theme 2: Parental Concern). This is supported by the findings of research carried out by Northouse et al. (2008) as reported earlier (see Chapter 2: Review of Literature – Anticipatory Grief).

The findings of Theme 3: Impact of Mother's Illness concur with those reported in previous studies about children's/adolescents' anxieties related to living with a parent who has a life-threatening illness (e.g., Visser et al., 2004; Osborn, 2007). The symptoms of the children/adolescents included difficulties in learning, family and social relationships, and behavioural, psychological and emotional problems. In terms of age and gender, Grabiak, Bender and Puskar (2007) found that adolescents (c.f. Elliot, Sara) show greater emotional difficulties than younger children, especially adolescent daughters of mothers with cancer (c.f. Sara). Younger children (c.f. Gabby) may be less affected emotionally as they may not fully comprehend the significance of parental cancer (Visser et al. 2005). Several studies indicate that parents are not as aware of their children's distress about living with a parent with a life-threatening illness as the children themselves report (Rosenheim and Reicher, 1985; Welch, Wadsworth and Compas, 1996; Beale and Sivesind, 2004).

The review by Haine et al. (2008) showed that parentally bereaved boys displayed higher levels of externalising behaviour (c.f. Johnny) whilst girls displayed more internalising problems (c.f. Sara, Farah and Gabby). Sara and Farah, however, also showed externalising difficulties (e.g., self-harming and relationship difficulties).

Parsons (2011) reported that 25% of girls and 16% of boys growing up in parentally bereaved families reported symptoms of depression at age 16 (and such symptoms were seen in the cases of Sara, Elliot and Lara, all 16).

The Theme which probably offered the greatest scope for in-depth understanding was Theme 4: Defences. Increased understanding of unconscious defences may help professionals working with families with a parent with a life-threatening illness.

Kennedy et al. (2008b) suggest that children and families with a terminally ill parent can be supported within their communities “drawing on their own social networks” (p. 230). Theme 5: Sustaining Factors supports this view as the children/adolescents in this study had family members and professionals supporting them, and their symptoms may well have been worse if that had not been the case. Visser et al. (2006) found that older children may support each other when a parent has a life-threatening illness. In this study we saw that Gabby felt supported by her older sister Farah who seemed more able to gauge what their mother needed; and that Elliot’s parents reported that he looked up to his older brother who provided him with advice about educational matters.

There is evidence in the literature that parentally bereaved children may feel different from their peers and may worry about their relationships (Servaty and Hayslip, 2001) and this could lead to feeling bullied by their peers (Cross, 2002; Rolls and Payne, 2007). Theme 6: Feeling Different supports these findings especially regarding Farah who worried about other children finding out about her mother’s illness.

Although child and adolescent psychotherapists have long worked in hospital settings, for example in neo-natal units and with ill children, there appears to be no research by a psychoanalytic child and adolescent psychotherapist in this specific field of clinical work with the families of parents suffering from life-threatening illnesses.

Kennedy et al. (2008b) looked at a UK (Scotland) service for families of terminally ill patients with children and adolescents up to the age of 19. This was a nurse-led study and there is no mention of the type of family work offered or the professional background of the family support worker. The study mentions interviews with individual family members for the *research* but it is not clear whether sessions were offered to individual family members as part of the

therapeutic process. The study does mention liaison work with other professions and services. However, the participants were recruited from a community palliative service and therefore the family support worker may have had the advantage of being able to liaise with the palliative care team (see Chapter 2: Review of Literature – Psychosocial Therapeutic Services)

Kennedy et al.'s (2008b) research found five themes in the therapeutic work offered to families with a terminally ill parent: 'Thrown into chaos'; 'Lost in panic'; 'Holding them steady'; 'Journeying together'; and 'The road ahead'. These themes chime with many of my experiences, especially in my previous work with families of parents who were terminally ill. The present study had mothers who were living longer, albeit still with the knowledge that they had or continued to have a life-threatening illness. This is an important distinction to make and services may have to be geared differently for the two populations (i.e., parents facing impending death and those with a longer life expectancy).

A Norwegian study conducted by Bugge, Helseth and Darbyshire (2008, 2009) focused on families with one parent who had incurable cancer. They were offered the opportunity to participate in the Family Support Program, which consisted of experienced health workers offering a combination of separate meetings with the family, the parents and the children individually, over a five or six-week period. As has been noted earlier, both parents and children found this input helpful (see Chapter 2: Review of Literature – Psychosocial Therapeutic Services). Short-term services such as these can offer valuable space for children/adolescents and parents to be heard; to be able to discuss their concerns in a safe environment; and to receive useful advice about the situation these families find themselves in.

I describe the clinical work with my clients earlier (see Chapter 4: Findings – Concluding Thoughts) and also later in this section (see The Clinical Work below). These descriptions emphasise the need for the containment of anxieties and flexibility to fit in with what is needed by each family. This description of therapeutic practice may help other practitioners – psychoanalytic child and adolescent psychotherapists and other professionals – working with this client group.

In summary, one can say that there is a growing knowledge base about the impact on children/adolescents who are living with a terminally ill parent and this study contributes to that. It also contributes to understanding about how one offers clinical treatment to this client group with emphasis on containment of anxieties and flexibility of approach. There is a recognition that families of minor children living with a terminally ill parent need psychosocial services but these are uncoordinated and fragmented in the UK (Kennedy et al. 2008a). (Objective 3 and Research Question 3).

Discussion and Recommendations

In this section I will discuss what worked well and what did not work as well in the clinical setting. This will be followed by a discussion of the value and criticisms of the case study research method for psychoanalytic psychotherapy and how the method could be improved if similar studies are undertaken by others in the future. I will end with some suggestions for training, and pointers from published studies for more integrated and comprehensive service provision in this field.

The Clinical Work

This study addresses a psychotherapeutic service offered by a psychoanalytic child and adolescent psychotherapist to families with minor children (under 18 years of age) with a mother who has a life-threatening illness. Although I have offered this form of psychotherapeutic work to families where the father had a terminal illness, the cases referred during the study period all involved mothers with life-threatening illness.

The psychotherapeutic service I offered was within a community CAMHS rather than being a hospital or hospice-based service, although it could be offered within those settings too. One advantage of this is that the service is being offered away from where the patient is being treated for their medical condition. This 'distance' provides the family members with the space in which to reflect about the situation they find themselves in. A second advantage is that the treatment is being offered within a calm setting in a specially appointed consulting room away from the

hurly-burly and interruptions of a hospital ward. In this sense a hospice setting would also be suitable. Flexibility of timing of appointments is important as the terminally ill parent progresses through their illness. I have met families in their homes and in a hospice previously but did not need to do so for these cases as the ill parents were well enough to attend the clinic. Being able to offer this service in a variety of settings depending upon the needs of the very ill parent would be another form of flexibility and fits in with the present-day practice of hospices offering, as far as possible, home-based palliative care.

Probably the main disadvantage of the CAMHS location was not being directly part of a palliative care service which meant that I did not have ready access to discussions with the palliative care team members about the needs of the adult patients and their children. I did liaise with other agencies where the need arose, with full knowledge and agreement of the parents and child/adolescent. Another form of flexibility is the ability to offer joint consultations with colleagues from different professions, both within the CAMHS team and in other relevant organisations. For example, in my previous work in this field, I met with families within the home or hospice with the relevant social worker.

In this applied form of psychoanalytic child and adolescent psychotherapy I met with children/adolescents on their own, with parents together and with their families. Each case is different in terms of what is needed at the time or what is allowed by the clients. I have spent many years working individually with children/adolescents in long-term psychotherapy using both verbal and non-verbal communication (e.g., play, drawings). It is interesting to note that some of the palliative care literature emphasises the use of non-verbal methods for adults and children. As we have seen earlier Kübler-Ross (1981) emphasised the importance of symbolic language and non-verbal communication in working with the dying and their families. Furth (1981, 1988) worked with dying adults and children using drawing as a medium through which the unconscious showed itself during the therapeutic process. Macleod (2009) mentions the usefulness of the concepts from psychoanalysis and Attachment Theory and non-verbal practice methods used in child psychotherapy whilst working with terminally ill adults. (See Chapter 2: Review of Literature – The Mourning Process; Psychosocial Therapeutic Services; Children’s Play and Drawings as Communication.)

I have discussed the form of parent work offered by child and adolescent psychotherapists earlier (see Findings: Concluding Thoughts). As a psychoanalytic child and adolescent psychotherapist, who has had lengthy and comprehensive training and subsequent experience, I was well placed in understanding children's/adolescents' communications in depth and therefore able to offer insights and understandings to their parents.

My practice has been to meet the whole family at least once at the initial assessment stage to clarify who knows what about the parental illness and to allow family members to hear each other's views. The importance of involving the whole family is highlighted in some palliative care literature. Schuler, Zaider and Kissane (2012) discuss the use of family grief therapy which is conducted before and after the death of the terminally ill patient. Chochinov et al. (2011), in their randomised controlled trial comparing terminally ill patients' experiences of dignity therapy, client-centred care and standard palliative care, found no significant differences in distress levels before and after completion of the study in the three groups. However, patients reported that dignity therapy was significantly more likely than the other two interventions to be helpful, improve quality of life, increase a sense of dignity and change how their family saw and appreciated them, and to be helpful to the family. The usefulness of family-based support services offered during and after the death of a parent of minor children (Kennedy et al., 2008b; Bugge, Helseth and Darbyshire, 2008, 2009) is discussed earlier in this chapter and is also covered in Chapter 2: Review of Literature – Psychosocial Therapeutic Services.

The main aim of this applied form of psychotherapy was to offer a containing therapeutic space where children/adolescents and their parents could communicate their feelings and thoughts about the difficult situation they found themselves in. It appears that a relatively short psychotherapeutic input, offered in a timely and flexible fashion, does alleviate, at least in the short term, the distress felt by children and adolescents with a parent suffering from a life-threatening illness.

The psychotherapist's ability to contain anxieties and carry on, despite the family members' defences and/or difficulties in attending regularly, was probably the

most important aspect of the therapeutic input. The clinical input could be seen as useful 'first aid' for the families at a time of crisis, allowing the anxieties to diminish enough for them to continue with their lives. Some of the children/adolescents may need further therapeutic input in the future and it is hoped that they would seek it and that appropriate help would be available.

The therapy was dependent on the psychotherapist's ability to respond flexibly to the needs of the children/adolescents and their parents. Very ill people may feel that they have lost control of what is happening to their bodies, and the invasive and prolonged treatments and their side effects add to this feeling. The parent's illness also leads to changes in routines and roles within the family. The two adolescents in this study were preparing for important exams and therefore could not miss crucial lessons. As the ill parent was often not able to work, the family was dependent on the well parent's earnings. Most of the mothers were still receiving medical treatment every few weeks and suffered with side effects in the days following. I therefore offered appointments, as far as possible, to fit in with the clients' needs (e.g., school, work, and medical treatments).

The psychotherapist's ability to understand what the clients are conveying, both at the conscious and unconscious levels, and to put it into words, however painful or difficult that may be, is important. But this needs to be tempered by gauging the atmosphere and assessing whether it would be wise to say something at a particular time. What one says can lead to further anxieties at a time when defences are important as coping mechanisms. This may not be straightforward to assess and at times I made mistakes. These can be weathered, both by the therapist and client, if the underlying therapeutic alliance is well founded, both with the child and their parents.

I think it is important to address the issues by meeting children/adolescents and their parents separately as well as meeting as a whole family. Both the children/adolescents and their parents may wish to have some privacy to discuss issues which are particularly relevant to them. They may not want to overburden their children or parents with their concerns, as the case may be. Family meetings are important to allow people to explore and clarify thoughts and feelings which may not be known to other members. Whether the different meetings need to be

delivered by the same clinician is debatable. The family members may feel more contained if they feel that one person has all of them in mind and understands things from the different perspectives. The therapist may feel she/he can work more effectively if she/he knows the minutiae of what is going on within the system. I think adolescents, with their particular developmental needs for separation and individuation, may need a different approach. It may be advisable for adolescents to have a different clinician to the one working with the parents/family. This could also help with issues of confidentiality. I made it very clear how I would proceed in terms of relaying information between parents and their children: that is, I would always let people know what I would be passing on. Despite this, adolescents at times may find it difficult to meet with a clinician who is also meeting their parents. If an adolescent enters long-term psychotherapy, then it would certainly be advisable for them to have their own therapist. This may not always be possible in resource-stretched services.

The families were coming to therapy sessions at a major crisis point in their lives and it seems it was easier to enact what was troubling the individuals rather than to think about or reflect on what was happening in them. This is understandable in the light of what has been discovered about trauma and its after-effects on the individual: that is, it can diminish the ability to think symbolically (Garland, 1998).

It is not easy to gauge whether the trauma or difficulties experienced by the children/adolescents were primarily due to their mothers being very ill. As these were Tier 3 CAMHS referrals it is more than likely that earlier and deeper difficulties in the children's/adolescents' histories contributed to the levels of distress shown. Some of the family histories indicated more complexity and difficulties than others.

The cases in the present study may have improved for several reasons. These cases were self-selected, given that the parents had been motivated to ask for a referral, and this may have been a factor in the improvements observed. The cases were picked up soon after referral. This meant that they were given priority which was usually given to cases indicating risk in the service I had worked in. The family members also seemed to be resilient enough to be able to receive some therapeutic input and then be able to carry on with their lives.

It was hoped that by offering therapeutic input before their parents' possible deaths, the children/adolescents would be able to grieve appropriately if the parents died, and not get stuck in their cognitive, emotional, psychological or social development. I had some indication of this positive post-parental death effect in my previous therapeutic work when I saw children/adolescents both before and after the death of a parent. As an example of this type of psychotherapeutic work I have included a description of a case in which I saw a little girl, Lara, first referred at age three-and-a-half, during her mother's terminal illness, and continued meeting her and father for two years afterwards. I then met her again when she was re-referred at the age of 16, meeting with her, her father, stepmother and stepbrother, for another two years. This case was unusual in that I had been involved at such important junctures in Lara's life. It did, however, give me a rare glimpse into how Lara was developing, at least up to the age of 18 (see Chapter 4: Findings – Lara).

As already mentioned I had had previous clinical experience of applied psychotherapeutic work with parentally bereaved children/adolescents and their families as well as families with terminally ill parents who subsequently died. What was different about the cases in the present study was that the seriously ill mothers were still alive when I closed the cases as the symptoms of the children/adolescents had diminished. In the latter cases there seemed to be a lessening of urgency felt by the families about their situation and therefore more active use of defences in order to keep going. It seems that the human propensity to keep hope alive even in the most dire situations is a useful survival mechanism. One could say that feelings of grief about the possible death of the mother had to go underground, so to speak, for the time being at least. T.S. Eliot's observation that "...human kind cannot bear very much reality" (2004, p. 172) comes to mind.

In terms of my own experience as a psychotherapist, this type of clinical work was very different to other work as I was dealing with parents who may not have long to live. I found that the humanity inherent in ourselves in the practice of psychotherapy came more to the fore. At times, I was caused to reflect more on my own mortality and how I would be if I found myself in a similar situation. Therefore, inner maturity and resources are needed to contemplate offering such work. In terms of other psychotherapists wishing to work in this field, I think it is

important that they feel equipped enough internally and have a choice to do so or not. Child and adolescent psychotherapists do undertake training psychoanalysis which may continue after qualification; therefore they may be more equipped to do such work than many other professionals.

I was able to offer this form of therapeutic intervention within a multidisciplinary team context in which it was still possible to develop and pursue one's specialist interests. The delivery of assessment and therapeutic services within CAMHS is becoming more standardised and therefore it may not always be as easy to offer a service which does not fit in with the prevailing ethos. For instance, The Choice and Partnership Approach (CAPA) may be standardised across all CAMHS within a Trust. This form of service delivery splits the initial assessment and the follow-up treatments offered in a more systematic way (Robotham and James, 2009). There is also an emphasis on the delivery of evidence-based treatments and this particular form of therapeutic input therefore needs further evaluation.

My clinical experiences could be relevant for child and adolescent psychotherapists and other professionals who are involved in offering psychosocial care in hospitals and hospices.

To summarise, the most important aspects of this form of service provision seemed to be: the ability to contain anxieties and thus offer a therapeutic holding environment; continuing working with the family before and after the death of a parent (if that is the outcome); and flexibility in how one offers the service. Added to these were what I brought to the therapeutic situation as a psychoanalytic child and adolescent psychotherapist. I was aware of the powerful role the unconscious plays in our lives and especially in the lives of those facing such a major life event as the possible untimely death of a parent. Being aware of transference and countertransference phenomena during sessions – even though it may not have been wise to use them directly at times in the sessions – certainly helped with the therapeutic process. And finally, as a child and adolescent psychotherapist, I brought years of experience in working both verbally and non-verbally with my young clients in order to facilitate communication.

The Research Study

This research study used a qualitative case study methodology with comparison across cases. The study explored six cases of families with life-threatening maternal illness and used an adaptation of Grounded Theory methodology to analyse the raw data, which consisted of detailed process notes of therapeutic sessions and included descriptions of play and drawings used by children.

This study follows a long tradition in psychoanalysis, starting with the work of Freud, of using case studies to increase knowledge of both theory and practice. Psychoanalytic child and adolescent psychotherapists have used case studies in the Tavistock–UEL doctorate programme which has enhanced both knowledge and practice in our profession (Anderson, 2003; Reid, 2007; Hindle, 2007). Anderson (2006) discusses how well suited the partnership is between psychoanalytic research and Grounded Theory methodology. Michael Rustin (2009) suggests that the type of research methods used need to fit the subject matter studied, and that in the case of psychoanalysis, as clinicians try to understand the complexities of individual patients “...its findings have been best represented in case studies...”. (p.38) (See Chapter 3: Methodology – Introduction; Case Studies.)

Research in this field has been criticised over the years on the basis that it is difficult to disprove hypotheses in psychoanalysis as it relies so heavily on subjectivity, both in the psychoanalyst and the patient. The criticisms about using clinical case studies as a method of research fall into three areas: reliability, validity, and generalisability (Midgley, 2006) (see Chapter 3: Methodology – Criticisms of the Case Study Research Method).

In terms of this study the sample size was small. I do not know how representative this sample was in terms of these types of cases. Therefore, it would be difficult to generalise the findings which emerged. More studies, including families from a wider variety of backgrounds, conducted by child and adolescent psychotherapists, would be needed to address this issue.

The criticisms levelled at the reliability of data when session notes are written by psychotherapists themselves have been discussed previously. As mentioned

before, I did not think it would have been in the best interests of the vulnerable clients in this study to have subjected them to the added anxiety of being recorded (audio or video) (see Chapter 3: Methodology – Criticisms of the Case Study Research Method). Future studies may try and find a way to overcome this.

Another criticism is that clinicians could be selective in writing up case notes, rather than being objective and comprehensive and being open to an alternate view or understanding. This can lead to data lacking validity and to justification of the clinician's own hypotheses or theories. It is true we view things from our own point of view and this subjective nature is inherent in all types of psychotherapy theories and practice, not only the psychoanalytic kind. The best we can do as clinicians is stay in tune with what is going on in the session and revise our views if what we perceive and experience does not fit with our preconceived ideas. Regular clinical supervision would also add an external view to what is being presented in the sessions. Getting information about the child from other sources (e.g., schools) would help with this too.

This study did not have control groups. For example, it did not have families receiving 'treatment as usual' or interventions offered from different theoretical modalities. If such a randomised controlled trial were to take place then one could evaluate the usefulness of these services for the families concerned and whether there were differences in outcomes depending on the type of intervention offered. If such comparative trials were to take place, like the IMPACT study (IMPACT, 2015) mentioned earlier (see Chapter 3: Methodology – Criticisms of the Case Study Research Method), there would be several challenges to surmount. These would include securing requisite funding and finding suitably trained and experienced clinicians and supervisors and appropriately supportive services where these trials could take place.

The importance of offering flexibility in this particular form of psychotherapeutic input for families with a parent with a life-threatening illness militates against comparing like with like between cases. I offered a similar service to all families but it was tailored to what was needed and this changed not only between families but also within families as therapy progressed. This flexibility helped with the

therapeutic process but it poses a challenge in offering uniformity across cases for research purposes.

I believe that the therapeutic input I offered was of value, although I have little independent evidence to support this, apart from the reports of the family members themselves and, in some cases, school staff. In order to address this issue, future studies would need to assess outcomes using well-established measures.

The findings from this study could have been made more robust if more than one person had coded the raw data, thus addressing any bias that the researcher-clinician may bring. Perhaps the Themes which emerged would have been different if there had been two coders supervised by an experienced third researcher to discuss and resolve any disagreements that may have ensued.

As stated earlier in this chapter, the children's/adolescents' symptoms diminished allowing them to continue with their lives despite the situation they found themselves in. Longitudinal studies would be needed to establish if these improvements continued to later life.

In conclusion one could say that research with a small number of clinical case studies cannot produce definitive answers. However, qualitative data of this kind can illuminate social interactions and their consequences, and can provide grounds for further comparative and empirical investigations of the hypotheses to which they may give rise.

Training Considerations

Specialist supervision for child and adolescent psychotherapists or other professionals undertaking this work is desirable, and perhaps even necessary. Supervision seminars related to child and adolescent psychotherapy work within hospitals generally might provide an appropriate setting for this, as therapeutic work in contexts of severe physical illness raises issues similar to those considered in this study. It would be advisable for palliative care training for all professions to cover the needs of minor children of terminally ill patients.

Pointers for Service Provision

Published studies offer some indications as to how to plan for integrated and comprehensive services for this client group.

Population-based studies in the USA (minor children living with parents who were cancer survivors; Weaver et al., 2010) and in Norway (children up to age 25 living with parents who are cancer survivors; Syse, Aas and Loge, 2012) indicate that the collection of this type of data is in its infancy. There does not seem to be a similar UK study and this gap needs to be addressed to establish a baseline to inform the development of more integrated and comprehensive services.

Syse, Aas and Loge (2012) mention that in Norway it is now enshrined in law for children living with severely ill parents to be targeted for special support within the national care system. Oncology departments are required to have one specific health care professional dedicated to ensuring that minor children are documented in the patients' notes and the needs of these children are assessed and referred on to relevant services. A corresponding legal framework is needed in the UK to ensure that such children's and adolescent's needs are identified at an early stage and referrals to appropriate services are made.

Akerman and Statham's (2014) overview of childhood parental bereavement mentions proactive and reactive support in schools for bereaved children. Proactive interventions include staff training on loss awareness and equipping children/adolescents with knowledge and skills to cope with bereavement and offer support to peers. Reactive interventions would be pastoral support when an event has already occurred. Schools could also include death and bereavement as curriculum topics in order to dispel myths and taboos, thus normalising grief, and making children/adolescents more aware of the support available.

The charitable sector offers family-based services to bereaved children and young people via online support and guidance as well as face-to-face individual and group interventions. Charities also offer consultancy and training to professionals, including school staff and others dealing with bereaved children/adolescents and their families. As mentioned earlier, these charities (e.g., Winston's Wish and Child Bereavement UK) offer useful services, but only

in certain parts of the UK, thus confirming the findings of the review of services offered to children facing the death of a parent conducted by Kennedy et al. (2008a). This review found widespread national and global recognition of the importance of assessing and meeting the needs of bereaved children but, in relation to the UK, the review concluded that, although there was a complex range of services for children facing the death of a family member, provision was fragmented. A survey about support services for bereaved children in England (Penny, 2010) also concluded that there was a lack of planning and coordination of such services (see Chapter 2: Review of Literature – Psychosocial Therapeutic Services).

In summary, one can say that there is growing awareness that parental bereavement in childhood has both short and long-term consequences as the child develops into adulthood. There is a need for a population-based study to map the number of minor children living with a parent with a life-threatening illness in the UK in order to plan integrated and comprehensive services. Comprehensive services would start with loss-awareness training for children and young people which could be offered in schools by appropriately trained teaching staff. Advice and support for children, adolescents and parents/family members – offered online, via the telephone or face-to-face – needs to be widely available. Training of professionals (e.g., teachers, social workers, family doctors) dealing with this client group is also recommended. Routine assessment in oncology departments could identify minor children of patients who may need further interventions. Palliative care training across the professions should cover the needs of minor children and their families.

Concluding Thoughts

This study was exploratory in nature and therefore the outcomes, both in the clinical work and the research, are suggestive pointers towards further useful work in this field. I hope that child and adolescent psychotherapists and other professional clinicians who are working with families facing this type of serious crisis will undertake further research so that more knowledge can be accumulated on the needs of these clients and the therapeutic techniques appropriate for them.

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APPENDIX I: ETHICAL APPROVAL

Ethical approval from Wandsworth Research Ethics Committee

Ethical approval from University of East London/The Tavistock and Portman
NHS Foundation Trust



National Research Ethics Service
Wandsworth Research Ethics Committee

South London REC Office (1)
Room 1.14, Jenner Wing
St Georges University of London
Cranmer Terrace
Tooting, London
SW17 0RE

17 DEC 2009

Telephone: 0208 725 1558
Facsimile: 0208 725 1980

14 December 2009

Ms Freni Chinoy
Consultant Child & Adolescent Psychotherapist
South West London & St George's Mental Health NHS Trust
Sutton CAMHS, Cotswold House,
Sutton Hospital, Cotswold Road,
Sutton, Surrey
SM2 5NF

Dear Ms Chinoy

Study Title: Children and young people with parents with life threatening illness: explorations into a model of psychotherapeutic work
REC reference number: 09/H0803/99
Protocol number: 2

Thank you for your letter of 22 November 2009, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information was considered in correspondence by a sub-committee of the REC. A list of the sub-committee members is attached.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Ethical review of research sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

This Research Ethics Committee is an advisory committee to London Strategic Health Authority
The National Research Ethics Service (NRES) represents the NRES Directorate within

For NHS research sites only, management permission for research (“R&D approval”) should be obtained from the relevant care organisation(s) in accordance with NHS research governance arrangements. Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at <http://www.rdforum.nhs.uk>. *Where the only involvement of the NHS organisation is as a Participant Identification Centre, management permission for research is not required but the R&D office should be notified of the study. Guidance should be sought from the R&D office where necessary.*

Sponsors are not required to notify the Committee of approvals from host organisations.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	Version	Date
CV for Prof. Michael Rustin		
GP/Consultant Information Sheets		
Letter from Sponsor		05 June 2009
Protocol	2	05 September 2019
Investigator CV	CV for Freni Chinoy	
REC application	2.2	29 June 2009
Participant Information Sheet: Adults/parents/carers/family members	2	22 November 2009
Participant Information Sheet: Young people 11-17 years	2	22 November 2009
Participant Information Sheet: Children up to 10 years	2	22 November 2009
Participant Information Sheet: Professionals	2	22 November 2009
Participant Consent Form: Parents	2	22 November 2009
Participant Consent Form: Young People 16-17 years	2	22 November 2009
Participant Consent Form: Family members	2	22 November 2009
Participant Consent Form: Professionals	2	22 November 2009
Participant Consent Form: Children up to 15 years	1	22 November 2009
Response to Request for Further Information		22 November 2009

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Now that you have completed the application process please visit the National Research Ethics Service website > After Review

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

The attached document “After ethical review – guidance for researchers” gives detailed information on how to give your views to the Committee. For more information, please visit the National Research Ethics Service (NRES) website. The National Research Ethics Service (NRES) represents the NRES Directorate within the National Patient Safety Agency and Research Ethics Committees in England

guidance on reporting requirements for studies with a favorable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

We would also like to inform you that we consult regularly with stakeholders to improve our service. If you would like to join our Reference Group please email referencegroup@nres.npsa.nhs.uk.

09/H0803/99

Please quote this number on all correspondence

Yours sincerely



**Dr Christine Heron
Chair**

Email: recwand@stgeorges.nhs.uk

Enclosures: List of names and professions of members who were present at the meeting and those who submitted written comments "After ethical review – guidance for researchers"

Copy to: Dr Andrew Kent

Wandsworth Research Ethics Committee

Attendance at Sub-Committee of the REC held in correspondence

Committee Members:

<i>Name</i>	<i>Profession</i>	<i>Present</i>	<i>Notes</i>
Dr Murray Bain	Senior Lecturer / Consultant Paediatrician	Yes	
Dr Christine Heron	Consultant Radiologist	Yes	

Ms Freni Chinoy
203 West Barnes Lane
New Malden
Surrey
KT3 6HY

27 February 2014

Dear Ms Chinoy

**University of East London/The Tavistock and Portman NHS Foundation Trust:
research ethics**

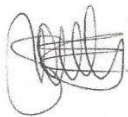
Study Title: ‘When a parent is dying: an exploration into a model of therapeutic work for children, their parents and families’

I am writing to inform you that the University Research Ethics Committee (UREC) has received your NHS approval letter, which you submitted to the Chair of UREC, Professor Neville Punchard. Please take this letter as written confirmation that had you applied for ethical clearance from our UREC at the appropriate time; it is likely it would have been granted. However, this does not place you in exactly the same position you would have been in had clearance been obtained in advance. Therefore, when responding to any questioning regarding the ethical aspects of your research, you must of course make reference to and explain these developments in an open and transparent way.

For the avoidance of any doubt, or misunderstanding, please note that the content of this letter extends only to those matters relating to the granting of ethical clearance. If there are any other outstanding procedural matters, which need to be attended to, they will be dealt with entirely separately as they fall entirely outside the remit of our University Research Ethics Committee.

If you are in any doubt about whether, or not, there are any other outstanding matters you should contact Mr William Bannister at the Tavistock and Portman NHS Foundation Trust (e-mail WBannister@tavi-port.nhs.uk).

Yours sincerely



pp: Catherine Fieulleateau
Ethics Integrity Manager
For and on behalf of
Professor Neville Punchard
Chair of the University Research Ethics Committee (UREC)

Tel.: 020 8223 6683 (direct line)
E-mail: c.fieulleateau@uel.ac.uk

c.c. Mr Malcolm Allen, Dean of Postgraduate Studies, Tavistock and Portman
NHS Foundation Trust
Mr Will Bannister, Associate Director, Education and Training, Tavistock and
Portman NHS Foundation Trust
Professor John J Joughin, Vice-Chancellor, University of East London
Professor Neville Punchard, Chair of the University of East London Research
Ethics Committee
Dr Alan White, Director of the Graduate School, University of East London
Mr David G Woodhouse, Associate Head of Governance and Legal Services

APPENDIX II: PROCESS OF DATA ANALYSIS

Theme: Impact of Maternal Illness: Strands, Aspects and Examples

Johnny		
Strands	Aspects	Examples
1. Emotional and behavioural effects on child/adolescent	Emotionally traumatised. Tantrums/challenging behaviour. Sad and frightened.	Play sequences in mother–child sessions showing danger to people and animals where even the emergency services’ rescuers die (e.g., drown). Mother reports major tantrums and challenging behaviour exhibited by Johnny. Johnny reports that mother had been sad and he had felt sad and frightened when mother had been very ill.
2. Child’s/ adolescent’s difficulties at school	Social/communication difficulties with peers and teachers.	School reports Johnny gets upset if friends play with others and gets frustrated when he cannot explain things to people or understand what people are saying to him.
3. Physical illness affecting ill parent	Mother has had surgery, chemotherapy and radiotherapy. Tiredness due to after-effects of radiotherapy. Feeling unwell. Short-term memory loss resulting from illness, surgery and medical treatments.	Mother being monitored by hospital. Mother and maternal grandmother report mother being tired and having less patience with the children at times. Mother reports shouting at children for making noise when she feels unwell. Mother forgets to get to psychotherapy sessions.
4. Emotional effects on well parent affecting his wellbeing	Father found mother’s illness intolerable to manage emotionally.	Mother and maternal grandmother report that father left the family home when mother was acutely ill.
5. Relationship difficulties within family	Major relationship difficulties between Johnny and mother.	Mother reports Johnny’s behaviour is difficult to manage. Sequences in sessions (i) when Johnny overtly and covertly challenges mother and (ii) when mother is unable to accept or contain Johnny’s angry feelings.

Sara		
Strands	Aspects	Examples
1. Emotional and behavioural effects on child/adolescent	<p>Depression.</p> <p>Self-harming.</p> <p>Challenging behaviour at home.</p>	<p>Sara reports feeling depressed when first seen by psychotherapist.</p> <p>Parents report Sara cutting her limbs and Sara agrees but says it was in the past.</p> <p>Parents report Sara's challenging behaviour is difficult to understand and deal with.</p>
2. Child's/ adolescent's difficulties at school	<p>Relationship difficulties with teachers.</p> <p>Difficulties with learning due to dyslexia.</p>	<p>Sara and parents report teachers do not understand and do not offer help for Sara's emotional and learning difficulties.</p> <p>Sara and parents report that Sara has dyslexia and is anxious about how she will manage revision and the forthcoming GCSE exams.</p>
3. Physical illness affecting ill parents	<p>Mother's recurrence of breast cancer had become metastatic. She had had surgery for the first bout of breast cancer and for recent ovarian cancer.</p> <p>Father has heart condition and chronic depression.</p> <p>Mother worried about Sara's future.</p> <p>Tiredness.</p>	<p>Mother continues to receive chemotherapy.</p> <p>Father has ongoing hospital treatment and feels very stressed.</p> <p>Mother worries about not being around to help Sara in the future.</p> <p>Mother feels tired due to her illness.</p>
4. Emotional effects on well parent affecting his wellbeing	<p>There is no well parent in this family.</p>	
5. Relationship difficulties within family	<p>Sara's challenging behaviour towards parents.</p> <p>Both parents' concerns about Sara.</p> <p>Mother feels stressed.</p> <p>Sara thinks parents over-react.</p> <p>Sara's concerns for her parents.</p>	<p>Parents report Sara being challenging, for example, coming home reeking of cigarette smoke.</p> <p>Parents report that Sara is immature and struggles with peer relationships but Sara denies this.</p> <p>Mother feels stressed by father's negativity due to his depression.</p> <p>Sara reports that parents tend to over-react and minimises difficulties with her parents.</p> <p>Sara reports guilt about her behaviour upsetting her parents.</p>

Farah		
Strands	Aspects	Examples
1. Emotional and behavioural effects on child/adolescent	<p>Very upset about mother's illness.</p> <p>Frightened mother will die.</p> <p>Self-harming.</p>	<p>Referrers (GP, hospital psychologist) report Farah very upset due to mother's second bout of breast cancer.</p> <p>In session with psychotherapist Farah says that she is worried that mother will die.</p> <p>Parents report Farah had been head-banging and had tried to cut off her own hair.</p>
2. Child's/ adolescent's difficulties at school	<p>Difficulties with peer relationships.</p>	<p>Parents report that Farah struggles with large circle of friends and can be bossy.</p> <p>Farah tells psychotherapist that she had been accused of spying by peers and she feels upset.</p>
3. Physical illness affecting ill parent	<p>Mother has recurrence of breast cancer and has had surgery, radiotherapy and chemotherapy.</p> <p>Work and maternal roles affected.</p>	<p>Mother continues with hospital treatment and has second breast reconstructive surgery.</p> <p>Parents report mother juggling with work and maternal roles.</p>
4. Emotional effects on well parent affecting his wellbeing	<p>Father feels very stressed.</p> <p>Father worried mother is doing too much.</p>	<p>Father somatises anxieties, for example, when mother is in hospital he gets shingles and links it with his anxieties about mother's ill health.</p> <p>Father reports he is worried mother is not slowing down and not learning from the recurrence of her life-threatening illness.</p>
5. Relationship difficulties within family	<p>Love-hate relationship between sisters.</p> <p>Sibling rivalry.</p> <p>Parents unable to discuss mother's illness.</p>	<p>Parents report a love-hate relationship between sisters with Farah bossing younger sister Gabby.</p> <p>Farah and Gabby compete for father's attention in sessions.</p> <p>Parents report not talking about mother's illness but concentrating on being good parents.</p>

Gabby		
Strands	Aspects	Examples
1. Emotional and behavioural effects on child/adolescent	<p>Frightened that mother will die.</p> <p>Feels sad about mother's illness.</p>	<p>Gabby voices her worries about mother dying in family handover meeting with hospital psychologist and CAMHS psychiatrist.</p> <p>Gabby draws a stark picture in psychotherapy of mother in hospital with father looking serious, and Gabby and sister looking sad (see Appendix III).</p>
2. Child's/ adolescent's difficulties at school	No difficulties reported at school.	Parents report that Gabby is very sociable and liked by peers.
3. Physical illness affecting ill parent	<p>Mother has recurrence of breast cancer and has had surgery, radiotherapy and chemotherapy.</p> <p>Work and maternal roles affected.</p>	<p>Mother continues with hospital treatment and has second breast reconstructive surgery.</p> <p>Parents report mother juggling with work and maternal roles.</p>
4. Emotional effects on well parent affecting his wellbeing	<p>Father feels very stressed.</p> <p>Father worried mother is doing too much.</p>	<p>Father somatises anxieties, for example, when mother is in hospital he gets shingles and links it with his anxieties about mother's ill health.</p> <p>Father reports he is worried mother is not slowing down and not learning from the recurrence of her life-threatening illness.</p>
5. Relationship difficulties within family	<p>Love-hate relationship between sisters.</p> <p>Sibling rivalry.</p> <p>Parents unable to discuss mother's illness.</p>	<p>Parents report a love-hate relationship between sisters with Farah bossing younger sister Gabby.</p> <p>Farah and Gabby compete for father's attention in sessions.</p> <p>Parents report not talking about mother's illness but concentrating on being good parents.</p>

Elliot		
Strands	Aspects	Examples
1. Emotional and behavioural effects on child/adolescent	Depression.	Elliot reports feeling depressed. Parents report that Elliot's depression began after being told mother's cancer can be treated but not cured. This is when he stopped going out with friends.
2. Child's/ adolescent's difficulties at school	Difficulties doing school work.	Elliot reports problems with concentration and motivation to do school work. Parents report that Elliot is a high-achiever and gets frustrated that he is not able to keep up high standards in school work. School reports that they have advised Elliot to drop one 'A' level subject in order to cope.
3. Physical illness affecting ill parent	Mother has metastatic breast cancer and has had radiotherapy and chemotherapy. Mother feeling tired.	Mother reports that she continues with three-weekly pharmacological treatment at hospital. Mother reports feeling tired, especially the week after hospital treatments. Mother cooks for the family but gets help with housework.
4. Emotional effects on well parent affecting his wellbeing	Father feels guilty. Father tries not to worry.	Father reports that he works long hours and feels guilty for not being available for his family. Father reports surprise at how well mother was coping and tries not to worry.
5. Relationship difficulties within family	Elliot's withdrawn state at home.	Elliot and parents report that he spends a lot of time in his room listening to music. He interacts more with his mother who is at home more than his father, who spends long hours at work.

Andrew		
Strands	Aspects	Examples
1. Emotional and behavioural effects on child/adolescent	<p>Major psychiatric problems – suicidal, depression, anxiety, Asperger's Syndrome.</p> <p>Angry with mother and becomes suicidal.</p>	<p>Psychiatrist continues to treat Andrew's anxiety, depression and suicidal ideation with medications.</p> <p>Mother reports that Andrew got very angry with her after her diagnosis of breast cancer, became suicidal and had to spend some weeks in an adolescent inpatient psychiatric unit.</p>
2. Child's/ adolescent's difficulties at school	In specialist school provision.	Andrew finds it difficult to attend specialist school and this has an effect on his GCSE results, although he is said to be bright.
3. Physical illness affecting ill parent	<p>Mother has metastatic bilateral breast cancer – has had surgery and chemotherapy.</p> <p>Mother's home-making and maternal roles affected by low energy levels.</p> <p>Loss of hair due to chemotherapy.</p> <p>Mobility problems.</p> <p>Difficulty in getting up from chair.</p> <p>Immunity affected.</p> <p>Mother did not want her identity to be defined by her illness.</p> <p>Shortening of lifespan.</p> <p>Creativity.</p>	<p>Mother reports that she is undergoing radiotherapy.</p> <p>Mother's low physical and mental energy levels affect house-keeping duties and looking after her children and pet puppy.</p> <p>Mother tended to keep her hat on when she first came for sessions.</p> <p>Mother could walk only short distances and did so slowly.</p> <p>If mother had been sitting down for a while she felt her joints would seize up and it hurt to stand up.</p> <p>Mother reported that her illness affected her immunity and she often got colds.</p> <p>Mother said several times that she did not want to be seen just as a cancer patient – she was the same person before and after the illness took hold.</p> <p>Mother said that now she was going to die she felt she had been robbed of her 'selfish years'. The children were growing up and did not need her care as much and therefore she would have finally been able to look at her own needs.</p> <p>Mother kept a humorous online blog about her experiences with cancer. She also took part in a theatre production based on this blog. Both</p>

		these activities attracted positive responses from others.
4. Emotional effects on well parent affecting his wellbeing	Mother's partner worried and sad about mother's illness.	Mother's partner realises that mother will not live long and cannot bear to think about it, so he denies seriousness of mother's illness and reports more positive discussions with mother's doctors than mother does.
5. Relationship difficulties within family	<p>Children's major needs affect relationships in family.</p> <p>Middle son's needs.</p> <p>Andrew's needs.</p> <p>Daughter's needs.</p>	<p>Mother reports that middle son with severe learning and physical disabilities would love to live at home, but she cannot manage to look after him and she finds that heart-rending.</p> <p>Mother has to monitor Andrew's mental state constantly and decide whether to call an ambulance if he appears suicidal.</p> <p>Mother supports daughter with Asperger's Syndrome, who has gone abroad as an au pair, via daily phone calls and texts.</p>

APPENDIX III: DRAWING MADE BY GABBY

