Finding the way to a ‘new normal’:
The journey of recovery for families following a paediatric intensive care admission

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Submitted for the degree of Doctor of Psychology
(Clinical Psychology)

Volume One

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July 2010

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Introduction to the Portfolio

Acknowledgements

I want to thank the course team for the support they provided throughout the programme, particularly Dr Sue Thorpe and Dr Nan Holmes. Additionally I am extremely grateful to Mary John and Gillian Colville for the advice and guidance they provided.

Additionally I would like to thank my placement supervisors for the opportunities they provided and the individuals who I worked with on these placements. In particular I am indebted to Julie Lloyd, Dr Sarah Johnstone and Gillian Colville, from whom I learnt a great deal.

I would also like to acknowledge all the children and families I have been fortunate enough to work with across my career to date because it is my experiences with them which have led me to this point (and continue to motivate me beyond the programme).

Finally I want to thank Pam for grounding me through her unfailing support and unconditional positive regard and David for his love, unshakeable faith, calming influence and ready supply of cakes.

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Introduction to the Portfolio

Introduction to the portfolio

This is a portfolio of work completed across three years of the Doctoral Training programme for Clinical Psychology.

The portfolio is split into two volumes. Each volume is further divided into the academic, clinical and research dossiers. The first is the public volume that will be held in the library of the University of Surrey. The second is a private volume as it contains sensitive and confidential material and thus will be stored securely in the psychology department at the University of Surrey.

This is the first volume. In this volume the academic dossier contains two essays, three reflective accounts of the problem based learning exercises, summaries of the two process accounts of the case discussion group or personal and professional learning group.

The clinical dossier contains summaries of the four clinical case reports and the oral presentation of clinical activity. Additionally there is a summary of experiences gained across the five placements.

The research dossier contains a service-related research project, a summary of the qualitative research project and the major research project. The appendices include publications and conference presentations by the author.

The aim of the portfolio is to demonstrate the variety of work completed over the three years of clinical training. Additionally it aims to convey the author's progression as a psychologist in both clinical and academic fields, and each dossier is laid out chronologically to illustrate this development. The work in this portfolio reflects a range of client groups, presenting problems and psychological approaches covered during the course. Identifying details have been changed or removed in this portfolio in order to maintain confidentiality and anonymity.
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Academic Dossier

This dossier contains two essays. The first is an Adult Mental Health Essay completed in year one. This is followed by an essay focused on Organisational and Professional issues, written in year two.

There are three reflective accounts which consider the work completed during the Problem Based Learning exercises, completed each year across the programme.

Finally there are summaries of the two process accounts of the Case Discussion Group (year 1) and the Personal and Professional Learning Group (year 2). These both reflect on the same group, but the name of this group was changed during training. The complete accounts can be found in volume two of this portfolio.
Critically evaluate the contribution of attachment theory to the formulation and treatment of borderline personality disorder

Year one
March 2008
Introduction
The role of the clinical psychologist is changing (BPS, 2007). In line with the aims to be a ‘scientific practitioner’ (Cheshire & Pilgrim, 2004; Harvey, 2001) and ‘reflective practitioner’ (BPS, 2006a) this essay aims to consider the evidence for interventions for people with borderline personality disorder (BPD) and will reflect on the role of attachment theory within this work. As a trainee psychologist it has provided me with the space to consider a small area of my practice and reflect on the evidence available.

This assignment therefore considers attachment theory and its importance and relevance to the clinical practices of formulation and treatment for clients with borderline personality disorder (BPD). I start by reflecting on my choice of essay and go on to consider attachment theory. BPD is discussed and I draw on service-user literature to consider whether a psychiatric diagnosis has value. I reflect on the tensions for psychologists working with a diagnosis-led system. The assignment then moves on to think about how attachment theory can be brought into a consideration of formulation and treatment. Focusing on a specific model of treatment is beyond the scope of this essay; instead the assignment focuses on Bowlby’s (1988) suggestions for the key principles to be employed by the psychologist. The essay concludes that attachment theory can have an important role to play in working with people who present with difficulties labelled as BPD. However there is recognition that attachment theory is just one model relevant to people experiencing distress.

Personal reflections on the title
I chose to focus on attachment because my background has primarily consisted of work with children. In a variety of roles I have applied aspects of attachment theory to understand children’s behaviour and offer support to care-givers who may be struggling to meet a child’s needs. Key amongst these experiences was working with children and care-givers in large institutions in Bosnia and Romania. In these settings the damage done to the children who had no primary carer was stark and at times very difficult to observe. Attachment theory provided the most usable framework to
conceptualise their distress. Spending a year working with adults is a new challenge. It is a field where I have little experience and therefore feel unsure about my skills with this client group. This essay offered an opportunity for my prior knowledge to be valued in a new sense.

As someone with a passion for facilitating positive service user experiences I had grown aware of the negative attitudes towards people with a diagnosis of BPD. This drove my desire to find out more about this label. Only a small portion of this journey can be documented in this assignment, but the wider learning I will take away from the process has been both valuable and thought provoking. This assignment will attempt to discuss the relevant clinical links in a way which will be useful for me on my current and future placements.

**Attachment theory**

Originally developed by Bowlby (e.g. 1969) attachment theory considers the relationship which develops between the child and their primary care giver(s). He defined attachment as ‘A way of conceptualising the propensity of human beings to make strong affectional bonds to particular others’ (Bowlby, 1979 cited in Woodward, 2004, p.7). The making of these bonds is considered to serve a biological and a psychological function (Woodward, 2004). Biologically forming an attachment aids survival of a vulnerable baby (Oates et al, 2005). However beyond simply surviving all humans have a need for closeness and security (Gerhardt, 2004) and attachment bonds enable this requirement to be fulfilled.

Bowlby and his successors developed the idea of a ‘secure attachment’ which reflected the experiences of infants whose emotional needs were met appropriately. Fundamental to secure attachment were the concepts of a ‘secure base’ and the need for emotional regulation of babies and young children (Bowlby, 1988). Bowlby saw a secure base as a ‘central feature of my concept of parenting’ (p.11) where the child can explore the world, knowing they have someone safe to return to (ibid). Emotional regulation occurs when distress is dealt with sensitively by care givers, emotionally ‘holding’ the difficulties the child is dealing with until they internalise the idea that such distress is not overwhelming (Dallos, 2006). Through these
experiences the child learns that their emotions are legitimate but manageable and in times of need they can return to their caregiver for support. Thus the child becomes securely attached (Cassidy, 1999). The experiences of emotional regulation and having a secure base also facilitate the development of positive internal working models of themselves, other people and the world (Liotti, 2007).

Mary Ainsworth developed the ‘strange situation’ to test the types of attachment children had developed with their primary care-giver (mainly the mother) (Oates et al, 2005). In the investigation the children start in a playroom with their mother, who leaves the child alone with the stranger and later on their own. She then returns and settles the child (ibid). In this situation securely attached children are distressed at their mothers leaving, but comforted on their return (Woodward, 2004). Ainsworth found that some children were not distressed when their mother left and these children were labelled as having an ‘insecure-avoidant’ attachment pattern. Other children refused to be consoled on their mother’s return, seeking comfort but not finding this to be soothing. These children were described as having an ‘insecure-ambivalent’ attachment relationship (Ainsworth et al., 1978 in Bowlby, 1991). Children develop these insecure attachment patterns as a result of parents who are either unavailable or inconsistent. The lack of secure attachment relationships results in children who have negative internal working models and more difficulty in dealing with their own distress (Cassidy, 1999).

Subsequently a fourth category was developed to describe infants whose responses to their mothers were confused and unpredictable (Woodward, 2004), often freezing on their mother’s return. These children were described as having ‘insecure-disorganised’ attachment pattern (Main & Solomon, 1990). Such children may have experienced extremely difficult situations, and may lack any coping strategies or be withdrawn or defensive as a result of parenting that is frightening, intrusive, un-boundaried or abusive (Dallos, 2006).

**Adult Attachment theory**

Following an investigation of attachment in young children, the concept was examined in adolescents and later in the context of close adult relationships (Shemmings, 2005). Adult attachment relationships differ from their childhood...
counterpart as either party can give or receive support, making them bidirectional relationships (ibid). However it is suggested that the patterns adopted by infants map onto the adult attachment styles (Spearman & Berman, 1994). The four adult attachment styles were suggested to be ‘balanced’, ‘preoccupied’, ‘dismissing’ and ‘fearful’ (ibid) the first three of which are said to develop from children who experience secure, ambivalent and avoidant relationships respectively in infancy (Shemmings, 2005). There remains some debate about how the disorganised style in young children develops through into adulthood and research has shown the pattern not to be enduring (Lyons-Ruth & Jacobvitz, 1999). For this reason there remains debate about how the fearful style develops (Shemmings, 2005).

**Attachment in the current context**

Attachment theory has been criticised for its political role in getting mothers back into the home following World War II (Goldberg, 2000). I mention this because I believe it is important to keep in mind that the social and political climate in the 21st century is quite different. Psychologists need to ensure that they retain this perspective when applying attachment theory in their practice. I wonder whether the power of attachment theory is reduced because of these different contexts, but from the evidence it would appear that there is still value in the model in mental health work today.

Attachment theory rests within the psychodynamic model of recognising early experiences as important. This is supported by the fact that research highlights the number of clients presenting to services who have experienced difficult early relationships (e.g. Schneider et al, 2007). However there is also evidence to the contrary, suggesting that many children who experience challenging or abusive early environments do not go on to experience mental health problems (Alterman et al, 1989). This suggests that attachment theory may be highly relevant to mental health services in the current climate, but that other factors are also relevant. However, even taking into account the variety of other factors, attachment theory retains a function in the formulation and therapeutic work in psychodynamic therapy (Bateman et al, 2000).
Issues of diversity seem particularly important to me at this point. Firstly whether a person develops mental health problems following a difficult childhood will depend on a number of factors, including their genetic make-up, their background (e.g. issues around poverty and deprivation) and their ethnicity to name but a few. Further whether a person engages with a certain type of therapeutic approach, such as CBT or psychodynamic therapy, will depend on their own preferences and opinions about therapeutic interventions. Rather than forcing a certain approach onto a client they should be given the choice from those therapies which are evidenced to make a difference for the difficulties they present with (Layard, 2004). The issue of diversity is one I have tried to embody in my practice, and attempt to retain in this assignment, especially in considering aspects of diagnosis and formulation, which now follows.

Definitions of borderline personality disorder

BPD is defined in the *Diagnostic and Statistical Manual* (DSM-IV-TR) with a number of distinguishing characteristics. These include efforts to avoid abandonment, intense and unstable relationships, an unstable sense of self, impulsivity and recurrent suicidal or self-harming behaviour (American Psychiatric Association, 2000). Under the ICD-10 classification system, set by the World Health Organisation the equivalent diagnosis is called ‘emotionally unstable personality disorder – borderline type’ which is similar to the DSM-IV criteria, but also includes ‘chronic feeling of emptiness’ in its identification (WHO, 1992).

Whilst such diagnoses have both medical and legal significance they are not without their critics. Pilgrim (2001) argues that personality disorder (PD) diagnoses are described differently in other cultures and in British mental health services the label is ‘a dustbin category of problematic ‘behaviour’ as judged by significant others or staff’ (p.255). Levenson further suggests that PDs are seen as an inability to measure up to society’s norms for behaviour, which raises questions about those who demonstrate against oppressive regimes such as apartheid law in South Africa (Levenson, 1992). Such a perspective needs to be retained by a psychologist seeing a
client with a diagnosis of BPD. The practitioner will need to ensure that both the medically defining symptoms and the wider social implications of such a diagnosis are held in mind.

As this assignment title addresses formulation rather than diagnosis it is beyond the scope of this assignment to critique the latter extensively. However psychologists invariably experience a tension between these medical and social model constructs (Albee, 2000) it is worth spending a little time considering how this tension can impact on a psychologist’s role in formulation and treatment. Generally a diagnosis aims to compare the presenting patient against a list of criteria and identify if they deviate from ‘normal’, thus earning a place in a specific group – such as BPD (Stalker et al, 2005). Conversely formulation is an attempt to understand the client as an individual with a specific set of difficulties at a certain time (Weerasekera, 1996 in Johnstone & Dallos, 2006). Further formulation has clear implications for intervention (Eells, 1997).

Service users have reflected on beliefs that a PD diagnosis is unhelpful and potentially damaging (Stalker et al, 2005). Horn et al argue that a BPD diagnosis often results in being seen as ‘bad rather than mad’ (Horn et al, 2007, p.256). Further it is argued that diagnoses allow a power imbalance with the professional sitting in the ‘knowing’ position whilst the service user is left with the opposite feeling (ibid). Given service users’ lack of comfort with diagnosis (Pilgrim, 2001; May, 2007; Campbell, 2007) psychologists may be in a key position to work collaboratively with clients in helping them understand and come to terms with their distress. However, whatever clinicians believe in the efficacy of formulation over diagnosis, the reality of the mental health system means that currently we must work with both constructs daily and sit with the tension this creates (Boyle, 2007).

**The contribution of attachment theory to formulation**

It is important to begin this section with a recognition that formulation attempts to identify what is occurring for a particular individual at a particular point in their life (Weerasekera, 1996 in Johnstone & Dallos, 2006). Therefore to discuss clients with a BPD diagnosis as a homogenous group will always have its limitations. Each client
will have different early experiences, have responded to this in a variety of ways and currently be experiencing an array of different difficulties or distress. However, attachment theory has demonstrated that it is possible to generalise people’s reactions to a certain degree (Bowlby, 1991), and the categories developed both for infants and adults may help to understand a service user with BPD.

There are a number of ways to formulate a client’s difficulties. A cognitive-behavioural formulation would include a section on early experience, and hypothesise about the effect of these early experiences on core beliefs about the self, others and the world (Beck, 1995). This would allow for consideration of the interplay between thoughts, feelings and behaviours in the present (ibid). Therefore, whilst attachment is essentially a psychodynamic construct there is a place for it in a cognitive-behavioural formulation (Gilbert & Leahy, 2007). From my limited experience of using cognitive behaviour therapy (CBT) in practice I have not found that attachment relationships are explicitly mentioned. Instead I have observed early parental relationships being noted as a general difficulty and generalised to generate core-beliefs such as ‘I am unlovable’, ‘other people cannot be trusted’ or ‘the world is not a safe place’. Perhaps it is felt that elaboration of specific attachment patterns might not add anything to the CBT formulation that relevant core beliefs cannot offer on their own. The evidence suggests that there is value in formulating around attachment theory, even in CBT (McBride et al, 2006), something my own experience would support.

Alternatively a psychodynamic formulation posits that behaviour has a function and meaning for the individual although the connotations may well be hidden from the person’s current awareness (Bateman et al, 2000). Therefore the presenting problems of someone with a BPD diagnosis would be considered in the light of early experiences. For example a distant or dismissing care-giver might result in an infant hurting themselves in an attempt to gain attention or support (Hopkins, 1991). Early attachment patterns often resolve into similar adult behaviour (Spearman & Berman, 1994). Therefore it is reasonable to assume that such self-harming behaviour might continue into adulthood with the function of asking for help and support, in the absence of any more adaptive strategies. A psychodynamic formulation appears to have more space to consider attachment issues relevant to a client with BPD (Bateman et al, 2000). This is therefore the model that will be used
for the remainder of the assignment, considering how attachment theory relates to BPD in adults.

Attachment theory for adults with BPD

As noted attachment patterns formed in infancy can have an impact on adult relationships. The importance of the crucial early relationships cannot be overstated. ‘Conflict and breakdown in these supportive and self-defining relationships cause distress and even illness’ (Bateman et al., 2000, p.33). Bowlby felt that ‘internal working models of attachment help explain the many forms of emotional distress and personality disorders’ (1977 in Levy et al., 2006, p.1028). Further it has been noted that children with insecure attachments may be psychiatrically at risk (Hopkins, 1991). Some of the reasons for this heightened risk will be considered.

Firstly a secure attachment enables the young child to develop skills in emotional regulation (Woodward, 2004), being able to contain their initially overwhelming emotions and recognise that distress is manageable and transient. A diagnosis of BPD includes the criteria ‘affective instability due to a marked reactivity of mood’ (APA, 2000, p.629), suggesting that such clients lack the skills in emotional regulation. In comparison with the infant attachment classifications from the strange situation this seems to reflect children who were described as ‘ambivalent’ – those who were distressed and yet unable to receive comfort from their mothers.

A further feature of secure attachments is that they allow children to learn that they are worthy of love, support and emotional containment (Gerhardt, 2004) hence supporting the growth of a positive self-image. Again a comparison with the DSM-IV-TR criteria highlights this as an area of difficulties for people with BPD. The diagnostic criteria include ‘identity disturbance: markedly and persistently unstable self-image or sense of self’ (APA, 2000, p.629).

Parallels can be drawn between disrupted attachment patterns in childhood and the existence of intense unstable relationships and the effort to avoid abandonment (APA, 2000) seen in adults diagnosed with BPD. However there is some lack of clarity over exactly which childhood attachment style may be a risk factor for developing
BPD. Some authors believe BPD is a reflection of disorganised attachments (e.g. Kernberg, 1987; Sable, 1997); whilst others attribute it to insecure patterns (Levy et al. 2006). In a recent study Holmes (2004) identified similar findings concluding that ‘a group of patients suffering from BPD were almost entirely classified as unresolved/preoccupied’ (p.183). This research appears to suggest that infants who experience both inconsistent parenting (ambivalent-type) or frightening/abusing parenting (disorganised-type) may be at risk of experiencing significant difficulties as they grow up, therefore attracting a diagnosis of BPD.

However whilst attachment theory has a great deal to contribute to the formulation of BPD it is not the only perspective to be considered. It is widely recognised that the reasons for a client’s distress are multifaceted (e.g. BPS, 2006). Other writers have attempted to capture this diversity by considering other factors which are present for the client with a diagnosis of BPD, such as biological or cognitive influences. These include Alwin’s biopsychosocial interpretation of a client’s presenting problems (2006) or the social constructivist view of BPD presented by Benjamin & Wonderlich (1994) which views the problems as relational and as a concept existing between people rather than within one person (Horn et al., 2007). To truly work within the social model that psychology professes to support (e.g. Boyle, 2007) would require recognition of the role society plays in compartmentalising people with mental health problems. Further it would require an acknowledgment of the lack of adaptation which can exclude people with BPD from meaningful participation in society.

A formulation which includes difficulties in attachment relationships might allow both clients and clinicians to sit more comfortably with the label of BPD. For the client attachment theory may be a reassuring perspective which reflects to them that they are not alone in having these kinds of difficulties, and that they are not inherently distressed, evil or dangerous (ibid). Freeman et al. write that ‘few categories strike as much fear into the hearts of clinicians as does the term borderline personality disorder’ (2004, p.1). The negative reaction that is achieved by the term BPD might be ameliorated by considering attachment difficulties as it provides a new way for clinicians to conceptualise the difficult behaviours that the client presents with.
The client has a great deal to contribute to formulation (Horn et al., 2007). It can be seen as an opportunity for the client and psychologist work together to understand the client’s current distress. Many service users have highlighted their difficult childhoods and disclosed abuse (Stalker et al., 2005) as a factor in their current distress. However equally, the client may be unwilling to discuss early experience because they are painful, or they do not want judgement to be passed on them or their family. Moreover they may not recall all the details of their difficulties possibly due to the abuse they experienced or because of current memory problems perhaps arising in combination with depressive symptoms. A client who is not yet ready to face the painful experiences of their past may perceive the formulation as a personal attack or as an irrelevant reminder of possibly traumatic memories they have worked to forget.

Formulations have immeasurable power in the therapeutic relationship (Slade, 1999) and need to be managed with care (Johnstone & Dallos, 2006). This is perhaps of special importance when working with clients who have a diagnosis of BPD, due to the difficulties experienced in managing interpersonal relationships appropriately. These issues are especially pertinent when working with people in extreme distress or who mistrust relationships. As a trainee I have found it important to remember that a formulation is simply a hypothesis (ibid) about someone’s difficulties and an inference of experiences a client might have had as a child, rather than an objective truth.

Therefore, whilst it can be of great benefit, a formulation cannot be a definitive guide to everything the client is experiencing. Formulation is a complex and contested construct (Johnstone & Dallos, 2006) which will generate issues that the psychologist needs to consider, especially if they are to undertake treatment with that client.

The contribution of attachment theory to treatment

Bowlby (1988) identified five key areas in which attachment theory contributes to psychotherapy.

1. Providing a secure base
2. The therapist-client relationship as a model
3. Considering internal working models of the self and others
4. Exploring significant relationships
5. Reflecting on current behaviours as a product of early experiences
(Adapted from Bowlby, 1988, p. 138).

These have since been further explored and developed by other writers. I shall briefly discuss these approaches with their relevance to a client with a BPD diagnosis.

**The therapist as a secure base for exploration**

The therapeutic relationship can be seen to function in a similar way to a secure parent-child attachment relationship with the therapist fulfilling the role of a secure base from which the client can start to talk about their difficulties (Sable, 1997). Within the therapy room the client can explore new possibilities (Faber et al, 1995) and as the bond strengthens and the client feels safe they may be able to experiment with these new ways of being outside the sessions. This will occur when the client internalises the therapist as a secure base and can therefore explore even when they are not physically present (Liotti, 2007).

Clients with BPD who are likely to have unresolved or preoccupied attachment styles may initially struggle to use their therapist as a secure base (Sable, 1997). One of the diagnostic criteria for BPD is ‘a pattern of unstable and intense interpersonal relationship’ (APA, 2000, p.629) so it seems likely the client would approach the relationship with the psychologist in a similar way. If the therapist is aware of potentially difficult attachment patterns they may recognise the client’s reaction as resulting from fears of rejection or abandonment (Sable, 1997). The therapist will need to encourage the client to trust them enough to explore their distress, and in this regard it will be vital to ensure that a strong therapeutic relationship is built.

Beyond simply providing a secure base an attachment relationship offers the opportunity for containment of the difficult and distressing emotions concurrent with a BPD diagnosis (Ryle, 1997). This ‘especially important with the fluctuating rage, anxiety and panic of borderlines’ (ibid, p.176). Having never learnt that they had capacity to manage their own distress or seek support the therapist needs to
model this aspect until the client can internalise it and manage their emotions appropriately without help.

The therapeutic relationship & internal working models

In therapies specifically designed for clients with BPD, such as transference focused therapy (Clarkin et al., 1999), dialectical behaviour therapy (Lineham, 1993) and mentalisation based therapies (Fonagy & Bateman, 2006) the key ingredient is the building and using of a secure therapeutic relationship. This is seen as a vital element for change (Bowlby, 1988). It is hypothesised that having experienced a secure attachment, clients are then more likely to be able to reproduce this in relationships in the outside world. In addition to the evidence service-user literature also places value on this aspect of therapy (Stalker et al., 2005; Horn et al., 2007). Finally it has also been noted that pharmacological interventions for BPD are less effective than talking therapies (Fonagy & Bateman, 2006), suggesting the relationship to be important in a person’s improvement.

Secure attachment relationships teach emotional regulation by containing distress and reflecting it back in a way which is manageable (Fonagy et al., 2004). Clients with insecure attachments may never have developed this understanding. The result will be an adult who finds it difficult to deal with the overwhelming emotions which are ‘...very real and greatly restrict what they could do’ (Stalker et al., 2005, p.372). The therapeutic relationship could be seen to be modelled on attachment relationships, with the therapist being attuned to the client and empathetic towards their distress (Sable, 1997). Further the clinician may be able to demonstrate emotionally ‘holding’ the material the client shares in therapy (Slade, 1999), and reflecting back that any distress is understandable but manageable (Gilbert & Leahy, 2007).

The diagnostic criterion for BPD goes on to say that the relationships ‘are characterised by alternating between extremes of idealization and devaluation’ (APA, 2000, p.629). Clients with insecure or disorganised attachments will by definition lack experience of stable, reliable relationships. It may therefore be
difficult for these clients to trust and rely on their therapist, as their internal working model will be that relationships do not work out, and are often painful or abusive (Liotti, 2007). There is a danger that these schemas will then overwhelm any positive representations as the client and therapist work together (Levy et al., 2006). The implications for treatment are therefore an explicit awareness of what is happening in the therapeutic process and recognition that things may be difficult for the client due to their previous experiences of relationships.

Exploring current relationships in the light of previous experience

Once secure attachments have be modelled and accepted in therapy the client may be ready to move forward and consider difficult experiences from their past. Most clients attend therapy driven by a desire to change their present experience (Stalker et al, 2005). It will therefore be important to look at what is happening in the client's life at present and consider goals for the future. Though it might be painful this will require an evaluation of childhood experiences in therapy. This will aim to identify unhelpful patterns which have been transferred from the past onto the current relationships.

However the exploration of the past is not the only route to discovering the client's internal working models. People with a diagnosis of BPD may experience deficits in social reality testing (Levy et al, 2006) which may result in fear the therapist is evaluating the client negatively, or is going to abandon them. Explicitly considering the effect of insecure or disorganised attachments on the therapeutic relationship may provide useful material (Bowlby, 1988). Holmes (2004) posits that the therapist must be able to recognise counter-transference and 'use her own emotional reactions in the service of the sufferer' (p186). Reflecting back the difficulties in a non judgemental manner may allow the client to integrate the previously repressed aspects of themselves, allowing a more complete understanding of their difficulties (Kernberg, 1987). Having recognised their behaviours in relationships, both past and present, the client may then be in a better position to ensure future interactions are more successful.
Reservations about the applicability of attachment theory

Attachment theory is but one tool to support clients and the interventions suggested have to sit amongst so many other theories, techniques and practices (Shemmings, 2005). Knowledge of attachment theory would seem vital (Slade, 1999) but alone it can never tell the full story or lead to complete distress amelioration.

Recreating attachment relationships has been the subject of some criticism (Faber et al, 1995). Whilst Bowlby (1991) emphasised the clinical relevance of attachment theory Hamilton (1987) suggested it was of limited use as a background theory but did not have clinical applicability (cited in Faber et al, 1995). My own personal experience of working with individuals with disrupted attachments suggests that there is a place for attachment theory within treatment models. This is supported by the literature on schema therapy which suggests spending the entire first year of treatment working on building a secure emotional attachment (Young et al, 2003).

Bowlby (1988) reflected that although attachment theory was originally designed for clinical use, it is generally applied to development psychology reducing the opportunities for psychologists to consider the difficulties their clients present with. Writing this assignment has enabled me to realise how applicable attachment theory is to the clients I am currently supporting. I have found this to be simultaneously comforting and daunting. I draw comfort from the recognition that my previous efforts to develop an understanding of attachment relationships provide me with useful material for my doctoral studies. However I find it intimidating to be unsure if I will ever reach a point where my knowledge feels adequate to support clients experiencing complex problems.

Conclusion

The diagnosis of BPD is multifaceted and complex. Many aspects are involved in a person developing the symptoms which our dominant discourse labels as BPD. These include biological, cognitive, interpersonal and developmental reasons (BPS, 2006b; Freeman et al., 2004). I believe that amongst these an awareness of attachment theory is vital, but care must be taken to ensure this is not simply one more weapon of blame. I am passionate about respecting people as individuals, with
their own unique challenges and therefore any work must include an awareness of the client's own successes and coping strategies thus far. It is vital that therapy includes an acceptance of negative attachments, and provide holding environment which helps the client manage their distress. Here the therapeutic relationship may be the first key to working towards a solution which allows the client more positive and satisfying experiences in the future.
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Organisational and Professional Issues Essay

Moving beyond the distress/disability of the individual: how can clinical psychologists work with local communities to reduce the stigma and discrimination that lead to social exclusion?

With a focus on the exclusion experienced by people who are homeless.

Year two

January 2009
"When we forget that people...share a common humanity with us, then the human is stripped...and the stage is set for the emergence of the inhuman and the inhumane"  

Introduction

There are multiple pressures on psychologists. These include being expected to see increasingly complex clients, consider the perspectives of service users and carers, take management roles, supervise staff and work to develop the multidisciplinary team (British Psychological Society (BPS), 2007). These complex and diverse roles require psychologists to think and work in a variety of different ways. This includes moving beyond the distress of the individual and ensuring that communities are considered and consulted (ibid) in order to make a positive difference. To achieve these aims psychologists are armed with a number of specialist skills and hold knowledge relevant to the challenges they face. Not least of these is the challenge of tackling stigma and discrimination which may be the daily reality for groups of vulnerable people (Division of Clinical Psychology (DCP), 1995).

I have chosen to focus on the social exclusion which is experienced by people who are homeless. After reflecting on the influences which have made this topic pertinent to me, I will consider social exclusion and reflect on how stigma and discrimination can lead to the exclusion from society which homeless people experience. The assignment then considers whether working with homeless communities is the role of the psychologist and there follows a discussion of the types of activities a psychologist could initiate to reduce stigma and discrimination. The essay recognises that psychologists have some key skills which equip them to work with communities in this area, but recognises that the reasons for homelessness and social exclusion are multi-faceted and the solutions are therefore equally complex.
Personal reflections on the title

I have chosen to write about the homeless population because of my experiences working with homeless people as a volunteer for a charity. In the seven years I have worked in this sector I am constantly faced with the dissonance which exists between society's perception of homeless people as uncouth and unkempt (Hocking & Lawrence, 2000) and my own experience of interesting, insightful, humble and respectful individuals. I also often encounter homeless people with complex needs, particularly with mental health problems, substance abuse issues and challenging behaviour. It is often important for me to hold in mind that our guests' lives have a complexity which extends beyond simply 'rooflessness' (Shinn, 2007). The dilemma remains that these members of the community seem to lack access to the very services they so desperately need.

As a volunteer I often find myself in a position of 'benevolent benefactor' with a palpable power differential in place. I feel uncomfortable to remain in this position in my interactions with homeless people who I believe should be co-collaborators in any attempt to support them. As a psychologist I struggle to know how best to work jointly with homeless people in a way which offers them opportunities to challenge the position they are placed in by society. I wanted to write this essay to develop my ability to apply psychological skills to inform any work with homeless people who are currently so isolated and excluded.

An introduction to social exclusion

Social exclusion is a contested term (Hills et al., 2002, p.2). It has been defined in a number of different ways, including lack of access to citizenship (Lee & Murie, 1999), material disadvantage (Rodgers et al., 1995) and 'active exclusion of one group by another' (Hills et al., 2002, p.2). However Levitas (1998) has argued that the term in itself is inappropriate because it separates people into two groups: the 'included' and the 'excluded'. Perhaps it would be more appropriate to consider a social exclusion continuum and that individuals and families can sit at any point along the scale. This might be a more helpful construction as it recognises that people can be on the margins of poverty and social exclusion (Lee & Murie, 1999) as well as deep in
poverty or chronically socially excluded. Additionally it is important to hold in mind that rather than being a static state, people may move along the continuum at different points in their life (Hills et al., 2002). This is known to be true of homelessness, with people moving 'in and out of housing and other supports over time' (Minnery & Greenhalgh, 2007, p.641).

Reeve (2007) has also highlighted the dynamic nature of homelessness as 'not merely an experience' or a 'sequence of temporary accommodation solutions' (p.3). She highlights that becoming homeless, and the social exclusion experienced, does not follow a simple trajectory. Instead there is interplay between an individuals personal characteristics and experiences and the structural and service contexts within which they must operate (ibid). These are summarised in figure 1.

![Figure 1: 'The landscape of Homelessness' adapted from Reeve, 2007, p.3](image)

Whilst this model, along with many others, recognises that there are a number of routes to social exclusion, the title of this essay emphasises the role of stigma and discrimination. 'Social exclusion starts with the identification of difference. But difference alone does not lead to discrimination: it is the way that difference is valued that is the key' (Repper & Perkins, 2003, p.41). Although the remainder of this essay will focus on this aspect it will be important to keep in mind that the
causes of social exclusion are complex (Hills et al., 2002) and a combination of factors may contribute to an individual's exclusion.

The role of stigma and discrimination

It is known that individuals and groups are stigmatised when they 'possess (or are believed to possess) some attribute, or characteristic, that conveys a social identity that is devalued in a particular social context' (Crocker et al., 1998, p.505). There appears to be a dominant discourse about homeless people being 'misfits' who have '...no morals and are blamed for their poverty (Lee & Murie, 1999, p.3). This conception inevitably sets up a power imbalance between the homeless community and wider society. These negative beliefs and the inequality they create would appear to be fuelling the stigma and discrimination directed towards people who are homeless. Further, Hogg and Vaughan (2005) suggest that such discrimination continues because the people doing the stigmatising gain a relatively positive sense of self and social identity by comparing themselves or their group with stigmatised individuals or groups.

In our capitalist society having a home and a job are valued as positive attributes, so to be without these aspects can lead to discrimination from those who have them, and shame for those who do not. This stigma can then go on to legitimise social exclusion. Often inequalities of status and resource distribution favour the dominant group, so these groups will ensure the stigma endures as it justifies the system which has developed (Jost & Kramer, 2003). Additionally, social exclusion is compounded by the fact that those in the dominant in-group tend to see those in the out-group as all the same (Hogg & Vaughan, 2005). In the case of homelessness this may lead to further stigma as often the most visible examples of homeless people are those begging for money in the street. Therefore those outside the homeless community may come to believe that every homeless person is like those they have observed begging, rather than realising that the homeless community is as diverse as any other group of people.

Stigmatised groups have relatively low status and little power in society (Hogg & Vaughan, 2005) and nowhere would this be more true than in the case of people who are homeless. They are often unable to access even the basic rights of
citizenship, such as applying for a passport or voting\(^1\) and homeless people are viewed by many as belonging to an 'underclass' (Levitas, 1998). Lee and Murie (1999) note that alongside this label people in the 'underclass' are deemed to be inadequate by virtue of their inherited psychological and pathological traits. This kind of stigma is likely to further isolate an already detached sector of society perpetuating the cycle of social exclusion (Office of the Deputy Prime minister: ODPM, 2004). As one service user so succinctly put it 'we get chucked out of society' (in Department of Health/ODPM, 2006, p.1).

Once 'outside' of mainstream society it can be increasingly difficult to journey back to inclusion, especially as many practices which exist may serve to keep people homeless. There is debate about whether some of the housing allocation tools are simply used to discriminate against people who may not have the level of understanding required to grasp the layers of meaning in the complex language used and recognise when they are entitled to accommodation (Minnery & Greenhalgh, 2007). Therefore once excluded it can be difficult to gain any kind of access to the system. People may find themselves caught in a negative spiral with few routes out and increasing levels of distress.

A role for psychologists?

Although the link is not often explicitly made, I believe homelessness can be considered within the remit of the psychologist. There are a number of reasons for this. Homeless people often have complex needs, such as mental health problems, learning disabilities and experiences of trauma (Croft-White & Parry-Crooke, 2004). It is estimated that up to 40 percent of homeless people have a psychotic disorder (Maguire et al., 2006) and many cases of mental health problems may remain undiagnosed. Psychologists are trained to work with complex and multiple needs, with their agenda for change banding recognising the complexity of their caseload (BPS, 2007). Although at present this work is mainly with those with more access to mainstream society, there is no reason why psychologists should not be working

\(^1\) Although people who are homeless can apply to vote they must have an address that they can access regularly (National Youth Agency, n.d.). This can be problematic for people with no fixed abode who move around a lot or who have chaotic lives.
with these difficulties when they appear in the homeless population. In fact, not to do so could be seen as further socially excluding a group who are already so disadvantaged.

Maguire (n.d.) argues that psychologists' awareness of context allows them to know that 'the factors leading to homelessness can be described and integrated' (p.3), leading to a formulation. The ability to formulate is a unique perspective which other professionals are not able to offer. However if such formulations are to tackle stigma and discrimination it is key that psychologists work not only at the individual level but also with groups and whole communities (British Psychological Society Social Inclusion Group: BPS SIG, 2008; Hayward et al., 2007), particularly as psychologists have key skills in recognising that stigma and distress are expressed and dealt with differently in different contexts (Tew, 2005). For homelessness this contextual awareness might lead to attempts both to prevent the social exclusion which can be so distressing, and to lobby for change for those already excluded.

However, for psychologists to work with the issues of homelessness and social exclusion is not without its challenges. Firstly the lack of literature suggests that clinical psychologists are not currently working to challenge the stigma around homelessness (Maguire, n.d). This also means there is no solid evidence base suggesting which interventions might be appropriate. An additional challenge is that social inclusion can be difficult to quantify (Burchardt et al., 2002) but managers and commissioners might expect evidence that any work done shows measureable improvements for individuals and groups and offers value for money. Psychologists may therefore struggle to find support for the work they would like to do and will need to work not only to develop interventions, but also to develop a context within which such work is recognised as valuable: part of this context includes defining target populations and how work with different communities might make a difference to social exclusion.

What is a community?

Community psychology is now an ever-growing discipline which aims to 'apply our psychological knowledge and skills to improve the mental health of communities in ways other than those of traditional psychological therapies' (Webster & Robertson,
Orford (1992) argues that this type of psychology aims to understand 'people within their social worlds' (p.vii) in order that this understanding can ameliorate distress and promote positive experiences. However recognising the need to work at community level does not in itself provide any easy answers. How the term 'community' is defined depends very much on a person's role and position within the social system. Therefore there are a number of communities which could provide a focus for psychological work around homelessness and discrimination.

Firstly 'community' could refer to society at large. Whilst the 'general public' is a wide and diverse community it is from society that much of the discrimination and stigma will come, directed at those who do not fit into the model of 'normal' which exists. Orford (1992) argues that problems are caused by interactions between people, social settings and systems, particularly looking at where the power lies. For the homeless population power is often attributed to wider society, who through stigmatisation rid many homeless people of the belief that they can change their situation. Therefore the wider community is a key place for targeted work to ameliorate the path to social exclusion which exists for so many people who are homeless or at risk of becoming so.

However just tackling 'community' in the wider sense means there is a danger of missing the sub-sections within society, particularly those who work directly with homeless people and aim to support them. Orford (1992) argues that the structure of social support can be as important as the structures which give power to certain groups over others. There are a number of statutory and third-sector agencies whose aim is to support and help people who are struggling with homelessness. Ultimately these agencies may be trying to reduce the social exclusion by providing routes back into mainstream society. With their knowledge and experience of working with homeless people they can be seen as key players in the reduction of stigma and discrimination.

Finally there is the homeless community itself. It has been noted that stigma is a reciprocal process where stigmatised individuals interact with those who define themselves as 'normal' (Goffman, 1963). Christian and Abrams (2003) note that attitudes towards institutional authority combine with beliefs about identity and social positioning and can affect how homeless people access the various services.
they are offered. Therefore any work which aims to tackle stigma and discrimination must also work with those who are being stigmatised and reflect on the impact of such experiences on the ability of people to move forward (Green, 2002). Community psychology therefore needs to facilitate people to gain ‘a sense of control and influence over their environment’ (Webster & Robertson, 2007, p.156).

How do psychologists work with these communities?

In this section there is a discussion of the general skills which may enable clinical psychologists to work with the stigma and discrimination which leads to social exclusion. There then follows a more specific consideration of how psychologists might work with each of the community groups discussed above. Finally the need to work between communities as well as within them is briefly examined.

There are some general principles of clinical psychology practice which will be important to bring into any work in the community arena. Firstly psychologists are able to pay attention to context and reflect on the lived experience and narrative of people experiencing difficulties (BPS SIG, 2008). Orford (1992) argues that a person’s behaviour must always been viewed in the context of their environment and interactions. For example Riggs and Coyle (2002) were able to identify that a group of homeless people experienced homelessness as ‘not belonging, feeling isolated, rejected or alienated, lacking emotional attachment with a place’ (p.13). Orford argues that psychologists must use such information to move beyond a focus on individuals to a consideration of communities as interventions targeted at this level will be more powerful and wide-ranging.

We know that ‘service-users prioritise the values and attitudes of staff over skills (Repper & Perkins, 2003, p.77). Psychologists explicitly consider values and attitudes in their training (DCP, 1995) and therefore are well placed to continue their mindfulness of this in work with communities. Other important skills which psychologists can bring to this field include recognising power dynamics and being explicit about these (Hayward et al., 2007) and remaining curious about the patterns and dominant discourses which exist or are developing (Vetere & Dallos, 2003) between members of the community and between the communities of focus. Finally psychologists may be well-placed to recognise the internal and external barriers
which exist (service-user quoted in BPS SIG, 2008) and can retain an awareness of the importance of inclusivity. This inclusiveness needs to encompass not only physical access to services (Health Scotland, 2008) but also in terms of language and attitudes, because without this psychologists may be unwittingly reinforcing the very stigma they aim to tackle.

**Work within the homeless community**

In working with the homeless community, it will be important to hold in mind that 'fear of stigma may be greater than reality' (Green, 2002, p.3). One service user noted that psychologists can work to tackle the areas which are often neglected, such as 'lack of confidence, motivation and hope' (in BPS SIG, 2008, p.8). With their understanding of both models of personal distress and how attitudes are developed psychologists may be well placed to tackle the internalised experiences of being a stigmatised group (BPS SIG, 2008).

My own experience of working in services for homeless people has taught me a great deal about the most powerful interventions to support people. Repeatedly what I have heard homeless people saying is that they value being treated as a human being with the respect and dignity they deserve. Whilst this may sound obvious, my experience is that so many people who are homeless spend the majority of their life without having this basic human right met. As a psychologist it will be important to hold in mind the importance of further levelling the power-imbalance and valuing homeless people as the most helpful commentators on their experiences.

It is beyond the scope of this assignment to consider interventions which might work at the individual level. However, to move beyond this is challenging because there appears to be no literature which addresses the question of how psychologists might work with the homeless community. Those few papers which fall into this category all focus on individual work and amelioration of personal distress. I will therefore draw on and extrapolate from the relevant literature which is written about social inclusion and that which focuses on the role that health services can play in working with the homeless community to reduce stigma and discrimination.
With both the theoretical and personal frameworks in mind it is important to consider what interventions by psychologists would actually look like in reality. Firstly psychologists can work at ground-level, developing materials or running skills groups which aim to enhance self esteem and other key skills which may ameliorate the effect of experiencing stigma from wider society. Additionally such groups could help homeless people re-engage in society, through increased confidence to search for a job or maintain a stable home. There are obviously occasions where other professionals such as teachers or occupational therapists, might be better equipped to run such groups. Psychologists could therefore offer support to skill-up other professionals to take on such work by sharing not only their resources but also their thinking around homeless communities as it impacts on people’s engagement. Further the unique skills which psychologists could bring include the ability to engage service users at a different level (Hayward et al., 2007), providing them with the tools to develop their own meaningful interventions.

As noted above homeless people who also have multiple needs, such as a mental health problem or learning disability, are likely to be doubly disadvantaged (Croft-White & Parry-Crooke, 2004). Psychologists therefore have a key role in ensuring the appropriate services are truly accessible to people from homeless communities, by providing outreach services, and in-reach approaches going into places where the homeless community already gathers. However beyond this they also have a role in working to reduce the stigma that surrounds accessing these services by advertising them positively within homeless organisations and ensuring that clients have a non-discriminatory experience that they are willing to share with those who are reticent to use services.

Finally the training of clinical psychologists places emphasis on the importance of research and psychologists are provided with the skills to carry out research which is relevant and important to the communities they work with (Plante, 1999). Therefore there is a role for psychologists to identify patterns and possible avenues for future work with homeless people, an area which is currently conspicuously lacking. However just to research is not enough, instead clinical psychologists should also strive to champion the involvement of service users within their research (Gorton, 2003). There are a number of models of involvement in research which include consultation and homeless people as co-researchers (Spiers et al., 2005). Some will
reinforce power imbalances whilst those which truly aim to challenge stigma will involve homeless people right from the start as the initiators of the research questions which are most pertinent to their lives. Additionally such involvement in research will equip homeless people with supplementary skills and possibly increased confidence, which may also serve to move people towards inclusion.

Work with communities that support homeless people

It has been noted that building supportive community networks and encouraging social, faith and family groups to support individuals experiencing difficulties is beneficial in reducing social exclusion (ODPM, 2004). Further providing help and support as early as possible to people who are homeless or at risk of becoming so is important in ensuring more positive outcomes (Department for Communities and Local Government: DfCLG, 2008). Psychologists have a role to play in this process contributing both their specific psychological skills and their leadership and management expertise.

To tackle stigma and discrimination psychologists may be involved in joint working within a multidisciplinary team and providing awareness training for local organisations and communities (Croft-White & Parry-Crooke, 2004). One such project currently running in London has been set up to provide for people who experience ‘multiple exclusion, chaotic lifestyles and negative social outcomes for themselves, families and communities’ (DfCLG, 2008, p.27). The team has worked to develop an index to identify people at most at risk. This index includes criterion such as ‘stress and anxiety’, ‘self harm’ and ‘social effectiveness’ (New Directions Team, n.d.) and it is aspects such as this where psychologists would be able to make key contributions, both during the tool development phase, and to training the team in the management of these difficulties. Further, part of the role of a psychologist in such teams is using psychological theories to help staff understand how these aspects contribute to the stigma and discrimination (Hayward et al., 2007) which have resulted in clients experiencing multiple exclusions and requiring the support of the team.

Beyond this, psychologists can also play a vital role in supporting frontline staff in other ways. Given the multiple challenges facing homeless individuals, frontline

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workers may find themselves working with complex clients without the psychological awareness which might help them in this role (Maguire et al., 2006). Particularly important is those staff who ‘interpret others’ attitudes as rejecting’ (ibid, p.4). In these situations workers run the risk of further stigmatising clients and this may ultimately result in the withdrawal of the service. Psychologists here may take a position of challenging the assumptions that are made on the basis of negative stereotypes or as part of an out-group bias (Hogg & Vaughan, 2005). By sharing formulations psychologists can enable workers to look beyond the current presentation of their clients to consider the wider context and relationships which have developed (Orford, 1992). Therefore, enabling staff to reformulate their original assumptions and negative beliefs can provide people with ‘frameworks and methods of working with interpersonal difficulties’ (Maguire et al., 2006, p.4). On placement I have observed supervisors gently challenging beliefs held by a team, leading to renewed efforts to engage someone who they might otherwise have been stigmatised and given up on. Given the perceived gap between those in mainstream society and homeless people (Croft-White & Parry-Crooke, 2004), such challenging will be vital for staff working with homeless communities.

Challenging stigma and discrimination in wider society

A service user notes that ‘prejudice...although a little more subtle than a few years ago, is still rife and mostly goes unchallenged’ (quoted in BPS SIG, 2008, p.12). To challenge such stigma one proposed model suggests utilising protest, education and contact (Corrigan & Penn, 1999). ‘Protest’ might include psychologists working to raise political awareness and challenge dominant discourses which exist around homelessness and social exclusions (BPS SIG, 2008). Key interventions would be public debates, dialogues with a variety of people and organisations, marches, campaigning and discussion groups (ibid). Such support would aim to ‘enable people to recover their sense of personal value and presence in the community’ (Cupitt, 2002, p.7).

‘Education’ could include providing the general public with the opportunity to understand more about both homelessness and the effects of stigma on homeless people. (Hope, 2004). Psychologists are well-placed to share their theoretical
understanding and unique perspectives with others, for example through public
talks or teaching sessions (BPS SIG, 2008). Finally ‘contact’ goes one step beyond
education, providing opportunities for different sectors of society to meet and
exchange views (Pinfold et al., 2005). Therefore in addition to offering sessions
which simply teach from an academic perspective, psychologists might want to
arrange opportunities for service users to share their stories. There is still a key role
for psychologists here, as the ‘holding’ or containment they provide (Winnicott,
1964) may be the very thing which enables a homeless or formerly homeless person
to feel confident enough to speak in front of others.

Whilst Corrigan and Penn’s model (1999) fits well with reducing the stigma around
homelessness more work is required before it will be possible to implement such a
programme of action. A great deal is known about social inclusion/exclusion in
general, but less is known about the debilitating discrimination experienced by the
homeless community. Therefore research will be necessary to develop a greater
understanding of the attitudes of the general public (Health Scotland, 2008).
Psychologists are well placed to complete such research, and through these
investigations they might identify key areas to educate the public about, or areas
where lobbying will be vital (Sayce, 2003).

Working with the wider community is not without challenges. Webster and
Robertson (2007) argue that psychologists must work within the constraints of
funding and the constant ‘drive to develop models of best practice’ (p.158).
Demonstrating efficacy of an intervention with a community (ibid) provides a
challenge to the psychologist working to ameliorate stigma and discrimination.
Outcomes may be difficult to measure or not be demonstrable for some time, and in
the current climate of result-orientated practice this may be difficult to market to
commissioners (Maguire, 2008). Clinical psychologists will need to begin with an
explicit awareness of these challenges and continue to be mindful of the constraints
they impose.

Supporting interactions between communities
Particularly key for psychologists will be to work not only within the communities
but also focus on the interactions between them. The skills of a psychologist in
bringing groups together for meaningful discussion can be seen to fit well with the
‘community cohesion’ agenda promoted by the government (ODPM, 2004). It is suggested that it is important to facilitate ‘proactive local action to promote greater knowledge, respect and contact between different cultures’ (ibid, p. 74). Areas where this might require the skills of a psychologist might include those where the system is ‘stuck’ or insists on laying the blame externally rather than accepting responsibility itself (Vetere & Dallos, 2003).

Having the ability to step-back and reflect on the interactions which are occurring is something which psychologists have particular skills in, as they are required to do this whilst engaged in therapeutic relationships (Lemma, 2003). Extrapolating these skills and combining them with theoretical awareness may be key when attempting to challenge the social exclusion being experienced.

Summary and conclusions
Homeless people require considerable support and guidance to rebuild their lives and re-enter mainstream society (Croft-White & Parry-Crooke, 2004). However it can be extremely difficult to establish new patterns of living ‘if, everywhere you turn, you face barriers that make it difficult for you to do the things you want to do’ (Repper & Perkins, 2003, p. 203). For homeless people these barriers are often stigma and discrimination which come from a society consciously or unconsciously attempting to maintain its dominant position. Psychologists are equipped with many professional tools which are invaluable in working with this population, including their ability to consider the context and to formulate considering the multiple needs of homeless people. Furthermore psychologists are skilled at challenging power imbalances and stereotypes, and working within various communities, including, crucially with service users themselves. All of these elements will be vital when attempting to challenge stigma and discrimination.

I am passionate about working with people at any point on the inclusion-exclusion continuum. I believe that as clinical psychologists we have a moral and ethical duty to ensure that services are accessible to those who are most in need. Paradoxically those most in need are also the people who find services most difficult to access (Vogel & Wade, 2009). As psychologists are increasingly required to move beyond individual distress to take wider perspectives (BPS, 2007) social inclusion (or lack of
it) is bound to be increasingly on our agenda. We must ensure that we have the knowledge necessary to tackle problems in this previously neglected arena. However in this specific field we must also hold in mind that the causes of homelessness, and of social exclusion are multifaceted and psychologists alone will not cause the tide to turn. Additionally homeless people often have complex needs, meaning that supporting them can be difficult and the route to re-inclusion is not a simple one. Therefore whilst we can never claim to hold all the answers, perhaps psychologists can be part of the solution rather than part of the problem.
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Organisational and Professional Issues Essay


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Problem based learning reflective account 1

Relationship to change

Year one
March 2008
Introduction

As a therapist learns their craft, her/his practice adapts towards their personality (Hogan, 1964). If therapy is 'a reflection of his [/her] personal idiom' (ibid, p.139) then it is ‘important for the practicing psychotherapist to have an understanding of self-reflection’ (Rossi, 1972, p.295). This will help to ensure that the parts of themselves which appear in therapy are in their awareness and occur because they are helpful for the client. In this account I will consider myself as a member of a group and use this learning to reflect on my therapeutic work.

As a group of seven new trainees, we were asked to plan and deliver a presentation around the title of ‘the relationship to change’. This reflective account will start by considering the task process from the initial choice of focus to the final presentation, and consider strengths and weaknesses of this approach. It will then go on to examine the group processes which occurred during the 6 weeks of the problem-based learning (PBL) task. I will investigate how the group changed over time and relate this to relevant theories.

The Task process

Our group decided to focus on the change process which occurred as the group learned to work together over the course of the exercise. Choosing this topic was something of a risk for the group. Because the process we were reflecting on was happening during the six weeks of the PBL task it was difficult to plan for the content of the final presentation until late-on in the exercise. I have subsequently reflected on what this choice of a risky topic says about our group. Schneider (1992) suggests that the way an option is presented affects whether people will be risk-averse or risk-seeking. During the discussion, the risk of undertaking a project with an unknown outcome was framed in terms of the potential gains our group might achieve. In making my decision I was swayed by evidence that we stood to gain a greater understanding of ourselves as a group and group-processes more generally.
Further I felt this topic offered an opportunity to bring some of my previous experiences to the work, in a setting where they would be appreciated. These prospective, subjective value judgements have been shown to be important in risk-taking (Kahneman & Tversky, 1984) and explain why an apparently risky choice was actually chosen.

Having selected the topic early on we moved on to considering relevant theories. Significant amongst the models I researched was a service-user developed theory of change (Orford et al, 2006). I was attracted to this because it was developed by people with personal experiences of difficulties. It demonstrated their ability to access support and change as a result. Through my clinical and personal experience I am constantly struck by the importance of the client’s perspective as a mediator of change. This model seemed to provide an authentic example which also has current clinical relevance for me.

I now realise that I have implicitly held this structure in mind with two of the clients I work with. Both are having difficulties with the change process, but are at different stages (see appendix 1). One client appears ‘stuck’ in the treatment system stage finding it difficult give up her obsessive compulsive disorder, which she sees as serving a useful function in keeping herself and her family safe (Veale, 2005). The second client has made a great deal of progress in therapy, and could be said to be working in the change system stage because she has a number of cognitive strategies enabling her to ‘think differently’. However she finds it hard to manage times when she is very distressed and is not yet able to ‘act differently’ at this time. I am now considering introducing this model in therapy sessions to think with the clients about whether the model is pertinent to them, and if so how they could be supported to move forward through the stages.

The transition theories (Adams et al, 1976) were eventually chosen as a focus, and we used them to look at the unplanned changes which the group was experiencing as the exercise progressed. I felt that this theory resonated with me personally. It is comforting to note that my personal struggles to cope as a trainee are mirrored in the literature. The model gives me hope that having already experienced something of a ‘crisis’, I am now entering into 'new confidence' and 'transformation'. I have found clients welcome this model for similar reasons.
In the presentation we were able to map the theories on to our experiences. Our feedback stated “clear evidence of thinking through the models and implications in relation to change” which I feel reflected how we felt as a group. Personally I was keen to make the evidence base central to our presentation. I wonder if this reflects my feeling of insecurity and ‘not-knowing’ as a new trainee, and therefore my desire to find out about tools which could be helpful for my clinical practice. This feeling of insecurity has definitely been present for me on placement and has been a recurrent topic of discussion in supervision. One of the things I have been working to accept is being comfortable with the ‘not-knowing’ position (Lawner, 1981). Reflecting on the PBL exercise now, it is encouraging to feel that I have made some progress in this area since the course began.

The group approach to the task, choosing to reflect on the actual process of creating the presentation, is a method which had both strengths and weaknesses. I believe that reflecting on what was occurring in the group week by week encouraged us all to be far more aware of group process and therefore discuss and overcome any difficulties. However by explicitly reflecting upon the process we will have affected and changed the group (Langley et al, 1996). Complexity theory suggests that as people and groups simultaneously adapt and this collection of adaptation builds perpetual novelty (Miller et al, 1998). Had our group, or member within it, acted even slightly differently the outcome could have varied enormously. Further as
members of the group we could only offer subjective interpretations rather than function as objective observers of the process.

The Group process

Our group consisted of six female and one male member. There is more than 20 years between the youngest and oldest members of the group, and all members are white and of British origin. This make-up meant that there were both significant similarities and differences between members of the group. We choose to have a different chair and scribe each week because we felt it was important for us all to experience the different roles and therefore engage more fully with the group. Further this decision meant we were able to engage with the diversity in our group and learn to accept different styles.

Early on in the exercise I noticed that I had to work hard to find common ground with the male member of our group. This was partly motivated by my frustration during the meeting in which he was chair as there seemed to be little structure or direction to the discussion. Afterwards I was able to recognise that my personal learning style means I appreciate a framework and clear boundaries in my learning. In discussion with the individual subsequently I was able to learn about his rationale for chairing the group in that fashion. This helped me to recognise that he had used his personal experiences of meetings and informal learning to develop his own style. The event led me to recognise the value of making an effort to engage with people who I do not immediately bond with, as the outcomes of such a venture can support my learning.

Throughout the exercise I found it interesting to reflect on the development of group cohesion. For a time I felt that there was a sub-group forming within the group, of which I was not a part. This was noticeable in a couple of sessions when the seating arrangement meant that three or four members of the group were both close and central, whilst myself and another member were sitting separate. In later meetings I made an effort to sit more centrally and to reflect on how I could feel more involved.
Social norms theory (Perkins & Berkowitz, 1986) seems particularly relevant here. This model posits that “behaviours are influenced by incorrect perceptions of how members in social group think and act” (Ramos & Perkins, 2006, p.60). I was aware that I was making assumptions about the other members of the group based on arbitrary factors like seating position. These assumptions included what I predicted others thought about me and my contribution to the process. Making a change, such as sitting in a new position was an example of my behaviour being shaped by the potentially erroneous beliefs I held.

I am mindful of how much this theory is also relevant in the therapy process. As therapists we only hear what the client is willing or able to share with us. We can consider what we think is happening beneath the surface, but these will always be hypotheses rather than certain knowledge. A formulation is one example of a hypothesis (Jonhstone & Dallos, 2006). Sharing this with the client is therefore vitally important because otherwise we may choose to steer the process in a direction based on our incorrect perceptions rather than fact. This has been useful reflection for me in working with a client I have who imparts intricate details of her week but finds it difficult to name or reveal any emotions she experiences. In sharing her formulation she began to feel able to name her perceptions about the therapy process and what she thought I wanted to hear. Being able to have an open discussion on this led to a more dynamic therapy conversation and the client being able to talk about feelings rather than just situations.

**Personal learning from this process**

Writing this reflective account has enabled me to consider the PBL exercise with a degree of objectivity. Whilst immersed in the process it was difficult to consider how it related to other parts of the course. Further as the task finished prior to starting placement I was not able to know how it might be relevant to my work there. However writing this account has made me mindful of the links between personal learning and development and the effect this has on my practice as a professional. By this I mean that whilst absorbed in the PBL exercise I reflected mainly on my role as a member of the cohort and thought a lot about how my input was perceived by
the group, and how I could moderate this if I thought it necessary. With hindsight I can now see how much I learnt generally about group processes which will be invaluable for therapy groups and what I have been able to take with me into individual therapy situations.

As a trainee generally and within this exercise specifically I have needed to adapt my thinking in ways I had not previously expected. When we met as a PBL group for the first time on the first day of the course, I was unaware of shape and nature of the challenges that I would face in training. Many of those challenges still exist, and many are still unknown. However changes have occurred for me because I have reflected upon the difficulties. I am now more prepared to accept these demands as learning opportunities (even without a complete understanding of the solutions). I have a long way to go in my development as a clinical psychologist and as a therapist. Being reflective as a learner, a group member and a professional would appear to be vital. Hopefully this reflection will allow me to develop the capacity to be receptive to the changes I need to make as I learn to be a clinical psychologist.
References


Problem based learning Reflective Account 2

Working with people in later life, their families, and the professional network

Year two

March 2009
Introduction

As a group of six trainees we were asked to plan and deliver a presentation around a case study looking at 'working with people in later life, their families, and the professional network'. The case study looked at a family, with 'Mr Nikolas' as the identified client; we were asked to consider the family and their situation in the context of some directed questions. Our group particularly focused around two questions; 'What is the problem?' and 'Who has the problem?'

This reflective account considers the processes which occurred in the group, looking at diversity issues, how we chose to tackle the tasks and how the group worked over the six weeks of the problem-based learning exercise (PBL). I then reflect on my own learning during the exercise and relate this to my development as a therapist in clinical practice. Finally I include some thoughts about my future development.

Group Process

Diversity

Our group consisted of three year three trainees and three year two trainees. I felt it extremely valuable to be working with the third year trainees. Firstly this provided me with the opportunity to notice the differences between the second and third years and therefore reflect on the development which I might be able to achieve in the next year. Further it provided me with opportunities to reflect on the changes I have already made since the PBL exercise we completed at the start of year one. At the start of the most recent PBL exercise I noticed how much more I now know as a second year, and the degree to which I now feel settled on the course, rather than feeling being overwhelmed by it as I had the previous year. I believe in this case it was the differences between myself and other members of the group which allowed me to reflect on my own personal growth. It felt like being in a group with both my peers and those more senior to me facilitated a level of personal reflection which I had not been able to access previously.
I am aware that if the exercise had combined me as a first year with third year trainees I might have been overwhelmed with the distance there was to travel and I wonder whether as therapists we ever set up this dynamic with clients. This leads me to wonder how clients experience their therapists if they perceive them to be at a different stage to them. I wonder whether for clients the gap feels too wide and unobtainable or whether it creates in clients a space to explore where they have come from and the direction they would like to go in the future.

Whilst working with the third year trainees enabled me to reflect on how far I had come, I was also intrigued about how a group with mixed cohorts would operate. I wondered whether the third years, with what I perceived to be their breadth of knowledge and experience, might assume a leadership role in the tasks. I felt unable to take on such a role, feeling I did not yet know enough about systemic practice or working in older-adults settings. Interestingly no-one in our group assumed a leadership role, which may have been a factor contributing to our lack of direction/strategic planning. This lack of leadership enabled me to feel more valued and able to share my thoughts in a non-hierarchical fashion. However I also experienced times when I felt ignored or overshadowed by the third years, particularly when I was presenting literature I had been researching. On reflection I think this might have occurred partly because I was slightly overawed by the third years and perhaps sometimes placed too much emphasis on their opinions. Therefore I did not feel able to emphasise the relevance of the work I had done when it was not recognised by the year three trainees.

Group approach to the task

Our group approached the task in a very enthusiastic way, generating a large number of ideas at the first meeting. As the task progressed we continued to develop hypotheses but seemed unable to bring these together in a coherent fashion to shape the final presentation. In fact until the penultimate day we were still discussing ideas rather than working to finalise our presentation. As a group we clearly demonstrated that we could generate ideas, make theory-practice links, develop hypotheses and remain curious about what was happening. These are all skills we spend a great deal of time focusing on in our clinical work and attempt to
hold in mind when working with clients. However equally important are the skills around drawing out relevant threads from the story, generating formulations and developing a holistic understanding of the client’s difficulties. I am unsure why some skills were unconsciously valued above others but wonder whether the neglected skills required more higher-order thinking and meta-reflection. On reflection I wonder if in our group we were concerned about appearing to be competent trainees, but from our desire to prove ourselves came an urgency which meant we missed some important skills.

It is more encouraging that we reflected in a number of meetings that we continued to generate ideas but were not synthesising these appropriately. This reflection formed an important part of our presentation and helped me to see how ‘stuck’ we had become in the material, to the detriment of creating an end-product. Johnstone and Dallos (2006) note that reflection on practice and integrating this into a formulation is ‘...increasingly important in all therapeutic traditions’ (p.2). This was clearly seen in our group, where after making this reflection we were more able to integrate the material and create a workable formulation to use in our presentation. In client work these reflections will be equally helpful when formulating, and may be particularly important where short term work requires formulations to be produced early on in the sessions so that the psychologist can work with the client to create collaborative and meaningful interventions (ibid).

Personal Process

Reflection-in-action

In my last reflective account one of my action points was to work more on reflection-in-action as opposed to reflecting after the event (reflection-on-action) (Schon, 1983). Being mindful of this during the PBL task was helpful because it enabled me to challenge some of the anxiety I had developed during the first year, particularly around being worried about how I was seen by others. Through reflection on my behaviour during PBL meetings I noticed that I was able to contain my anxiety, reflect on it and identify patterns that I had not previously been aware of. This new insight allowed me to change things which I felt were unhelpful, such as...
interrupting people because I was anxious to show that I had a valuable contribution to make.

Whilst reflecting on how I was behaving in the group I became aware of my desire to prove myself and show that I had knowledge which was helpful. I am aware that this is an experience I carry through all areas of my life, with both positive and negative outcomes. Wanting to be valued can be motivating, particularly in increasing my knowledge and understanding of topics and completing work for tasks. However this can also result in me being very hard on myself if I feel I have not worked hard enough or feel I let myself down by the way I came across in a group setting. I was aware of these tensions existing within the PBL group, particularly as I did not know the third years and did not want them to think badly of me. However reflecting-in-action allowed me to step back from this internal struggle and recognise when I was getting into an unhelpful cycle. At these points I found it helpful to stop and listen to others to give myself the space to recognise what was important and what was just anxious thinking. By the fourth meeting this felt much more manageable, and although it is something I remain mindful of, I have noticed that I am now better at challenging some of my negative beliefs. I have found myself more able to do this in clinical practice on my current placement and wonder whether the practice in the PBL exercise as well as in my Case Discussion Group (CDG) meetings have enabled me to work on developing this skill in therapeutic relationships.

Learning results from a combination of factors
Social learning theory suggests that behaviour is ‘uniquely determined by the interactions of personal factors (including cognitions) and environmental influences’ (Ramos, 2006, p.60). For me this combination of factors seems to have been vital in the significant learning I was able to do during the PBL task. The environmental factors included finishing a difficult placement and starting a supportive one, which enabled me to have enough ‘space’ for learning to happen. Additionally this task enabled me to really think about my clinical skills, partly because the task required thinking about a particular family and their difficulties. However it also felt like coming to this task as a second year, with a degree of experience in clinical settings meant that it was easier to make links to other clinical work in a meaningful way. For
Problem Based Learning Reflective Account 2

me a final concurrent process was my own awareness of areas I wanted to work on both in the academic and clinical parts of the course. Having concrete targets developed from both placement reviews and from my previous reflective accounts meant that I was already cued into areas where I needed to be mindful of myself or observe others to notice how they demonstrated certain skills.

Additionally this task, although focused on older people, required an ability to think systemically and consider a number of viewpoints. This arises daily on my current placement, in children’s services. During the PBL exercise it was valuable to have time to debate issues such as ‘who is the client here’, something which is a constant tension when working with parents and young people, and something which there never seems to be enough time to consider when working in services. Having had that space during the academic task I now feel more able to be mindful of the differing views of service users, carers, family members and other professionals when I am assigned to a case. However I think this will continue to be a tension in my work and is an area where I hope to continually develop skills.

Action points

Given the discussion here there are a number of key learning points which I would like to carry forward for the future.

★ Being mindful of the experience of clients in therapy, particularly thinking about times when they might feel like their development is unobtainable
★ Constantly working to integrate reflection with formulations and retain an awareness that sometimes the breadth and depth of information or working in a group can make this more difficult
★ Reflecting on my desire to be seen by others as knowledgeable in order to feel valued, and continuing to work on stepping back from this
★ Considering the value of thinking systemically and holding all perspectives in mind.
Summary

Overall I found this PBL exercise a helpful adjunct to my learning in clinical practice and it enabled me to reflect on my skills in a way which has been transferable to my work on placement. Additionally the timing of the task fitted well with my development as a trainee more generally, and the mixed-year groups allowed me to reflect on this progress in helpful ways. Finally, I felt able to carry forward some of my learning points from previous reflective accounts and developed my skills in the area of reflection-on-action. I valued the opportunity to participate in this task and look forward to returning to the PBL stage in a year’s time, where I hope working with the year below will also prompt helpful reflection and useful skill development.
References


Evaluating the Increasing Access to Psychological Therapies (IAPT) programme

Year Three
February 2010
Introduction
This account reflects on the group work completed for the problem based learning exercise (PBL). The group task was to consider how the Increasing Access to Psychological Therapies (IAPT) programme could be evaluated. My account will consider my participation in the group as a third year trainee in a mixed group of second and third year trainees. It then reflects on the group processes occurring as we prepared for the presentations. Finally I will make links with my clinical practice and reflect on the learning I will take forward from this task.

Reflections on my role in the group
When I was a second-year trainee we participated in a cross-year PBL exercise for the first time. Being grouped with third-year trainees at that time was extremely helpful: it enabled me to reflect on where I would like to be in a year’s time, and to appreciate how far I had come since the start of training. This year I hoped that I would be able to provide a role-model for year two trainees and share with them the learning I had mastered in the last year. I noticed that in early meetings the other year-three trainees and I contributed most to the group discussion. On reflection I wonder whether I was keen to share ideas because I wanted to prove to myself and others that I was knowledgeable and had progressed since my second year. However as the task progressed I became aware of the significant level of knowledge and skills held by my year-two colleagues and this helped me to reflect on my own position as a trainee and consider the contributions year-two colleagues could make to the process.

On this course I have often found myself struggling with confidence and experiencing an overriding feeling of not being ‘good-enough’. As a result I have been anxious about work assignments and can vividly recall worrying about last year’s presentation, being concerned that my contribution would again be ‘not good-enough’. Whilst this was uncomfortable at times it also enabled me to critically consider what was being asked of us and strive to reflect on how I could improve. However, whilst completing this year’s task I noticed a reduction in my anxiety, and less concern about whether our presentation and my contribution in particular
would be appropriate. This mirrors the research showing that PBL tasks enable students to develop more self-directed learning skills, including being able to evaluate their contributions more effectively (Williams, 2004).

As well as the self, it is also important to consider the concept of self within group. French (2006) argues that individuals' sense of their own identity is crucial to the overall development of the group. I noticed that feeling more secure in my role as a trainee this year compared with last year enabled me to participate more fully in the group and thus I was able to contribute appropriately to the material we developed together. I think this reflects my increasing confidence in myself as both a trainee and a clinician. As I have progressed through training I have become more able to evaluate my work and attempt to take an objective stance where possible. I therefore felt more able to reflect on the group work and the presentation we were creating and feel secure that it was 'good enough' and would satisfy the requirements of the course. Figure one below shows a model of skill development, moving from 'unconscious incompetence' towards increasing awareness of one's own knowledge as the skills improve (Taylor, 2007). Taylor's model emphasises reflection as a key component of the development, and this was also vital for me, as being able to compare with last year's exercise helped me to notice the areas of movement. The opportunity to complete four PBLs over the course of training has enabled me to both develop my skills, but more importantly reflect on the process, allowing me to recognise the differences as I progress through training.
Feedback from my fellow group members was that I was task-focused and was a grounding influence on the group. This mirrors my own perspective on my work in the group, as I attempted to make an active contribution to the process, in particular offering to draft the reflective section of our presentation. Although I recognised the amount of work involved in this I was keen to practice the skill of ‘reflection in action’ (Schon, 1983) which I have been working on because of the value this skill has for reflecting on the process during therapy sessions. Having to look critically at the way our group approached the task helped me to understand more about the reasons behind our reactions. I therefore felt confident to formulate our behaviour in a way that would be helpful in terms of moving beyond our initial ‘stuck’ position to one where we were able to hold in mind the multiple perspectives around the IAPT problem. I valued the feedback I received from my colleagues once I had written the reflexive piece, and felt that the fact it was adopted by my group without adaptation meant that I had reflected on the work of the group appropriately.
Reflections on group process

One of the most notable reflections is the initial approach within our group to the task itself. In other PBL tasks we have been curious and posed a number of questions about the material we are presented with. However being confronted with IAPT as a topic resulted in us being very un-psychological in our initial thinking. Rather than asking questions and generating hypothesis we began by sharing our (often negative) thoughts and feelings about the IAPT system.

Through our conversations it emerged that not all members saw IAPT as a negative intervention and it was the dissenting views which forced us to reflect on the strength of feeling we were expressing. DeChurch and Mesmer-Magnus (2010) argue that 'team effectiveness is largely a function of interaction processes...' (p. 33). It was the interactions between our members which allowed us to move forward from this initial, quite 'stuck' position. Only then were we able to consider the many stakeholders and consider the multiplicity of views which exists around IAPT. This could be aligned with our need in some aspects of clinical work to gather all the facts and viewpoints before starting a piece of work. Whilst not always practically possible it provides a richness which enables a fuller picture to be assembled.

We then found ourselves formulating about the position of clinical psychologists within the system which IAPT also exists within. We recognised the insecurities of a relatively new profession which is still battling to have its voice heard beside the dominant medical model discourses. Additionally we are trainees who will soon be seeking jobs in the workforce and this task left us wondering if we will struggle to find work because funding has been diverted into IAPT programmes, or jobs are taken by CBT therapists. This feeling of vulnerability resulted in an initial defensiveness which is not usually our preferred position. Perhaps being overwhelmed by the threats to our future jobs and to the career we have invested so much of our lives in led to us becoming quite stuck in the negative aspects of IAPT. What is interesting is our need to work through this stage before we were able to move forward and be more balanced and holistic.

It felt that the work on this formulation was the key to motivating us to create a presentation which represented the thinking we had done around the group task. By
collectively creating a map of the territory, we were able to communicate and function more effectively. The team had effectively created a ‘team mental model’ (DeChurch and Mesmer-Magnus, 2010) which allowed us to share each others' understanding. I am struck here by the congruence with sharing formulations with clients in therapy, and how the process can again provide a platform of shared understanding from where the therapy can move forward productively. Having a shared ‘mental model’ is vital if clients are to feel truly an equal part of the therapeutic process, and to reduce the possible power imbalances which are inherent in therapy.

In later sessions we were able to hear about the positive benefits of IAPT and the successes of the programme. Nevertheless we felt it important to remain mindful of our initial feelings, recognising that if we felt so threatened by a well-meaning and evidenced initiative then other colleagues in mental health teams may feel similarly passionate. However our initial biases were also a sobering reminder of how easy it is to rush into a piece of work with preconceived ideas which are not always based in fact. These reflections led us to a presentation based on the stakeholders which we felt was the most effective way to highlight the multiplicity of opinions around IAPT, in the hope that we could show effectiveness is not simply about outcome measures, but embodies a much broader set of ideas. Crucially we wanted to point out the experiences of individuals in the programme rather than seeing people as just statistics which average out to a positive result.

**Implications for practice**

I think I learnt a salutary lesson from our initially ‘un-psychological’ approach to the task. It reminds me very much of the approach a multi-disciplinary team (MDT) sometimes takes towards a client. I have seen this happen on placement, particularly when the team has some information about a client’s history, but does not have the full picture. On my current placement in an Older Adults inpatient service I have participated in ward round meetings where information about a client is considered, without a holistic view of the diversity of the client’s experience or a consideration of the reasons for their current difficulties. I have felt that my role in these meetings is to work with the team to formulate around a client’s difficulties, bringing in space for alternative views to be held. This view is echoed in the ‘New Ways of Working’
paper (British Psychological Society, 2007) which suggests psychologists need to challenge dominant ways of thinking, in the best interests of the client. I feel that our performance in the PBL exercise indicates to me that I still have some way to go in developing this capacity, but I look forward to being able to provide alternative perspectives on my final placements in preparation for qualifying in nine months time.

However, having recognised that psychologists in an MDT have a unique perspective to share, I also feel it is important to recognise that I do not yet feel that I have the knowledge or skills which might be required to expertly intervene in a pathologising narrative. In the PBL task I felt unable to assume an ‘expert’ position, despite being one of the more senior colleagues in the group. I felt unsure about my knowledge of the IAPT programme, and therefore became drawn into the initial discourse as much as everyone else. I can imagine that on qualifying I will feel in a similar position, being unsure of my knowledge and skills and therefore in danger of again being drawn into conversations which remain unhelpful to the client. I am encouraged that in this task we were able to move forward, towards a more reflective formulation, but also recognise that we were a group of psychologists, and I may work with colleagues who exist within a more ‘medical’ model of thinking.

Conclusion
I valued participating in this PBL task as an opportunity to further reflect on my progression during clinical training. Whilst I have recognised the move from a position of feeling ‘not good enough’ to one where I am ‘consciously competent’ (Taylor, 2007), in some areas this exercise has also highlighted areas where I still need to develop my skills, particularly in working within teams to formulate and hold in mind alternative perspectives. I shall endeavour to work on these skills in my remaining time on training.
References


Summary of Case Discussion Group Reflective Account 1

Year One

September 2008
Summary of Case Discussion Group process account 1

This assignment reflects on my involvement in the Case Discussion Group (CDG) over the last year. It uses Johns’ (1994) model of structured reflection as a template. It begins with a brief description of the experience which covers how the CDG was organised. I reflect on my own contribution to the group and consider why I continually dwelt on one topic of discussion. This may have occurred from a desire to seek support from other trainees or understand the experience and thus seek alternative strategies. In an attempt at deeper reflection I consider where the worries about my contribution may have originated and note that I worry about being ‘good enough’.

The account then reflects on the group as a whole and considers how the mix of personalities may have helped the group to coalesce. There is a consideration of the diversity within the group, particularly in our pre-training experience, something I felt was pertinent for me. I then consider possible personal alternatives which include more reflection ‘in action’ (Schon, 1983). Group alternatives include creating structure, whilst still maintaining the relaxed atmosphere. Next I consider the impact that being a member of the CDG has had on my clinical work. Sharing my difficulties around my placement allowed me to gain support and hear suggestions for action. Further my work with clients has also been positively impacted. I finish reflecting on my development as a reflective writer and hope that as the course progresses my writing will also evolve.

References


Summary of Personal and Professional Learning Group process account 2

This account reflects on my involvement in the Personal and Professional Learning Group (PPLG) during year two of my clinical training. It also reflects on the changes I have noticed since participation in the group in year one. The account notes that my growing confidence as a trainee was mirrored in PPLG sessions and recognises that this year I felt more able to see myself as competent within the group. This is considered using Taylor’s (1997) model of competency which seems to reflect my progression, using reflection as an integral process of change. When considering wider group processes I look at the shift in our discourse from more medicalised or simple formulations to more complex and socially inclusive ones. I feel I have been able to contribute to this change, drawing on learning from lectures and placements. I reflect on the key role our facilitator played in our progression this year, noting how much I learnt from her which I would like to use in my own therapeutic practice. Finally I consider the diversity in our group, looking at the different contributions members brought and how these were valued.

These reflections allowed me to consider how I would work differently if the experience was repeated. I would like to be more aware of my desire to constantly be learning and how this can conversely prevent me from learning in different ways. Additionally I would like to be more respectful of different types of diversity, being more curious about people’s contributions.

References

Clinical Dossier

This Clinical Dossier contains a summary of the experiences gained across the five clinical placements. More detailed information about work undertaken on placements can be found in Volume 2, including placement contracts, log books and evaluations.

The four clinical case reports are summarised in this dossier, along with a summary of the Oral Presentation of Clinical Activity. These reports represent a variety of client groups and presenting difficulties. Additionally a number of different models of assessment, formulation and intervention are covered in addition to one case report which presents a piece of neuropsychological work. The full reports are included in Volume 2.

All case material in this dossier has been anonymised, with names and other identifying details being changed or omitted. All individuals provided consent for their work to be presented in the case reports/oral presentation.
Summary of Clinical Placement Experiences

Years one-three

October 2007 – September 2010
Adult Mental Health (November 2007-September 2008)

Setting: Placement split across a Community Mental Health service and a Specialist Psychological Therapies Service

Clients and Presenting Difficulties: Adults (aged 17-65) with mild, moderate, severe and enduring mental health problems. Presenting difficulties included Body Dysmorphic Disorder, Obsessive Compulsive Disorder, Bulimia, Health Anxiety, personality disorders, anxiety, depression, self harm and suicidality, Bipolar disorder, early onset Alzheimer's disease.

Modes and Types of Work: Direct work with individuals. Joint work with other professionals. Group work jointly with Nurses, Occupational Therapists and Psychologists. Neuropsychological testing.

Model: Integrative, with an emphasis on CBT. Also work with motivational interviewing, relaxation and mindfulness and psychoeducation.

Service Delivery Settings: Out-patient Community team and Day Hospital, specialist tier-4 setting.

Teaching, training and presentations: Planning training for school pupils around mental health. Presentation on Audits to team and Psychology staff. Training on ‘The stepped care model for eating disorders’. Case presentation to Psychology staff on work using ‘STEPPs’ model for people with a personality disorder.

Children and Families (September 2008-April 2009)

**Setting:** Placement split across a Child and Adolescent Community Mental Health Team and a Children with Disabilities service (principally for children under 5 with developmental disabilities).

**Clients and Presenting Difficulties:** Children and young people (aged 2-17) and parents. Presenting difficulties included anxiety, social phobia, depression, anger management difficulties, family relationship breakdown, challenging behaviour, toileting difficulties, developmental needs associated with ASD, Aspergers’ syndrome, ADHD and cerebral palsy. Difficulties managing disability. Psychometric testing of young people to ascertain strengths and weaknesses.

**Modes and Types of Work:** Direct work with individuals and families. Joint work with other professionals. Indirect work with parents and teachers. Consultation work to Educational Psychologist, school staff, other professionals and parents.

**Model:** Integrative, with an emphasis on systemic practice. Integration of narrative ideas with CBT tools as appropriate. Additional consultation was used extensively.

**Service Delivery Settings:** Out-patient Community team, inpatient medical hospital, outpatient hospital setting.

**Teaching, training and presentations:** Training to CAMHS team on ‘Working with Teachers’.
People with Learning Disabilities (April 2009-September 2009)

**Setting:** Community Team for people with learning disabilities

**Clients and Presenting Difficulties:** Adults (aged 17-75) with significant, severe and profound learning disabilities. Presenting difficulties included coping with illness and dying, bereavement work, anxiety, sexual health training, parenting difficulties, health related problems, challenging behaviour and trauma. Difficulties associated with autistic spectrum disorders and dementia. Working in teams around Adult protection issues and service provision.

**Modes and Types of Work:** Direct work with individuals. Joint work with other professionals. Group work. Assessment. Indirect work with groups and individual carers and with home managers. Neuropsychological testing.

**Model:** CBT, systemic, psychodynamic, Cognitive Analytic Therapy, functional analysis, motivational interviewing, intensive interaction, relaxation and mindfulness and psychoeducation.

**Service Delivery Settings:** Clients home, National Autistic Society building, community team, residential homes.

**Teaching, training and presentations:** Training to people with a learning disability on Bullying. Training to multi-professional meeting during Safeguarding week on Bullying in people with a learning disability. Presenting work of Bullying group at a national Cognitive Analytic Therapy conference. Training to care staff on working in a multi-sensory way. Case presentations.

**Research/Audit and service development:** Audit of clients on healthy living course. Development of resources and running of a bullying group for people with a learning disability and ASD. Development of appropriate resources for care home for people with profound and multiple disabilities. Running workshops at ‘valuing people’ days on wellbeing, and on bullying. Videoing ‘an audience with Tony Ryle’ to develop training resources. Mentoring of a new assistant psychologist.
Older Adults (September 2009 – April 2010)

Setting: Placement in an inpatient setting for other people with both Mental Health difficulties and for organic difficulties (primarily dementia). Three residential wards covering these difficulties including one long stay/end of life ward.

Clients and Presenting Difficulties: Adults (aged 60-93) presenting with severe and enduring mental health difficulties including psychosis, depression, anxiety, bipolar disorder, personality disorders. Additionally difficulties associated with dementia, physical health problems, challenging behaviour, relationships difficulties and trauma, bereavement and loss.

Modes and Types of Work: Direct work with individuals and couples. Running inpatient groups for both people with dementia and those with mental health difficulties, consultation to multidisciplinary team. Assessment of clients. Joint work with other professionals, especially nurses, psychiatrists and occupational therapists. Neuropsychological testing.

Model: Integrative, with an emphasis on psychodynamic work. Use of CBT (particularly in mental health group), systemic and narrative ideas. Intensive interaction and behavioural approaches also utilised. Further providing consultation to the staff team on a weekly basis through the ‘clinical review’ meetings.

Service Delivery Settings: Mainly ward-based, although also worked in care homes and clients’ homes.

Teaching, training and presentations: Training on using the ‘Health of the Nation – 65’ (an outcome measure). Training on working with groups.

Research/Audit and service development: Development of a ‘modular group’ including plans and resources which could be used by nursing staff to continue the group. Working with a multidisciplinary team to support the development of more patient-centred care on the ward for people with dementia. Development of staff training package.
Paediatric Psychology - Advanced Competency Placement (April 2010 – September 2010)

Setting: A Paediatric Psychology in a large London teaching hospital

Clients and Presenting Difficulties: Children who are being treated at the hospital (inpatients and outpatients) and their parents, carers and siblings with a focus on difficulties related to their medical condition. Presenting difficulties include difficulties with medication adherence, struggling to adjust to a diagnosis of a chronic condition, procedural phobias (such as needle phobia), Chronic Fatigue Syndrome, Psychosomatic illnesses.

Modes and Types of Work: Direct and individual work with children, family work and individual work with parents. Liaison, consultation and joint-working with other professionals, especially medical staff.

Model: Integrative. Utilising a number of modalities including CBT, psychoeducation, behavioural programmes, exposure work, narrative and systemic approaches.

Service Delivery Settings: Mainly outpatient work on the hospital site, with some ward-based work and home visits.

Summary of Clinical Case Report 1

Cognitive behavioural therapy for a single mother in her thirties presenting with distress around her appearance

Year One
April 2008
Cognitive behavioural therapy for a single mother in her thirties presenting with distress around her appearance

Presenting problem
Sarah was referred for psychological support, presenting with difficulties and distress because of perceived flaws in the appearance of her hair. She was given a diagnosis of Body Dysmorphic Disorder (BDD).

Assessment
Sarah described her difficulties going out and how much time she spent thinking about and doing her hair. Sarah scored in the clinical range on the Clinical Outcomes in Routine Evaluation (CORE) questionnaire, and the Beck Depression Inventory (BDI).

Formulation
A CBT formulation suggested that triggers for this distress had been Sarah’s highly critical boss, and then becoming a new mother. Maintaining the difficulties was constant checking, catastrophisation and negative thinking styles. Underlying this was a core beliefs about not being good enough

Intervention
Sarah was offered 18 sessions of CBT. We explored her ambivalence about recovery and avoidance of social situations. The work included how to manage ‘blips’ or times when Sarah would relapse having made progress.

Outcome
The work was still ongoing at the time of write-up. Qualitatively Sarah had made progress in that she was able to recognise negative thinking styles and introduce more positive thinking. She made some behavioural changes. However she was still organised by her avoidance and safety behaviours.

Critical Evaluation
This was my first piece of clinical work as a new trainee. This case made me aware of my discomfort with ‘not knowing’ and in supervision I recognised the need to be comfortable with this. Additionally it taught me that work needed to be more collaborative.
Summary of Clinical Case Report 2

A neuropsychological assessment of a woman in her late forties to identity areas of strength and support needs as part of ongoing care planning.

Year One
September 2008
A neuropsychological assessment of a woman in her late forties to identify areas of strength and support needs as part of ongoing care planning

Presenting problem
Judith was referred for a neuropsychological assessment as there was a need to establish her level of cognitive functioning and ascertain her strengths and weaknesses. This assessment formed part of a larger piece of work devising a multi-agency support strategy.

Assessment
Judith had mobility difficulties and epilepsy amongst other medical conditions. She had been engaged with mental health services since her early teens. Judith completed a number of neuropsychological tests.

Discussion
Judith’s scores showed a significant impairment on intellectual functioning, meeting the criteria for a learning disability as defined in ICD-10 (World Health Organisation, 1993). But it was difficult to ascertain the cause of these problems given the complex presentation. Judith’s memory and executive-functioning were also poor or low-average. During testing Judith showed an inability to tolerate mistakes and her performance tended to trail off over time.

Recommendations
A number of recommendations were made to the multi-agency team supporting Judith. These included presenting information to her orally and using praise and positive feedback. Finally as her processing speed was reduced the likelihood of Judith becoming ‘overloaded’ was discussed with the recommendation to slow and simplify presentation of information.

Critical evaluation
Testing sessions were not optimal, being too far apart and shorter sessions might have helped Judith perform better. Whilst useful information was ascertained it was not possible to fully answer the referral question regarding Judith’s potential learning disability because the Occupational Therapist was not able to carry out a test of adaptive functioning.
Systemic work with a 15 year old girl and her family

Year Two
April 2009
Systemic work with a 15 year old girl and her family

Presenting problem
Farrah was a 15 year old girl of Iraqi parents. She requested a referral to the Child and Adolescent Mental Health service (CAMHS) because of her angry outbursts and difficult relationship with her father.

Assessment
Farrah described wanting to be at peace with herself, but not being able to do this because her memories of the verbal and emotional abuse from her father made her angry. Farrah’s depression score on the BDI (youth version) was slightly elevated.

Formulation and Intervention
In systemic work formulation is seen as part of the intervention. Before the work I was curious about Farrah’s ‘single storied identities’ (White, 2007) and impoverished descriptions (thin stories; Morgan, 2000) which the client uses to tell their story. During the work it emerged that Farrah’s anger was about being heard, releasing difficult feelings and keeping people at arm’s length. In addition to individual sessions we met with Farrah and her parents together and explored how to resolve the difficulties.

Outcome
Farrah described that ‘the wall is crumbling’ meaning she was able to be less defensive. She also felt calmer and happier and more positive about her life and the future. There was also an improvement in her BDI score.

Critical Evaluation
In this work I was able to feel more confident about sitting with uncertainty and working collaboratively to achieve change. I also worked to hold both the parents’ and young person’s views in mind throughout the work and learnt from observing my supervisor in this respect.

References
Summary of Clinical Case Report 4

(Oral Presentation of Clinical Activity)

Cognitive Analytic Therapy with young woman with a diagnosis of Autism and a Mild Learning Disability: Building confidence and building relationships

Year Two
September 2009
Cognitive Analytic Therapy with a young woman with a diagnosis of autism and a mild learning disability: Building Confidence and Building Relationships

Oral Presentation of Clinical Activity

Presenting problem
Sally was a 20 year-old white British woman. Sally has a diagnosis of autism and a mild learning disability. Sally currently attends a work placement three days a week. She is working towards a qualification in catering. When not at her placement Sally spends the majority of her time in her room on the computer.

Sally was referred to the Community Team for People with Learning Disabilities for support with social skills, particularly in the context of Sally’s work placement in a cafe. Additionally the referrer reported that Sally wished to move out of home in the future and it was felt some social skills might support her. Sally was not aware that a referral had been made for her.

Assessment
4 hours of functional assessment observations noted that Sally works well with some members of staff and can cope with short, structured instructions, but tends to become overwhelmed. Discussions with staff highlighted that Sally’s angry outbursts were difficult to manage and were putting her work-placement in jeopardy.

Sally was initially hard to engage, finding it hard to talk about how things were going and feeling singled-out. My feelings at the start of the work provided useful information which could be discussed in supervision and thus we were able to develop some hypotheses about the Sally’s experience in relationships with others.

Formulation
The formulation utilised the Cognitive Analytic Therapy (CAT) framework and noted that our reciprocal role in the relationship was controlling/critical/unhelpful to striving or resentfully compliant. Other reciprocal roles in Sally’s life included neglecting/rejecting to anxious/abandoned/frustrated and the longed-for position of idealised caring to idealised carer.

Intervention
The work took place at a number of levels within Sally’s system. Firstly Sally was offered individual sessions using a CAT model. We worked to understand what was happening in the relationship between Sally and myself and use this as a model for what might be happening in other parts of Sally’s life. Training was also provided for the staff at Sally’s work placement and close liaison with social services occurred due to a number of risk issues which were raised by the work.
Outcome
Sally was more able to reflect on her feelings and share with cafe staff when she was sad or overwhelmed. Further cafe staff were more understanding of her mood-swings and angry outbursts because they understood the reasons for them. Staff used a feelings-chart to help Sally talk about her feelings.

Critical Evaluation
Sally reported finding it easier to open up when she knew me better and began talking about more difficult things. I felt much more able to use supervision to talk about how I was feeling in the therapeutic relationship, which enabled the CAT formulation to be developed. Additionally I felt this work demonstrated my move towards a position of ‘conscious competence’.
Summary of Clinical Case report 5

Integrative therapy with a lady in her late sixties presenting with difficulties coping with her early life experiences

Year Three
April 2010
Integrative therapy with a lady in her late sixties presenting with difficulties coping with her early life experiences

Presenting problem
Iris was an inpatient in an Older People’s Mental Health service. She was admitted because of concerns about self-neglect and increasing confusion. Nursing staff were also concerned about Iris isolating herself from patients and staff and her reports of sexual abuse.

Assessment
Iris described struggling to cope with her childhood sexual abuse memories. It also emerged that Iris had taken a significant caring role as a child, being the oldest of 16 children. A cognitive assessment indicated a cognitive impairment.

Formulation
I wondered about the way problems were located in Iris, leaving staff to negate responsibilities for any difficulties. I reflected on the lack of exceptions in Iris’ narrative and wondered about how she had become so resilient.

Intervention
Iris was given an opportunity to tell her story using a narrative framework, but ideas around attachments were also held in mind, particularly given her difficult early experiences.

Outcome
Iris died suddenly during therapy. However she had a validating experience of being heard. Further she was able to identify exceptions, and towards the end appeared more grounded. She had begun to rebuild relationships with staff and other residents.

Critical Evaluation
Whilst the literature suggests that older adults are unable to utilise therapy effectively I found that Iris was very engaged and used the sessions well. Working with Iris taught me about speaking up for clients and this led me to express another client’s views when a similar situation arose.
Research Dossier

This Research Dossier contains evidence of the research completed across the three years of the training programme.

It starts with the Service Related Research Project, investigating client satisfaction in a Specialist Psychological Therapies Service. There is then an abstract of the qualitative project completed in year one, looking at division in a shared-learning environment. Then the Major Research Project is presented, which is a Grounded Theory study which investigates recovery in families following a Paediatric Intensive Care admission. The research log presents a list of the research experiences achieved.

Appendices for each piece of research presented follow directly on from the related reports. The appendices to the Research Dossier present published works and conference presentations completed during training.
Canvassing service users’ views on the service provided by the Specialist Psychological Therapies department.

Year One

July 2008
Abstract

Objectives

This study aimed to create a questionnaire which could investigate the views of service users towards a Specialist Psychological Therapies (SPT) service, and use the questionnaire to gather views of service users referred in 2007.

Method

A questionnaire was developed incorporating ideas from the National Patient Survey and other SPT services. The staff team at the SPT and a Service User Advisor were also involved in designing the questionnaire. It was posted out to 58 service users who had been referred to the service in 2007 and had finished therapy at the time of mailing. A reminder letter and repeat copy of the questionnaire were sent out three months later.

Results

Responses were received from 14 clients representing a return rate of 25.9%. Most respondents rated the service positively with the majority of participants feeling they were understood, valued and respected by their therapists. Most were satisfied overall with the service. These results need to be considered with caution given the low response rate and small sample size.

Conclusion

There are a number of limitations of this study, including the potential ceiling effect in the questionnaire, lack of external validity and reliability and difficulties with postal surveys as a methodology. Further research which aimed to address these limitations might be more successful in generating useful audit data for the service.
Introduction

This service evaluation aimed to survey the experiences of clients using the SPT department. This department is a tertiary level service which takes client referrals from the four local Community Mental Health Teams (CMHTs). It offers ‘psychological treatments not generally available within the local Community Mental Health Service.’ (Solts & Ang, 2006, p.1). Prior to the present study the service had gathered no data about client satisfaction. However other services in the region have gathered data on satisfaction for some time.

The rationale for auditing service satisfaction could be seen to be two fold: firstly ensuring that trusts are continually improving the standard of care they offer to clients; and secondly to value and consider the views of service users.

The trust as a whole endorses a recovery approach (Sussex Partnership NHS Trust, 2007). The recovery framework highlights the importance of rights and advocacy of service users, and recognises the diversity of the service users’ experiences (NICE, 2002). In practice one way of recognising and valuing service users involves canvassing the views of clients. Trusts that are already gathering the views of service users have found that ‘the process of involving service users engenders a different mind-set towards greater collaborating and sensitivity.’ (Oliver et al, 2008, p.40).

Inevitably in addition to benefits to clients there is also a service led agenda. The Department of Health now sets a number of targets around the quality of service users’ experiences (DoH, 2000). More recently guidance has been produced on Organising and Delivering Psychological Therapies (DoH, 2004). This includes involving service users and carers as a ‘desirable feature of a psychological therapies service’ (p.51). Specific targets include ‘a good range of audit and...service user involvement and opportunities to reflect on services in the light of research’ (p.51). Additionally the Healthcare Commission’s annual health check (Healthcare Commission, 2007a) emphasises the importance of service user views in the audit process (Healthcare Commission, 2007b)
Despite the drive to gather information in order to improve services this area also creates some tensions. It has been noted that many clinicians believe that improving the standard of patient care is best achieved by focusing directly on the people they work with (The Health Foundation, 2007). However simply attempting to develop better practice in individual consulting rooms ignores the impact that the wider service working with a client may have on the outcome (ibid). Additionally service-users offer ‘an incredible richness’ and their participation ‘ensures that we are more likely to get it right’ (Buckland, 2007, p.1). To manage such tensions this project aimed to involve both clinicians and service users from the initial stages and provide staff with a clear rationale for the value of this type of service evaluation.

Research aims
The review of the literature has highlighted that involving service users in audit can be beneficial for services. It provides an opportunity to gather useful data to both improve services and meet national standards. Additionally it promotes an openness where service users may feel more valued and may experience some degree of control (Masterson & Owen, 2006) over the services they receive.

The current project therefore aimed to:

1. Develop a questionnaire which could be used to gather information about client satisfaction
2. Use this tool to investigate levels of satisfaction amongst service users referred to the SPT service in 2007

Method

Questionnaire design
To develop the questionnaire existing instruments which assessed service user views were reviewed (Gill et al, 2005). These included the National Patient Survey (Healthcare Commission, 2007a) and another SPT service questionnaire (see Appendix 1). SPT staff offered initial suggestions for topics. (e.g. Sonnentag & Fritz, 2007), including: asking for views on the environment; the experience of therapy;
and the relationship with the therapist. Once developed the initial draft was considered by the staff team at two psychology meetings. At these meetings were the Clinical Psychologists working in the SPT service, and the Consultant Psychiatrist in Psychotherapy. These staff members gave consideration to the wording of questions and adapted drafts of the questionnaire to produce a final version. Additionally the questionnaire was emailed to all staff working in the SPT service on two occasions during its development. Further a service user viewed the questionnaire and made suggestions about layout and wording.

The final questionnaire consisted of two sections (see Appendix 2). The first gathered general information such as the number of sessions offered to, and attended by the client and what kind of therapy was provided. The second section had 9 questions which asked for a response on a 5 point Likert scale. The scale was anchored by ‘strongly disagree’ (score=1) and ‘strongly agree’ (score=5). The questions considered overall satisfaction with the SPT service, information provided prior to attendance and various aspects of the therapeutic relationship. Each question also had the option to make comments. Finally there were 5 questions asking for a written response which aimed to offer the opportunity to comment more generally on the service.

Procedure

It was decided that the questionnaire should be posted to clients once their contact with the SPT service had been completed. An alternative option was considered, where individual therapists handed out questionnaires at their final session. However this was thought to be onerous to therapists and might complicate the issue of anonymity.

A covering letter was written to accompany the questionnaire (see appendix 3). Care was taken to explain the anonymous nature of the questionnaire and the procedure for returning the completed survey. Additionally the letter contained contact details so the client could ask any questions about the research and included information about making a formal complaint if service users felt this important.
Postal surveys are more likely to produce a lower response rate (Robson, 2002). To maximise return rates authors have suggested carefully constructing the covering letter and personalising it, anonymous questionnaires of a reasonable length, including a stamped addressed envelope and sending follow-up letters (Dillman, 1978 & Norman, 1989 cited in Kuyken et al, 1998). All of these considerations were adhered to in the present study.

An initial posting was sent in March 2008. A follow up letter (see Appendix 4) was sent to participants in May 2008. This mailing included a second copy of the questionnaire as this has been shown to increase response rates (Edwards et al, 2008).

Ethical Considerations
The following considerations were felt to be important in this study

- Participants concern that feeding back to the department might have a detrimental effect on further services they are offered (Dormandy et al, 2008).
- Questionnaires received whilst a client was in therapy might have a detrimental effect on the therapeutic relationship.

Questionnaires were therefore designed to ensure anonymity of participants and this was emphasised in the covering letter. Additionally questionnaires were only posted to participants whom clinicians confirmed they had discharged.

Participants
To gather participants the 2007 referral list to the SPT service was used. There were 104 clients on this list which was compared with the current case-loads of the practitioners in the service. Of the initial referral list a large number were still in therapy when the questionnaire was posted out (March 2008). Therefore only 49 service users could be sent questionnaires. In May 2008 a further nine were sent to people who had finished therapy since the initial mailing. Therefore in total questionnaires were posted to 58 service users. Additionally in May the reminder letter was sent to the original 49 clients.
Results

Of the 58 questionnaires posted, 15 were returned representing a 25.9% return rate. One questionnaire needed to be excluded from analysis as the client indicated he/she was still in therapy so a final sample of 14 questionnaires will be analysed here.

Quantitative Data

A Cronbach’s alpha was carried out to test the reliability of the scale being used. This was run on questions 1-9 in section two of the questionnaire, which asked for a response on the Likert-scale. A Cronbach’s alpha of 0.898 was achieved. This indicates that the scale has internal reliability with the current sample, as the alpha score is above the 0.7 level (Pallant, 2005). However this is based on a sample of just 14 questionnaires so must be considered with caution.
Table 1: Service accessed by respondents

<table>
<thead>
<tr>
<th>QUESTION</th>
<th>RESULTS</th>
</tr>
</thead>
<tbody>
<tr>
<td>Reason for attendance</td>
<td>Reason for attendance</td>
</tr>
<tr>
<td></td>
<td>Assessment only = 2</td>
</tr>
<tr>
<td></td>
<td>Individual therapy = 9</td>
</tr>
<tr>
<td></td>
<td>Group therapy = 2</td>
</tr>
<tr>
<td></td>
<td>Other = 1 (‘Sexual’ therapy)</td>
</tr>
<tr>
<td>Professional providing service</td>
<td>Professional providing service</td>
</tr>
<tr>
<td></td>
<td>Psychologist = 6</td>
</tr>
<tr>
<td></td>
<td>Psychotherapist = 1</td>
</tr>
<tr>
<td></td>
<td>CBT therapist = 3</td>
</tr>
<tr>
<td></td>
<td>Other = 2 (‘Counsellor’ and ‘CAT therapist’)</td>
</tr>
<tr>
<td></td>
<td>Don’t know = 2</td>
</tr>
<tr>
<td>Receiving copies of letters</td>
<td>Receiving copies of letters</td>
</tr>
<tr>
<td></td>
<td>Yes = 7</td>
</tr>
<tr>
<td></td>
<td>No = 6</td>
</tr>
<tr>
<td></td>
<td>Not appropriate = 1</td>
</tr>
</tbody>
</table>

The mean number of sessions offered was 10.7 (n=10) whilst the mean number attended was 9 (n=13). The range of scores was 2-16 sessions. Four people were unclear about the number of sessions they were offered and one did not know how many they had attended.

Table 2: Range and modes from Likert-response section of the questionnaire

<table>
<thead>
<tr>
<th>QUESTION</th>
<th>MODE (N=14)</th>
<th>RANGE (N=14)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 Overall I was satisfied with the service I received</td>
<td>5</td>
<td>2-5</td>
</tr>
<tr>
<td>2 I was provided with the appropriate information</td>
<td>4</td>
<td>4-5</td>
</tr>
<tr>
<td>3 I was welcomed into the building</td>
<td>5</td>
<td>1-5</td>
</tr>
<tr>
<td>4 Therapy helped me with the issues I wanted to deal</td>
<td>5</td>
<td>2-5</td>
</tr>
<tr>
<td>5 I felt understood by my therapist</td>
<td>5</td>
<td>3-5</td>
</tr>
<tr>
<td>6 My therapist respected me</td>
<td>5</td>
<td>3-5</td>
</tr>
<tr>
<td>7 My opinion was valued</td>
<td>5</td>
<td>3-5</td>
</tr>
<tr>
<td>8 I was offered enough appointments with my therapist</td>
<td>5</td>
<td>2-5</td>
</tr>
<tr>
<td>9 I would recommend the department to a friend</td>
<td>5</td>
<td>3-5</td>
</tr>
</tbody>
</table>

Table 2 shows the scores on questions 1-9. Although there was a range of responses, all questions showed a cluster of responses at the top end of the scale (agree or
strongly agree). One participant gave consistently low scores (mode=3) whilst all other respondents achieved a mode of between 4 and 5.

Qualitative Data

Participants were also able to write comments under the Likert-scale questions and in the final four open questions (see Appendix 5 for a full list of comments). Due to the brevity of the comments it was not possible to carry out any formal qualitative analysis. However a number of themes have been identified from these comments.

These were:

- The overall positive nature of the experience
- The skills of the therapist in supporting the client
- The length of waiting times, timings and number of appointments offered
- The environment

Three of these themes will be explored in more depth, because they were the ones which the majority of people commented on. The final theme ('the Environment') was only mentioned in three comments and so has not been expanded here.

Theme one: The overall positive nature of the experience

Firstly the comments were overwhelmingly positive with only one person remarking they were dissatisfied with the service they had received. For example one participant felt

‘all of my needs were met’, and another said ‘the whole experience was helpful’. This supports the findings in the quantitative section of this report. This can be contrasted with the negative comment from one person saying ‘...I didn’t like the attitude or process so I didn’t go back’. Under the section on what was unhelpful most people wrote ‘nothing’ with only two respondents making any suggestions, which were about specific features such as appointment times and the environment.
Theme two: The skills of the therapist in supporting the client

Overall, people valued the opportunity to talk about their difficulties and gain support and advice from their therapist. Most helpful was: 'Being able to share my problems and feeling that I was being understood. It felt more of a 'team' effort, not just me on my own. I felt encouraged!' Another participant commented 'The therapist helped me put things into perspective'.

Theme Three: Appointment organisation

The quantity and timing of appointments was something which a number of people felt could be improved on. For example one service-user commented 'Could have done with a lot more [appointments] only cos I'm screwed me!' [sic]. Another participant noted:

I had many years often in utter depression before receiving any help. It would be of such benefit to service users if only they could be seen in a timely manner – it would put an end to terrible suffering and give hope and help so much sooner

Discussion

The questionnaires which were returned were mainly positive with most people marking agree or strongly agree for all questions. The majority of respondents stated that overall they were satisfied with the service they were receiving from the department and felt valued, respected and understood by their therapist. On average lower scores were given for the questions asking about the welcome into the building and being offered an appropriate number of sessions, but overall most people still viewed these aspects positively. The qualitative part of the questionnaire revealed that most people consider the service helpful although more flexibility in number and timing of appointments was requested. One respondent, who had accessed the service away from the main location, reflected that it was not a positive experience.
All of these results must be considered in the light of the poor response rate. Overall the survey achieved a response rate of 25.9%. Moser and Kalton (1971, cited in Sim & Wright, 2000) suggest that response rate of below 30% will produce results which are ‘of little, if any, value’ (p.266). However other studies canvassing the views of service users have achieved similar response rates to the current study. For example Dormandy et al (2008) and Bernard et al (2007) recorded response rates of 26% and 32% respectively. However these studies sought responses from people with physical health problems and a more valid comparison may come from surveys specifically seeking data from people with mental health concerns. The National Patient Survey, canvassing a similar sample to this audit achieved a higher response rate of 38% (Healthcare Commission, 2007b). As it will be shown, low response rate was just one of the limitations inherent in this study.

Limitations

A number of limitations existed in this study and these limit the usefulness of the findings for the SPT service.

Firstly whilst the questionnaire was shown to have internal reliability no attempt was made to ensure external reliability and validity. For example whilst question wording was considered at a number of stages in the development process no operationalising of terms was done (Robson, 2002). Further no attempt was made to compare the questions asked in this study with other published studies measuring satisfaction.

Secondly the overwhelmingly positive results may indicate that a ceiling effect exists with this questionnaire (Hammond, 2006). The fact that the majority of questionnaire responses were clustered around the top end of the scale suggests that the questions were not discriminating enough to identify individual differences of opinion. All questions in the Likert-section were worded positively and no items were reversed which may have resulted in a response bias amongst participants (Langridge, 2004). Additionally the questions could be seen as value-laden, something which Langridge (2004) suggests should be avoided. Alternatively (or additionally) there may have been problems with the Likert-scale terms selected with response categories being too broad to gather meaningful data about clients' satisfaction (Robson, 2002).
Further the methodology used in this survey proved to be a limitation as a small sample size and low response rate resulted. One limitation of postal surveys is that because they are not completed in the presence of the researcher misinterpretations of questions are impossible to detect (Robson, 2002). Limitations around time, cost and ensuring anonymity of service users meant that the degree of follow-up employed in a large scale study such as the National Patient Survey (Healthcare Commission, 2007b) was not possible in the present project.

Additionally this project gathered no information about respondent demographics. Whilst this was done to reassure participants about anonymity it has meant that it is not possible to see whether responses were received by certain groups of people, and thus ascertain whether the questionnaire was accessible to a range of people. Brealey et al (2007) note that: ‘Poor response rates to postal questionnaires might introduce bias due to differences between responders and non-responders which limits the generalisability of results.’ (p.2).

Finally, this study provided no incentive for service-users to participate. Whilst some studies (e.g. Brealey et al, 2007) found that material rewards (such as payment) increased participation other writers have noted that feeling involved in the research motivates respondents. For example Rawlins et al (2002) suggest that users should be ‘genuine collaborators rather than merely sources of data’ (p.10). The covering letter sent with the original mailing noted that service user feedback would be used to consider how the department could be improved. This was echoed in the comment at the bottom of the questionnaire thanking clients for participation. However both these statements did not guarantee any changes would occur as a result of feedback and service users may have been unsure about the real effect they could have on practice (Masterson & Owen, 2006).

Suggestions for future research
A study which attempted to address some of the limitations in the present project might generate useful audit data for the department. If the method used was sensitive enough it might be able to discover both areas of good practice within the SPT department and considerations for adapting or changing the service offered as necessary.
Conclusions
Overall the majority of respondents felt their experience of the SPT department was positive, with particular strengths demonstrated in feeling understood, respected and valued by the therapist, and overall satisfaction. However a number of limitations exist in the present study which means that the significance of the data is reduced. Further studies which address these limitations may generate more meaningful data.

Dissemination of results
The results were fed back to the service at a meeting on 4/8/08. Additionally a summary will be provided for all staff in the service. The project was also be shared with the Health and Social Care Governance Support team and was logged in their clinical audit list.
Acknowledgements

Thanks must be given to all the staff who helped develop the questionnaire, and to the Service User Advisor who consulted on the project. Many thanks also to my clinical supervisors who invested their time and energy into supporting me with this project and to my research tutor for her unfailing calmness in the face of low response rates.
References


The Health Foundation (2007). Necessary Measures: How teams involved in The Health Foundation's engaging with quality schemes have used measurement to improve standards of patient care. *The Health Foundation Briefing, August 2007.*
Appendices

Appendix 1: Other SPT questionnaire

Client Code:

(Office use only)

User Satisfaction Survey for XXXXX Psychology Service

Our department is conducting a survey, involving all our service users, in order to gather opinions on our service. We value your views of our service, so please take your time in filling out this questionnaire. Your participation is entirely voluntary, and information given by you will be strictly confidential and be used for audit and research purposes only. Please try to answer all of the questions, including those on the reverse of this page.

Please circle on the following scales the point which you feel best describes your opinions.

1. Overall, how satisfied are you with the psychology service that you received.

<table>
<thead>
<tr>
<th>Very Satisfied</th>
<th>Uncertain</th>
<th>Very Dissatisfied</th>
</tr>
</thead>
<tbody>
<tr>
<td>Satisfied</td>
<td>Dissatisfied</td>
<td></td>
</tr>
</tbody>
</table>

2. Did therapy help you to sort out your problems/symptoms?

<table>
<thead>
<tr>
<th>Completely</th>
<th>Not at all</th>
<th>Uncertain</th>
<th>Not Really</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pretty Much</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

3. How confident do you feel in the long term with sustaining any changes that you may have made through therapy?

<table>
<thead>
<tr>
<th>Totally</th>
<th>Not at all</th>
<th>Undecided</th>
</tr>
</thead>
<tbody>
<tr>
<td>Not at all</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

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4. In your own words, if you would like to, please describe your own experience of the therapy you received.

______________________________________________________________________________
______________________________________________________________________________

5. Please circle a point on the following scales which you feel describes your view of whether your psychotherapist:

a) Understood you?
   Completely                                      Uncertain                                      Not
   At All                                           
   Quite a lot                                      Not Much

b) Made herself/himself clear to you?
   Completely                                      Uncertain                                      Not
   At All                                           
   Quite a lot                                      Not Much

c) Respected you?
   Completely                                      Uncertain                                      Not
   At All                                           
   Quite a lot                                      Not Much

6. Would you refer a friend to the department? (Please tick a box)
   Yes                                                No

7. Do you have any suggestions to enable our service to suit you better?

______________________________________________________________________________
______________________________________________________________________________
______________________________________________________________________________

If you have any other comments, please write them below.
8. Please tick the box if it would be OK if we put this survey in your file for your psychotherapist to see?  

9. Please tick the box if you would be willing to be contacted again in a year's time so that we can enquire about longer term effects.  

10. Please tick the box if you would be willing to be contacted about opportunities to participate in service developments.
Appendix 2 - Questionnaire used in this study

User satisfaction survey for the Specialist Psychological Therapies Service

We are conducting this survey because we want to find out what service users think of the specialist psychological therapies service. Your feedback will help us to look at the service and improve it as necessary to make sure it is meeting the needs of the people who use it. Thank you in advance for your help.

General information

1. How many sessions were you offered with the specialist psychological therapies service? ___
2. How many sessions did you attend with the specialist psychological therapies service? ___
3. Did you attend for: (please circle)
   - Assessment only
   - Individual therapy
   - Group therapy
   - Family consultation
   - Other (please specify) __________________________

4. Did you meet with: (please circle)
   - A psychologist
   - A psychotherapist
   - A CBT Therapist
   - Other (please specify) __________________________
   - Don’t know

Your experience of the Specialist Psychological Therapies Service

Please read the following statements, and circle the extent to which you agree with each statement. Please circle only one box for each question.

1. Overall I was satisfied with the service I received from the department
   - Strongly Agree
   - Uncertain
   - Disagree
   - Strongly disagree
   Comments:

2. I was provided with the appropriate information prior to attending the department
   - Strongly agree
   - Uncertain
   - Disagree
   - Strongly disagree
   Comments:
3. I was welcomed into the building  
   Comments:
   Strongly Agree Uncertain Disagree Strongly agree disagree

4. Therapy helped me with the issues I wanted to deal with  
   Comments:
   Strongly Agree Uncertain Disagree Strongly agree disagree

5. I felt understood by my therapist  
   Comments:
   Strongly Agree Uncertain Disagree Strongly agree disagree

6. My therapist respected me  
   Comments:
   Strongly Agree Uncertain Disagree Strongly agree disagree

7. My opinion was valued  
   Comments:
   Strongly Agree Uncertain Disagree Strongly agree disagree

8. I was offered enough appointments with my therapist to be of help  
   Comments:
   Strongly Agree Uncertain Disagree Strongly agree disagree

9. I would recommend the department to a friend  
   Comments:
   Strongly Agree Uncertain Disagree Strongly agree disagree

10. Did you receive copies of the letters written by your therapist? (please circle)  
    YES  NO

11. What was most helpful about attending the specialist therapies department?

12. What was least helpful about attending the specialist therapies department?

13. What suggestions would you make so the service could best meet the needs of service users

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14. Is there anything else you think we haven't covered?

Thank you for taking the time to complete this questionnaire. Your replies will enable us to ensure we are offering the best service we can to meet the needs of service users. Your help is much appreciated.

NB Version of questionnaire sent out fitted onto two pages, and was made double sided for participants.
Appendix 3: Covering letter sent with questionnaires

NHS headed paper

Address of service

Dear [NAME HANDWRITTEN HERE]

The specialist psychological therapies department at XXXXXX would like to find out what kind of service we are offering to clients. For this reason we are conducting a survey to find out the views of people who have used the department.

If you have time we would appreciate you filling in the short questionnaire which is attached. It can be returned in the envelope provided. The questionnaire is anonymous so there will be no way of identifying where the responses come from. We hope this will make it easier to be honest about the service.

We plan to use this information to look at areas of success and areas for improvement within the department. This will help us to ensure that we offer the best possible service to future users of the department.

If you have any other comments you would like to make, or want to make a complaint please contact the Patient Advice Liaison Service (PALS). You can also contact them with any feedback or compliments you would like to make. They can be contacted by telephone on 01243 815503 or by email at pals@sussexpartnership.nhs.uk.

If you have any questions about this survey please contact [NAME] (consultant clinical psychologist) on [PHONE NUMBER]

Thank you in advance for your help

Yours sincerely

[NAME] [NAME]
Consultant Clinical Psychologist Trainee Clinical Psychologist

Professional lead – Psychology
Appendix 4: Reminder letter sent with questionnaires

NHS headed paper

Address of service

Dear [NAME HANDWRITTEN HERE]

A questionnaire gathering service user views of the specialist psychological therapies department at XXXXXX was recently posted to you. If you have already returned your questionnaire thank you very much for your participation.

Participation in this survey is voluntary. However your views are important to us so we would like to hear from you. If you have time we would appreciate you filling in the short questionnaire which is attached. It can be returned to [NAME] at the address above, or in the envelope already provided. The questionnaire is anonymous so there will be no way of identifying where the responses come from. We hope this will make it easier to be honest about the service.

We plan to use this information to look at areas of success and areas for improvement within the department. This will help us to ensure that we offer the best possible service to future users of the department. If you have any other comments you would like to make, or want to make a complaint please contact the Patient Advice Liaison Service (PALS). You can also contact them with any feedback or compliments you would like to make. They can be contacted by telephone on 01243 815503 or by email at pals@susexpartnership.nhs.uk.

If you have any questions about this survey please contact [NAME] (consultant clinical psychologist) on [PHONE NUMBER]

Thank you in advance for your help

Yours sincerely

[NAME] [NAME]
Consultant Clinical Psychologist Trainee Clinical Psychologist

Professional lead – Psychology
### Appendix 5 Written comments

<table>
<thead>
<tr>
<th>Question no</th>
<th>Question</th>
<th>Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Overall I was satisfied with the service I received from the department</td>
<td>• All of my needs were met</td>
</tr>
<tr>
<td>2</td>
<td>I was provided with the appropriate information prior to attending the department</td>
<td>• I had discussions with my nurse XXXX</td>
</tr>
<tr>
<td>3</td>
<td>I was welcomed into the building</td>
<td>• I received a warm welcome</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Meetings were in a room at XXXX health centre, not welcoming and the room didn’t feel very private and was cramped.</td>
</tr>
<tr>
<td>4</td>
<td>Therapy helped me with the issues I wanted to deal with</td>
<td>• The psychologist helped me put things in perspective</td>
</tr>
<tr>
<td>5</td>
<td>I felt understood by my therapist</td>
<td>• I felt at ease and reassured</td>
</tr>
<tr>
<td>6</td>
<td>My therapist respected me</td>
<td>• The therapist listened and offered advice</td>
</tr>
<tr>
<td>7</td>
<td>My opinion was valued</td>
<td>• Without question</td>
</tr>
<tr>
<td>8</td>
<td>I was offered enough appointments with my therapist to be of help</td>
<td>• The appointments were sufficient</td>
</tr>
<tr>
<td>9</td>
<td>I would recommend the department to a friend</td>
<td>• Could have done with a lot more only cos I’m screwed me!</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• I would most definitely recommend the service to a friend</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• The listening skills and the advice offered were exemplary</td>
</tr>
<tr>
<td>10</td>
<td>What was most helpful about attending the specialist therapies department</td>
<td>• Talking to people the same as me</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• That others services have been offered to me after my psychologist</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Having somebody else’s opinion</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• The whole experience was helpful</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• The help I received in working through the issues that had been raised</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Being able to share my problems and feeling that I was being understood. It felt more of a ‘team’ effort, not just me on my own. I felt encouraged!</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Being able to talk and no be judged</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Not sure, I didn’t like the attitude or process so I didn’t go back</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• The whole experience was excellent and really helped</td>
</tr>
</tbody>
</table>
What was least helpful about attending the specialist therapies department

- Offloading
- Someone to listen and normalise problems
- None
- It was all helpful
- Nothing!
- No complaints
- Nought
- The environment
- Nothing
- Time of appointments and work

What suggestions would you make so the service could best meet the needs of service users

- Meeting after course once every few months
- More sessions made available and family therapy if relevant
- To ensure more people are aware of the service that is available
- I had many years often in utter depression before receiving any help. It would be of such benefit to service users if only they could be seen in a timely manner – it would put an end to terrible suffering and give hope and help so much sooner
- Not such a long wait for an appointment
- More colour in the rooms
- To tell people how long the session is at the beginning. To have a nicer, more relaxed and confidential environment. To not make the client feel you are under pressure to get results.
- Nothing – all good
- More sessions
- Probably impossible but later appointments

Is there anything else you think we haven’t covered

- No
- No
- I think you’ve pretty much covered everything
- Thanks for use of the service - very helpful to myself
- No
- Very impressed with service and staff as opposed to those at the adult mental health service where I felt patronized, disrespected and unsafe.
Appendix 6: Feedback to the service

Email from Professional Lead for Clinical Psychology

Dear {TRAINNEE NAME},

Thank you so much for attending our local Specialist Therapy Group on 4th August 2008 to present your feedback on the Service Project which has helped us to develop a service user service satisfaction questionnaire.

Although the response rate was quite low, the PowerPoint presentation of the data was very meaningful. We will be using your questionnaire on an ongoing basis as people are discharged from Specialist Therapies, so in this respect your work has been invaluable.

I thought your presentation was clear and well structured. Thank you.

Best wishes
Yours sincerely

Dr XXXX XXXX
Consultant Clinical Psychologist
Professional Lead XXX Psychology {AREA}

XXX NHS Trust
ADDRESS
Tel: XXXX
Fax: XXXX

Help us to be the best we can be ...

Become a member of XXXX NHS trust and help us to fight stigma and raise the profile of mental wellbeing.

Visit our Foundation Trust membership web page for more information and a membership application form.

*******************************************************************************

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Qualitative Research Project

“...at the moment we’re just sharing space not sharing the experience”

Investigating division in a shared learning environment

Year One

June 2008
"...at the moment we’re just sharing space not sharing the experience"

Investigating division in a shared learning environment

Whilst there are benefits to inter-professional learning, bringing multiple viewpoints to the classroom can result in tension (Crow & Smith, 2003). This study aimed to explore the experience of counselling and clinical psychology trainees in joint weekly research methods teaching sessions. The research sought to explore the constructions of reality which resulted from the different subjective experiences and how the professionals in the two groups made sense of these experiences. Interpretive Phenomenological Analysis (IPA) was used to analyse the transcripts of two focus groups, one made up of six clinical trainees and another of two counselling trainees. Seven superordinate themes arose from the analysis and the report focuses on the theme of ‘division’ as this was of most relevance to the research question. Firstly the theme ‘we all write separate reports’ was important in illustrating the trainees were unable to work towards a common goal, and were blaming course structure for divisions. Further ‘it wasn’t the right kind of room’ was a reflection of the limitations in the physical environment. Finally ‘it seems almost symbolic’ is concerned with the trainees’ responsibilities to integrate with the other group, and focused on trainees choices to sit with members of their own cohort and not seek collaboration. It was concluded that rather than being a shared learning environment, the research lectures simply functioned as shared teaching. To overcome divisions more cooperation is required, with a reliance on others to achieve common goals. Limitations and implications for practice are discussed.

References:

Finding the way to a ‘new normal’:
The journey of recovery for families following a paediatric intensive care admission

Year Three
July 2010
Abstract

Admission to a Paediatric Intensive Care Unit (PICU) can be very traumatic for children and parents. This study explored families’ experiences and investigated how they recovered from a PICU admission. Semi-structured interviews were analysed using Charmaz’s (2006) Grounded Theory. This methodology is based on the concept of social constructivism, seeing reality as subjective and created through social interactions. Eighteen parents and young people who had been on PICU participated in the research. Analysis of interview data highlighted the centrality of the admission experiences and the need to develop an understanding of these post-discharge. Further key findings include the way participants describe their recovery as ‘a journey’ and the initial use of coping strategies to avoid thinking about the trauma. There is then movement to cognitively, socially and emotionally process the event with the aim of developing a coherent narrative about their experience. Finally children and parents then worked to integrate this narrative into their wider identity and life, and developed a model for recovery which helped them to manage the after-effects of the PICU admission. This involved accepting a ‘new normal’ and moving away from a desire to achieve the pre-admission or ‘old normal’. The model developed through this research is biopsychosocial in nature and emphasises the importance of processing to create a coherent narrative. It is noted that failure to construct a narrative or to integrate this effectively can stall the recovery process. Clinical implications for medical staff and psychologists’ practice are discussed. These include creating a ‘map’ to provide families with information about what they can expect after leaving PICU and providing appropriate interventions depending on the stage of processing the family is in.
Acknowledgements

I would like to thank the families who agreed to take part in this project, especially for their honesty and insight into their experiences.

I also want to thank Mary John and Gillian Colville, my supervisors for their ongoing support, encouragement and insightful comments on the research. I could not have hoped for better supervisors and I will be eternally grateful for the time they spent with me. Additionally Sally Hall supported much of the initial administration and her help was invaluable. Finally to David for the constant and unshakable support he gave throughout the project.
‘There are two lasting bequests we can give our children: One is roots. The other is wings’

_Hodding Carter (Original source unknown)_

‘We worry about what a child will become tomorrow, yet we forget that (s)he is someone today.’

_Stacia Tauscher (Original Source unknown)_
# Major Research Project

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1 Introduction

1.1 Context

Meeting the emotional and psychological needs of children is a complex task. Adults must work collaboratively with young people to ensure the appropriate balance is struck between providing support and encouraging autonomy, between developing attachments and promoting independence. Additionally, there is a need to recognise that children’s needs change dramatically over time, requiring perspective about who the child is in the present as well as who they may develop into in the future (Mayall, 2003).

When children are taken ill this challenges the whole family. The child’s needs for support, containment and understanding must still be balanced with the many social, financial and emotional pressures on parents at this time. Professionals must work with these families in a unique way under difficult circumstances. These challenges continue beyond the hospital, as families then have to negotiate the complex recovery period and simultaneously manage their feelings about the admission.

This study will explore the experiences of families in the year following discharge from a paediatric intensive care unit (PICU). The terms ‘child’ and ‘young person’ will be used interchangeably to mean anyone under the age of 18. As a context for the study, the experience of hospital admission will be reviewed, followed by a discussion of the various ideas around recovery which exist in the literature.

A systematic review of the literature was carried out using the databases Psychinfo and Medline. The titles and abstracts of articles were reviewed to identify relevant papers. Additionally articles were located using the website www.picupsychology.net which has a useful reference list for this topic. Following this, the references of all identified articles were searched to identify any further relevant articles.

---

2 See appendix 24

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1.2 Children, trauma and hospital admission

1.2.1 An introduction to trauma

A traumatic event is one that is described as ‘a stressful event (either short- or long-lasting) of exceptionally threatening or catastrophic nature, which would be likely to cause pervasive distress in almost anyone’ (World Health Organisation; WHO, 1993, p.99). Up until the 1980s most authors were of the opinion that children only had transient reactions to traumatic events (Yule, 2001) and were not negatively affected by trauma symptoms in the long term. More recently there has been an acknowledgement that children do indeed suffer from post-traumatic reactions.

There remains difficulty determining and classifying these reactions. The diagnosis ‘Post Traumatic Stress Disorder’ (PTSD) has been applied to children, although the category was originally designed for adults. Current estimates of the number of children affected ranges widely, as it does in the adult population. However around 20% of children who had been in a road traffic accident met the criteria for PTSD (Yule, 2000) in the diagnostic and statistical manual (American Psychiatric Association, 1994). As the literature around PTSD in children becomes more sophisticated there is recognition that the PTSD diagnosis may be flawed when applied to children. It has been noted that children experience and react to trauma in different ways to adults with their response also depending on their age (Salmon & Bryant, 2002). It seems that simply applying an adult construct to children may not be adequate to describe the breadth or depth of their experiences. In time a new concept may well replace the current adult-centric definition of PTSD.

1.2.2 The traumatic nature of hospitalisation

In 1952 James Robertson filmed the hospitalisation of a child and the suffering she experienced facing ‘the fears, frights and hurts with no familiar person to cling to’ (Robertson films, 2007). Robertson noted the ‘depth of their distress and the risks to later mental health’ which he felt went largely unrecognised (ibid). This film and the papers he subsequently wrote were said to be critical in helping professionals to recognise the difficulties children experience in hospital and
changed practice as a result. Visible changes have taken place, including parents being allowed to stay with their children both in the day and subsequently overnight, although some authors have argued that these changes must be placed in a wider context and not just attributed to Robertson's work (van der Horst & van der Veer, 2009).

Thankfully there is now an awareness of the potentially traumatic nature of a hospital admission. Bryant and colleagues (2007) note that children may experience an increased sense of vulnerability and fear that they have suffered a 'disturbing and permanent change', believing they are 'a feeble person in a scary world' (p.2504). Engaging in these negative appraisals after hospitalisation was a predictor of developing PTSD (ibid).

1.3 The psychological impact of PICU admission

PICU caters for the most seriously ill babies and children providing a high level of observation and intensive medical care. Traumatic experiences on PICU might include being ventilated, having lines inserted to get blood out or medicines in, being in pain which doctors are struggling to control and being around other extremely sick or dying children.

The experience of being in PICU fits the criteria for a trauma as listed above, because of its stressful and life threatening nature. In the context of PICU admission children may experience both injury/illness-related trauma and treatment-related trauma. It can be hard to distinguish between these two variables (Ward-Begnoche, 2007), but both types are likely to affect the child's experience and subsequent recovery. Additionally parents may also be traumatised being a witness to the severe, life-threatening illness of their child and the invasive treatments which are necessary in their medical care. Further this kind of experience can have a sensitising impact on families, meaning future hospital visits become highly feared and upsetting.
1.3.1 Research considerations

Whilst the potentially traumatising nature of PICU is acknowledged, gathering information about the experience can prove challenging. Research into PICU admission is complicated, partly because many children admitted to PICU will die during admission or subsequently due to serious and ongoing health problems. Additionally children and families may not want to share their traumatic experiences with a researcher, despite the evidence that talking about it can be helpful and is rarely regretted by research participants (Newman & Kaloupek, 2004).

Further research into developmental factors has concluded that responses to trauma will differ according to the age of the child, particularly because children are constantly developing, with an uneven pattern of change (Salmon & Bryant, 2002). Varying cognitive and verbal abilities will include children's ability to process information, encode memories and regulate their emotions, which will also impact on how they respond to a hospital admission or other traumatic event (Cohen, 1998; Salmon & Bryant, 2002). Finally children may struggle to think and talk about their psychosocial functioning (Kaplow et al., 2006) making it difficult for researchers and parents alike to ascertain the way a child has been affected.

1.3.2 The impact of PICU admission on the child

There are a number of reasons why the PICU environment can have such a large psychological effect on children. These include ‘The highly invasive technological interventions, lack of control over events, severity of the child’s illness, and high levels of parental distress...’ (Rennick et al., 2008, p.252). Further, admission is usually a result of an accident or serious illness and involves ‘displacement from the home or community’ (Rennick et al., 2008, p.259) often without any warning, so it is not only the PICU environment which is traumatising but also the absence of a familiar environment.

The presence of other extremely sick young people, who are also subjected to painful and invasive procedures can be traumatic (Colville et al.,2008a). Jipson and Melmed (2007) noted that witnessing coping was a protective factor and the evidence from PICU would appear to show that the opposite is also true; to see
children and families in distress and not coping would appear to have negative implications on those who are watching.

Whilst the experience is significantly traumatising for a large number of children, many young people who experience an admission do not develop PTSD (Colville et al., 2008a). For some children the 24-hour attention they receive from medical staff and their parents may mediate against the painful and uncomfortable experiences they are having. Some children also note the positive changes they have observed since admission, such as developing maturity or a greater sense of perspective on illness (Colville, 2004), although there is a paucity of information on positive experiences which may be related to the reality that PICU admission is difficult for all involved. Research into the more traumatic aspects can be justified as this enables the development of interventions to support children and families who find the experience difficult. However knowing what is going well and giving voices to those who do report positive experiences may also suggest ideas for interventions which would be less pathologising and evoke adaptive coping strategies.

1.3.3 The impact of PICU admission on parents

Whilst it is the child who is ill, a PICU admission impacts on the whole family, particularly the parents. Post traumatic reactions are observed in parents, particularly if they are concerned their child may die or if the PICU admission is unplanned (Balluffi et al., 2004; Colville, 2001). Parents worry about the level of pain their child is in and the potential for a poor outcome (Salisbury et al., 2007). Parents also report difficulties after seeing other children dying or in considerable distress (Colville et al., 2008a). Further, they find the highly technological environment of PICU overwhelming, but do welcome knowing that they are in the right place.

One key area of concern for parents is the impact that their child’s admission has on their parental role (Carter et al., 1989; Colville et al., 2008a). Parents have a vital role to play in the care of child in PICU. They know their child best and can be present to meet the emotional needs of the child whilst staff attend to their physical needs. However many parents feel out of control when not able to
decide about eating, clothes and bedtimes. Further their usual role as primary protector and decision maker is also changed as medical staff take on this role (Graham et al., 2009). Parents in Graham et al.'s study felt that family-centred care was not emphasised when on PICU, leading to parents feeling helpless and undervalued. In reality how much the parental role changes will also depend on the age of the child. Parents of very young children will be used to meeting all of the child's needs all of the time and may miss this, whilst parents of teenagers may find themselves needing to attend more to their physical and emotional needs than previously. Equally, social changes in parental roles, such as the increased involvement of fathers in a child's care, will also impact on how a PICU admission affects parents (Johnson et al., 1988).

1.3.4 A systemic perspective

There is also evidence that the way parents respond to the child's admission and diagnosis influences how the child reacts (Eiser et al., 2000). Critically some models of trauma do not take into account this interplay between the child and those around them, instead focusing on within-child factors (e.g. Meiser-Stedman, 2002). The relationships between a child and their parents are of significant importance when assessing the impact of a PICU admission. Bush et al. (1986) found that when mothers were overtly anxious about a hospital procedure the child's distress was higher and they exhibited less pro-social behaviours. Additionally mothers were less anxious and more communicative when they had a secure attachment to their child (ibid), suggesting that they were more able to act as a secure base and provide containment, having previously created a secure and loving relationship. Bowlby (1988) saw a secure base as a 'central feature of my concept of parenting' (p.11) and involves the child being able to explore the world, knowing they have someone safe to return to (ibid). In the case of hospital treatment or admission the parent is able to emotionally regulate the child by dealing with the distress sensitively, emotionally 'holding' or containing the difficulties the child is dealing with until they internalise the idea that such distress is not overwhelming (Dallos, 2006).

One difficulty with research into children's distress following hospitalisation is that often only the parent's views are sought. A study by Shemesh et al. (2005)
found that parents’ reports of their child’s level of trauma were not predictive of their child’s PTSD diagnosis. The authors highlighted that parents’ trauma symptoms lead them to over-report their child’s trauma symptoms. Further the level of distress a parent is experiencing may in turn affect the child who is not initially distressed by their hospital admission. For these reasons the authors note that ‘in medical care settings [staff/researchers] should seek the child’s report...and should not rely exclusively on parental reports’ (p.582).

Whilst a systemic perspective is now recognised as valid, it appears difficult for authors to hold this in mind when considering how best to help children and families. For example Meiser-Stedman (2002) reviews the literature noting the systemic nature of trauma reactions, but then goes on to propose a model which appears strongly medicalised, focusing on a cognitive behavioural understanding of children’s reactions. Whilst this is helpful within a system which offers more Cognitive Behavioural Therapy than other therapeutic approaches it is just one approach and may miss other vital factors in response to trauma (Hall & Marzillier, 2009).

1.4 What might be happening post-discharge?

The present study investigates the experience of children and their parents as they negotiate their lives after a PICU admission. This is important as the behavioural and emotional consequences which can result from experiencing trauma increase the likelihood of the family requiring psychiatric support later in life (Stevenson, 1999). To date few studies have investigated families post-discharge. Ward-Begnoche (2007) notes that research is still required into additional stressful or traumatic life events which may mediate the development of PTSD or other difficulties. Therefore this section explores models which look at both children and adults and attempts to consider the key factors which may interplay in a family’s recovery after a PICU admission.

1.4.1 The effect of specific PICU experiences

Firstly, it is important to acknowledge the significant effect that the actual experiences during the PICU stay may have on the child after they have been
discharged. From the research it is now possible to generate hypotheses regarding which PICU-related events impact on psychological recovery. Risk factors for trauma symptomology include being younger or having more painful or invasive procedures (Rennick et al., 2008). Further, it is known that even young children can remember their PICU admission experiences (Rennick et al., 2008) and literature from adult admissions would suggest that having a memory, even for unpleasant events, can be protective (Jones et al., 2001). However Colville and colleagues (2008b) found that at a three-month follow-up children who reported delusional memories had more symptoms of trauma whilst factual memory did not correlate with trauma reactions. Clearly the role of memory in psychological recovery is ambiguous as other papers have concluded that not remembering negative events can be a protective factor and result in less distress (e.g. Playfor et al., 2000). Perhaps this ambiguity remains because children and adults encode, recall and express memories in different ways, reflecting their levels of neural development, understanding and expression. Further research to explicate the differences and explore developmental factors in PICU memory would seem important.

Whilst children's reactions after discharge depend on their medical experiences in PICU the same is not true for parents. No correlation has been found between the child's illness severity and maternal distress (Balluffi et al., 2004; Bronner et al., 2010; Colville & Gracey, 2005). This all suggests that there are key mediating factors for both the parents and the children after a PICU admission, but the factors are not necessarily the same for each group.

It is known that some children who are not symptomatic three months post-discharge may show signs of being traumatised when followed-up in the following year, and the reverse is also true, with recovery occurring over the year (Colville & Pierce, 2007). However, few studies look at long-term experiences of children or families, with most not assessing beyond eight months. Therefore more research is required to unpick the processes which occur over the year following discharge to understand more about the varying responses shown by children and their parents.
1.4.2 Models of recovery

Recovery from trauma

A model looking at the effect of trauma which occurred in childhood was developed by Finkelhor and Browne (1985). In this model the authors highlight key influences on psychological functioning which impact on someone’s ability to recover. These include feelings of betrayal, powerlessness and stigmatisation. Although their model was designed specifically for children who had been sexually abused they noted that it could be useful for other types of trauma (Stevenson, 1999). For PICU admission powerlessness would appear to be particularly poignant as children have so little control over what their body is doing (e.g. causing them pain) or what others do to them (e.g. invasive medical procedures).

Additionally children may feel stigmatised, holding onto shame, guilt and badness (Stevenson, 1999) because of their illness or the things that happen to them as a result. For example the experience of being catheterised or intubated may feel invasive and disturbing. Additionally if the children do not understand their hospitalisation they may think they are to blame for the admission. Finally children may also experience a sense of betrayal because their parents cannot stop their pain, and their previously-held beliefs that medical staff make you better may be irrevocably changed. Glaser (1991) later added further components to this model, including the recognition of extreme fear and isolation (in this model related to secrecy surrounding abuse) which would be present for children in PICU, removed from their peers, aware that something was seriously wrong with them.

The recovery model

In reality, the term ‘recovery’ has many meanings and remains a contested term (Bonney & Stickley, 2008; Davidson et al., 2006). Initially coming from the physical health paradigm ‘recovery’ referred to returning to a previous level of functioning or fitness (Oswald, 2006). However, there are a number of problems with this definition when applied to psychological or psychiatric difficulties. Firstly, emotional difficulties simply are not the same as a broken leg or a heart attack
and cannot neatly be classified in the same way. Secondly people often report learning and changing as a result of their difficulties, and so are not the same person they were prior to the start of any problems. This means that the idea of returning to the same place they were prior to their difficulties is no longer helpful. Finally, a sufferer may find themselves functioning better than they previously did because of the psychological journey they take (Chadwick, 2002).

The recovery model was developed in relation to previously institutionalised individuals suffering from severe and enduring mental health difficulties (e.g. Anthony, 1993) and most research has focused on this population. Therefore the links to families who have experienced a hospitalisation for a severe physical illness may seem tenuous, but admission can be significantly traumatising and recovery following an admission will need to look beyond just physical healing. Following life-changing circumstances families will need to consider what their new goals are (Davidson & Roe, 2007), and will be helped on this journey by the qualities of ‘hope, optimism and a positive orientation to the future’ (Friesen, 2005, p.8). In the context of this study therefore it is important to consider how children and families might come to understand their experience and how they come to live with what has happened to them, rather than assuming that ‘normal’ life will be resumed following a return to physical health.

**A service user perspective**

The literature around recovery has emerged at a similar time to service users finding a voice amongst the dominant discourse of academic writing. In serious or chronic illness, as in trauma, there has long been an active service user movement and an embracing of the concept of recovery as ‘living with’. In trauma, particularly around sexual assault, there exists the notion of the individual as ‘a survivor’ with the trauma becoming part of their history whilst not dominating their life (e.g. Bennice & Resick, 2002). Similarly the notion of survivorship exists within the health literature, focusing on people’s experience post-treatment (Turner *et al.*, 2009). Finally carers have been active in child health for many years, creating organisations to provide information and mutual support.
1.4.3 Resilience

One concept which fits well with the recovery model and has been explored with the adult population is that of resilience. This refers to the capacity of people to ‘thrive despite their difficult experiences’ (Waugh et al., 2008, p.1032).

Hoge et al. (2006) reviewed resilience in the context of ‘children at risk’. They identified three factors which influence resilience in children:

1. ‘Temperamental or dispositional factors of the individual
2. family ties and cohesion
3. external support systems’ (p.140)

This model highlights intrinsic factors in the child as well as the wider system they exist in (see also Pynoos et al., 1995). This might suggest some congruence between how trauma is understood and the resilience an individual is able to bring to the experience.

Resilient people are less likely to experience mental health problems and are more able to preserve their sense of self following a traumatic event (Waugh et al., 2008): People who were resilient recovered more completely from an anticipated threat than people who were not as resilient. This suggests that how families negotiate the year following discharge may depend on longstanding personality traits predating the admission, particularly as hospital admission will have included a number of anticipated threats, most significantly, that the child might die. As this research was laboratory-based there is little real-world validity to the study. However whilst there are criticisms of Waugh’s work, the findings are congruent with the research by Bryant et al. (2007) suggesting that ‘children’s posttraumatic stress is associated with perceptions of threat’ (p.2503).

Whilst this adds to our understanding of recovery after PICU, this model does not include any reference to the actual event or experience which the individual must be resilient against. Additionally the resilience model proposes that some individuals are more resilient than others, although a trauma is defined as being distressing to anyone who experiences it (WHO, 1993). Therefore, resilience remains a useful tool but has limitations when applied to families’ responses to a PICU admission.
**Post Modern perspectives on resilience**

The terms ‘posttraumatic growth’ and ‘adversity activated development’ (AAD) are starting to become more prevalent in the literature (Papadopoulos, 2007). Posttraumatic growth is where ‘a positive psychological change [is] experienced as a result of the struggle with highly challenging circumstances’ (Tedeshi & Calhoun, 2004). AAD is defined as ‘positive developments that are a direct result of being exposed to adversity (Papadopoulos, 2007). Whilst both refer to the positive effects that a person may experience as a result of a difficult or stressful situation AAD has relevance to this study because

a) It does not assume that the significant event was traumatising (although it may have had the potential to be so).

b) It recognises that development and positive behaviours can occur during as well as after an event (Papadopoulos, 2007).

In the PICU parents endorsed two particular aspects of post traumatic growth more strongly than other factors. These were increasing ‘personal strength’ and ‘appreciation of life’ (Colville & Cream, 2009, p.920). Additionally, Colville and colleagues (2008a) found that closer relationships with friends and family and the knowledge that they could cope with difficult experiences were positive consequences of their hospitalisation.

1.4.4 Cognitive models of recovery

**Locus of control**

The way recovery is negotiated will depend on how the individual chooses to think about the experience both at the time and afterwards. For example, often people tend to relate positive outcomes to events within their control, but blame negative outcomes on external factors (Capps & Bonanno, 2000). Whist this reduces the amount of self-blame or guilt it can also result in individuals feeling helpless and unable to control what happens to them (Weiner, 1992), leading to considerable anxiety, depression or post-trauma symptoms.

Alternatively, an individual may have an 'internal locus of control', believing that
life is under their control. This position has been shown to result in reduced likelihood of developing PTSD symptoms in adults and has been related to better outcomes in children who have witnessed war or violence in the home (Hoge et al., 2006). However little is known about how the concept of locus of control relates to children in hospital, particularly as control over the body itself is reduced by medical equipment and interventions. This may be more frightening for children who previously believed they were in control than for those who had more externally focused beliefs.

**Coping strategies**

Grootenhuis & Last (2001) argue that because children who have experienced serious illness have lost the physical control of their body (due to the disease or interventions of doctors) they must retain and develop cognitive coping strategies. The literature suggests there is a range of possible coping strategies. In a study on children in hospital two coping styles were identified: ‘sensitizers’ seek additional information associated with the stress whilst ‘repressors’ evade information (Field et al., 1988). In the study ‘sensitizers’ protested more about interventions but required less intensive care support than ‘repressors’. It has been suggested that developing coping mechanisms to manage a serious illness can result in having more strategies to deal with the normal stressors of life (Hampel et al., 2005).

In the recovery period, coping strategies will still be important as families are faced with returning home and reintegrating alongside coming to terms with what has happened to them. It is known that some people use ‘task-focused coping’ (thinking about and then taking action to tackle the challenges faced, often with action to ameliorate the situation) whilst others employ ‘emotion-focused coping’ (talking about their feelings or showing distress) or ‘avoidance-focused coping’ (not thinking about what is happening). In adults this last method of coping was shown to result in significantly higher PTSD symptoms. However as this study gained retrospective accounts of the traumatic situation and coping styles it remains unclear whether the avoidance being reported was related to the current experience of PTSD rather than how the person actually behaved at the time (Hoge et al., 2006). If the individual believes they can cope with the difficulty
('coping self-efficacy') then they are less likely to develop negative thoughts which can lead to PTSD (Cieslak et al., 2008).

1.4.5 Emotional models of recovery

Narratives

The way in which a traumatic event is understood and responded to by a family will depend on how they think about it, and how they communicate their experience between themselves and to others outside the family. Narratives, or the stories people tell about an event, are 'the most pervasive and powerful human resources for recalling and reconstructing personal experience' (Capps & Bonanno, 2000, p.3). Meaning-making through conversation exists within the bounds of a 'grand theory' known as social constructionism, which proposes that the process of knowing and understanding about something must exist within the cultural frame of reference, particularly how language is used and how people interact with others (Schwandt, 2001). The narratives told are formed by the narrator, but are also responded to by the listener. The interaction between these two players is complex and may result in changes to the story for future telling. For example narratives which minimize the teller's responsibility may elicit more support from others (Capps & Bonanno, 2000). Equally the actual telling of the story about trauma is significant, rather than any outcome which may result from the narrative being told (Warin & Dennis, 2009).

Narratives about trauma

Therapeutic approaches which support recovery after trauma generally require the client to tell their story in a way that helps them to process what has happened to them, understand their responses to it and then to move forward with the trauma as a part of their history (e.g. Herman, 1998). The narrative approach therefore seems to fit comfortably with therapeutic work in the trauma arena.

Studies into childhood PTSD have found that trauma narratives tend to be negative, with children focusing on their sense of vulnerability or feeling there have been 'adverse changes to their self-image' (Bryant et al., 2007, p.2505).
There is mixed opinion as to whether negative stories have a helpful function, in terms of being cathartic for the person who has gone through a difficult experience. Peebles-Kleiger (2000) argues that naming the PICU hospitalisation as traumatic allows for acclimatization to the fact the event has happened. Adversely this may lead to excessive rumination where the stories are replayed over and over and the narrator is unable to move forward (Capps & Bonanno, 2000). Further narratives which have a negative content tend to elicit less supportive reactions from listeners (Baddeley & Singer, 2008). Focusing on positive aspects and positive emotions results in better emotional adjustment (Davis et al., 1998) and elicits more support from others (Capps & Bonanno, 2000).

Whilst the narrative concept is helpful there are limitations to this model. Importantly research on narratives has thus far focused on adults. The differences in the articulacy, understanding, power and agency between adults and children, and between children of different ages mean that their ability to express themselves will be mediated not only by context but also by their developmental abilities.

**Reflexivity**

This social constructionist perspective clearly has implications for the present research, which is being carried out at a particular point in the families' journeys, but also represents a conversation between the researcher and the family. If meaning is seen as jointly constructed and influenced by context, then the families may tell a different story to a researcher than they would to someone they know, or someone with a different role, such as a doctor or mental health professional. The story which is told to the researcher may therefore be a reflection of the type of emotional support needed at the time of interview, as well as reflecting the researcher's position and how families have constructed and understood their experiences.

**1.4.6 Combining cognitive and emotional models**

Research into recovery following bereavement suggests a dual-process model is appropriate (Stroebe & Schut, 1999) combining the areas of cognitive and emotional processing after a distressing event. In this model the individual copes
best when they are able to strike a balance between expressing emotion alongside carrying on with life and actively putting distress to one side. There are clear parallels with recovery after a PICU admission. Children and parents need to return home, re-engage with other family members and return to school or work. This may take significant planning and processing, so cognitive coping strategies will be helpful. Alongside this families need to make time for their emotional responses to their experiences and any ongoing difficulties.

1.4.7 Developmental and systemic perspectives

Developmental mediators

Importantly all of these models of recovery need to sit within a developmental framework. Younger children are highly aware of their environment, but often less able to take in all of the details meaning they may be harder to access at a later date (Salmon & Bryant, 2002). How the experience is encoded will also depend on a child’s existing knowledge base, emotional maturity and language abilities. Additionally young children’s attention shifts more rapidly and they can become more overwhelmed by a situation they are struggling to process (ibid).

Children’s awareness of risk and threat perception will also mediate their response to a traumatic event (Salmon & Bryant, 2002), with younger children being less affected because for example they are not aware of the significance or level of danger involved in their PICU admission. Older children may be more able to talk about and process their experience and receive support from family and peers, but conversely are also likely to experience more reminders of the trauma as their exposure to the outside world, including via the television and other forms of media, will be much greater than for younger children (Pynoos et al., 1999).

Systemic mediators

For children there is the additional confounding factor that they will have parents and siblings around them who will also have been profoundly affected by the experience. The child’s development following a trauma will be complexly related to the responses of others around them. Parents have claimed that PICU
admission changes the relationship they have with their child (Colville, 2001), not just during admission but continuing post-discharge. Many reported being more anxious than before, particularly about their child’s health (Colville et al., 2008a). However many parents also felt that they noticed positive benefits, both personally and for their family.

Herman (1998) argues that ‘recovery can take place only within the context of relationships; it cannot occur in isolation’ (p.51), and for children this would seem particularly pertinent. Parents of young children have a role in emotionally regulating their child when they are distressed (Salmon & Bryant, 2002). Children’s ability to manage their feelings improves as they get older, and as their understanding and knowledge about feelings and the world improves (ibid). However in times of significant distress they may still need their parents to provide reassurance and support. At these times children need to feel contained, once again turning to their parent to provide a ‘secure base’. However, if the parent is also distressed by either memories of the event, or seeing their child distressed, they may be unable to perform this function leaving the child feeling very aroused by traumatic memories without a way to calm themselves down. Additionally, for families where creating a secure attachment bond between parent and child has been difficult, the child may never have developed the concept of a ‘secure base’ or skills in emotional regulation. For these families, coping with a serious and distressing event may be significantly harder.

1.5 What is and is not known

The above research suggests that the process of children’s longer-term psychological recovery after a PICU admission is complex (Colville et al., 2008a). It is known that children and families are distressed by their experiences but it is unclear what initiates, maintains and ameliorates this distress in the recovery phase.
"It [is] difficult to determine what it is about the child's subjective experience of the PICU that puts them most at risk for a poor psychologic outcome" (Colville, 2008a, p.612-3)

Bryant et al. (2007) argue that it is important to carry out research with ‘traumatised children over longer periods and across developmental stages’ (p.2506). Whilst it is now clear that some children and families experience significant distress following discharge it is not known why some families are newly symptomatic at one year, yet other families recover or never develop trauma symptoms. The ‘natural history of psychologic adaptation’ (Colville et al., 2008a, p.613) for children following PICU admission requires exploration.

Therefore further investigation into the experiences and significant events during the year following discharge may provide vital information which can be used to help families during and after PICU admission. There is also a need for a study which links parents and children’s subjective accounts in an attempt to answer some of the outstanding questions and provide clinically relevant information which could positively impact on children and families in the future.

No research has qualitatively studied parent and child recovery at 1 year post discharge from PICU. It is anticipated that such research will:

a) provide rich data that broadens understanding of the process of recovery in children and parents following discharge from PICU
b) examine how families come to understand the recovery process.
c) help inform child and family interventions to support families following a PICU admission

1.6 Aims and Objectives of the study

The principal objective is to gain an increased understanding of the process of children and families’ longer-term psychological recovery following discharge from PICU
Specific aims are:

1. To develop an understanding of how parents and children uniquely understand their journey of psychological recovery (the 'recovery process') following discharge from PICU

2. To establish main themes which emerge out of discussions with children and parents, and use these to support the process of developing a theory.
2 Method

2.1 Rationale and Ontology

Qualitative methods have been chosen for this study for a number of reasons. Firstly this paradigm assumes that no objective reality exists (Lyons & Coyle, 2007). Rennie (2000) argues that ‘knowledge production is a matter of perspective’ (p.492) and qualitative methodologies uniquely capture this diversity. In this study a qualitative approach allowed the individual voices of each child or parent to be ‘heard’ and valued. Secondly, qualitative methodologies recognise that the context and system around the participants will also influence what they choose to share (Dallos & Draper, 2000). For example in this study the timing of data collection may have influenced how participants told their story, with anniversaries and current significant life events affecting how they recalled the past. Finally the role of the researcher is seen as integral to the process, recognising that to observe a phenomena is to have an effect on it. This paradigm recognises that ‘social interactions are meaningful and these shared meanings are influential in society.’ (Payne, 2007, p.66). This was important in the present study as families may have reflected on their experiences in a way which would not have happened without involvement in the research.

2.2 Methodology

The field of qualitative research can be characterised by conflicts and concerns (Dezin & Lincoln, 2008; Cutcliffe, 2000). Unease exists about the subjectivity of qualitative research (Payne et al., 2005), with authors noting that participants may share only certain aspects of their experience and that researchers may unduly influence the process. Qualitative research has also been criticised as being merely descriptive and not analytical or interpretative (Lincoln, 2008). Alternatively Carter and Little (2007) have argued that research exploring experiences and aiming to understand meanings does not preclude systematic analysis or overall academic rigour: but it also aims to capture individual
perspectives rather than aiming for 'one truth' about an experience when many divergent views may exist.

Criticisms of qualitative methodologies sit within a wider academic and research context. For many years quantitative research has been heralded as the 'gold standard' in research, and claims to have the monopoly on discovering the objective truths about the world (Denzin & Lincoln, 2008). If commentators use the positivist paradigm as a benchmark, then qualitative methodologies will be seen as deficient or inferior, but there are a number of positions from which methodologies can be evaluated, comparison with traditional methods being just one. It continues to be concerning that qualitative methodologies will be compromised because of the dominance of 'methodological conservatism' which see evidence-based, scientific research as only arising from quantitative techniques (Lincoln, 2008).

Quantitative methodologies can be aligned with the medical model (Coles et al., 2009) which aims to scientifically study, name, measure and treat symptoms (Shah & Mountain, 2007). This can be an advantage within the health psychology domain as evidence-based practice and observable outcomes become increasingly important (Carter & Little, 2007). However there is also a role for qualitative methodologies within the health service, because they take a more systemic view, seeing problems as subjective, interactional and dynamic.

2.3 Grounded Theory

Within the qualitative paradigm Grounded Theory was chosen, as it allows the researcher not just to describe the data, but synthesise it into a theory which can be useful both for future researcher and clinicians. Unlike other qualitative methodologies Grounded Theory moves beyond individual case studies (Smith & Eatough, 2007) and through rigorous analysis that allows the development of a model or theory with explanatory power.

This study meets Payne's (2007) criteria for Grounded as:

- 'relatively little is known about the topic area
- there are no 'grand theories' to adequately explain the psychological constructs...under investigation
• researchers are interested in eliciting participants’ understanding, perceptions and experiences of the world’ (p. 70)

Grounded theory is particularly appropriate as this study elicits children’s and parents’ understanding of their experiences post-discharge and no studies have yet looked into the period post eight months. It aimed to ‘develop theoretical explanations about [their] views and how they have influenced behaviours’ (ibid, p.70).

In this study Charmaz’s (2006) Grounded Theory method is used. This is a constructivist method, seeing analysis as ‘created from the shared experience and relationships with participants’ (p.130). However, the original creators of grounded theory aligned this methodology with the positivist paradigm (Payne, 2007), believing there was an ‘ultimate truth’ and that theories developed could be tested empirically (Glaser & Strauss, 1967). This mirrored the dominant discourse centred on quantitative methods, and as noted above, any attempt at developing a new methodology would have been required to be accepted by an academic society who had no other experiences of research. Qualitative methods have now gained more acceptance amongst academics, and later versions of grounded theory have ‘emphasised a more interpretive stance... [and] highlighted the tension between the epistemological positions of ‘realism’...and ‘constructivism’ because it is the researcher who creates and interprets the data to develop a new theory’ (Payne, 2007, p.66).

The process of data collection and analysis in grounded theory has been described as involving ‘spiral patterns of activity’ (Payne, 2007, p.73).

![Figure 1: 'Spiral patterns of activity' in Grounded Theory (adapted from Payne, 2007)](image)
Uniquely Grounded Theory aims to be open to the participant's ideas and allows them to actively direct and create meaning (Morse & Field, 1995). The method is iterative as early transcripts and coding dictates the interview schedules and coding of later interviews. The complexity of the data is appreciated through repeated readings of the data. As key themes or codes appear the researcher can begin to recognise what is significant for all participants and what has been important for just some of them.

There remain 'conflicting opinions...regarding the nature and process of Grounded Theory' (Cutcliffe, 2000, p.1476). Concerns exist about sampling, because early interviewees act as 'gatekeepers'. The earlier participants will influence what is asked in later interviews and must be chosen carefully to avoid missing avenues for exploration because the gatekeeper's experience is limited (ibid). Further concerns exist around the theory-development stage. Researchers may be tempted to discount their own values or describe the data using language which attempts to give the research more detached and scientific credibility (Morse, 1994). Charmaz's Grounded Theory aims to move away from the belief in an objective reality. Instead, the end-product of the research is rooted in the participants' subjective experience and the narratives developed between researcher and participant during this process (Cutcliffe, 2000).

2.4 Detailed method

2.4.1 Ethics

Ethical approval for this study was received from the NHS Research Ethics Committee, and from the University of Surrey. Additionally the NHS Research and Development Committee for the research site also granted approval.

The methodology was developed using advice from a number of parents who had children in the age-range and was discussed with a service-user who had previously accessed psychiatric and psychological support. A pilot interview was
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carried out with a family who had a PICU experience and feedback was elicited from participants following this interview.

2.4.2 Setting and recruitment

The research focused on families who had been in PICU in one large London teaching hospital, for a stay of more than 24 hours. The inclusion criteria were:

- Child aged 5-16 at admission
- Admission in the previous 8-18 months.
- Child has at least one biological parent in participating family

To recruit for the study the PICU logbook was reviewed by a member of the clinical team to identify children who met the inclusion criteria. The GPs of these children were contacted to establish whether the child was still living and if there was any reason for exclusion from the study. Following this families were contacted by letter. Those families who opted into the study were visited at home by the researcher.

2.4.3 Data Collection

One or both parents were interviewed, and if the child did not have a learning disability then the child who had been admitted to PICU was also interviewed. Consent was gained from each parent participating in the study. Assent was gained from the child before interviewing them, using an age-appropriate information sheet and consent form.

A semi-structured interview format was followed3, using prompts but allowing the interviewee to share information they thought was important. The interviews briefly explored the admission, then centred on experiences since discharge. Interviews were recorded with the permission of all participants. In addition to interviews, field notes were written during and immediately after interviews. These notes included events which occurred in the interview which were not captured on the tape, such as non-verbal behaviours, facial experiences and levels

3 Interview schedules Appendices 12a & b
of distress being displayed (Rosedale, 2009). These notes included a genogram and the researcher’s overall impressions of the family and interview process.

Finally a reflective journal was kept throughout the research process. This included reflections on the evolution of the research project, alongside thoughts and feelings about the interview process and the experience of transcription and analysis. Here initial or nascent codes were recorded alongside evidence to support their development.

### 2.4.4 Screening information

Participants were asked to complete a demographics form. Young people also completed the Child Impact of Events Scale (short form; CRIES-8, Horowitz, 1979 in Sclare, 1997) and parents completed the Trauma Screening Questionnaire (TSQ, Brewin et al, 2002). These were administered to screen for trauma symptoms so an appropriate referral could be offered if families scored highly, and in order to describe the sample.

### 2.4.5 Analysis

The interviews were transcribed verbatim by the researcher. Repeated readings of the transcripts were carried out to highlight meaningful units and line-by-line coding was completed. Labels were closely dependent on the data and aimed to 'capture the details, variation and complexity of the source data' (Payne, 2007, p.79).

The interview schedules were adapted as initial codes emerged, with new interviews being dependent on the themes highlighted by participants in previous interviews. The data from later interviews was studied to identify both the initial categories and any new ones. Following this definitions of the categories were created and reconsidered to produce 'more conceptually refined codes' (Payne, 2007, p.80).

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4 Complete interview protocol Appendices 11.
5 Appendix 15 considers reliability and validity of scales.
6 Copies of all forms—Appendices 5-10 and 13-14.
The categories were examined for relationships and hypotheses were tested against the data. This led to 'theoretical integration', where core categories which had major explanatory power were identified and linked with existing theories. In Grounded Theory the process stops when no new categories are identified, as saturation can be said to have been achieved.

Grounded Theory requires that participants are given an opportunity to comment on the emerging theory and judge whether they feel that the data and its interpretation matches their views. Therefore participants were sent a summary of the research findings and given an opportunity to respond. This was provided as both an adult and a child-friendly version. Additionally one family was recruited to discuss and explore the emerging model and to comment/suggest changes as appropriate. Data was subject to peer-checking (Rolfe, 2004), where a colleague not related to the study attempted to match quotes with codes. Finally, the project was presented at a conference during the analysis process and feedback elicited from seminar participants.

2.5 The researcher in the process

The choices and decisions made by the research team will influence what information is collected and how sense is made of the data (Lyons & Coyle, 2007). My reflective journal enabled me to become more aware of my own biases and reflect upon the research decisions made. My personal and theoretical leanings influenced the choice of research topic and will undoubtedly have influenced which questions I decided to ask and my interaction with participants during interviews.

Initially, it had been suggested that a project interviewing parents was necessary. Such a project would have been logistically less complicated but my passion for ensuring children have a voice and that their stories are noticed meant I was eager to interview children. I entered clinical training with a number of years experience of working with children and this had taught me how much children

7 Appendices 20-23
are able communicate about their lives. Throughout training this awareness has been coupled with a deeper understanding of the theoretical rationale behind such a practice and has led me to include this aspect in my research.

However, I thought it was vital to combine the important perspective of parents with the voice of children as commentators on their own experience. I have also found systemic formulations (e.g. Vetere & Dallos, 2003) provide a great deal of information about a child and their system, which can then be used to design an appropriate intervention. I was therefore keen to design a project which would be clinically useful in supporting the whole family post-discharge.
3 Results

3.1 Demographic data

In total, 48 families met the inclusion criteria for this study. Of this number, three were uncontactable, having moved since discharge. A further four families were considered by the GP to be inappropriate to contact, in most cases because the child had died or was extremely unwell. 41 families were therefore invited to participate in the research. Ten families agreed to participate in the research (representing 24% of the original sample), however two families later withdrew when their children relapsed. One further family (not from the original 48) indicated they were happy to participate in research was then recruited to check the emerging model. The ages of children participating (\(\bar{x} = 9.11\) years, range = 5-17 years) was not significantly different from Non-participants (\(\bar{x} = 11.66\) years, range 6-19 years). Families who participated had longer stays in PICU than those who did not. Those of white, British origin were far more likely to participate than families from other ethnic backgrounds. One family who participated were Asian and spoke Tamil at home, but to protect the identity of the family I will not identity ethnic background. One participant was a step-father but has been labelled ‘father’ in this study to protect the family’s confidentiality.

It is important to acknowledge the heterogeneous nature of the sample in this study. The families were from a range of socio-economic groups and the ages of parents and children varied substantially. Further the reasons for admission and lengths of PICU stay were very diverse. This is an important part of the grounded theory methodology, which seeks to hear views of people which can contribute to and enrich the developing theory. Therefore rather than seeking a homogenous sample, or attempting to reproduce population distributions grounded theory develops through this theoretical sampling method (Charmaz, 2006).

In total nine families were interviewed, 13 parents and five young people. Interviews lasted between 1 hour and 2.5 hours in length. All participants were
then sent a summary of the results to comment on. Six participants returned feedback forms, four parents and two young people.
<table>
<thead>
<tr>
<th>FAMILY NUMBER</th>
<th>STAGE</th>
<th>PARTICIPANTS</th>
<th>AGE OF CHILD AT ADMISSION</th>
<th>TIME SINCE LAST PICU DISCHARGE (MONTHS)</th>
<th>UNDERLYING DIAGNOSIS</th>
<th>NUMBER OF PICU ADMISSIONS</th>
<th>REASON FOR PICU ADMISSIONS</th>
<th>LENGHT OF PICU STAY (DAYS)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Pilot – developing interview schedule</td>
<td>Father, young person</td>
<td>5</td>
<td>8</td>
<td>None</td>
<td>1</td>
<td>Acute Septicaemia</td>
<td>4</td>
</tr>
<tr>
<td>2</td>
<td>Initial data gathering</td>
<td>Mother, Young person</td>
<td>14</td>
<td>14</td>
<td>Leukaemia</td>
<td>4</td>
<td>Post-operative; management of significant pain</td>
<td>4</td>
</tr>
<tr>
<td>3</td>
<td></td>
<td>Mother, Young person</td>
<td>16</td>
<td>11</td>
<td>Leukaemia</td>
<td>1</td>
<td>Hickman Line infection</td>
<td>1</td>
</tr>
<tr>
<td>4</td>
<td></td>
<td>Mother, Young person</td>
<td>14</td>
<td>12</td>
<td>None</td>
<td>1</td>
<td>Acute Meningitis</td>
<td>3</td>
</tr>
<tr>
<td>5</td>
<td></td>
<td>Mother, Father, young person</td>
<td>8</td>
<td>8</td>
<td>Brain Tumour</td>
<td>3</td>
<td>2 short post-operative admissions Cardiac arrest</td>
<td>1</td>
</tr>
<tr>
<td>6</td>
<td>Adapted schedule – focused data gathering</td>
<td>Mother</td>
<td>8</td>
<td>15</td>
<td>Lennox-Gastaut syndrome (associated with severe epilepsy)</td>
<td>1</td>
<td>Management of status epilepticus</td>
<td>14</td>
</tr>
<tr>
<td>7</td>
<td></td>
<td>Mother, Father</td>
<td>5</td>
<td>14</td>
<td>Learning disability</td>
<td>3</td>
<td>Chest infection 2 for Management of status epilepticus</td>
<td>1</td>
</tr>
<tr>
<td>8</td>
<td></td>
<td>Mother, Father</td>
<td>7</td>
<td>18</td>
<td>Learning disability</td>
<td>1</td>
<td>Post operative management of double hip fracture</td>
<td>9</td>
</tr>
<tr>
<td>9</td>
<td>Checking the model</td>
<td>Mother, Father</td>
<td>5</td>
<td>6</td>
<td>None</td>
<td>2</td>
<td>Bowel obstruction Post-operative</td>
<td>35</td>
</tr>
</tbody>
</table>
Where quotes are used families are referred to by number (column 1 of Table 1), as well as identifying who the comments were made by. This approach ensures the comments can be put into context of the young person’s illness and the time in the study when they were interviewed. All names in the text are pseudonyms.

Each participant also completed a trauma screen (Table 2). The data is given as an average of all the families, as the aim was not to compare one family against another. On the TSQ any combination of at least six symptoms is sufficient at predicting 90% of PTSD cases (Brewin et al., 2002). Therefore overall in this sample some parents scored within the PTSD range but on average people did not score in the clinical range. On the CRIES-8, 17 is the clinical level, again this score correctly identifying 90% of cases (Smith et al., 2003). Therefore, in this sample children were likely to be experiencing trauma symptoms.

<table>
<thead>
<tr>
<th>MEASURE</th>
<th>MEAN SCORE</th>
<th>SCORE RANGE</th>
<th>TOTAL POSSIBLE SCORE</th>
<th>CLINICAL CUT-OFFS</th>
</tr>
</thead>
<tbody>
<tr>
<td>TSQ (parents)</td>
<td>4.25</td>
<td>0-10</td>
<td>10</td>
<td>6</td>
</tr>
<tr>
<td>CRIES-8 (young people)</td>
<td>21.5</td>
<td>13-32</td>
<td>40</td>
<td>17</td>
</tr>
</tbody>
</table>

### 3.2 The evolution of the interpretative process

The analysis of data occurred in stages. Following the interpretation of data for interviews 2-5 an emerging model was developed. Gaps in the data were identified and further interviews were completed using an adapted interview schedule. The adapted interview schedule focused on the categories of ‘coping strategies’ and ‘models of recovery’ in more detail and asked further questions which explored participants’ ideas about normality and how the admission had changed their lives. In analysing these interviews it became clear that the codes emerging needed reorganisation to ensure the axial codes represented participants’ reports. Table 3 reflects the codes after reorganisation. Participants were sent a summary of the main categories emerging from the data. Their feedback was built into the new version of the model which synthesises the data.
In this report these comments from families are noted as ‘written feedback’. Finally, the model was shown to family 9 who were at a different stage in the recovery journey, having been discharged more recently. Their feedback led to further adaptations.

### 3.3 The development of analytic codes

In interviews participants were asked about their experiences since discharge from PICU. However, without exception, participants also talked in depth about their experiences and memories of PICU itself. This therefore emerged as a key organiser to people’s narratives and there was a sense that without providing the interviewer with this information, their post-discharge story had no context. This has been important in considering the emerging model, discussed further in section 3.4. During data analysis participants’ accounts were coded and organised to reflect their admission and post discharge experiences, described in Table 3.

**Table 3: Axial codes and sub-categories identified through analysis of interview data**

<table>
<thead>
<tr>
<th>CONTEXT</th>
<th>AXIAL CODING</th>
<th>SUB CATEGORIES</th>
</tr>
</thead>
<tbody>
<tr>
<td>DURING ADMISSION</td>
<td>Experiences during admission</td>
<td>Emotional</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Social</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Physical</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Environmental – hospital as containment</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Time related aspects of admission</td>
</tr>
<tr>
<td></td>
<td>Seeking normality during admission</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Choice and control</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Relationships</td>
<td></td>
</tr>
<tr>
<td>POST DISCHARGE</td>
<td>Impact on identity</td>
<td>Physical &amp; practical</td>
</tr>
<tr>
<td></td>
<td>Striving for normality</td>
<td>Developmentally</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Comparison of pre- and post-normality</td>
</tr>
</tbody>
</table>
In the next section admission experiences will be explored to discuss how these factors affected the families following discharge. Then post-discharge experiences will be discussed at length, consistent with the initial research questions exploring recovery following PICU admission. In the following text words in italics refer to focused codes – that is important or recurrent themes which describe the participant’s experience (Charmaz 2006).

### 3.4 Experiences during admission

Participants’ narratives about their experiences during discharge highlighted how pivotal and traumatic this experience had been in their lives (*Enormity*).

‘*I don’t think she was aware of the enormity of being there’* (Mother, 2)

‘*And I thought this is where children come to die* (cries).’ (Mother, 3)
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‘It’s one of those things that’s absolutely terrifying and um yeah we did think we were going to lose her and it’s very hard...’ (Mother, 4)

Additionally parents felt punished (unfairness/anger/feeling punished) by having to endure such a difficult experience and would often recount other traumatic events or difficult experiences (parallel traumas/ other difficult events) which coincided with the PICU admission. Young people tended to focus more on their emotions but both parents and children noticed how disconnected being in hospital made them feel. The physical experience was not focused on in detail by any family, although details of procedures and interventions were sometimes mentioned.

3.4.1 Seeking normality

Families talked in detail about seeking normality (desiring normality and trying to achieve normality in hospital). They noticed how abnormal their experience was and felt this contributed to the difficulties.

‘You feel pretty rotten as it is, because you can’t keep normal life going, do the things you would normally do...’ (Father, 5)

All parents noticed how different and difficult being in PICU was, particularly in the context of the impact on family life and functioning.

‘I was worried about Greg [sibling of sick child] because he was farmed out every night to someone, we had to rent this house out and go and live with my mum...we both had to give up our jobs...it was really hard and you have every bad stress at once...’ (Mother, 5)

However, where the child had a developmental learning disability ‘normal’ had been changed from the moment of their child’s diagnosis. These families had often had multiple hospital admissions, including PICU stays. Therefore, these families recognised that life did need to be put on hold whilst their child was unwell and seemed more accepting about the lack of normality in their routine.
‘Well it’s keeping him alive so you have to let them do what they do’ (Mother, 7)

These families lived constantly with a medicalised routine and had more interventions from other agencies when compared with children without ongoing health difficulties. This meant that hospital admission, and even PICU was less alien for them then for some parents. Some parents went even further, constructing their PICU admission as ‘normal’, in the context of long or repeated admissions.

‘It’s nothing out of the ordinary for him...it’s just another thing that’s happened.’ (Mother, 6)

### 3.4.2 Choice and control

Families discussed the difficulties with allowing medical staff to make decisions about the life of their child. This felt intrusive and reduced participants belief in their control over their own destiny. Both parents and young children felt they had no options or choices.

‘I have this image...the sword of Damocles waiting over your head to strike your child down...’ (Mother, 3)

‘I think I like to be very independent and I like to be in control...which were two things I couldn’t have when I was ill, which was really hard.’ (Young person, 3)

Mainly parents felt they trusted and respected staff but sometimes inaction caused distress and frustration and participants felt powerless to change things.

‘You can’t do anything, you can’t make any decisions...I did often feel like a spare part. I couldn’t do, I couldn’t take the pain away, I couldn’t’ make her feel any better...I couldn’t get nothing right sometimes’ (Mother, 2)
3.4.3 Relationships

Participants talked about the changes to their relationships which resulted from the PICU admission. This was often related to the fact that they had been so seriously ill and therefore looked and felt different.

‘When I was in hospital my little sister was like really scared...and it was a bit weird for them to see like tubes in my arms and everything...my face being swelled up...it was a bit shocking for them’ (Young person, 4).

Additionally participants reported being disconnected from the outside world, lacking social contacts beyond immediate family and medical staff. There was the sense that other people were unable to understand the traumatic experience the family were enduring and therefore sometimes not involving them caused less stress.

‘My mother in law came up to see us once... I’d just nip down to [local shops]...when I came back she was worried about the time because she’d been there so long and I think at that point I’d been in hospital for two weeks and she was a bit cross because I’d kept her there for two hours’ (Mother, 6).

Parents and young people often had different narratives of their admission experience, representing their differing perspectives on the situation. This resulted in tensions in the relationships:

‘When they moved him [to PICU] I honestly though he was going to die. It’s the worst thing that’s ever happened to me’ (Mother, 3)

compared with:

‘I have to say one of the main problems with intensive care was how noisy it was...compared to the other kids in there I was healthy...’ (Young person, 3).
3.5 Experiences after discharge

3.5.1 Process and content in interviews

Participants’ narratives were not always sequential and they often returned to the PICU experience when talking about recovery. Similarly to setting the context with details of the admission, returning to their experience in order to process where they had come from and where they were now was important for participants. Some were able to tell coherent stories about both their admission experiences and their journey post-discharge. Other participants found it more difficult to answer questions and seemed to be inexperienced at talking or thinking about what had happened to them. These observations have been integrated into the analysis and contributed to the development of analytic categories.

When participants shared their experiences since discharge these fell into five major categories. Each of the categories, ('coping strategies', 'impact on identity', 'striving for normality', processing the experience and 'ideas about recovery') were seen as stages in the journey. For simplicity the stages are described separately below, but are inter-related (Figures 2 and 4).

3.5.2 Coping strategies

When people were first discharged from hospital they needed to physically recover and reintegrate. Coping strategies were activated to help them manage the day to day reality post-PICU. In this stage people were still aiming for ‘normality’, which had existed before they had become unwell, often seeming not to realise that life was far from normal.

Families noted that whilst in hospital they did not have space or time to think about and understand what they were going through and they became aware of this forcefully when they came home. Coping strategies therefore provided a buffer and a way to avoid thinking about what had happened until participants were ready to deal with it (coping by avoidance or forgetting).
‘You have to cope for yourself, your child...and the other members of your family’ (Parent, 6, written feedback).

‘I think you just gotta stay positive and you’ve gotta know if you don’t you drive yourself insane’ (Mother, 7)

‘I think I’ve almost suffered more since she’s got a bit better. It’s weird because I don’t think you have time and my feet didn’t touch the ground...it was like a nightmare...you sort of put it to the back of your head a bit and when you actually sit down and think what could have happened you know it frightens you a little bit I think’ (Mother, 5)

A range of different coping strategies were described. Some were helpful in the short term, and seemed to be ways of protecting themselves or others. These included detaching, hiding emotions, avoidance and going on to autopilot.

‘You just sort of go on autopilot in those situations but it’s hard because it wouldn’t sink in for quite a while...’ (Father, 5)

‘It was very much detached...I didn’t really know what to say to anyone else’ (Young person, 3)

Other strategies included constant fighting, comfort eating, being positive and seeking information. Coping occurred through relationships (e.g. forming of relationships, taking time out, finding and sharing joy) and coping alone or through personal resources (e.g. ‘Buckling down’, being hard on self/judging self).

During the coping stage participants noted that the experience remained very volatile, with days when they felt positive and other days which were a struggle (coping being situation dependant). This point was added to the original model following feedback from participants.

‘I think in the coping stage it’s still up and down, like it is when you are in hospital. Perhaps not as extreme, but it’s the same pattern’ (Father, 9).
In this early stage parents and wider family were very important to young people as even those in late adolescence were often very isolated in hospital and just after discharge. As people returned home rebuilding relationships became vital on their path to recovery. Coping strategies remained important throughout the recovery process, but overtime became replaced by longer-term recovery strategies which were more effective in coping with the new reality, allowing space for new narratives to be heard and integrated.

3.5.3 Impact on identity

The young people’s experience of illness and their PICU admission had a significant impact on their identities.

‘I’d been listening to rock music but that changed and then my friends changed, my friends thought I was totally changing, yeah I didn’t feel myself anymore, everything was changing for me. It was like a chapter of my life had been taken out so I don’t know if I’d changed during that...’ (Young person, 4)

Parents roles changed (impact on parent), and they were required to provide round-the-clock parenting for a child who was previously very independent. They also recognised the effect that being with one child had on any other siblings in the family and talked about the pressures of focusing all your attention on one very sick child. This became significant post-discharge as families had to re-adjust following a change in relationships and roles.

The impact on identity (how the illness affects identity/who you are) became significant when participants were exploring the idea of normality and used identity as a marker during the recovery period:

‘I think she must...be happy that I’m getting better and like I’m getting back to my usual self’ (Young person, 2)

Identity and relationships were interconnected as many participants talked about how they were viewed by others (How others see you).
‘I think people feeling sorry for me, I really couldn’t handle that, I like to be, I didn’t really like that’ (Young person, 3)

Overall identity was talked about by all participants and the hospital admission represented a challenge to both how they viewed themselves, and their role-identity (that is, how they related to others). Once discharged, this legacy remained and participants found they needed to work to understand their new identity in the context of their PICU experiences.

3.5.4 Striving for normality

In striving for normality participants began to notice the effect of their illness on their life. They focused on returning to physical health, then attempted to reconnect with friends and colleagues and cope with the psychological impact of their experiences. After discharge, families assumed that life would return to ‘normal’, described as going back to how life was before (Trying to achieve normality out of hospital). In reality, families found that life did not return to the pre-admission status-quo in a smooth or immediate way. In fact some things were never the same again (Normal being different to before).

‘It affected him far more than we thought it would...he was very very quiet and withdrawn which we didn’t expect.’ (Father, 1)

Striving for normality was an ongoing process which occurred from discharge (and sometimes predated admission) continuing to the present day.

‘It’s weird though; it’s weird doing normal things again because we didn’t do normal...’ (Mother, 5)

Participants emphasised how long the process of ‘getting back to normal’ was taking them and their frustration with this.

‘It was really frustration. I was better, I’d finished chemo, I didn’t have cancer anymore and yet I was still having to be driven everywhere...’ (Young person, 3)
‘There haven’t been any easy times here, because we’re only just getting to the point ... this will be the first time since Julia was sick’ (Mother, 4) (exactly one year after discharge)

‘...the important points that these results highlight is how difficult it is to return back to normality’ (Young person, 2, written feedback)

People described life prior to the illness in an idealised fashion and it had become an impossible illusion to strive towards. For example many participants described achievements and qualities which highlighted them as ‘special’ and better than others (Specialness). This was helpful as it also imbued people with resilience which allowed them to manage the difficult times in hospital and stay with the long and arduous process following discharge.

However whilst they wanted normality, many people struggled to return to life as it had been prior to admission. Young people described struggling with routine and other, practical aspects of life such as parental discipline which was reinstated as they got better (Struggling with routine).

‘Slowly as I got more and more healthy more restrictions got put in place and that was a bit difficult after having that freedom’ Young person, 3

Parents emphasised their role in helping their child recover from the experience and felt that by being at home in a familiar environment, their child would slowly improve. Generally, striving for normality involved getting back to physical strength first, although parents also recognised the need for emotional recovery.

Interviewer: ‘...once you’re out of hospital what are your priorities for Alan?’
Mother: ‘Making him happy again, getting him back to his lively self...’ (7)

Additionally both parents and children were anxious about upsetting the other, often resulting in the experience not being talked about and the family attempting to act as if things were ‘normal’ despite what they had been through.
Whilst normality was craved by all families they all became aware that the experience of a serious and life-threatening illness had significantly changed them and the road they were travelling on. Therefore, ‘normality’, as it had been before the experience was no longer achievable and seeking a new normality became the key task families tried to engage with. This process of recognising how things have changed was ongoing and dynamic, and is reflected further in the next section.

3.5.5 Processing the experience

Throughout the interviews it was clear that both young people and parents needed to tell their story and have it heard and understood. There was little opportunity to share their narrative with others, and often there was a fear of upsetting others.

‘I’ve never really had the whole story to anyone before, no I’ve never been secretive about it, if anyone wanted to know about it I’ve told them...’ (Young person, 3)

Interviewer ‘Do you think that’s something you’ll go on to do, like tell other people?
Young person ‘I would like to but it’s hard to explain it and stuff...’ (4)

There was a sense that as people shared their stories with me they were again trying to understand it (Connecting with the emotional experience; factual story telling; telling the whole story).

For many families their narrative was incomplete or clearly unrehearsed. This was evident when participants found it difficult to answer questions in the interview and reflected that they had not thought about that topic. This was often the case for young people who were unwell or sedated and therefore could not recall or understand all the details of what happened to them. However parents also experienced this sense when they were unclear what had happened to their child (Being disconnected from the experience; unprocessed or incomplete narratives). There seemed to be two parallel processes, one of missing memories (where the
participant had been present but could not remember what had happened) and the other of missing information (where the participant did not have factual knowledge about an event).

Young person: ‘Uhh, I remember when I was asleep for six sleeps’
Interviewer: ‘Ok, and do you remember what happened when you were in hospital?’
Young person: ‘I don’t know. It’s hard to remember’ (1)

‘Still to this day we don’t know what happened...’ (Father, 7)

Importantly, despite often incomplete narratives, participants did have some unforgettable, stark memories.

‘Waiting for the ‘sword of Damocles’ to fall on your child and the relief that it doesn’t, does not erase the memories of the other children and their parents’
(Mother, 3, written feedback)

Additionally creating narratives was an ongoing, organic process which families continued to engage in over the time post-discharge. Indeed, this creating and re-authoring of narratives seemed to be important in the recovery process (Building a narrative over time). It was clear that this had produced movement as families not only created a story of their experience but could then feel more control and ownership over what had happened to them.

‘I don’t remember much, it’s from like my sister, my mum, my mum’s boyfriend, my dad, it all blends in and makes more sense now...over the year I’ve found out more and more and it makes, it puts the picture together.’ (Young person, 4)

Participants had differing levels of emotional investment in their narratives, with some sharing the intense emotions they experienced at the time, and indeed recalling these vividly as they recounted the story (Emotional processing; connecting with the emotional experience). Other participants presented a more
factual account, providing significant detail but not sharing their emotional reactions to the events (Factual story telling).

‘and when she did come round it was quite traumatic, very emotional for everybody (cries)’ (Mother, 4)

Compared with

‘I remember there was quite a lot of babies. I don’t really know, there were a few beds like this, and there was nurses...’ (Young person, 2)

Finally families reported being unsure about whether processing was normal, and how they went about this process. This links closely with the striving for normality theme.

‘I mean we don’t really know, we bounce off each other, but not really know what to say I mean...we don’t really know how to answer that you know because we sort of say, we don’t know what to say.’ (Father, 5)

3.5.6 Ideas about recovery

Families noted that they reached a turning-point in their journey, moving from ‘just coping’ to ‘recovering’. This included recognition that life was different now but that life could go on and continue to be positive despite their traumatic experiences.

‘She kind of lost interest in everything um so it’s taken her literally a whole year to actually get to the point where you can say she’s anything at all like what she was...’ (Mother, 4).

Recovery was not just related to health, despite the defining experience of serious and life-threatening illness. Instead recovery included social and psychological goals. Participants at this stage recognised the lack of normality and the challenge to their identity which had occurred as a result of their admission. The recovery
phase therefore involved integrating the newly-processed narrative into their sense of identity (Acceptance, A journey/rebuilding; reflecting on life). Only by doing this could families move forward with a real sense of who they now were.

‘It’s definitely a character building experience, and obviously not one that I would recommend, but having had to have it, it’s um character building because before well I wasn’t too happy with who I was anyway and that reputation sort of wiped clean anyway because I got ill...’ (Young person, 3).

‘I don’t really know what went on in her head but she changed a lot’ (Mother, 4).

Both parents and children had many ideas about how ‘recovery’ would work and what was personally important for them (Personal understandings of recovery). For example one young person described getting his social life back together as top of his priority list (Reconnecting).

‘I just managed to do one step at a time. But top of the list was my social life; I ignored everything else to get that back because I wanted to get a bit of independence...’ (Young person, 3)

In another family the mother described the importance of taking time to process what happened to you. Families emphasised that recovery needed to be in a familiar environment.

‘The recovery afterwards is easier here, cos we know how to deal with it...’ (Father, 7).

Many people talked about their priorities and goals for life being different than they would have been before this experience. This meant ‘recovery’ wasn’t about returning to where they had been before, but was about choosing a new direction and heading there instead (Goal setting; being realistic about what can be achieved).
'I just spent 6 months recovering from a potentially deadly illness... it [school] just didn't seem worth the time. It's [time] the only thing in the world you can't buy; you can't suddenly get more of it...' (Young person, 3)

Interviewer: 'What does the future hold?'
Father: 'I don't know, we never plan that way now, we plan day to day' (8)

Participants described how recovery was slow and took time (Slowness of recovery).

'Um (deep sigh) so it was, it's taken a long time for her to and it's only really been the last few months or so that she has actually started getting back out....' (Mother, 4)

Parents noted that the child has to work through their emotions, and needs the support of their parents and others to help them do this (Needing space to talk).

'I also knew that she needed to space to do or not to do what it was so she could go through what she needed to so she could get her head straight and things. Get back on track, um, and you know, realise she's got a future and you know she can do what she wants' (Mother, 4).

Accepting the pace of recovery could be quite challenging. Further parents and children worked through this process at different rates and as they rarely knew others who had been through the same experience, questioned if what they experienced was to be expected.

'Still, six months on I think about it all the time. I mean is that normal?' (Father, 9).

'The important points reflect how hard it is to get back to a normal life! Or moving on from an experience like this' (Mother, 2, written feedback).

Note how, in this second quote, the parent talks about 'a normal life' rather than simply 'normal life'. This illustrates how families at this stage were starting to
accept that whilst life settled down eventually ‘normal’ was different to before. Recovery included accepting that the families lived within an uncertain world and had discovered things which they wish they had never needed to learn (Ambivalence about recovery). For example, many families talked about seeing other children unwell and realising there were so many more ways to become seriously sick then they had been aware of before. There was a sense that during their recovery families needed to mourn the losses they had experienced, including the loss of a belief in a benign and unthreatening world (Ongoing vulnerability; Unstable/unable to be relied upon).

‘I’m always scared that if it happened, scared that I won’t, I know I won’t survive because there was a low chance of my surviving and I did and my body will be weaker next time...’ (Young person, 4)

‘It’s quite a shock because you don’t realise how many sick children there are...’ (Mother, 5)

However participants also felt they had a greater perspective on life because of their experiences.

‘You’ve got a scale now, where as before, he had a cold you’d be like doctors blah blah but now it’s a case of he’s got a cold, he’s going to be fine’ (Father, 1).

‘Going through this experience can have a positive effect on people. It can make you stronger as a person and to appreciate the smaller things in life. In your recovery you look back and realise what you’ve overcome and that’s a wonderful feeling’ (Young person, 2, written feedback).

The concept of ‘wellness’ shifted for families and they realised they now compared the present with their experiences in PICU, gaining more perspective because they had lived through the very worst experiences (Shifting concept of wellness).
'This is the problem you know, that's a life, that's our life, you plan something you do everything. It just changes just like that...' (Father, 8).

In families where the child had a learning disability, their concept of recovery was also different. They had different goals and aspirations for their children, related to their happiness and wellbeing and, as noted above, their goals had shifted from the time of diagnosis of their child's learning disability. As these families often had multiple experiences of hospitalisation they had more developed models of recovery and were sometimes able to progress more quickly. However, this is not always the case, as one parent whose son has a learning disability noted:

'The recovery period is...as long as the person requires. Sometimes quickly out of PICU, yet recovery at home can be a long process' (Parent, 7, written feedback).

This category was developed and adapted following feedback from families. This included ensuring that positive outcomes of the experience were highlighted, as well as noting how long it takes to recover and that the process is ongoing.

### 3.6 Developing a model—integrating the categories

#### 3.6.1 The journey through illness to recovery

Despite the initial aim to focus on the post-discharge period, all families emphasised both explicitly and implicitly that any model about recovery after PICU needed to be put within the context of whole journey: the admission, and life before and after it. Therefore the model attempts to place the experience of recovery into a wider context. Figure 2 describes this journey over time, visually portraying the emotional experience through the red line that moves across the page. This is a similar portrayal to that used in Transition Theories (Adams *et al.*, 1976), a model which also tracks personal change over time. In Figure 2, families move from 'Old normal', which includes how family life functioned, participants'
identities and families’ level of knowledge. These same categories are important in the ‘new normal’ and, significantly, all have changed as a result of the journey.

'It's like BC and AD, you know 'life before' hospital and 'life after', since all that happened' (Mother, 9).

As families begin to process their experience they begin to recognise that life is not the same any more. This can be negative, especially for those families where the young person continues to face challenges. For other families it is a time of personal growth and revaluation having survived the experience.

For parents whose child has a learning disability, ‘old normal’ is their concept prior to the first diagnosis, so often they already have experience of ‘new normal’ by the time their child is discharged from PICU. These families still need to cope, process what has happened to them and create a narrative about the event. However they generally do already have a model of recovery which they can engage once they are discharged and have already realised life will never be as it was before the PICU journey.

The model was re-evaluated following feedback from participants. In particular changes have been made in the positing of the ‘processing’ and ‘creating of a narrative’ phases within the whole journey, together with reflection of how the model applies to parents with a child with a learning disability. Finally the pattern in the coping and recovery sections has been developed to show that participants continue to feel a range of positive and negative emotions, and that key events such as going on holiday or returning to work or school can trigger distress, reflection and movement.
Figure 2: The Journey through illness to recovery
Figure 2: The Journey through illness to recovery

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3.6.2 The process of recovery

Following discharge families talked about a number of strands. Physical recovery seems to be people’s first priority and milestones are noted in physical achievements.

‘I know she’s [mother] hoping that I would be, that I would get better. I think she should be happy that I’m getting better and like I’m getting back to my usual self yeah’ (Young person, 2).

However participants emphasised that the physical aspect of the recovery was only a part of overall progress.

‘I think the illness is a small thing, I mean it’s not a small thing because it’s there all the time, but you’ve got so many people helping you with that’ (Father, 5).

Social recovery is also important and all recovery seemed to exist within the relationships in the family. As time passes reintegration with the wider social network becomes possible, with young people returning to school and their friends and parents reconnecting with friends, family and work.

‘I did fall apart in that time and then rebuilt. And then finally I went back to work, a new job in March, and at that point I was crying pretty much everyday and once I started it dropped right back down to once a week’ (Mother, 3).

Finally psychological and emotional recovery was important for families. This process started with ‘coping’ and progressed through to developing a model of recovery.

‘I think just in herself she took a long time to realise, I think to accept what had happened and to get her head around it and deal with it and move on’ (Mother, 4).
Figure 3 focuses on families’ experiences after discharge, looking at three concurrent strands of physical, social and emotional/psychological. It shows that at the start families focus on physical recovery, and concurrently, are still feeling quite isolated: they have just been discharged but have not yet reconnected with others (and cannot until physical health improves). At the same time participants are in the ‘coping’ stage where they are just trying to get through each day and with the aim of getting back to normal.

‘I think for quite a while to start with um it [her experiences] was pushed away and ignored, because if you ignore it, it didn’t happen, you know. So um yeah, it’s taken her a long time.’ (Mother, 3)

As physical recovery progresses families start to reintegrate and manage their emotional recovery. The circles on the far right of Figure 3 represent the ‘new normal’ and look at all the things that make ‘new normal’ different from ‘old normal’ for families.
Figure 3: Strands of the recovery process for children and parents

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Key terms and concepts: Physical recovery, Being physically recovered, Reintegration, Notable activities, Social-emotional processing & recovery, Emotional recovery, Developing your own narrative, Head-down – focused on physical recovery, Coping, Striving to return to normal, Physical changes, Ongoing vulnerability, Vigilance, Health anxiety, Physical limitations, Social/relationship changes, Being different to others, Having different needs/wishes/desires, Becoming closer, Knowing who you can rely on, Wanting to educate, Emotional Changes, Personality, Strengths, Awareness of illness, Medical knowledge & understanding, Sense of choice & control, Strategies for managing situations, Identities.
Figure 3: Strands of the recovery process for children and parents

Emotional Changes
- Personality
- Strengths
- Awareness of illness
- Medical knowledge & understanding
- Sense of choice & control
- Strategies for managing situations
- Identities

Physical changes
- Ongoing vulnerability
- Vigilance
- Health anxiety
- Physical limitations

New Normal

Social/relationship changes
- Being different to others
- Having different needs/wishes/desires
- Becoming closer
- Knowing who you can rely on
- Wanting to educate

Social/ emotional processing & recovery
- Sharing story with others
- Processing story with others
- Space to talk about it
- Shared space to be self/develop identity

Reintegration
- Seeing friends
- Returning to school
- Returning to work
- Notable activities e.g. Prom, work experience

This model represents the three main strands of recovery which run concurrently, starting at discharge and culminating in reaching ‘new normal’

Coping
- Head-down – focused on physical recovery
- Striving to return to normal

Physical recovery
- Eating
- Drinking
- Temporary changes
- Physical appearance changing
- Participation in activities
- Stamina
- Being physically recovered
- Ambivalence about ending treatment
- Unsure about next steps
- Loss of focus/confusion
- Adjustment to ‘new’ physical body

Emotional recovery
- Memories of experience
- Processing experience
- Narratives of ‘specialness’
- Developing your own narrative
- Accepting new identities
- Being ok with being normal again
- Exploring identity – new & existing

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4 Discussion

4.1 Introduction

This section summarises the findings and aims to integrate them with existing theory. This involves a further level of abstraction, as is required in grounded theory (Charmaz, 2006), and it attempts to provide a theoretical interpretation of the participants’ experiences (Bartlett & Payne, 1997). The purpose of such analysis is to create a theory which can be more widely applied. This section starts with reflections from the researcher as it is important to place the analysis within a positioning framework. This is to recognise the role of the researcher as active in the interpretative process, with layers of meaning being ascribed as a result of the researcher’s experiences as well as the participants’ descriptions.

This discussion explores the processes on the journey, looking at how a family moves through the pathway, achieving acceptance of ‘new normal’ at the end of this journey. Importantly it highlights that it is the way families negotiate the key processes which enable this recovery to occur. There is an exploration of the stalling or disruption of these stages, leading to families finding recovery more challenging. Finally consideration is given to the clinical implications of these findings and the limitations of this study are discussed.

4.2 Summary

This study aimed to explore the recovery process for families in the year following a PICU admission and to investigate how families negotiated this experience. In particular there was a need to understand why some families struggle after discharge whilst others manage well and to discover what puts children and families at risk of poorer outcomes (Colville et al., 2008a).

This study found that families’ experiences depended both on their experiences during admission and how they negotiated the process following discharge. Themes identified during admission included ‘seeking normality’, ‘choice and control’ and the ‘impact of admission’ on relationships and identities.
Immediately after discharge families employ coping strategies to manage the multifaceted recovery which must be faced and engaged with. Clark (2001) refers to this stage as ‘survival’ in the context of bereavement, and this seems a suitable label to describe families in this study who are trying to get through each day as they come to terms with what has happened to them. As people progress they begin to develop models of recovery, supported by their greater understanding of their experiences. Families talked about needing to negotiate physical recovery alongside reconnecting with their social network and processing what had happened to them. Figure 3 highlights that this recovery process is biopsychosocial (Ogden, 2000) in nature. This extends the existing biopsychosocial model of illness and shows that in addition to informing ‘assessment, diagnosis, treatment and prevention’ (Sperry, 2006, p.26) this model has implications for recovery as well. Single-discipline constructs, such as medical or psychological models cannot encompass all the aspects involved in recovery, and models must be ‘integrative, comprehensive and systemic’ (Sperry et al., 2008, p.370).

4.3 Reflexivity

My initial motivation for selecting a project which could be explored using qualitative methods related to my previous experience as a research assistant, working in laboratory settings. In this role I was struck by the lack of ecological validity and the distance between tests participants were asked to do and their real life. By contrast this research has attempted to capture the realities for families following a distressing experience and is thus able to reflect on the difficulties in a way which might be helpful for other families. Whilst the small sample cannot result in bold claims about universal applicability it nonetheless feels important to have given participants a voice and then listened carefully to what they had to say.

Researching using a qualitative method involves an acknowledgement of the researcher as integral to the process of data collection and analysis (Lyons, 2007). I was acutely aware of the privileged nature of my role, and of the potential for me to influence the development of a model. My personal curiosities focused around how the child would tell their story and the systemic interaction between
parent and child. However as the data began to emerge it was clear that other factors were also important in the recovery process.

In the interviews I made space for participants to talk about what was really important to them. This proved to be fruitful, as all participants wanted to talk about their admission experiences, and this enabled me to recognise how the recovery narratives were being created. During analysis I again attempted to hear the participants’ voices, but also followed up areas where I was particularly interested, recognising my role in shaping the data. I held in mind that Charmaz (2006) notes the valued and integral role of the researcher in the analytic process. I reflected on the fact that my personal experiences of working with children and families influenced the analysis and therefore the creation of the model. This was vital given the amount of data I needed to process, and reflects Charmaz’s method, where ‘the theory depends on the researcher’s view; it does not and cannot stand outside it’ (p.130; emphasis Chamaz’s).

Whilst I only visited each family once I developed a sense of feeling close to the families, particularly as I spent many hours analysing their data. It was also interesting to note how different families evoked different reactions in me. There were several families that I wanted to keep in contact with, and I noticed that these families were particularly expert at recruiting support into their systems. I had to remain particularly mindful of the danger of shifting from researcher to clinician. This was difficult as I experienced a desire to help these families further and to support them with their distress. However conversations with my supervisors helped me to recognise the therapeutic nature of providing a safe space so participants could tell their story to an interested and sensitive person and participants’ feedback confirmed that they had found interviews therapeutic.

At times it felt unethical to develop a relationship with families in order to hear stories of their traumatic experiences, knowing that I would never see them again and could not offer any therapeutic follow-up. Whilst the offer of a referral for further support was always available it was difficult when families did not want it, despite clearly struggling with their recovery. Here I needed to remain mindful of my heroic desire to make everything better for these families and the
development of the model following analysis has shown me that many families are able to recover and heal without intervention.

4.4 The Pathway to recovery

Figure 4 attempts to understand the recovery process, integrating it into a theoretical framework. This model shows that families have to navigate a number of stages (numbered 1-8 in the diagram) during their recovery journey. This model makes explicit how families move from coping to recovery and the processing which families must engage with in order to advance along the pathway. However these stages are not discrete and in reality families move between stages in a fluid way, sometimes moving backwards and at other times engaging in two processes at the same time.

Families negotiate this pathway at different speeds, and indeed children and parents from the same family may be at different points at any one time. However from this research it seems clear that parents and children do follow a similar pathway, with both having to complete the key tasks as they recover. How quickly people move along the path to recovery will depend to some extent on the ages of the children and their emotional and cognitive maturity, alongside the structural composition of the family (Dielman et al., 1984; Salmon & Bryant, 2002). Younger children might require more support to create a narrative but may find it easier to accept a ‘new normal’ because they do not clearly recall ‘old normal’. Where the child has a developmental learning disability parents do still follow the same pathway, but they often already hold a model of recovery, have already recognised life is irrevocably changed and have mourned the losses before.
1. Admission experiences
   - How experienced at time
   - Previous experiences
   - Communication
   - Containment

2. Coping day to day
   Individual & family strategies

3. Try to get back to normal
   Biopsychosocially
   First focus physical health

4. Discover that normal is not the same as before
   Identity challenged

5. Realise effect of illness and experience on identity

6. Mourning the losses

7. Integrate story into new identity

8. ‘New normal’ becomes normal

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Model of what normal was like (both memories and inferences with hindsight)

Search admission experience for reasons/explanations
Narrating the experience
Searching for meaning

As you process you understand the experience differently

Social processing of experience

Cognitive processing of experience

Emotional processing of experience

Conscious

Unconscious

Pathway followed by families following discharge
- Development of narrative
- Processing – Meta level

Figure 4: The pathway to recovery

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Figure 4: The pathway to recovery

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4.5 Key processes on the journey

4.5.1 Processing the experience to create a coherent narrative

Creating a narrative of the event was vital to all participants, but participants were not able to engage in this process directly following discharge. At this stage they did not build their story because they did not realise this was necessary. They expected to reconnect with their life quite easily and expressed a desire to put the PICU experience behind them. Goldsmith et al. (2004) argue that directly following a trauma people chose to repress information which would challenge their current way of thinking. All participants noted that it came as a shock when they realised that they still had a long way to go before they could say they had ‘recovered’, and with time came to realise this encompassed more than just physical recovery. It was therefore the cognitive dissonance (Goldsmith et al., 2004; Neal & Summerville, 2005) which prompted families to reflect on their experiences, attempting to find a reason for the delay in a complete recovery.

‘I think that...it’s harder now than it was before because you get more time to think about it so you dwell on it to a certain extent and you think my god this is what happened’ (Father, interview 5)

In her paper about adult survivors of intensive care Lecky Williams (2009) notes that constructing a narrative can be challenging for this population due to temporal confusion during the experience and limited access to all the facts. Whilst families echoed this they also noted that through the parent-child dyad there was always someone else present, resulting in an additional source of information. Much of the literature also notes that narratives are contextual and the actual telling of them also engenders movement and change (Capps & Bonanno, 2000). Therefore processing some families will have found it helpful to talk between themselves and with others. It is illustrated in Figure 4 as ‘social processing’.
However processing and re-processing the experience was not something participants always wanted to engage in. As with other trauma, participants described intrusions in their thinking, and being unable to think about other topics (e.g. Verwoerd et al., 2009). Additionally, although much of the processing was conscious, participants shared examples of unconscious processes occurring, such as finding themselves crying without reason or reacting to a situation or piece of music which they did not expect would upset them (represented in Figure 4 by the triangle; reminiscent of Freud’s iceberg analogy: Scherer, 2005).

This makes the link between the themes of ‘processing’ and ‘choice and control’ explicit. It was as if through processing participants were attempting to take back the control from their unconscious. Processing their memories was an attempt to know more and understand their experiences (Vaindervoot & Rokach, 2003) and an attempt to gain a ‘sense of mastery over the posttraumatic recovery’ (Benight et al., p.678). Despite being unpleasant at times, creation of a narrative was therefore vital in taking back control of the past and present (Lecky Williams, 2009). This mirrors general trauma recovery literature which emphasises retelling the story as vital if people are to feel empowered (Herman, 1998).

In addition to processing the admission (now in the past) participants also described having to create a narrative about what was happening to them in the present. Benight et al. (2008) describe the dual process of both understanding the trauma and ‘managing the unfolding environmental stressors the trauma produces’ (p.677). Families had a number of demands on their time and their cognitive capacities, such as engaging in physical recovery and social reintegration. These experiences also needed understanding, partly because they were new and different and partly because they had a relationship with the initial trauma. Thus the narrative that families created was constantly being rewritten (Beaudoin, 2005) and came to be understood in different ways at different stages.

Creating a narrative was not simply a process of gathering facts. Instead it involved people reviewing and reappraising what had happened repeatedly, considering how they had behaved in that situation, how they had felt at the time and their feelings with the benefit of hindsight. Benight et al. (2008) emphasise
that reflection is key in the recovery process after a traumatic experience. It was evident that parents and children were examining both their memories and more generally their identity. There was a sense that people did not know who they were for a time because being in hospital had fundamentally challenged what they knew about themselves as individuals, and about their roles in relation to others. Currier et al. (2009) suggest that when personal and long-held assumptions are challenged people are left unsure if they ‘are competent to deal with life’s challenges’ (p.182). Therefore processing was vital in participants finding out who they had been whilst in hospital and relate this to what they had previously thought about their identity and who they were now.

4.5.2 Integrating the narrative into your identity

Grounded theory is particularly interested in ‘how and...why participants construct meanings...in specific situations’ (Charmaz, 2006, p.130). This research aimed to discover why the narratives participants were struggling to build were so important to them. This data showed that, once a coherent narrative had been created and rehearsed, people had a product which they could use to understand where they were in the recovery journey and who they were as a person. Participants talked about losing a year of their life, or their belief that the world was a safe place. In stage six, as participants are mourning the losses they are also attempting to continue along the recovery journey. This process mirrors Stroebe and Schutt’s (1999) model of bereavement where the individual both feels sad for what they have lost and also actively engages with life, putting aside the distress for a time.

Alongside this mourning is recognition of the positive changes which have occurred. Many participants recognised that they had gained from the experience as well as experiencing losses and difficulties.

‘...this experience can have a positive effect on people. It can make you stronger as a person and...you look back and realise what you’ve over come’ (Young person, 2, written feedback).
This mirrors Papadopoulos’s (2007) concept of adversity activated development where ‘positive developments are a direct result of being exposed to adversity’ (p.306) occurring both during admission and post-discharge. Noticing gains as well as losses seemed to be important as participants came to integrate their narrative into the wider experience of their lives. However Davis and McKearney (2003) argue that this perception of growth after trauma is illusory and maybe employed to ‘protect or buffer one from reminders or mortality’. It is possible that having been close to death (both personally, and through physical proximity to other dying patients) on PICU that participants were keen to exaggerate the growth aspects to compensate for the loss of a benign view of the world (ibid.).

In addition to integrating the experience into their personal identity, people also began to view others in different ways. Parents were able to see the resiliencies in their children. Families were able to reflect on the perspectives of others outside the family, noticing how they related differently to others because of their experiences. This matches with Lebowitz et al. (1993) model of trauma recovery which includes reconnecting with others as the trauma becomes more processed and further in the past.

4.5.3 Accepting ‘new normal’

Nightall (2006) argues that because serious illness has such a significant impact and results in many changes, at least in the short term, people move to a position of thinking that life has been irrevocably changed. Families in this study attributed all changes to the illness and their hospital admission. In this study ‘old normal’ (what life was like before admission) was seen as a static state and was awarded special status, remaining idealised in families’ minds. However, in reality ‘old normal’ would have changed over time anyway, as the children grew and developed and families naturally changed even without a PICU admission.

Concurrently, participants were creating a model of recovery, which both described their journey to date and predicted how the recovery journey would continue. Participants had not been able to do this earlier. Silverman (2001) argues this is because creating a model can only occur after meanings and actions have been understood, in this case through the development of a narrative of the
PICU admission. Participants also described resources and support they would need for the next part of the journey. These models matched Friesen's (2005) definition of recovery as something positive and future-orientated and showed participants setting themselves meaningful goals.

Eventually, if families had processed effectively, integrated this narrative into their identity and developed a recovery model, then this 'new normal' simply became 'normal'. As families moved along the recovery path they seemed more able to integrate the changes into their everyday lives, noticing that whilst some things had returned to normal (such as returning to school or work, achieving physical recovery) they were different people because of the experience and would always have the memories of what had happened to them.

In her model of grief Clark (2001) maps the route, culminating in 'reorganisation' and 'new life'. The experience of coping with trauma is similar in many ways to bereavement. Mourning what has been lost and balancing the sadness with the need to continue living is important in both experiences. For people following a PICU admission 'reorganisation' involves the integration of a narrative about the experience and a new identity into their everyday life, thus creating a 'new normal'. This matches models of trauma recovery which seek to encourage reconstruction of systems (Herman, 1998).

4.6 Roadblocks to recovery

Previous research has shown that some families were able to recover from their experiences in PICU whilst others become more traumatised over time (Colville & Pierce, 2007). There are some general factors which will affect families' ability to recover. Research into serious childhood illness has found that levels of expressed emotion and the quality of the parent-child relationship affects resilience following illness and difficulties in these areas can result in internalising difficulties and behaviour problems (Minden, 1999). Additionally, a lack of social support (Lebowitz et al., 1993), poverty or financial difficulties and lower education or intelligence (Vogt et al., 2007) can all impact on poor recovery outcomes. However, these difficulties alone do not cover all that participants expressed
about difficulties following discharge and it is vital that any model put forward to explain the recovery process after PICU also explains how this process can be interrupted. This section explores what can go wrong, again focusing on the key processes discussed above. These roadblocks may explain why some people develop post-traumatic symptoms and others recover.

4.6.1 Stalled narratives

The creation of a narrative about admission experience involves being able remember physically and emotionally painful experiences and families need to be ready for this. If families are able to use coping strategies effectively, straight after discharge, then they can give themselves time and space before they move into the processing stage. Tolerating uncertainty is important for these families immediately after discharge, but is a huge challenge when the hospital admission itself was fraught with uncertainty and constant threats of danger. Some families simply lack adequate coping strategies, meaning that they have no way to postpone thinking in detail about their admission experiences.

Other families chose not to employ coping strategies because they wanted to begin processing in an attempt to regain choice and control in their lives. Any belief which families held about the world being a safe and just place to live may have been shattered by their PICU admission leaving them feeling significantly vulnerable (Vaindervoot & Rokach, 2003). Thus families attempt to reconstruct their story too early before they have had a chance to feel safe and grounded in the present (Lebowitz et al., 1993). This can result in families becoming overwhelmed, particularly when the narrative confirms the belief that the world is not safe or just.

Narrative creation may also be stalled because of a failure in the social environment. When identities or roles are changed, particularly by illness and hospitalisation, social interaction can become difficult or even impossible (Bluebond-Langer, 1978). Many parents and children said they did not talk about their admission experiences because they wanted to protect the other, or feared upsetting them. Further, as parents are struggling to come to terms with their own experiences, it is possible that they may be too preoccupied to provide
opportunities for the younger child to develop their narrative. This was observed
during interviews and mirrors research suggesting that parent’s own experience
of trauma can result in inaccurate judgments of their child’s emotional responses
(Shemesh et al., 2005). It is known that the teller’s understanding of their
narrative is enhanced by eliciting feedback (Schwandt, 2001). Therefore families
who are not talking about the PICU experience may have nascent narratives which
remain underdeveloped.

Moreover parents may chose which parts of the narrative to co-construct,
emphasising certain aspects of the experience and marginalising others. This will
leave the child with an incomplete narrative which may be confusing and result in
a feeling of powerlessness. Parents may also fail to contain emotional reaction
which may arise when reconstructing the PICU narrative. If the child becomes
overwhelmed with information or they do not receive appropriate emotional
regulation from their parents they may lack security and feel unable complete
‘emotional processing’.

However, even if parents make every attempt to support them, the child may
struggle to accept their help if they blame or associate their parents with the pain
and trauma they experienced. Vandervoort & Rokach (2003) argue that if trust is
damaged by trauma relationships may be significantly affected, particularly if the
child fears they will have to go through the same experience again.

Finally many families said they felt unsure if thinking and talking about their
experiences was pathological. This fear may hinder narrative creation because of
the anxiety it engenders. Many families felt that it was difficult to mourn their
losses because they were expected to be happy that the child was physically
better and out of hospital. Because a PICU admission is so rare families often
knew no other people who could normalise their experience. This resulted in
feelings of isolation and no clear pattern for their recovery. Additionally, other
people around the family tended to avoid talking about the PICU admission for
fear of upsetting the person, and would sometimes shut down conversations.
Whilst some families expertly negotiated this roadblock others felt very confused
about what they ‘should’ be doing and in the absence of any ‘map’ their developing narrative was stalled.

4.6.2 Problems integrating the narrative into a new identity

Participants talked clearly about the effect of the PICU admission on their identity. The model highlights the realisation which occurs as participants begin to reconnect with the outside world, thus noticing the gap between themselves and others, as well as the difference from who they were prior to falling ill. Part of the recovery process involves integrating the narrative into the new identity and building a recovery model on this new sense of self. Assuming the narrative is created successfully there are a number of possible roadblocks at this later stage.

Learning theory suggests that whilst congruent information is easily integrated into existing schema, information which does not match original ideas can either be rejected, or through the process of accommodation, the schema is developed to take account of the new information (Monson et al., 2007). Therefore it is possible that families fail to accommodate new information following a PICU admission, perhaps because the person has changed so significantly, or because there is a dogged desire to hold on to existing beliefs about their identity. Additionally those with a more rigid thinking style might struggle with the cognitive flexibility required to accommodate new information into what they see as a fixed way of thinking about themselves.

The social constructionist school would suggest that learning occurs through interactions and feedback with others. Cooley’s model of ‘the looking-glass self’ (Cooley, 1902 in Gross, 2001) highlights that identity is formed through the reflection of ourselves which occur when we communicate with others. It is therefore likely that the integration of a new identity would also require the existence of supportive relationships. If families are unable to re-connect following significant separation from the social world, then they may lack peers through which they can develop a new identity and assimilate the new experience they have had.
It is most likely that a combination of these theories explains why people struggle to integrate the new narrative into their identity. This mirrors the tri-model of emotional, social and cognitive processing which is identified in Figure 4.

Concurrently with integrating the story into their identity, participants also created personal and family models of recovery. This research has highlighted the importance of a biopsychosocial approach to the recovery process, rather than simply noticing the health improvements (Davidson et al., 2006). However families may receive confusing messages from medical staff who emphasise that ‘recovery’ has been achieved because the child is physically well. Families may struggle to hold in mind multiple models and integrate the different expectations of doctors and close friends and families alongside their own ideas. This may result in families not feeling able to create their own model, or even to recognise that their recovery will need to involve social and psychological healing in addition to physical wellness.

4.7 Clinical implications

4.7.1 Mapping the journey

This project originated from a desire to investigate a topic which could have significant clinical implications, with the aim of improving life for families who will go through PICU in the future. There are a number of clinical implications which are suggested by the model.

Importantly, some families are able to negotiate the recovery journey for themselves (Colville & Pierce, 2007), but all could do with support knowing more about the journey they are embarking on, thus avoiding some of the possible roadblocks. It therefore seems important to give families a ‘roadmap’ which describes the journey, normalising the process. Such information, given at the time of discharge could be referred to a number of times after discharge and would also provide a stimulus for families to talk about their experiences. Important messages a leaflet could communicate include:
• Informing families that recovery involves physical, social and psychological elements and continues long after discharge.

• Normalising the recovery journey

• Encouraging processing of experience when ready

• Highlighting the need to support identity and identity changes in hospital and beyond by suggesting parents balance keeping things the same and providing growing and changing space for their child

• Acknowledging that life will be different and encouraging thinking and conversation about these differences

Funding has been secured for this researcher to develop a leaflet. Work to develop and evaluate it is now in progress.

4.7.2 Recommendations for clinical staff

During admission, medical staff and psychologists can ensure that they are encouraging families to use short-term coping strategies such as looking after yourself, taking time for yourself and using the support around you. Developing these strategies in hospital will support families as they enter the first stages of recovery. Clinicians might also encourage activities such as keeping a diary or log of events when the child is on PICU so this information can be used during recovery when families are attempting to recreate their narrative.

Furthermore, families should be advised about what they can expect from a biopsychosocial recovery experience, and be prepared for the time it will take to reach a place where things feel ‘(new) normal’. This will be most appropriately done in the ward rather than on PICU once the child is out of danger and is more alert, meaning both the child and parents can engage in discussions. Here a balance must be struck between worrying families about what they will face in the future and making them aware of the paths which lie ahead. The leaflet discussed above would support these discussions.

Once discharge has taken place, families often return for follow-up clinics. At these, medical staff should hold in mind a biopsychosocial model of illness and

8 More detailed recommendations can be found in Appendix 25
recognise the integrated nature of recovery. Further medical staff should be prepared to provide additional information about the PICU admission when families are attempting to generate a narrative. Additionally families should be able to access psychological support if they need it following discharge. Commissioners will therefore need to ensure funding is available to provide long-term, ongoing support to families, and not just limit clinical staff to working with inpatients.

Finally, there are implications for psychologists about when they should intervene to support families. This intervention will depend on the stage the family is at. When families are still in hospital or early on in their recovery journey the psychologist's role will be educative and supportive, being mindful of the danger of starting processing too early. In later stages a clinician might need to support narrative creation and integration and help families to challenge unhelpful beliefs.

**4.8 Critique and limitations of the study**

A strength of this study is the involvement of key stakeholders in the design and implementation of the study. Parents, young people and users of psychological services were all consulted and contributed ideas and a clinical psychologist working within a hospital setting reviewed the interview schedule. This ensured that the research design mirrored the needs and concerns of participants. But all these stakeholders will have had personal and professional ideas which may have influenced the direction the research then took.

During recruitment families self-selected to participate. This is ethically appropriate but it is possible that the families interviewed differed from those who declined the invitation to take part. Colville *et al.* (2010) found that families experiencing admission-related stress symptoms were more likely to attend follow-up clinics suggesting people self-select further involvement with services if needed. This finding is evidenced in the present study by the relatively high level of reported post-traumatic symptoms. Additionally most families were White British and only one family was from a minority ethnic group, despite the sampling pool containing a large number of families who were of other ethnic origins. 'Cultural factors significantly influence the context and way in
which...illness is understood’ (Sperry, 2006, p.25) so further research into non-white/non-British families is necessary.

Additionally, each family was only seen once, and therefore their stories were gathered at a particular time point in their journey. It was possible that had the same family been interviewed at a different point they would have shared their narrative differently. Stories are constantly ‘re-authored’ (White, 2007) and it is possible the research did not capture all possible narratives. This led the researcher to seek out families who had been discharged at different points, which was a helpful sampling technique as it highlighted that families move through the journey at different speeds and that their narrative at different points depends on the amount of processing they had done.

Further theoretical sampling was also possible in this study, for example seeking the views of parents of a child with a pre-existing learning disability and canvassing fathers as well as mothers. However, rather than purposively sampling from a large base it was necessary to interview every family who opted-in and for ethical reasons it was not possible to contact those families who did not opt-in. This might have been ameliorated by widening the study beyond a single hospital. Whilst logistically this was not possible in the present study this would have enriched the data and made it more representative of the overall PICU patient population.

Yardley (2008) suggests a framework for further evaluating the validity of qualitative research. Whilst saturation of focused codes was not achieved no new axial codes emerged after interview six, suggesting that the overarching model is an accurate representation of the experiences of participants. This was confirmed by interview nine and the written feedback comments, where participants commented on how well the results and the model reflected their families’ experiences.

‘Having felt my experiences were unique, it is clear that others have similar stories.’ (Young person, 3, written feedback)

These are explored in more depth in Appendix 1.
This feedback, along with that from other professionals' and the peer-checking contributes significantly to the validity of the study (Rolfe, 2004). It is important to highlight that this research sits within the qualitative paradigm and assumes there is no objective reality. Instead reality is seen as subjective and created in the context of relationships and the social world. Therefore this model, whilst representing the views of participants in this study, may not represent the views of those who did not participate. Further whilst it has validity because it was reviewed by participants and developed through their feedback the results represent an interaction between participants and researcher, and the highlighted themes were selected because they were emphasised by participants and noticed as important by the researcher.

Further research is needed to explore these findings across a wider sample, particularly focusing on families from minority ethnic groups. Moreover research with siblings and other family members (such as grandparents) might reveal interesting insights into their experience of recovery given that they are often involved when there is a PICU admission and witness what occurs post-discharge. Research could investigate which therapeutic interventions were most appropriate to support families in difficulties. Finally, an evaluation of the leaflet which will be a product of this research could examine the efficacy of this intervention in helping families smoothly negotiate the recovery journey.

4.9 Conclusions

This research has shown that the process of recovery after serious and life-threatening illness is complex. Families negotiating the pathway to recovery have to cope with the immediate aftermath of their hospitalisation, then slowly process what has happened to them and integrate this story into their identity, preparing for a future which will be fundamentally changed by their experience. This path is similar to other models of recovery from trauma, but importantly it notices the systemic nature of processing following a trauma, and links the physical and social recovery with the psychological and emotional healing. Most families are able to
travel this path on their own, but may benefit from a ‘map of the terrain’ which helps to normalise the intense emotional experience they are trying to cope with. Other families may need further support or, metaphorically, a guide who will help lead them on the journey. Expertly done, this can support the families’ own self-efficacy whilst also providing tools which will facilitate narrative processing and integration. If this is achieved then it could result in a reduction in the families still troubled by their experiences in PICU after a year, and has huge potential to influence the lives of children, both directly and indirectly through the support they will gain from parents who themselves are adequately processed and integrated.
Afterword

I started this project with the quote about roots and wings. Without conscious intent the model developed in this research seems to map onto this quote. Giving children and families roots involves helping them to feel grounded, cope with the day-to-day and develop a story about what has happened to them. Only though this can children and families then develop wings, integrating their story into their wider identity and therefore managing to not be weighted down by their experiences, instead, recovering from it and flying onwards.
References


Chadwick, P. (2002). How to become better after psychosis than you were before. *Open Mind, 115*, 12-13.


Colville, G., Cream, P. & Kerry, S (2010). Do parents benefit from the offer of a follow-up appointment after their child’s admission to intensive care?: An exploratory randomised control trial. *Intensive and Critical Care Nursing (In preparation)*


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Appendix 1: The quality of the procedure – assessing validity

Rolfe (2004) has argued that rather than having a set of criteria by which establish the scientific nature of the research and the rigour of the process, qualitative research should demonstrate its ‘trustworthiness’. Further the author should be transparent about processes in an attempt to allow the reader to ‘track and verify the research process’ (p.305) and thus judge whether the work is trustworthy. In an attempt to demonstrate the trustworthiness extensive appendices have been included. However I have also chosen to evaluate the project against Yardley’s (2008) criteria, recognising the need to validate the research, particularly in a climate where qualitative research still requires justification and needs to prove that it is a genuinely scientific endeavour. Yardley’s (2008) model is useful as it recognises the diversity of qualitative methods and the need to reflect on the research without being overly prescriptive or inflexible.

Sensitivity to context

Yardley argues that the research should be set within a relevant theoretical and empirical background. Pertinent literature was evaluated as a context to the present study, and a clear research question was developed given the findings of other studies. In this study the research question had not been considered before and a qualitative methodology was most appropriate to explore the topic as personal experiences and participants’ voices needed to be heard. In line with grounded-theory protocol this literature was considered, but then not attended to during model development, ensuring the voice of the participants was heard. However once the model had been developed it was possible to re-establish links with the existing literature (Payne, 2007), thus validating the model which was developed.

Additionally sensitivity to context relates to the socio-cultural setting and making space for participants’ perspectives. Grounded theory provides a framework to hear and present a model which is truly grounded in participants’ experiences (Charmaz, 2006). Further, as the researcher I was aware that my position as a white woman, with a high level of education and no children, might have influenced how parents and young people interacted with me. To ameliorate this I
thought carefully about how I introduced myself and worked hard in interviews to build a working relationship. I also developed an interview schedule which had open-ended questions and gained feedback on my questioning technique through supervision and feedback from participants.

Further, empirical data must be analysed in line with the theoretical underpinnings of grounded theory, and provide space to allow participants’ stories to be heard. At the analysis stage I attempted to hold two ideas in mind, firstly staying close to the data and analysing what had been said, but also looking beyond what had been said to consider why it had been shared and what was not being said. This was evident in the annotation of transcripts (appendix 18) and can also be seen in the memos (appendix 20).

Finally this category involves consideration of ethical issues, which was imperative in this project, and thought about from an early stage due to the potentially sensitive topic under investigation. Following rigorous scrutiny by the NHS ethics committee (appendix 2) I remained mindful of ethics throughout the research process, and particularly at the interview stage, offering participants a break or to terminate the interview if they were distressed.

Commitment and rigour

Commitment to the area of children and families and to ameliorating distress caused by difficult life experiences is evidenced by the various posts I have held in this area, both internationally and in the UK. Commitment to participants can be seen in the attempts made to actively seek a range of views. Firstly both parents and children were canvassed and the researcher spoke to fathers and mothers. Participants from different socio-economic groups and from an ethic minority were included. Through purposive sampling alternative views were sought and this included speaking with parents whose child has a pre-existing learning disability. This group is often marginalised in studies about PICU (Graham et al., 2009) and it was expected that they would have different views to other families. The parents in this group further supported development of the model, and in particular the idea that families move through the process at markedly different speeds dependant on previous experiences and their expectations. Additionally participants voices can also be heard in the space given to in-hospital (as opposed
to post-discharge) experiences, which this researcher did not anticipate including at the outset of the research process. However as interviews were conducted it became clear that telling the narrative of the admission was vital to setting the context for any conversation about recovery.

Codes which arose from that data were qualitatively compared at various stages of collection and then shared with participants to assess their representativeness. Yardley (2008) argues that depth of analysis relates to both rigorous application of method and empathic understanding of participants’ perspectives. Each interview took at least 20 hours to transcribe and analyse meaning I spent a great deal of time considering the data, and I attempted to draw on my own experiences of being hospitalised as a child in connecting with the emotional content of the narratives.

Using the process of peer-checking (Rolfe, 2004) and getting feedback from participants and professionals in the field (appendices 22-24) during the analysis process ensured that the analysis was rigorous and the researcher was not disproportionately directing the analysis in a direction which took it away from participants’ stories. In the peer-checking (appendix 25) process all of the open codes were matched to quotes in the same way as the research had done. For the axial codes (the wider and more theoretical codes) all codes had at least one correct quote and most quotes were also matched in line with original analysis. Of those codes which were organised differently all were placed in close, related or over-lapping categories.

Coherence and transparency

This area includes being explicit about the fit between theory and method and being transparent about these aspects. This research sits within a methodological paradigm which argues there is no objective reality, but instead suggests that reality is created by participants and the interactions between researcher and participants. Participants contributed to analysis and the development of a model through the feedback and suggestions they provided. Further this research sits within a social constructivist framework, seeing reality as developing through conversations, including those with the researcher, and this has been acknowledged throughout the work.
At times during this research project it was challenging to engage other key stakeholders who did not understand or embrace qualitative methodologies. For example one NHS reviewer requested further clarification on aspects such as outcome measures and hypotheses, none of which are relevant for qualitative projects, and in particular Grounded Theory, which allows participants to dictate outcomes and the products of the research. Having to champion the relevance and power of qualitative research and to be explicit about methodological underpinnings has profoundly supported the research development process and positively impacted on the outcomes of the research.

Transparency and clarity are also important. In the present research this has been attempted through inclusion of a coded transcript in the appendices. Additionally examples of the various levels of coding, all the codes developed and memos have been included to make explicit the process of development of the model. Finally reflections have been included throughout the text to integrate my thinking into the wider project.

Impact and importance

This project has significant importance and the potential to impact a number of areas of psychology. Firstly it proposes a theoretical model for recovery following serious and life-threatening illness, which considers both the child and parents’ voices. Additionally and more importantly it has clinical relevance and aims to produce a leaflet mapping the journey which can be given to all families leaving PICU the leaflet produced will directly support all families with the recovery journey, and provides a tool for family discussions and a way of accessing wider social and professional support as required. Finally it offers suggestions for clinical psychologists and other practitioners who work with families following serious illness, particularly highlighting areas where families may face difficulties.
Appendix 2: NHS REC Ethical approval for the project

The Royal Marsden Research Ethics Committee
St George's University of London
South London REC Office (1)
Room 1.13
1st Floor - Jenner Wing
Blackshaw Road
Tooting, London
SW17 0RE
Telephone: 020 8725 0252
Facsimile: 020 8725 1897

24 February 2009

Miss Ellie Atkins
Clinical Psychology Department
University of Surrey
Guildford
GU2 7XH

Dear Miss Atkins,

Full title of study: Towards a theory of the recovery process and the ability to cope with the trauma experienced in the year following discharge from a paediatric intensive care unit (PICU)

REC reference number: 09/H0801/22

The Research Ethics Committee reviewed the above application at the meeting held on 16 February 2009. Thank you for attending to discuss the study.

Ethical opinion

- The Committee would like to commend you for a well thought out and presented study.

- The Committee questioned the provisions for translation. You confirmed that, you've since received approval for the funding to include provision of interpreters.

- The Committee acknowledged that the GP would be contacted before the family is approached, but wanted to know whether this could not be extended to the Child's Paediatrician, considering the relationship between the two and the knowledge that would have been gained. You confirmed that they would expect to do this and that systems are in place also to check the database.

- The Committee suggested that within the parents PIS, it should be clear that the Child will be given the choice of having their parent present or not.
The members of the Committee present gave a favourable ethical opinion of the above research on the basis described in the application form, protocol and supporting documentation, subject to the conditions specified 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.

Management permission at NHS sites ("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 is available in the Integrated Research Application System or at http://www.rdforum.nhs.uk.

**Approved documents**

The documents reviewed and approved at the meeting were:

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Major Research Project (Appendices)

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Membership of the Committee

The members of the Ethics Committee who were present at the meeting are listed on the attached sheet.

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 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 guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- 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/H0801/22 Please quote this number on all correspondence

With the Committee’s best wishes for the success of this project

Yours sincerely
Ms Shelley Dolan  
Chair  

Email: royalmarsden.rec@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:  
Mrs Mary John, University of Surrey/Sussex Partnership Trust
Appendix 3: University of Surrey Ethical approval

Dr Adrian Coyle
Chair: Faculty of Arts and Human Sciences Ethics Committee
University of Surrey

Ellie Atkins
Trainee Clinical Psychologist
Department of Clinical Psychology
University of Surrey

24th March 2009

Dear Ellie

Reference: 323-PSY-09

Title of Project: Children and Families experiences of Paediatric Intensive Care

Thank you for your submission of the above proposal.

The Faculty of Arts and Human Sciences Ethics Committee has given favourable ethical opinion.

If there are any significant changes to this proposal you may need to consider requesting scrutiny by the Faculty Ethics Committee.

Yours sincerely

Dr Adrian Coyle
Appendix 4: NHS Trust R&D committee approval

Dear Miss Atkins,

Project Title: Towards a theory of the recovery process and the ability to cope with the trauma experienced in the year following discharge from a paediatric intensive care unit (PICU)

Protocol version #: 2
Protocol date: 01/02/09
REC Reference: 09/H0801/22
RO Reference: 09.0078
Sponsor: University of Surrey
Host site: 
Principal Investigator: Miss Ellis Atkins

Notification of host site approval

The research approval process for the above named study has been completed successfully.

The conditions for host site approval:

- The PI must ensure compliance with protocol and advise the host of any change(s) to the protocol. Failure of notification may affect host approval status.
- Under the terms of the Research Governance Framework, the PI is obliged to report any Serious Adverse Events to the Sponsor and the Research Office, in line with the protocol and Sponsor requirements. Adverse events must also be reported in accordance with the Trust Adverse Incident Reporting Policy & Procedures.
- The PI must ensure appropriate procedures are in place to action urgent safety measures.
- The PI must ensure the maintenance of a Trial Master File (TMF).
- The PI must ensure that all named staff are compliant with the Data Protection Act, Human Tissue Act 2005, Mental Capacity Act 2005 and all other statutory guidance and legislation (where applicable).
- The PI must be compliant with monitoring and auditing by the Research Office.
- The PI must report any cases of suspected research misconduct and fraud to the Research Office.
- The PI must provide an annual report to the Research Office for all research involving NHS patients, Trust or SGUL staff and/or resources. The PI must notify the Research Office of any
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Hospital logo and address

Presentations of such research at scientific or professional meetings, or on the event of papers being published and any direct or indirect impacts on patient care.

All research carried out within the Nuffield Department of Paediatric Surgery and Developmental Medicine, London, must be in accordance with the principles set out in the Research Governance Framework for Health and Social Care (2005, sec. 1).

Failure to comply with the above conditions and regulations will result in the suspension of the research project.

Please contact the Research Office if you require any further guidance or information on any matter mentioned above. We wish you every success in your research.

Yours sincerely

Priscitia Aryee
Research & Development Facilitator

Cc: Gillian Colville, Head of Paediatric Psychology Service
Appendix 5: Letter to GPs

[Hospital address]

[GP address]

Dear [GP name],

RE: Research Project – Children's recovery after PICU

We are writing to inform you that, as part of a research project investigating recovery in the year following a child’s admission to paediatric intensive care, we are hoping to shortly contact the family of one of your patients

[Child name, DOB and address]

who was admitted to XXXX Hospital PICU in the last 14 months. We will be asking parents and children to complete a short questionnaire and answer some interview questions. We have included the parents’ information sheet for your information. This project has been approved by the NHS Research Ethics Committee (REC reference: 09/H0801/22, passed on 16th February 2009).

We would be most grateful for your permission to contact the family. We would also be grateful if you would let us know if, in your opinion, there is any reason why we should not approach the family directly. In particular, we would appreciate it if you could inform us if the child has died since discharge, as we are not including bereaved parents in this research.

Please indicate whether or not you agree for us to contact the family by faxing (number), phoning (number) or emailing [supervisor name and title] on [email address]. Alternatively you can return the slip below using the enclosed envelope. If we have not heard from you after two weeks we will contact you by telephone to check that you are happy for the family to take part.

It is hoped that by learning in more detail about children’s recovery process the year following PICU, we will be able to improve the support services currently offered. In the meantime if we learn of the existence of significant distress in a family member in relation to issues raised during the interview, we will, with the family’s permission, contact you again.

Thank you for your attention

[name]
Consultant Clinical Psychologist
Surrey

Ellie Atkins
Researcher, University of Surrey
I am happy for you to contact the family for involvement in the research project looking at children and parents experience of the year following discharge from pediatric intensive care.

☐ I would recommend that you do not contact the family for the following reason:

........................................................................................................................................

GP name: __________________________  Child's name: __________________________

Signature: _________________________  Date: ________________________________
Appendix 6: Invitation letter to families

[Department address]

Dear

The experiences of children and families following discharge from Paediatric Intensive Care Unit

We are writing to you to invite you to take part in a research study. Before you decide to participate it is important for you to understand why the research is being done and what it will involve for you.

Please would you take time to read the enclosed information carefully and discuss it with others if you wish. You are welcome to contact us if anything is unclear or if you would like more information. We would be grateful if you could let us know whether you would like to take part in the study by returning the attached slip in the pre-paid envelope provided.

Yours sincerely

[name] Ellie Atkins
Consultant Clinical Psychologist Researcher, University of Surrey

I would/would not like to take part in this research project (please delete as appropriate)

Child’s name:...........................................................................................................

Your Name:........................................Relationship to child....................................

Telephone number or email address:........................................................................

Best times/methods of contact.................................................................................

Signed:....................................................................................................................

Date:...........................................................

(Please return slip in envelope provided)
Appendix 7a: Information sheet for participants

INFORMATION SHEET FOR PARTICIPANTS

Dear (Parent)

PROJECT TITLE: The experiences of children & families following discharge from Paediatric Intensive Care Unit (PICU)

We are writing to you to invite you to take part in a research study. Before you decide to participate it is important for you to understand why the research is being done and what it will involve for you. We ask you to please take time to read the following information carefully and discuss it with others if you wish. You are welcome to contact us if anything is unclear or if you would like more information.

What is the project about?
This project is looking at children’s experiences in the 8 to 14 months following discharge from a Paediatric Intensive Care Unit (PICU). Other patients and families have fed back to us in the past that they can have a number of ups and downs in the year after PICU. Some people have also said that while they may have felt ok straight after PICU, things may become difficult further down the line. We are interested in talking to children and parents about their experiences over the year so that we can begin to understand the process of recovery better and provide more help and information to families who go through this process. In addition, research regarding young children is often limited which can mean that our understanding of children in this group is restricted.

Why have I been chosen?
We have chosen to invite you and your child to take part in this project as your child was aged 5 to 16 at the time of admission to PICU and this admission was between 8 and 14 months ago. Your participation in this study is entirely voluntary. If you agree to take part you will be able to withdraw from the study at any time.

What will happen to me if I take part?
If you decide you would like to take part you we will contact you to arrange a time to meet. This meeting will be at a suitable time for you and your chosen location of your home or [name of hospital]. We will ask you to complete some basic details about yourself and your child and to complete a consent sheet. A copy of the consent sheet is provided within this pack for reference. Then your child will be asked invited to talk with the researcher, which might include playing with some toys and doing some drawing depending on their age. You can be present at this interview. The questions will be about your child’s experience of being in a PICU and what
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has happened since discharge from PICU. This may last up to around 30 minutes but you can stop the interview at any point or request a break. Then your child will be asked to complete a short questionnaire and you will be asked some questions to fill in some of the details following your child’s interviews. Finally you will be asked some questions which should take around 10 minutes, and to complete a short questionnaire which will take about 5 minutes.

What are the possible advantages and benefits of participation?
Many people say that talking about difficult things such as a child's stay in PICU can be beneficial and help them process and make sense of what has happened to them and their family. Additionally sometimes children don't know how to start talking about these things, and giving them the opportunity can help them to feel ok about talking about it with you if they want to. By sharing these experiences we hope to be able to give more informed help and support to families who go through PICU in the future.

What are the possible disadvantages and risks of participation?
A small minority of people report that talking about distressing times can have a negative impact on them. Should this happen during your participation in the study further support shall be provided by the Consultant Clinical Psychologist in the Paediatric Psychology Service. If the right kind of support is unable to be provided by the psychology service you will be supported to find and access the service that best meets your needs.

Will my participation be kept confidential?
All the information you give us will be confidential and used for the purpose of this study only. Information will be collected via questionnaires and tape recorded interviews. This information will only be seen by the researchers (names). The data will be collected and stored in accordance with the Data Protection Act 1998 and will be disposed of in a secure manner following a ten year retention period (in line with University of Surrey guidelines). All information collected will be anonymised and therefore not allow you or your child to be identified individually. Quotes from your interview may be used in a report following the project, and if so this will also be anonymous.

What will happen to the results of the research project?
When we have completed the research, we may contact you to give you the opportunity to comment on our findings. This research will be submitted for publication in an academic journal. All participants will be provided with a summary of the results.

Who is organising and funding the research?
The research is being funded by the University of Surrey and being organised by [name] Hospital.

What are my rights?
If you have any concerns about any aspect of this study, you should ask to speak to the researchers who will do their best to answer your questions (Ellie Atkins, see details at bottom of sheet). If you remain unhappy and wish to complain formally, you can do this through the NHS Complaints Procedure. Details can be obtained from the hospital.
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What if I have a first language that is not English?
If you have a first language which is not English and would like to receive a copy of this information pack in another language, we can arrange for this to be done by a qualified translator. Such a translator can also be provided at the meeting so that questions are clear.

What happens now?
We would be grateful if you could send back the reply slip attached to the letter using the prepaid addressed envelope. You can also email us using the address below. We will then contact you to discuss the research.

Thank you for taking the time to read through this information

Yours sincerely
Ellie Atkins
Researcher, University of Surrey Email: e.atkins@surrey.ac.uk
Appendix 7b: Information sheets for participants
(where child has a learning disability)

INFORMATION SHEET FOR PARTICIPANT

Dear (Parent)

PROJECT TITLE: The experiences of children & families following discharge from Paediatric Intensive Care Unit (PICU)

We are writing to you to invite you to take part in a research study. Before you decide to participate it is important for you to understand why the research is being done and what it will involve for you. We ask you to please take time to read the following information carefully and discuss it with others if you wish. You are welcome to contact us if anything is unclear or if you would like more information.

What is the project about?
This project is looking at families experiences in the 8 to 14 months following discharge from a Paediatric Intensive Care Unit (PICU). Other patients and families have fed back to us in the past that they can have a number of ups and downs in the year after PICU. Some people have also said that while they may have felt ok straight after PICU, things may become difficult further down the line. We are interested in talking to parents about their experiences over the year so that we can begin to understand the process of recovery better and provide more help and information to families who go through this process.

Why have I been chosen?
We have chosen to invite you to take part in this project as your child was aged 5 to 16 at the time of admission to PICU and this admission was between 8 and 14 months ago. Your participation in this study is entirely voluntary. If you agree to take part you will be able to withdraw from the study at any time.

What will happen to me if I take part?
If you decide you would like to take part you we will contact you to arrange a time to meet. This meeting will be at a suitable time for you and your chosen location of your home or [Hospital]. We will ask you to complete some basic details about yourself and your child and to complete a consent sheet. A copy of the consent sheet is provided within this pack for reference. Then you will be invited to talk with the researcher. The questions will be about your experience and your child’s experience of being in a PICU and what has happened since discharge from PICU. This may last up to around 60 minutes but you can stop the interview at any point or request
a break. Finally you will be asked to complete a short questionnaire which will take about 5 minutes.

What are the possible advantages and benefits of participation?
Many people say that talking about difficult things such as a child’s stay in PICU can be beneficial and help them process and make sense of what has happened to them and their family. Additionally sometimes families don’t know how to start talking about these things, and giving them the opportunity can help them to feel ok about talking about it with you if they want to. By sharing these experiences we hope to be able to give more informed help and support to families who go through PICU in the future.

What are the possible disadvantages and risks of participation?
A small minority of people report that talking about distressing times can have a negative impact on them. Should this happen during your participation in the study further support shall be provided by the Consultant Clinical Psychologist in the Paediatric Psychology Service. If the right kind of support is unable to be provided by the psychology service you will be supported to find and access the service that best meets your needs.

Will my participation be kept confidential?
All the information you give us will be confidential and used for the purpose of this study only. Information will be collected via questionnaires and tape recorded interviews. This information will only be seen by the researchers (Sarah Flood, Ellie Atkins, Mary John and Gillian Colville). The data will be collected and stored in accordance with the Data Protection Act 1998 and will be disposed of in a secure manner following a ten year retention period (in line with University of Surrey guidelines). All information collected will be anonymised and therefore not allow you or your child to be identified individually. Quotes from your interview may be used in a report following the project, and if so this will also be anonymous.

What will happen to the results of the research project?
When we have completed the research, we may contact you to give you the opportunity to comment on our findings. This research will be submitted for publication in an academic journal. All participants will be provided with a summary of the results.

Who is organising and funding the research?
The research is being funded by the University of Surrey and being organised by [Hospital].

What are my rights?
If you have any concerns about any aspect of this study, you should ask to speak to the researchers who will do their best to answer your questions (Ellie Atkins, see details at bottom of sheet). If you remain unhappy and wish to complain formally, you can do this through the NHS Complaints Procedure. Details can be obtained from the hospital.

What if I have a first language that is not English?
If you have a first language which is not English and would like to receive a copy of this information pack in another language, we can arrange for this
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to be done by a qualified translator. Such a translator can also be provided at the meeting so that questions are clear.

**What happens now?**
We would be grateful if you could send back the reply slip attached to the letter using the prepaid addressed envelope. You can also email us using the address below. We will then contact you to discuss the research.

**Thank you for taking the time to read through this information**

Yours sincerely

Ellie Atkins
Researcher, University of Surrey
Email: e.atkins@surrey.ac.uk
There follows:

*Appendix 8a: Information sheet for 5-8 year olds*

*Appendix 8b: Information sheet for 9-12 year olds*

*Appendix 8c: Information sheet for 13-18 year olds*
This is Ellie

She is finding out about children who have been in hospital.

Ellie wants to find out what it is like to be in hospital and what happens when you come out.

Ellie will ask you some questions about when you were in hospital.

You can do some drawing and Ellie will bring some toys with her.

You don’t have to talk to Ellie if you don’t want to. Your mum or dad can stay with you when you talk to Ellie.
This is Ellie

She is doing a project about children who have been in hospital

Ellie wants to find out what it is like for a child to go to hospital and get better so she can help other children who might get ill

Ellie will ask you some questions

She will ask about when you were in hospital

**You are the expert!**

She will ask about what happened after you came out of hospital

**It might even be fun!**

You can do some drawing and Ellie will bring some toys with her

You don’t have to talk to Ellie if you don’t want to.

Your mum or dad can stay with you when you talk to Ellie.
This is Ellie

As part of her university studies Ellie is doing some research into the experiences of children who have been in intensive care.

Ellie wants to find out about what it is like for a child to go to hospital, and recover afterwards so that she can help other children who might get ill.

Ellie would like to interview you as part of the project. This would involve asking you some questions about when you were in hospital and your experiences since you have been discharged.

The interview will mainly involve talking, but might include some drawing to create a ‘film-strip’ of your experiences. Ellie will ask you what you would prefer to do.

You don’t have to talk to Ellie if you don’t want to. You can choose whether you would like mum or dad to be present when Ellie interviews you.
Appendix 9: Consent form

Children and families experiences of paediatric intensive care

Consent form

This study involves interviewing parents and children about their experiences of paediatric intensive care.

Please read this form carefully and sign at the bottom if you are comfortable with being involved. Feel free to ask any questions before you sign the form.

I understand that:
• I don't have to consent to this study if I don't want to be involved
• I can stop the interview at any time
• I can change my mind about consent after the interview is finished
• The interview will be tape recorded
• I will be asked my view about the data before the final research is written up
• All the data will be anonymised, so no one will be able to identify me or what I have said
• That the data will be written up for a doctoral project
• The project may be published in a relevant academic journal
• I will receive a summary of the research findings

I consent to participate in this study

Name ______________________

Signed ___________________   Date ______________

Name of child you are consent on behalf of:

Parent/Guardian of ______________________

For confidentiality and anonymity this form will be kept separate from the interview data.
Appendix 10: Child Assent form

Children and families experiences of paediatric intensive care

Ellie wants to ask some questions about when I was in hospital and what it has been like since I came out.

What do you think?

Remember

✓ Ellie will change my name so what I say is kept private
✓ I don’t have to answer questions if I don’t want to.
✓ I can stop the interview if I want to
✓ Ellie won’t mind if I say no.
✓ I can change my mind if I want to

My decision

It is ok for Ellie to ask me about when I was in hospital

✓

Or

I don’t want Ellie to ask me about when I was in hospital

✗

My name:

My signature:

Today’s date:
Appendix 11: Interview protocol

Data gathering format for each family

1. Consent form with parents
2. Explain to parents how interview will run, their role etc
3. Give parents demographic form
4. Introduce to child, talk with child about interview, gain their assent
5. Interview with child
6. Thank child
7. Child over 8 - Give child CRIES-8 (to complete independently or read to child depending on age and ability)
   Child under 8 – no questionnaire. Include questions in parent interview
8. Interview with parent
9. Parents complete TSQ (and answer questions on child if child under 8)
10. Ask for any relevant feedback. Explain timeline, e.g. for getting summary of research findings to parents. Answer any questions or concerns parents/child have
11. Thank parents for their help and support
Appendix 12a: Interview schedule

Children’s experience of paediatric intensive care
Interview schedule

Introductions & Settling

Thank child for letting me talk to them
Introducing myself
I’ll be asking some questions. If you don’t understand or you don’t want to answer, that’s ok. You can tell me if you want to stop, or ask me anything.

I’m going to ask some questions about you, and about when you were in hospital. I’ll also ask about what has happened since you came out. At the end I’ll also ask you if you have any suggestions for me, or if you have some suggestions for things I could change to make this interview or my research better.

I’m asking these things so we can try and help other children who might have to go into hospital

You are the expert, so I’m hoping to can tell me what it’s been like. What do you think about answering some questions? Is that ok with you? If yes get ch to sign assent form (parents will already have completed consent form prior to starting).

Interview

1. Can you tell me about yourself? (Depending on age of child, this may be done using puppet – e.g. ‘this is Freddie, he is in yr 2 and likes football. What can you tell him about yourself?)
   Prompts:
   • Age
   • School (year, friends, teachers, subjects, play time, clubs)
   • Extracurricular activities & Likes/dislikes
   • Any significant things that have happened (inc going into hosp, accidents, being ill)

2. Hospital experience
Tell me about what happened when you got ill/went into hospital
Prompts:
   • What do you remember about when you were in hospital?
   • When you were in the hospital, you were in the Paediatric intensive care unit. Do you remember that? What was that like?
   • What did you think then?
   • If you were telling another child about it, what would you say?
   If child looking anxious or worried about talking about it, check in with them what is it like to talk about it, does it ever make you sad/worried. How could I help you to tell me about it? Do you want to show me instead with these toys? (small-world figures with hospital bed, child, doctor, nurse, parents and other figures)
3. Experiences since hospitalisation (Film script)
This is a film script. I’d like you to draw a film that starts with your hospital experience and carries on until now. This will tell me about what your life has been like since you went into intensive care. Give support to child as necessary.

- Age dependant – Can you remember how long you were in hospital?
- Did you stay in the PICU all the time? Where did you go then after you left the PICU? Can you draw that?
- When did you come out of hospital? Tell me about that time. What happened next?
- After you came back – what happened then? (draw or write onto film strip during discussion if appropriate)
  - Prompts – home, getting better, seeing friends/other visitors, back to school, birthdays, Christmas,
  - What did you miss out on by being in hospital? Or being ill/recovering?

4. Feelings about the experience
- Younger children – using stickers
  I have some questions about your feelings. (show stickers) what feeling is this person showing (show happy, sad, worried, scared faces)
  - What times were you happy? What made you happy? (put happy face on strip)
  - When were you sad? What made you sad (put sad face on film strip)
  - When did you think about your time in hospital (mark on film strip) – how did you feel about this?
  - Were there times when you were worried/stressed/scared (chose word according to vocab of child)? Why did you feel like this?
  - Are you the same or different since your PICU admission?

- Older children
  I have some questions about what the last year has been like
  - Tell me about your thoughts and feelings about having been in hospital
  - How, if at all, have your thoughts and feelings changed over the last year?
  - Tell me how you learnt to handle your experience in PICU
  - What positive changes have occurred in your life since being in hospital?
  - What negative changes, if any, have occurred in your life since you were in hospital?
  - Tell me about what kind of person you are now. What most contributed to this change (or continuity)?
  - As you look back on the last year, are there any events that sand out in your mind? Could you describe (each one) it? How did this event effect you and how did you respond to it?
  - Who has been most helpful to you since leaving hospital? How has he/she been helpful?
  - What helps you manage your feelings about being ill/in PICU?
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- How often do you think about the time when you were in hospital?
  o Dreams, memories, thoughts (when are they around a lot?)
  o What do you think about these (use same feeling faces as earlier).
    What do you do when you get these?
  o What helps? What doesn’t help?

- Do you ever talk about it? What was that like? Did it help? If not why not?
  o With mum/dad/guardian
  o Siblings
  o Friends
  o Teachers
  o Other people

- What do you think are the most important ways to cope with being ill and being in hospital? How did you discover this?

- How has your experience of being in hospital affected who you are now?

5. If I asked mum or dad about when you were in hospital, what would they say? (use speech bubble post-it notes)
  o How did mum/dad/guardian feel when you were in hospital?
  o If I ask them how you feel about it now, what would they say?
    (use speech bubble post-it notes)

6. After having these experiences what advice would you give to another child who has to go into PICU?

7. Is there anything that you might not thought about before that has occurred to you during this interview? Is there anything else you think I should know to understand your experience better.

8. Do you have any questions for me? Is there anything you are worried about or not sure about? Do you have any feedback about this interview or how I could make it better?

9. Thanks for taking part. It was really helpful. If you think of anything else I’ll leave my contact details with mum/dad and you can get them to contact me.
Children’s experience of paediatric intensive care
Interview schedule

Interview with parents (after child interview)

- Firstly any questions for me, or comments, having seen the child interview (or if parents not present, any questions about what we did, what happened etc)
- Can you start by telling me what X was like before going into PICU
- Can you tell me about when X went into hospital
  - Prompts – what happened, injuries sustained, where were they taken first, when sedated, level of alertness at different times
- Tell me about your thoughts and feelings when X was in hospital
- Tell me how you handled that experience?
- How, if at all, have your thoughts and feelings about X’s admission changed in the last year?
- Looking back, what events in the past year stand out in your mind? Can you describe each one? How did this event affect how X has managed?
- Can you describe the most important lessons you’ve learned in the last year?
- What positive changes/negative changes have occurred in your life since X’s admission?
- What/who has been most and least help during this time?
- Tell me about the person X is now? What contributed to this change (or continuity)?
- How well do you think your child has changed and coped? (at different points since discharge) Why?
  - Consider child’s development across the year
  - Consider factors which have affected adjustment
  - Elicit parent’s theories about why their child has reacted in the way they have
  - Is your child upset by the experience? Why/why not?
  - Has your child changed since the experience? In what ways? Why?
  - Have they thought about the PICU (dreams, memories, thoughts)? How does this affect them?
  - What strategies have you tried to help them? Are they working?
- Show parents child’s filmscript
  - What was the child like at these significant events (which child noted already) e.g. what were they like going back to school
  - Ask parent to elaborate on significant points for them e.g. discharge, going back to school, holidays
  - Any significant events they didn’t talk about?
  - Can you fill in any gaps for us?

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- Any times when child showed a particular reaction (e.g. overly clingy, worried, seemed more positive etc)
  
- Can you tell me about X now
  - Compare to pre-admission, and since discharge.
  - Character changes?
  - Any new fears/worries
  - Strengths discovered
  - Things they value since admission

- How has the year been for you? Any strategies you’ve used? Have they worked?
- What have been the easiest and hardest times since discharge? Why?
- Is there any help you would have liked at the time or since?
- Is there anything that you might not have thought about before that occurred to you during this interview?
- Anything else that is important for me to know to understand yours and your child’s experience better?

- Any questions or comments for me?
- Thanks for your input
Appendix 12b: Adapted interview schedule

Children's experience of paediatric intensive care
Interview schedule

Interview with parents

If interviewing child first:

- Firstly any questions for me, or comments, having seen the child interview (or if parents not present, any questions about what we did, what happened etc)
- Show parents child's filmscript
  - What was the child like at these significant events (which child noted already) e.g. what were they like going back to school
  - Ask parent to elaborate on significant points for them e.g. discharge, going back to school, holidays
  - Any significant events they didn't talk about?
  - Can you fill in any gaps for us?
  - Any times when child showed a particular reaction (e.g. overly clingy, worried, seemed more positive etc)

Explain I'll be asking more about post-discharge than the actual PICU experience

- Can you start by telling me what X was like before going into PICU

- Can you tell me very briefly about X's admission – and the PICU part of the admission

- How were you affected by that experience at the time?

- After you came home from hospital what were your priorities?

- How did you cope when you came home from hospital?

- How did you expect X to recover
  - Physically
  - Emotionally
  - Psychologically
  - Socially

- How did you re-connect with life/people after the hospitalisation?

- How well do you think your child has changed and coped? (at different points since discharge) Why?
  - Consider child's development across the year
  - Consider factors which have affected adjustment
  - Elicit parent's theories about why their child has reacted in the way they have
Is your child upset by the experience? Why/why not?
Has your child changed since the experience? In what ways? Why?
How does this affect them?
What strategies have you tried to help them? Are they working?

Can you tell me about X now
- Compare to pre-admission, and since discharge.
- Character changes?
- Any new fears/worries
- Strengths discovered
- Things they value since admission

In what ways were you/your child resilient or not resilient

How, if at all, have your thoughts and feelings about X’s admission changed in the last year?
- How have you come to understand your PICU experiences with time?
- How do you feel about the PICU experience now? Has that changed over the year?
- Can you describe the most important lessons you’ve learned in the last year?
- What positive changes/negative changes have occurred in your life since X’s admission?

When you think about that experience now – what’s happening? What’s it like?

Are there any things you’ve noticed that you think were more unconscious (E.g. crying but not knowing why, doing something automatically)

Do you have a theory for how people recover after an experience like this?

How would you explain to other families what post-PICU experience might be like?

Is there anything that you might not have thought about before that occurred to you during this interview?

Anything else that is important for me to know to understand yours and your child’s experience better?

Any questions or comments for me?
- Thanks for your input
**Appendix 13: Demographics form**

**General information**

Please answer these general questions about yourself. Do not put your name on this form – all the data is anonymous. These details will be kept confidential.

*Please tick the appropriate boxes.* It would be helpful if you could answer all the questions, but you can choose to leave blank any question you do not wish to answer.

<table>
<thead>
<tr>
<th>ABOUT YOU</th>
<th>ABOUT YOUR CHILD</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender (of parent completing form)</td>
<td>Gender of your child</td>
</tr>
<tr>
<td>□ Female</td>
<td>□ Female</td>
</tr>
<tr>
<td>□ Male</td>
<td>□ Male</td>
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<table>
<thead>
<tr>
<th>Age (of parent)</th>
<th>Number of children in the family</th>
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<tbody>
<tr>
<td>□ 16-20</td>
<td>□ 1</td>
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<td>□ 20 - 24</td>
<td>□ 2</td>
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<td>□ 25 - 29</td>
<td>□ 3</td>
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<td>□ 30 - 34</td>
<td>□ 4</td>
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<td>□ 35 - 39</td>
<td>□ 5 or more</td>
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<td>□ 40 - 44</td>
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<td>□ 45 - 49</td>
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<td>□ 50 - 54</td>
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<tr>
<td>□ 55 and over</td>
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</table>

What is your occupation? __________________________

What is your child’s occupation? Now __________

At time of admission __________

What is your ethnic group? __________________________

What is your child’s ethnic group? White, Asian, Black, Other ethnic background (please specify) __________________________

What language would you usually talk at home with the family? English, Other (Please specify) __________

What is your child’s first language (i.e. the first language they heard spoken)? English, Other (Please specify) __________

Other (Please specify) __________
Appendix 14: Trauma screening measures

CHILDREN'S IMPACT OF EVENTS SCALE (IES)

Below is a list of comments made by people after stressful life events. Please check each item, indicating how frequently these comments were true for you during the past seven days. If they did not occur during that time, please tick the 'not at all' box.

1. I thought about it when I didn't mean to  
2. I tried to remove it from memory  
3. I had waves of strong feeling about it  
4. I stayed away from reminders of it  
5. I tried not to talk about it  
6. Pictures about it popped into my mind  
7. Other things kept making me think about it  
8. I tried not to think about it

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Please consider the following reactions which sometimes occur after a traumatic event. This questionnaire is concerned with your personal reactions to your child's admission to PICU. Please indicate (by circling 'yes' or 'no') whether or not you have experienced any of the following at least twice in the past week.

1. Upsetting thoughts or memories about the event that have come into your mind against your will
   Yes  No
2. Upsetting dreams about the event
   Yes  No
3. Acting or feeling as though the event were happening again
   Yes  No
4. Feeling upset by reminders of the event
   Yes  No
5. Bodily reactions (such as fast heartbeat, stomach churning, sweatiness, dizziness) when reminded of the event
   Yes  No
6. Difficulty falling or staying asleep
   Yes  No
7. Irritability or outbursts of anger
   Yes  No
8. Difficulty concentrating
   Yes  No
9. Heightened awareness of potential dangers to yourself and others
   Yes  No
10. Being jumpy or being startled at something unexpected
    Yes  No

Appendix 15: Reliability and Validity of Trauma screening measures

Trauma screening questionnaire (TSQ)

The TSQ is a brief screening instrument listing 10 symptoms of Post traumatic stress disorder (PTSD). The questions relate to re-experiencing or arousal symptoms which can follow a traumatic event. Participants are asked to circle yes/no to indicate whether they have experienced the symptom at least twice in the last week. 'yes' answers score one point, and 'no' answers score zero.

The criterion of any combination of six or more re-experiencing or arousal symptoms is required to suggest the presence of PTSD. Overall this measure was able to predict 92% of PTSD cases accurately (Brewin et al., 2002). In a study using victims of sexual assault, sensitivity (that positive cases are identified) and specificity (that negative cases were not identified) were found to be 0.85 and 0.89 respectively (Walters et al., 2007). The TSQ has also been validated against other measures, including the Davidson Trauma Scale and the Clinician Administered PTSD Scale and performed favourably. Further the TSQ meets the criteria for the UK national Screening Committee and could therefore be utilised in national trauma screening and treatment programs (Walters et al., 2007).

Child Impact of Events Scale (CRIES-8)

This study used the eight-item questionnaire which is the shortened version of the CRIES. The small number of questions and accessible language makes it more appealing to children and young people. Children are asked to rate symptoms over the past week on a four point scale: 'not at all', 'rarely', 'sometimes' or 'often'. Questions cover arousal, intrusion and avoidance symptoms.

It has been found if the cut-off is set at 17 then 90% of PTSD cases are classified correctly (Smith et al., 2003). Cronbach's alpha for this version of the scale is 0.75, which shows satisfactory internal consistency. In factor analysis two clear factors emerged, representing intrusion and avoidance (ibid). Finally this scale is robust cross-culturally and has been tested in a variety of trauma situations.
### Appendix 16: Example transcript

16/9/09 Interview 3

J (aged 15) and mum S

<table>
<thead>
<tr>
<th></th>
<th>E</th>
<th>[explaining context of research, getting forms signed, then started tape recording]...and then what happens is all of the information is anonymised. There will be no identifying details. Then I'll send you a copy before the report is finished so you can comment on it before it's finalised. Then you will get a copy of the finished report. Does that sound ok? So are you happy if I talk to mum first and then to you?</th>
<th>Context of the research</th>
</tr>
</thead>
<tbody>
<tr>
<td>7</td>
<td>J</td>
<td>Yeah, that's fine</td>
<td>Expressing consent</td>
</tr>
<tr>
<td>8</td>
<td>E</td>
<td>Ok. Can you start by telling me about J before she went in to hospital</td>
<td>Exploring previous personality</td>
</tr>
<tr>
<td>10</td>
<td>S</td>
<td>Um, typical teenager, v confident, v outgoing, lots of friends,</td>
<td>Typical as outgoing; valuing confidence; defining normality as outgoing</td>
</tr>
<tr>
<td>11</td>
<td>E</td>
<td>And then how long ago was it that she got ill</td>
<td>Ascertaining time since discharge</td>
</tr>
<tr>
<td>12</td>
<td>S</td>
<td>It was a year ago this month, in fact this week last year she'd have been coming out of hospital. A year ago. Pretty much on the anniversary</td>
<td>Recalling dates &amp; events accurately; Sense of passage of time; Significance of event</td>
</tr>
<tr>
<td>15</td>
<td>E</td>
<td>And can you remember how it started. How you first knew J wasn't very well</td>
<td>Exploring initial illness</td>
</tr>
<tr>
<td>17</td>
<td>S</td>
<td>We – it was one of those in at the deep end things. She'd not been well the night before, gone to bed with what we thought was a migraine, and really honestly, just migraine symptoms, um, but she was quite poorly and she'd gone to bed with paracetamol and the next morning we were um going to see friends and we were literally just ready to go out the door and I heard her call out and I went in to make sure she was alright, because we were just going to leave her there, we thought she's not very well, let her sleep in,</td>
<td>Overwhelmed by experience; 'drowning'; out of control; Beginning of narrative; Perceiving illness as normal - minimising symptoms; Measured concern; Continuing with normal life - before everything changed</td>
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Compare with 2 as also had a lucky escape - nearly missed illness

Increasing intensity and fear

Good sense of
Major Research Project (Appendices)

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<td>don't want to drag her round when she's not very well, um and I went in to see if she was ok and um she was mumbling and um I tried to talk to her, um tried to wake her and I couldn't wake her and um then I tried to wake her a bit more ferociously because I was getting a bit worried cos I couldn't wake her um and she wasn't waking up but she was still um like garbling I suppose. And um so I called her sister um to see if she could help me try and wake her up and um and she tried and she was picking her up and she wasn't being responsive at all, so we rang the GP call and asked the Doctors advice and they said can you get her into the car and bring her in for us to look at um because she might just have a fever or something and I said we'd give it a go and they said if not just call an ambulance. Well we um we tried to lift her up and she was a dead weight, just wasn't happening. By this time she wasn't talking at all so we were pretty panic mode um and my eldest daughter was crying, so we called an ambulance and um then my friend from round the corner cos we called her she used to be a nurse, we called her round as well in the meantime, and um she tried to wake J up. Well she woke but she didn't wake. She didn't open her eyes at all, but she was saying things but she couldn't recognise anybody and she was crying but there were no, you know, the, horrible like cry but I mean there were no tears or anything. And it was as though she was in pain. And she was getting quite violent. But she wasn't waking up. It, she was there but she wasn't there. It was a really hard thing to explain. And we were trying to wake her up and sit her up and she wasn't having any of it, and she got quite violent with it. Um I mean that was all explained to us later but at the time we didn't really know what was going on, I mean to be honest meningitis never entered our heads. But I knew there was something very wrong. And we called the ambulance, and because she'd been violent, we had to wait for the police to come um and they took their time and oh cos the</td>
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<td>26</td>
<td>Not recognising seriousness, still unaware</td>
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<td>27</td>
<td>Making allowances</td>
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<td>28</td>
<td>Being sensitive to illness</td>
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<td>29</td>
<td>Concern and allowances</td>
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<td>30</td>
<td>First signs of difficulties - alarm bells</td>
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<td>31</td>
<td>Trying to connect; attempting to gain reassurances</td>
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<td>32</td>
<td>Being ferocious</td>
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<td>33</td>
<td>Increasing concern</td>
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<td>Being 'not normal'</td>
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<td>Recruiting support - connecting with someone</td>
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<td>36</td>
<td>Repeating patterns</td>
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<td>37</td>
<td>Lacking responses - not able to move, not being normal</td>
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<td>38</td>
<td>Not connecting with seriousness</td>
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<td>39</td>
<td>Minimisation?</td>
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<td>40</td>
<td>Giving options</td>
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<td>41</td>
<td>Trying to access help</td>
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<td>42</td>
<td>Being unable to connect - unable to rouse</td>
</tr>
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<td>43</td>
<td>Decreasing consciousness, increasing anxiety; 'panic mode'</td>
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<td>44</td>
<td>Expressing distress</td>
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<td>45</td>
<td>Seeking further support</td>
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<td>46</td>
<td>Recruiting support</td>
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<td>47</td>
<td>Attempting to connect. Being unable to explain</td>
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<tr>
<td>48</td>
<td>Wanting help/cure/answers?</td>
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<td>49</td>
<td>Expressing distress, but not normal</td>
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<tr>
<td>50</td>
<td>Overwhelmed, out of control; experience of hearing that cry</td>
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ambulance men got her first didn’t they, and they’d tried to get her out and she wasn’t being very cooperative, but she wasn’t awake. I be honest the ambulance men who attended here, one of them was lovely, her was very nice. One of them was an absolute pig. He walked in, he saw J’s lip ring and just assumed it was a drug overdose. Four times and if you can imagine I was in absolute panic mode I knew she was ill. Four times that man asked me if there was any way she’d taken any drugs. And he was told point blank no. And he still continued to ask and um I nearly lost it with him at one point because they just weren’t being helpful and it really didn’t look like he was taking it seriously. We all knew she was really ill and they just, even just filling the forms out – so slowly and I was getting more and more frustrated my friend that had come round from round the corner, J had bitten her, they wanted to wait for the police because they thought she was a risk – which ok, fair enough, but still very frustrating because I’ve got a really sick child and the police...I felt like I was banging my head against a wall because I really felt they weren’t taking it seriously, um and he’d got it in his head that’s what it was, he’d made his decisions and you know he was just even the way he looked at us as if we were lying to him, and it was quite upsetting but everything was just, everything was taking too long and I was getting more and more frustrated because she needed hospital attention. And um you assume that they would have known basics, but because I mean we were told later that the aggression is part of the illness and um, it just, oh, oh, I was so angry, my friend from round the corner was so angry, she said that they acted...it was disgusting. And um, the police asked her even asked her if she wanted to press charges and she said don’t be so stupid it’s a sick child. And then when they went to take her down the stairs she just got up and went. And for whatever reason something had changed, and she just, they managed to take her down the stairs. Um and they took her to FP

Communicating at a primal level
Struggling to explain
Lack of vocab - such a unique situation
Different to anything ever experienced
Making sense of experience post-event; using
Hindsight to reflect (reprocessing with this?)
Not knowing; Guilt - lack of awareness
Recognition of seriousness; acknowledgement
of level of fear
Shame? Waiting in the middle of such
distress
Frustration - lack of recognition of the
seriousness/urgency
Inaction
Being uncooperative; giving
reasons/explanations
Making judgements
Noticing diversity; Lacking
support/understanding
making judgements/assumptions
strength of panic - absolute
seeking clarity or wanting a difference
answer - not shared - not being heard or
listened to; lack of congruency/connection
not coping - being out of control -
frustration/anger; Difference of opinion
feeling unsupported/un-helped by helping
profession
unable to express seriousness - out of control
recognition of need
out of control; increasing level of concern

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<th>Page</th>
<th>Text</th>
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<tbody>
<tr>
<td>89</td>
<td>(local hospital) and um when we got there she was given some a really really high doses of antibiotics and she was taken to them, oh I can’t remember which bit it was, the resuscitation area um I mean she was properly out of it by the time we’d got to the hospital. She looked as if she was in a coma and there was nothing. And ur I don’t know, it seemed like we were there forever. We weren’t they actually worked quite quickly and then they said that there might be a possibility that it was meningitis and they needed to transfer her um somewhere else, that could deal with it properly um and they moved her to another room whilst waiting and so they’d given her a high dose of antibiotics, they had her on a load of tubes and things. And then I think within a couple of hours she was being transferred to [hospital].</td>
</tr>
<tr>
<td>90</td>
<td>overwhelmed – no voice – no power not being taking seriously; no control Position of power/agency – ability to act being judged disbelief – narrative not validated Frustration and inertia increasing frustration; awareness of need Lack of knowledge Constructing narrative after the event Angry, without avenue to express Being disgusted; questioning professionalism Differing agendas Trying to focus on difficulties Changing presentation – lack of understanding, no model for this; unclear of reasons finally movement occurs treatment finally starting decreasing awareness; illness severity increasing no consciousness – fear/anxiety; like death? Distorted sense of time Changing pace – different experience from above Getting a diagnosis – assimilating information Taking it seriously Continual waiting: taking responsibility Pace: speed – out of control, but at least being taken seriously</td>
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</table>
| 102 | E | Did that happen by ambulance again? | Increasing medicalisation  
Speed of work - time changing |
| 103 | S | Yes, We, um her father went with her and we took our car and went down cos we’d come back here first and got some bits and pieces and she went into an intensive care unit | Sharing responsibilities - Level of planning  
Able to think despite experiences  
Being admitted |
| 104 | S |  |  |
| 105 | S |  |  |
| 106 | E | So straight into IC when she got to St G’s? | Exploring admission  
Being separated/isolated  
Unable to remember details - overwhelmed?  
Too much to take in? |
| 107 | S | Yes, she was in an isolation unit – one to the side um for I can’t remember how long, at least two days, I can’t remember to be honest |  |
| 108 | S |  |  |
| 109 | S |  |  |
| 110 | J | I think it was 4. | Sharing in building of narrative |
| 111 | S | It was quite a while in that side room and they said that before they could clarify they needed to do a lumbar puncher and things and I couldn’t be in there with her with that bit | Further waiting - but contained  
Needing space - carrying out procedures  
Separated - but relief at pressure being removed |
| 112 | S |  |  |
| 113 | S |  |  |
| 114 | E | What was it like being on IC for you? |  |
| 115 | S | Scary. But when she was in the isolation ward she wasn’t left, not for one second. There was a nurse in there at every moment with her. Um which I thought was brilliant, because if I needed to go to the toilet or anything I didn’t worry about leaving her. Because we, I just left my older daughter her. And myself and my partner just went down there and didn’t leave her really. And um it was really really scary but it’s quite surreal but they were absolutely brilliant, um and then the and then the diagnosed her with meningitis, bacterial meningitis, um and she was extremely lucky um and they pumped her fully of antibiotics for a few days and she was kept sedated while it worked and tried to work and um it was one of those where you just don’t know and we have to take each moment as it comes um and pray a lot really | Fear, but reassured by IC - contained  
Constant pressure, but staff support  
Feeling reassured and contained  
Feeling safe/secure  
Family presence - continual containment for  
Not leaving - being presented  
Fear, but unable to process at time; valuing staff  
Receiving diagnosis  
Feeling ‘lucky’; fate? Treatment access?  
Being treated - action happening; working hard ‘pumped full’ |

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<th>Page</th>
<th>Code</th>
<th>Quote</th>
<th>Themes</th>
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<tbody>
<tr>
<td>128 E</td>
<td><strong>Did you think she was going to die?</strong></td>
<td>Not knowing - moving slowly, taking each moment&lt;br&gt;Unable to consider future; accessing faith</td>
<td></td>
</tr>
<tr>
<td>129 S</td>
<td>Yeah, yeah. And um it just this helplessness, it's horrible. And I can't fault the care that she got. They were absolutely brilliant, and the moment they knew it was meningitis we were all arranged treatment and the baby was only a few weeks old then and he hadn't even had his injections yet, so we were all like oh my god and you panic about everything else</td>
<td>Helplessness; out of control&lt;br&gt;Confidence in care provided&lt;br&gt;Immediacy of response&lt;br&gt;Multiple stressors - increased sense of panic&lt;br&gt;Vulnerability&lt;br&gt;Fear of repetition of experience, panic, emotional response</td>
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<td>135 E</td>
<td><strong>So it had like a knock-on effect on your whole family</strong></td>
<td>Reflecting on waves of influences&lt;br&gt;Enormity of potential effect; feeling responsible&lt;br&gt;Interruption of normal teenage activities&lt;br&gt;Comparing before illness and since - different lives&lt;br&gt;Enormity of task - huge burden&lt;br&gt;Warning others,&lt;br&gt;Being traumatised; not knowing&lt;br&gt;Wishing wanting to erase; highlighting awfulness&lt;br&gt;Importance of being present - feeling connected&lt;br&gt;No limitations; being allowed to stay (shift of power here)&lt;br&gt;Needing to make other plans&lt;br&gt;Being considered - being held in mind by others&lt;br&gt;Potential for further illness - increased fear&lt;br&gt;Not knowing - running out of vocab to</td>
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<tr>
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<td>done. They did say that because the quick response was so vital, but we’d managed to catch it so quickly, I think that’s what infuriated me more with the ambulance men because then when you’re sat being told you caught it so quickly and you’re sat there thinking, they’d had been, if we hadn’t caught it that quickly and relied on the ambulance man to do their job more efficiently, we’d have lost her. Because the time that they took and their attitude just...</td>
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<tr>
<td>157</td>
<td>express</td>
</tr>
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<td>158</td>
<td>Being terrified</td>
</tr>
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<td>159</td>
<td>Fearing death</td>
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<td>159</td>
<td>Physical changes</td>
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<td>160</td>
<td>Changing as a result of the illness</td>
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<td>Becoming someone different</td>
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<td>Reduction in treatment</td>
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<td>163</td>
<td>Being tested - key marker - unsure of outcome</td>
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<td>164</td>
<td>Receiving information - becoming aware, knowing stakes</td>
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<td>164</td>
<td>Relief at response</td>
</tr>
<tr>
<td>165</td>
<td>Being infuriated - now knowing possible implications</td>
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<td>165</td>
<td>Considering information</td>
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<td>165</td>
<td>Knowing other outcomes</td>
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<td>165</td>
<td>Relying on others - being let down; inappropriate response</td>
</tr>
<tr>
<td>165</td>
<td>Facing possibility of death</td>
</tr>
<tr>
<td>166</td>
<td>So I wonder if when you look back now there’s even more frustration than at the time?</td>
</tr>
<tr>
<td>166</td>
<td>Exploring hindsight and reflecting</td>
</tr>
<tr>
<td>167</td>
<td>Absolutely, yeah, every time I think about it it just annoys the hell out of me to be honest, because if I’d of lost my daughter over somebody’s ignorance or their being pre-judgemental um and there would have been nothing we could have done about it, but he just took one look of her, see the piercing thought teenager, looked at her and you know they shouldn’t be able to judge. You know an illness is an illness, they asked, we told them, maybe ask us twice, but it was just yeah four times and it...</td>
</tr>
<tr>
<td>168</td>
<td>Continuing emotional arousal</td>
</tr>
<tr>
<td>169</td>
<td>Considering scenarios which didn’t occur</td>
</tr>
<tr>
<td>169</td>
<td>Fear for what might; judging others by being judged</td>
</tr>
<tr>
<td>170</td>
<td>Impotence - overwhelming</td>
</tr>
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<td>171</td>
<td>Being judged - rub off on family through insinuation</td>
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<td>172</td>
<td>Unfairness - sense of righteousness</td>
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<td>173</td>
<td>Using hindsight to judge</td>
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<td>Disbelief - repetition of insults - no movement</td>
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<th>E</th>
<th>When you were already so distressed already</th>
<th>Reflecting on distress</th>
</tr>
</thead>
<tbody>
<tr>
<td>175</td>
<td>S</td>
<td>It really was, I mean I've got my older daughter crying her eyes out, I've got little ones screaming and crying - and as a parent if you can't help your child it's so frustrating and you expect somebody else to do it and just you know. Paperwork could have been done in the van, don't sit there at the time we didn't know that but she was dying and oh, it's just...</td>
<td>Multiple family distress - attempting to meet all needs</td>
</tr>
<tr>
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<td></td>
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<td>Collective distress: role of parent</td>
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<tr>
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<td></td>
<td>Expecting help/support</td>
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<tr>
<td>178</td>
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<td></td>
<td>Devolving of parental role</td>
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<td>179</td>
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<td>Later awareness - increased sense of outrage</td>
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<td>180</td>
<td></td>
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<td>Not knowing but intense fear - lack of control</td>
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<tr>
<td>181</td>
<td>E</td>
<td>I can see how frustrated you are</td>
<td>Reflecting on experience</td>
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<tr>
<td>182</td>
<td>S</td>
<td>I don't have the words. It angers me way too much. And me and my friend tried to put in a complaint because as far as we were concerned it warranted something being done – you can't have that job and um assess a situation if you're not qualified to assess that situation. Um but pah, nothing, they weren't really interested.</td>
<td>No words - intense frustration - lack of vocab to express</td>
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<td>183</td>
<td></td>
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<td>Complaining - attempting to be heard</td>
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<td>184</td>
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<td></td>
<td>Wanting action, wanting validation of perspective, seeking power redress; identifying inadequacy - needs not met</td>
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<td>185</td>
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<td>Not being heard (again)</td>
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<td>186</td>
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<td>187</td>
<td>E</td>
<td>Which seems a bit unjust for you</td>
<td>Exploring injustice</td>
</tr>
<tr>
<td>188</td>
<td>S</td>
<td>Yeah because I'm still angry about it, but if there's nothing you can do there's nothing you can do. It just worries me that somebody else might lose their child.</td>
<td>Feeling defeated/impotent</td>
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<td>189</td>
<td></td>
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<td>Fear for others</td>
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<td>190</td>
<td></td>
<td></td>
<td>Knowing worst case</td>
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<tr>
<td>191</td>
<td>E</td>
<td>And tell me about when you were in IC – I was wondering about that lack of control, because lots of parents talk about the doctors making all the decisions- what was that like for you and your partner</td>
<td>Exploring lack of control</td>
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<td>192</td>
<td></td>
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<td>Relating to experiences of others</td>
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<td>193</td>
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<td>194</td>
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<tr>
<td>195</td>
<td>S</td>
<td>To be honest although you feel very useless to know that somebody else is dealing with it, like when we were in our side room and you knew there was a nurse there constantly, it relieves some of the pressure because I can go to the toilet I can go and get a drink of water and I don't have to worry about leaving her because I know she's monitored. And they didn't, not for a second,</td>
<td>Feeling useless - loss of parental role</td>
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<td>196</td>
<td></td>
<td></td>
<td>Devolving parental responsibility</td>
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<td>197</td>
<td></td>
<td></td>
<td>Being contained by staff - but also not been needed</td>
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<td>198</td>
<td></td>
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<td>Feeling relieved</td>
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<td>199</td>
<td></td>
<td></td>
<td>Reducing worry</td>
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<td>200</td>
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273
| 201 | when one wanted to leave, one came in first and then they left. |
| 202 | Um and then when we went into the other ward when they were |
| 203 | taking her off the medication to wake her um, it is frustrating but I |
| 204 | think you just have to stand back and think they are trained, that’s |
| 205 | they’re the ones with the knowledge, they have to do what they |
| 206 | have to do |

| 207 | Sounds like you trusted them quite a lot |

| 208 | I think you have to. You’ve got no choice really, because you don’t |
| 209 | have any knowledge there’s nothing you can do, so it’s all that you |
| 210 | can do to just stay there really. It’s one of those things where you |
| 211 | are scared to leave in case something happens, but I mean even |
| 212 | you know with other kids and that at home we wouldn’t have left |
| 213 | her. Not for a minute if she’d been at FP let alone all that distance. |
| 214 | Um, but yeah, I think you just have to I don’t know they made me |
| 215 | feel confident about letting them get on with it., you know we |
| 216 | were informed about everything, if we asked a question um we |
| 217 | were explained it so that we understood um and there was always |
| 218 | a nurse or somebody on hand to you know there were a few points |
| 219 | when she was getting really quite hot again and I was thinking oh |
| 220 | god oh god oh god and they were saying you know she’s got |
| 221 | paracetamol and you get a bit frustrated and think is that all you |
| 222 | can do? And you just have to try and keep it under control and |
| 223 | think you know at the back of your mind they know what they’re |
| 224 | doing, they know what they’re doing, but um, yeah and then there |
| 225 | was that scary period where you are waking for them to wake up |
| 226 | and J took longer than most to wake up and that was even scarier, |
| 227 | because we were like – usually you know within this time span and |
| 228 | she’s way over this bit and my god – is she going to wake up? And |
| 229 | then how much damage is there um and she still not looking like J |
| 230 | and it’s all really quite traumatic |

| Trusting staff and procedures |
| Valuing level of support |
| Changing location/treatment |
| Standing back - no control - reticence to relinquish control |
| Not having knowledge; having to rely on others |

| Parenting role - identity |

| 207 | Exploring trust |

<p>| 208 | Lack of choice/control - impotence, but contained |
| 209 | Not knowing - therefore not being able to act |
| 210 | Only intervention is presence (and does she even know?) |
| 211 | Fear of deterioration; the unknown |
| 212 | Prioritising] - greater needs |
| 213 | Needing proximity |
| 214 | Lack of choice or agency |
| 215 | Feeling confident - trusting staff |
| 216 | Valuing being informed - increase knowledge |
| 217 | increases sense of control |
| 218 | Constant support - to J and mum |
| 219 | Ongoing concerns - not over despite interventions, |
| 220 | Intense fear - overwhelming |
| 221 | Wanting more (magic wand) - never enough |
| 222 | Trying to stay calm, struggling with feelings |
| 223 | Trying to convince self -wanting safety |
| 224 | Discontinuous memories - still processing story |
| 225 | Fear for the future |</p>
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<tbody>
<tr>
<td>231</td>
<td>E</td>
<td>And did they do that waking her up on IC</td>
<td>Being different to norm - inducing more fear</td>
</tr>
<tr>
<td>232</td>
<td>S</td>
<td>She was on the IC unit, but in the main bit. Yeah</td>
<td>Having knowledge - not always helpful</td>
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<td></td>
<td></td>
<td></td>
<td>Fearing the worst</td>
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<td></td>
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<td>Facing the unknown</td>
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<td></td>
<td></td>
<td></td>
<td>Being traumatised - feeling overwhelmed</td>
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<tr>
<td>233</td>
<td>E</td>
<td>What was that like, moving from your own room into the main bit because you’re a bit in the thick of it on the main ward</td>
<td>Noticing locations - importance of positioning</td>
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<tr>
<td>234</td>
<td></td>
<td></td>
<td>Exploring meaning of moving</td>
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<tr>
<td>235 236 237 238 239 240 241 242 243 244</td>
<td>S 22. 35</td>
<td>Well it was a bit strange but and although when you’ve got your own room it’s quite nice and you’ve got the constant care there, one on one, so it’s a bit daunting to then go to a whole room with...we think god there’s quite a lot of children needing care and we’re down to just a few nurses or doctors. That’s a bit scary, but I was trying to see it as a step forward – because we went from her not needing 24 1 on 1 to being in this bit, so I was trying to look at it that way, as being a step up, um...and then um when she did come round it was quite traumatic, very emotional for everybody (cries)...</td>
<td>Mixed emotions around move</td>
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<td>Being reassured by constant care</td>
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<td>Feeling daunted (refer memory code in t1)</td>
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<td>Recognition of care needs - realisation of needs</td>
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<td>Fear of others needing care more? Not wanting to share?</td>
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<td>Reduction in support</td>
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<td>Trying to be positive - coping strategy to spin positively</td>
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<td>Recognising progress</td>
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<td>Regaining consciousness - significant and traumatic event</td>
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<td>Distress - overwhelmed - ongoing reminders</td>
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<tr>
<td>245 246</td>
<td>E 247 248 249</td>
<td>Particularly as you’d been waiting for so long – longer than you thought you were going to have to wait...</td>
<td>Reflecting need to wait</td>
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<td>Accepting reassurance</td>
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<td>Recognising individual differences</td>
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<td>Reflecting on individuality – but still fear</td>
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<thead>
<tr>
<th>Line</th>
<th>Character</th>
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<tr>
<td>250</td>
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<td>They were just all so good, and then um, we were down there for a while, I don’t know how many days we were in there, and then she was sent up to um upstairs to the children’s ward and um some of the nurses in there were absolutely fantastic, they were so good with her and that’s where she done her recovery really, um she had an eye patch for a while and her face took quite a long time to go down but um she wasn’t allowed out of bed for a little while and then again it was just rehabilitation, just little bits you know they were trying to build it up for her really, um, she couldn’t remember anything um after being ill until she woke up, so (cries)</td>
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<td>260</td>
<td>E</td>
<td>Yeah – it’ll be interesting to hear what you tell me</td>
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<td>261</td>
<td>S</td>
<td>Strange. Yeah. It’s got a little twist to her story haven’t you.</td>
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<tr>
<td>262</td>
<td>J</td>
<td>Yeah</td>
</tr>
<tr>
<td>263</td>
<td>S</td>
<td>My mum died five years ago, and J swears that she saw my mum and my mum told her to go with these people because they were going to make her better (cries), which is, it’s a bit weird because when she told us we already knew that her attitude and everything about her, the aggressiveness and everything just stopped and she just cooperated, um so we already knew that and when she told us that I was like ooh, that’s a bit spooky. But um yeah she did quite a, I think the problem was she knew she’d been ill, but for a long long time she didn’t really understand how ill she’d been and how close we were to losing her. So um I think a lot of it...</td>
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<tr>
<td>273</td>
<td>E</td>
<td>It’s hard to get your head around</td>
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<td>274</td>
<td>S</td>
<td>I think a lot of it, it did take her a very long time and she had quite a lot of time off school, um lucky enough um the school were absolutely brilliant, very very supportive through the illness and afterwards weren’t they?</td>
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<td></td>
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<td>that there was a problem;</td>
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<td>Lack of sense of time</td>
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<td>Moving - progress</td>
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<td>Valuing staff</td>
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<td>‘doing recovery’</td>
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<td>Slow changes, returning to normal</td>
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<td>Being restricted</td>
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<td>Slow rehab</td>
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<td>Supporting recovery</td>
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<td>Memory gaps - not remembering</td>
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<td>Family histories</td>
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<td>Unusual/spiritual experience</td>
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<td>Evoking emotion</td>
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<td>Constructing the story</td>
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<td>Connecting two narratives</td>
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<td>Noticing changes in behaviour</td>
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<td>‘spookyness’ in story</td>
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<td></td>
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<td>Not knowing – lack of awareness</td>
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<td>Not understanding</td>
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<td>Highlighting seriousness - no awareness</td>
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<td>Highlighting complexity</td>
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<td>Length of recovery (here recovery constructed as longer)</td>
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<td>Time off - not being normal for a while - ongoing impact of serious illness</td>
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<td>Feeling supported by school</td>
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<td>Needing support</td>
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<td>278</td>
<td>E</td>
<td>So tell me about that year, after that all happened – tell me about what have been the key points do you think that have happened in the year since?</td>
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<tr>
<td>279</td>
<td></td>
<td>School was definitely one of them, because she’d missed so much time, but she was a different person afterwards, um didn’t hardly go anywhere, turned into a bit of a recluse at one point, wasn’t socialising. In herself um she wasn’t half as confident or anything. Um she went through a whole phase of comfort eating, put on a load of weight, just I don’t know, I think whether that was a way of coping. I don’t really know what went on in her head, but she changed a lot. And dealing with trying to catch up at school and she went from being a very intelligent child to you know, even the simplest things she didn’t seem to understand. Um (deep sigh) so it was it’s taken a long time for her to and it’s only really been the last few months or so that she has actually started getting back out and socialising and mixing you know with groups of friends and stuff. And the school work is only just getting up together, um because she kind of lost interest in everything um so it has taken her literally a whole year to actually get to a point where you can say she’s anything at all like what she was but she’s nearly there. I mean but it’s been a long hard struggle um and without the school being as good as what they were um, I’m not sure we could have coped to be honest, because of all the time she had off. Bit of a nightmare wasn’t it.</td>
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<td>280</td>
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<tr>
<td>281</td>
<td>S</td>
<td>Note no reflection of cognitive effects of meningitis in long/short term - it seems they have little understanding of this</td>
</tr>
<tr>
<td>282</td>
<td></td>
<td>Stuff here about wanting to get back to how life was before - no comments about seeing permanent change</td>
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<td>283</td>
<td></td>
<td>Able to emotionally connect with what experience was like</td>
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<tr>
<td>302</td>
<td>E</td>
<td>So there was school and the socialising. Anything else that was key</td>
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<table>
<thead>
<tr>
<th>Page</th>
<th>In this year?</th>
<th>Aspects of recovery</th>
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<tbody>
<tr>
<td>303</td>
<td>Um, don’t think so. I think just in herself she it took her a long time to realise, I think to accept what had happened and to get her head around it and to deal with it and to move on, um which she had to do, um and I think for quite a while to start with um it was pushed away and ignored, because if you ignore it, it didn’t happen. You know. So um yeah, it’s taken her a long time.</td>
<td>Needing to accept what had happened integrating story into experience Taking time to process Coping as then coming to terms with it - starts with denial Defences - repression/avoidance Lengths of holistic recovery - psychological, social, physical</td>
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<tr>
<td>310</td>
<td>And tell me about – do you think there are lessons you’ve learnt from this year? I don’t know if lessons is the right word, but things that have come out</td>
<td>Exploring lessons from recovery period</td>
</tr>
<tr>
<td>311</td>
<td>I don’t know really. We’re quite a strong family unit and we all pulled together when it happens and we’ve had to all pull together since it happened, um I don’t honestly know how anybody would have coped if they had to do all of that on their own. I can’t imagine that. Um so, I don’t know, um I mean I am eternally grateful to the hospital. As far as I’m concerned they acted really fast. A couple of the nurses won J’s heart didn’t they? And I thought they were absolutely brilliant and you know if it hadn’t been for them you know I wouldn’t have her</td>
<td>Defining family role/make up valuing family support Reflecting on coping Admiration for others (but not wanting that position) Emphasising speed of response (key factors as slowness of paramedic) Affection for staff Valuing staff intervention Absorbing power to staff</td>
</tr>
<tr>
<td>322</td>
<td>It sounds like maybe you’ve learnt something – I mean I guess all parents know this anyway, but about your kids and how important they are?</td>
<td>Reflecting on learning around valuing family</td>
</tr>
<tr>
<td>325</td>
<td>Yeah I think, um until something you can say my kids are really important and that, but until something absolutely you know shocking that gives you this G-force action into realisation um of how easy it is to lose them, um I don’t think you really understand, so yeah definitely.</td>
<td>Valuing children Power of experiencing - shifting attitudes Being shocked into realisation Awareness of fragility of life Definite agreement</td>
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<td>330</td>
<td>Ok – and you’ve mentioned about J changing and I wonder if you</td>
<td>Exploring changes around illness</td>
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<td>Text</td>
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<td>331</td>
<td>can tell me what J’s like now and if that’s any different to what she was like before this happened</td>
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<td>333</td>
<td>S It’s different, but she’s definitely more of her old self than she was the first 8 months or so, um she lost herself totally for a while. I mean she started smoking, like a said she gained a lot of weight, um it was all I don’t know whether it was dealing mechanisms or what but she changed a lot um like I said she wasn’t kind of socialising. The friends that she was socialising with, it was just always arguments, always ending in tears, rows over stupid — I mean I know teenagers do that anyway, but way more intense than it should have been and she’s finally getting back to where she was, you know, she’s got her group of friends back and she’s socialising more and she’s concentrating on her last year at school, um you know we’re definitely nearly there,</td>
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<td>345</td>
<td>E And what do you think has helped to make that change? How do you think that’s happened</td>
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<td>347</td>
<td>S I don’t know really. A lot of bullying from me, but I think most of it she’s had to do by herself. She knows were here, but some things just you have to deal with yourself, there’s certain things you have to go through and you have to experience and they’re things that you can only do for yourself and no matter how much you want to help somebody if they don’t want to be helped you can’t help them. They’ve gotta want to help themselves, so you’ve got to wait until they are ready for that help</td>
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<tr>
<td>355</td>
<td>E What was that like for you doing that waiting?</td>
<td></td>
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<tr>
<td>361</td>
<td>S Frustrating. But um (deep sigh) I don’t know, apart from wanting to have them all adopted. No it is very very frustrating, but also um, I think losing my mum helped me realise If I hadn’t have done then I might not have understood as much what she was going through, um but I also knew that she needed the space to do or not to do what it was so that she could go through what she needed to so</td>
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| 362 | she could get her head straight and things. Get back on track. Um, and you know realise that she's got a future and you know, she can do what she wants. So... | Going through experience alone  
Getting your head straight/getting back on track  
Recognising future - relies on knowing past |
| 363 |  | Exploring difficult times |
| 364 |  | |
| 365 | E | What have been the hardest times of this year since discharge? |
| Recognising that life changed as a result of the experience | 366 | S | (Deep sigh). The first few months after discharge were absolutely chaotic, because of all the time off school. Because when something like this happens you kind of have to drop your whole life and then you have to be somewhere else, and that's your life until it's finished and then you have to come and deal with all the aftermath, what you've left behind, you know everything that's gone wrong or whatever and I think you spend I'm not as bad now, but I don't know about the rest of the parents, but paranoid. Oh my god. The tiniest little headache, sneeze, cough, you haven't a hernia every time. It's really is just so ummm (big in-breath) you don't want to breath just in case |
| 367 |  | Being in chaos - feeling out of control  
Not doing 'normal' activities  
Life changing  
Dealing with aftermath - trying to manage life  
Dealing with what you left behind  
Fear changing with time  
Being paranoid  
Fearing more illness  
Being hyper-vigilant  
Fear at each detail  
Not wanting to breathe - intense fear of things going wrong |
| 368 |  | |
| 369 |  | |
| 370 |  | |
| 371 |  | |
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| 373 |  | |
| 374 |  | |
| 375 |  | |
| 376 |  | |
| 377 | E | Yeah – I hear that a lot actually. |
| Coping immediately after herp was to wrap in cotton wool | 378 | S | Really? I mean I was terrible, really terrible, I wanted to wrap her up in bubble wrap for 6 months and that took me a long time to go ok J you can walk to your friends, instead of me driving you there and picking you up and knowing exactly where you are every second of your life. I'm still a little bit like that but much better now. But to start with, I (deep sigh) I was terrible wasn't I? |
| 379 |  | Feeling terrible - feeling out of control  
Judging self?  
Taking time to change - trying to prevent same thing again  
Wanting to protect  
Wanting to be in control  
Improving with time  
Recognising ongoing worries |
| 380 |  | |
| 381 |  | |
| 382 |  | |
| 383 |  | |
| 384 | J | Yup |
| Sense of the overwhelmingness of the experience | 385 | S | And if anybody was sick near her – oh god help them. Just... and it had a knock on effect with all the kids and I found myself analysing them- every little thing, just a little cough or whatever. Um I think |
| 386 |  | Fearing infection - hyper vigilance  
Anxiety affecting family life  
Being hypersensitive |
| 387 |  | |
| processing story in social settings | 388 | just because she didn’t even have very obvious where people say oh my god how do you know? I don’t know is all I can say, is that we were extremely lucky. You know and there’s not a day goes past when we were and I wouldn’t have a clue – but she didn’t have those, our family suffer with migraines. That’s what we thought she had, um so yeah, that was a scary old one | Hidden symptoms/illness
Not knowing - out of control
Feeling lucky/relieved
Fearing not knowing - reflecting on story
Justifying initial reactions
Ongoing fear/anxiety |
| Gngoing processing of what happened | 389 | 390 | 391 | 392 | 393 | And how about the good things that have happened this year, or the best times or the easiest times? | Exploring positive events |
| New experience bit more processed they can make plans for the future - e.g. for holidays | 394 | E | 395 | | | | |
| Returning to normality | 396 | S | There haven’t been any easy times here, because we are only just getting to a point where she’s…there’s a few bits of work outstanding um so but we have a holiday to look forward to in a few weeks. Yeah, my um my mother-in law are taking the two medium ones, so we’ve only got the baby, and me, X and her older sister, we thought oh – perfect chance – we’ve only got the baby, let’s do it. Well deserved holiday for everybody. And this will be the first time since J was sick. | ‘only just’ length of recovery - difficult recovery time
Slow recovery
Trying to get back to normal - taking time
Looking forward to future
Making plans
Taking opportunities
Needing a break
Marker of events being normal again |
| | 397 | 398 | 399 | 400 | 401 | 402 | 403 | And if you were going to give advice to other parents who are maybe going through the same experience or the year after – what kind of things would you say to them – first about when you were on ICU? | Exploring advice to others – seeking ideas about recovery in PICU |
| | 404 | E | 405 | 406 | 407 | | |
| | 408 | S | I think you just you have to trust the doctors, you have to just step back and let them do their job, because no matter how hard it is for you they can’t do their job if you’re in their face and I suppose I know how hard it is to step back it is very very hard but you really have to, um and what will be will be because they’re going to do everything they possibly can and I suppose that’s the most anybody can do. So… | Not being in control - giving power to others
Letting go
Needing to keep distance (but difficult)
Finding it hard - not wanting to step back - impotence
Leaving it to fate and control of staff
Resigning self to reality lack of control |
| | 409 | 410 | 411 | 412 | 413 | 414 | | |
| | 415 | E | 416 | 417 | | Sounds like good advice, and how about if a child’s had an ICU admission in the year afterwards, what advice would you give then? | Emphasising post-discharge aspect of recovery |

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| 418  | S  | That’s a hard one. I think keep the family unit strong um because you know where your blaming each other or whatever and you know anything is going on and little ones not mending the way the way that you thought they are going to, or they are changing or whatever you just have to stay strong, as a family um, because that’s the only way that you can get though it I think to be honest, as I say I wouldn’t have wanted to have done that on my own. And then you can all support each other, which I think is the only way round it. | Valuing ‘strong family’ Blaming each other - reflective on process Not mending - concern for others Identifying changes in family ‘hanging in there’ Lack of alternatives Needing others, needing support Looking for options for coping |
| 427  | E  | Ok that’s the end of my questions, but is there anything I haven’t asked that might be important to know about your experiences? | Exploring further topics |
| 429  | S  | I don’t think so. |
| 430  | E  | Do you have any questions for me? |
| 431  | S  | Not really. Um, I think it’s a shame we don’t get to thank the hospital in some way, you know more than just a card or whatever because there is so much appreciation or whatever | Wanting to show appreciation Feeling a card is not enough Feeling very grateful |
| 434  | E  | Well they will get a copy of this so they will know what’s being said about them |
| 436  | S  | Well that’s good |
| 437  | E  | Well if you think of anything else my email address is on the bottom here, or there are phone numbers so you can contact me and let me know |
| 440  | S  | Ok, thank you |
| 441  | E  | Thank you so much for letting me interview you |
| 442  | S  | That’s ok. I’ll leave you to it. |
| 443  | E  | You ready? (to J) |
| 444  | E  | What was it like listening to mum talk about your experiences? |
| 445  | E  | Exploring experience of hearing another’s story (but about you) |
| 446  | J  | It’s a bit weird because I don’t remember much from, I remember a day before the day I was sick and before I went in, into this panic mode when mum was saying everything, with the paramedics |
| 447  | J  | Not remembering – disconnection |
| 448  | J  | Attempting to describe experience |
| 449  | J  | Narrative from mum |

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<p>| 449-455 | Ok, so it’s been helpful to hear other people’s stories? | Exploring processing with others’ stories |
| 456-460 | Yeah, | Exploring memory |
| 457-460 | So tell me about what you do remember then | Exploring memory |
| 459-461 | Um, on the Thursday it was just a normal day and then on the Friday I dyed my hair and went to see my friends in town | Ore-event normality; nothing out of the ordinary |
| 461-466 | So was this in August this happened? | Recalling dates - accuracy of some aspects |
| 462-466 | Yeah I was ill on 31st and went in on 1st September. Then on the Saturday I went with my mum’s friends daughter because we’re friends, to see her uncle and on the way back we popped into McDonald and I said I didn’t feel well and she said if you’re going to be sick can you just hold on it’s just around the corner. And then I put my head up thinking it would slow it down, and I was just sick everywhere in her new car. And then she took everything out of the McDonalds bag and gave it to me, and then I got dropped off home, had a wash, jumped into bed, like a normal illness, jumped into bed had some medicine type thing, and then I remember waking up every 10 minutes during the night filling my bottle up, being sick, filling my bottle up, being sick. But I was asleep in my sisters bed because it’s easier to get out of, instead of mine. And then I don’t remember anything since then and then I remember sitting up in my bed, feeling like I was in my bed and two people in | Sense of narrative here |
| 467-471 | Recalling sections of story |
| 468-471 | Disconnected narrative |
| 472-476 | Re-connecting with coherent story |
| 473-476 | Disconnected from narrative: unable to ‘own’ story |
| 474-476 | Seeking other’s stories - processing narrative |
| 475-476 | Creating a story which makes sense |
| 476-476 | ‘putting the picture together’ | Normality being disrupted by illness |</p>
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<td>the room, a load of other people and my Nan saying it was the best thing to just go and I don’t remember nothing from that onwards. And then I remember waking up in the IC unit and someone was trying to feed me some food, and seeing my mum and my dad crying in the chairs, and then I remember going in my, I don’t remember what it’s called, but in a tube thing where you have like a scan, and ultra sound or something like that and I remember going in that and mum saying you’ll be ok, you’ll be out in a minute and then nothing else, and then I remember when I was just in the normal ward, being normally daily medicine every couple of hours, checkups. And that’s it really, I don’t remember nothing much.</td>
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<td>478</td>
<td>Gap in narrative - disconnection with experience</td>
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<td>Recalling disconnected memories - confusion</td>
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<td>Unusual/spiritual experience</td>
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<td>Not remembering - disconnection</td>
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<td>Gap with no memory</td>
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<td>Observing distress - but no personal emotional content</td>
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<td>Disparate, disconnected memories</td>
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<td>Being acted on (through treatment) with no part</td>
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<td>Being supported by parent</td>
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<td>Recurring gaps in memory</td>
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<td>Highlighting gaps and flashes - discontinuous</td>
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<td>Feeling of returning to normality</td>
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<td>Highlighting gaps in memory; impoverished memories</td>
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<td>488</td>
<td>It’s quite hazy the rest of it?</td>
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<td>489</td>
<td>Yeah – I remember when I woke up it was quite blurred and so it was quite a blurred picture</td>
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<td>490</td>
<td>Lack of clarity</td>
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<td>Difficulties seeing - again hard to create a narrative from blurred picture</td>
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<td>491</td>
<td>What was that like – because the last thing you’d remembered was being in your bed?</td>
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<td>492</td>
<td>Exploring emotional reaction to gap</td>
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<td>493</td>
<td>Yeah it was quite weird because I was all shocked and I couldn’t move much um, and like I tried to sit up but couldn’t move and I just saw a couple of people around me and my mum and dad and someone trying to feed me food and that was quite blurred as well, but then when my mum says there was a nurse there trying to feed me food, seeing if I’d wake up to that, and that’s all I remember</td>
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<td>Feeling shocked</td>
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<td>Being incapacitated - out of control</td>
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<td>Presence of others</td>
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<td>Blurred memories and vision</td>
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<td>Connecting 2 narratives - using this to process</td>
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<td>Story helps in processing</td>
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<td>500 E</td>
<td>And so your mum and dad were crying because that’s the first time you woke up?</td>
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<td>502 J</td>
<td>Um, I’m guessing so yeah, it was the first time I woke up out of the coma Um, I’m guessing so yeah, it was the first time I woke up out of the coma um yeah</td>
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<td>506 J</td>
<td>Um I don’t remember how I felt how I feel how I felt at all, it was just a bit weird that I was still in somewhere else instead of my bed or my sister’s feeling like whoa where am I</td>
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<td>509 E</td>
<td>So it was more just weird</td>
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<td>510 J</td>
<td>Yeah like whoa, and then I remember nothing until I was in my own ward in my own bed having daily checkups and my mum or my sister, one of them was always with me and every time I needed to toilet I had to take a little plug out of my hand off of my thumb and then I’d have to press the button and my sister or my mum would follow me and help me and everything. Um I was quite weird though, knowing that after a year or so, a couple of months afterwards you’re out of it and you get told the story of what happened and you really think I was in a coma, on a life support machine, and all the things that happened at home, afterwards you think, that wasn’t me that was someone else – she must be getting this story mixed up because I don’t remember none of that. And at school when I went back and I still get the questions to this day how did it feel to be in a coma and I say I don’t actually know because all I remember is going to sleep in my sisters bed and waking up someone feeding me, so it’s like a huge bit of my life chucked out and that’s pretty much it. Um I’ve always wanted other people to learn about it so they know what it is, and I get questions like what is meningitis what bit of meningitis did you get, how did you feel, and it’s like mixed emotions really because one</td>
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<td>529</td>
<td>Ongoing disconnection - poor memory</td>
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<th>no narrative</th>
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| 530 | minute you know you’re here and the next minute you’re there and you realise what happened to you and you think whoa. How did that happen to me, how did I get meningitis but I don’t really know the answers myself so I can’t answer any of the questions. |  |  | Regretting lack of memory  
‘chucked out’ – loss of ‘huge bit of life’ – lost the story  
Wanting to teach others (also wanting to know yourself?)  
Curiosity about meningitis  
Being questioned  
Mixed emotions – being unsure  
Overwhelmed at realisation  
Questioning self – trying to process  
Not knowing – unsure |
| 534 | So on the one hand you want people to know, but on the other hand talking about it is a bit strange |  |  | Reflecting on ambivalence about sharing experience |
| Seems tale of awareness raising is actually her trying to create a narrative and understand what happened for herself |  |  |  | Feeling disconnected; sense of unreality  
Requiring witness to experience  
Wanting to raise awareness  
Unexpected experience  
Wanting to prepare others  
Fearing guilt/culpability  
Feeling unable to help  
Not knowing/not understanding own experience  
Creating narrative post-discharge  
Noticing media focus  
Identifying similarities with others  
Identifying her key features  
Noticing difficulties in diagnosis  
Misdiagnosis  
Seeing meningitis as rare  
Recognising wider infection rates  
Reflecting on ignorance |
| 536 | Yeah because you don’t feel it was you, and you want people to know you’ve been there, you want them to know what the effects are, like um you want them to know it can happen to anyone, because we weren’t expecting it so how can they know if they’re expecting it or not, and knowing that if your friends don’t know about it and they get it I feel like, I would be like I should have told them, I should have helped, but obviously you can’t because you don’t know how it affects you and how you get it so it’s a bit weird. Because a couple of weeks after I came out of hospital there was a couple of ads in the newspaper about kids getting meningitis there was a boy when I was in hospital, roughly my age, and I watched the news every morning and there was another boy on there and he had a piece and because of that he had a problem with his heart and they thought it was meningitis. And it was quite weird seeing that because you know it’s rare, but actually quite a lot of kids get it but nobody knows about it. And I feel like everybody should know about it but |  |  |  |
| 553 | E | Do you think that’s something you’ll go on to do like tell other people and stuff? | Exploring raising awareness post-discharge |
| 554 | J | I would like to, but it’s hard to explain it and stuff, because I wasn’t like, I feel like if me and my mum told the story together people would like understand it more because story was there to see me, what I don’t remember and then I know the things mum doesn’t know, going on in my head and things like that and if you put the two stories together people might understand it more, | Finding it hard to explain – not having vocab  
Needing support to tell story  
Recognising joint narrative  
Awareness of gaps in narrative  
Recognising her unique insight  
Enmeshing 2 stories |
| 555 | E | And tell me about, so you went into the ward, how long were you there for | Exploring post-PICU experiences |
| 556 | J | When I came out of ICU I was in there for about 2 or 3 weeks I think two weeks | Length of stay (compare with 2 where time measured as treatment) |
| 557 | E | And what did you do when you were there? | Exploring post ICU experiences |
| 558 | J | It was just a daily routine really, I just wake up in the morning, have my breakfast about 9 and then at like 10 someone would come in and give me my medication and then at lunch time I’d have more medication after I’d eaten, then some more and then it’d be dinner and then some more. I’d just do what I could during the day, but most of the time I had double vision and I had like eye checkups a couple of days during it, and they gave me an eye patch and then I found the eye patch actually helped more because then I could only see one version of it, but year I still have the eye patch up stairs and everything um but it’s quite shocking to know that you had double vision, you were in a coma, you don’t remember nothing | Returning to normality (or a new normality)  
Time markers around meals and medication  
Being helped/nursed  
No other activities – no focus on wider recovery  
Limited activities – reduction from previous normal  
Limiting factors  
Having medical interventions  
Finding interventions helpful  
Keeping reminders of experience  
Feeling shocked  
Dawning realisation  
Shock at not remembering enormity |
| 559 | E | So it was kinda dawning on you then -like my gosh my visions really affected | Previous lack of awareness  
Awareness of serious consequences |
<p>| 560 | J | Because I didn’t know what meningitis was before I had it but I read in magazines that people lose their arms, legs, go deaf, go | |</p>
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<tr>
<td>Needing to hear others stories to make sense</td>
<td>blind, and I was thinking is my vision going to go because I was slightly blind so “I was a bit worried about that. Obviously I had my legs and arms still, but my hearing was a bit funny so I wasn’t sure. But everything was a bit confusing at the time, and everyone tells you the stories of what they saw, what they heard of what happens to me, and it all gets put together the whole picture and it actually makes sense what happened to you.</td>
<td>Fear of losing vision</td>
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<tr>
<td>Not really understanding what’s happened</td>
<td>And so when you came out of hospital so that must have been mid September, what happened then?</td>
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<td>Trying to return to normal but struggling</td>
<td>It was a bit weird because like walking up the stairs it’s like a daily thing up and down all the time, but walking up it was like at least four times longer than it is and then walking down it it felt like I couldn’t feel the steps it was just really weird walking up and down, because the furthest I’d walked as my bed was say here and my toilet was like there where the computer is and that’s all the walking I’d done, because if I had to go down for the eye check up, the hearing test, I’d get a wheelchair down there, but it was just really weird walking around everywhere, when I was in the car I had double vision but it had got so much better and I could see people straight up and you think you can see people and it’s fine, but when I was in the car I always looked out the window but when I looked out I couldn’t see people or anything it was just a blur of colours, and I couldn’t study or anything</td>
<td>Comparing normal activities</td>
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<tr>
<td>E</td>
<td>Did you go straight back to school or did you have some time off</td>
<td>Exploring this return to normality</td>
<td>Feeling worried - post event</td>
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<td>J</td>
<td>I had a couple of weeks off and then I’d go in for a bit it depends on my sleeping—we went in and had a meeting with them and they said do I sleep in during the morning um and I said that I did and they said why don’t you start coming in at 12 for a couple of hours, not till the end of the day, just for a period or two, so I didn’t that for a week or two, and eventually I did lunchtime until the end of</td>
<td>Feeling scared about long term effects</td>
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<tr>
<td>J</td>
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<tr>
<td>Exploring needs</td>
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<td>Negotiating return to school</td>
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<td>Limited attendance</td>
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Here gives context for changes

I wonder about ongoing cognitive recovery and how this impacted on social relationships and social recovery

Time measured as since being in hospital

Curiosity of others - how was this experienced? Esp as j doesn't have a narrative

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<td>the day, and then I did a little bit earlier than lunch time until the end of the day, and each one or two periods would be a couple of weeks, then adding the end of the day on, another couple of weeks. I don’t think I got back to whole lessons until January, December January because I wasn’t too sure any everything, but I feel like because at the end, in year 9 I was at C school which is in F, and a month or two before end of school I moved to S school which is where I am now, and I had a group of friends, and obviously during the summer holiday is was with them, and Seeing my friends I knew in F, but then I come back to school I wasn’t there so they were like where’s J, has she moved again? And it was weird, and I didn’t really speak to them much when I went back to school and I wasn’t in lessons with them and I was at home ill, and it was a bit weird not seeing them all the time, and then I just started going back to school, um I had a lot of arguments with mum, so like anything and everything really, and then I didn’t go out at all and if I did mum would drive me there and back, I’d only be out for a couple of hours, um and then I started making new friends and then I’ve been going out more um but I remember one day when id did go out when I came back, I think I was out of hospital for a couple of weeks, and I was really eager to go back to school and mum was like you can’t you can’t and mum had rung the school and they said start on the Monday and we’d had a meeting with them on the Friday and I said I felt well enough to go out and see my friends and on Friday night so I went to this youth club called G-way which is next to my school, and quite a lot of my friends I knew from S were there and I went to see everyone on the Friday before the Monday back at school and it was quite nice to see everyone, and everyone was like what’s happened what’s happened and I was like I don’t know because you’re still trying to put the pieces together, what happened, when it happened, which way round it happened and stuff like that</td>
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<td>very slow process</td>
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<td>slowly building up attendance</td>
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<td>unable to manage full days</td>
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<td>slowly returning</td>
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<td>long time to return to normal</td>
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<td>feeling unsure</td>
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<td>changes just prior to illness</td>
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<td>moving schools, new beginnings</td>
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<td>621</td>
<td>developing friendships</td>
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<td>622</td>
<td>building friendships</td>
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<td>623</td>
<td>not doing ‘normal’ activities of peers</td>
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<td>624</td>
<td>disruption to new start</td>
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<td>625</td>
<td>losing connection</td>
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<td>626</td>
<td>not being present</td>
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<td>627</td>
<td>feeling disconnected/out of touch</td>
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<td>628</td>
<td>reconnecting</td>
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<tr>
<td>629</td>
<td>lots of things going on - but unclear narrative of this</td>
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<tr>
<td>630</td>
<td>being protected – difficulties separating</td>
</tr>
<tr>
<td>631</td>
<td>making new friends - creating new connections</td>
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<td>632</td>
<td>starting to go out - returning to normal social activities</td>
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<tr>
<td>633</td>
<td>wanting to get back to normal ‘eager’</td>
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<td>being restricted by mum</td>
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<td>635</td>
<td>planning return to school</td>
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<td>636</td>
<td>feeling well enough - but not better/recovered?</td>
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<td>wanting to reconnect</td>
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<td>639</td>
<td>preparing to return</td>
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<td>640</td>
<td>stepped return to social life - so as not to be</td>
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<td><strong>668</strong></td>
<td><strong>J</strong></td>
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<table>
<thead>
<tr>
<th>Identity</th>
<th>669</th>
<th>a sudden I feel like it’s dropped because some of my grades are like Ds to Cs, and there was a couple of Bs in there. But when mum said that I’d changed I feel like I’ve changed a lot, because obviously my grades have changed, my friends have changed, I wasn’t going out as much and everything was just changing. I used to dying my hair and listening to rock music and emo, and now I’m into R&amp;B and stuff like that. Quite a lot has changed for me</th>
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<tbody>
<tr>
<td></td>
<td>670</td>
<td>Changing abilities</td>
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<td>671</td>
<td>Dropping grades</td>
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<td>672</td>
<td>Noticing changes</td>
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<td>673</td>
<td>Changes in all aspects of life</td>
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<td>674</td>
<td>Feeling ‘everything’ has changed</td>
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<td>675</td>
<td>Changes to preferences</td>
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<td></td>
<td>676</td>
<td>Exploring precipitators for change</td>
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<tr>
<td>677 J</td>
<td></td>
<td>My moving to a new group of friends I’m in and they like that stuff and I might have felt weird listening to my music, but it might have been the fact that dying my hair scares me now, it scares me to dye it because I dyed my hair on the Friday and then obviously on the Saturday I was ill on the 31st and I went into hospital on 1st, on the Sunday. And I don’t know if it’s an effect of it or not but it scared me since. And when I went into hospital I had blonde at the front, black at the back and it started growing out, and then mum said eventually I could dye it, that was 6 or 7 months afterwards, and I dyed it brown, and that’s the last time I’ve dyed it. I’m just too scared it will happen again. Because my mum’s friends mum um she was a nurse and she when I was round her house she said it was a possibility it could happen, possibly not, I was but what the nurse said and that and I’m always scared that if it happened, scared that I won’t, I know I won’t survive, because there was a low chance of me surviving and I did but my body will be weaker next time so I feel I won’t surviving and that so I’m scared of anything, like getting ill, or dying my hair, just scared me a lot</td>
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<td>678</td>
<td></td>
<td>Recognising some changes related to other bits of life</td>
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<td>679</td>
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<td>Noticing discrepancies</td>
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<td>680</td>
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<td>Fear, feeling scared</td>
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<td>681</td>
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<td>Attributing cause of illness</td>
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<td>682</td>
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<td>Linking events</td>
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<td>683</td>
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<td>Lack of knowledge</td>
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<td>684</td>
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<td>Blaming illness on own actions</td>
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<td>685</td>
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<td>Needing permission</td>
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<td>686</td>
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<td>Making a changing</td>
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<td>687</td>
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<td>Waiting a long time - previously enjoyed activity</td>
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<td>688</td>
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<td>Behaviour change post-illness; fear of becoming ill again</td>
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<td>Seeking advice</td>
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<td>690</td>
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<td>Living with possibilities</td>
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<td>691</td>
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<td>Ongoing fear</td>
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<td>692</td>
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<td>Believing/fearing not surviving</td>
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<td>693</td>
<td></td>
<td>Feeling weakened</td>
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<td>694</td>
<td></td>
<td>Increasing vulnerability</td>
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<tr>
<td>695 E</td>
<td></td>
<td>Multiple fears</td>
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<tr>
<td>696</td>
<td></td>
<td>Exploring relationship with body</td>
</tr>
</tbody>
</table>

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| Page | J   | 697   | 698   | 699   | 700   | 701   | 702   | 703   | Feeling changed by illness
|      |     |       |       |       |       |       |       |       | Changes to normal reflexes
|      |     |       |       |       |       |       |       |       | Avoiding illness
|      |     |       |       |       |       |       |       |       | Comparing previous behaviour (like old and new normal)
|      |     |       |       |       |       |       |       |       | Changing behaviour
|      |     |       |       |       |       |       |       |       | Fear of repetition of experience
|      |     |       |       |       |       |       |       |       | Investigating fears and avoidance
| 704  | E   | 705   | So what would it feel like, say you got the flu or a bad cold, or tummy bug or something, what would you think then? | 706   | J   | Um, I had a tummy bug a month or so ago, and I was in bed sat up my sister would always be with me or my mum to make sure I’m ok, because obviously they know what it’s like they wouldn’t want it to happen again, me to die so because you want to make sure it’s not happening, so if there’s anything like me drowning off or doing any of the talking or arguing like I was they knew to get me there straight away, so it’s kind of scary | 707   | J   | Getting ill
|      |     |       |       |       |       |       |       |       | Needing support - presence of others - not safe to be alone
|      |     |       |       |       |       |       |       |       | Needing people who know - narratives
|      |     |       |       |       |       |       |       |       | Fearing dying
|      |     |       |       |       |       |       |       |       | Hyper vigilant for symptoms
|      |     |       |       |       |       |       |       |       | Needing others to monitor
|      |     |       |       |       |       |       |       |       | Fear of becoming ill
|      |     |       |       |       |       |       |       |       | Reflecting on level of fear
|      |     |       |       |       |       |       |       |       | Exploring other emotions
| 713  | E   | 714   | So it sounds like fear, like scariness is really around for your experience, I wonder if there are any other feelings that have particularly come through for you~? | 715   |     |       |       |       |       | Valuing family and friends
|      |     |       |       |       |       |       |       |       | Recognising value
|      |     |       |       |       |       |       |       |       | Comparing previous attitudes (old and new normal)
|      |     |       |       |       |       |       |       |       | Noticing changes in attitudes
|      |     |       |       |       |       |       |       |       | Awareness of fragility/unpredictability
|      |     |       |       |       |       |       |       |       | Fear at pace of death - lack of preparation
|      |     |       | Fear and loss and fragility | 716   | J   | Um, it’s been like keep your family and friends close because obviously they do mean a lot to me, but obviously every since that I always took family and friends for granted and since I had meningitis I took them more serious, because you don’t know when it’s going to happen to you if you’re going to die or anything you don’t have the chance to say goodbye, it’s just on the dot type thing | 717   | J   | Recognising changing attitudes
|      |     |       |       |       |       |       |       |       | Completing work earlier - fear something might happen
|      |     |       |       |       |       |       |       |       | Completing work earlier - fear something might happen
| 723  | E   | 724   | Yeah. So you maybe take life a bit more seriously? | 725   | J   | Yeah, every since I started year 11 now and I’ve just buckled down so much, um if I have homework I’d do it on the day so I know I don’t have it outstanding like I did in year 10 still and if my friends
|      |     |       |       |       |       |       |       |       |
| 726  |     |       |       |       |       |       |       |       |
| 727 | want to see me I’ll be like got homework, can’t, but I’ll go out if I don’t have homework and I’ll be back at a sensible time and I’ll always contact my mum to let her know I’m ok, and because my school is in S, which is a half an hour walk from here um I always make sure I walk aback with someone, so it’s safe that way | Reducing socialising  
Acting responsibility  
Being sensible  
Maintain contact  
Being with others  
Seeking safety - planning for that |
| 732 | E  | So you think a lot about that |
| 733 | J  | Yeah, mum and me, we’re always like secure now, always like making sure everything is ok | Becoming close - increased connectedness  
Need to protect - to have back up |
| 735 | E  | And do you think it’s affected other people in your family, like your sister is older than you isn’t she |
| 737 | J  | Um I’m not so sure about my big sister because she wasn’t the person to be ill so much, but she’s become more serious, like she’s got a job now, she likes to have fun, but she used to go out partying a lot, but just like a couple of months ago we’ve all started buckling down now, she’s stopped that making sure work and family comes first and then in her spare time she’d do that | Being unsure  
Changing -becoming more serious  
Normal activities of growing up?  
Family changes - increased seriousness  
Changing priorities  
Putting family first |
| 743 | E  | And what about —so you’ve got two little brothers and |
| 744 | J  | And a sister |
| 745 | E  | Do you think it’s affected them |
| 746 | J  | When I was in hospital my little sister was like really scared, and I think my family have come close to her more than like more little brother and it was a bit weird for them to see like, tubes in my arms and everything like that needles, and my face being swelled up, so they didn’t come to see me until a couple of weeks before I was allowed out because obviously I didn’t want them to see me in the state I was in and neither did my mum, so they it was a bit shocking for them as well, but B, he’s only a year old now, so he was just a couple of months old when it happened, and normally he’d be the happy, sitting with anyone, go to anyone, but when I tried to hold him he’d cry or and R wouldn’t come that close to me, |
| 756 | J  | | |

**Major Research Project (Appendices)**

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| 757 | 758 | 759 | 760 | 761 | 762 | 763 | 764 | 765 | 766 | 767 | 768 | 769 | 770 | 771 | 772 | 773 | 774 | 775 | 776 | 777 | 778 | 779 | 780 | 781 | 782 | 783 |
|-----|-----|-----|-----|-----|-----|-----|-----|-----|-----|-----|-----|-----|-----|-----|-----|-----|-----|-----|-----|-----|-----|-----|-----|-----|-----|-----|-----|
|     |  he wouldn’t hug me that much, and normally if someone is ill they would hug them and stuff and I felt quite scared type thing I thought something, when I was in hospital I didn’t really know much about meningitis, I thought it was just an illness, but when I found out about it it clicked why R wouldn’t hug me and stuff and it must be because he was scared I was going to die or something and obviously he’s only little so he didn’t really understand it that well. |
|     |  Becoming different/special/marked and rejected |
|     |  Changing character due to illness |
|     |  Keeping distance - unusual reactions |
|     |  Being scared by others’ Realisation |
|     |  Lack of awareness - naivety |
|     |  Finding out - making sense through processing - realisation of fear |
|     |  Interpreting motive - reflection of own fear of dying? |
|     |  Not understanding - theme of J’s as well |
|     |  Depending on life stage/age |
|     |  I don’t remember that, but I do shout a lot but I knew something like that was going to happen, me shouting or that, but normally when I’m ill no one knows I’m ill unless I’m sick or something really serious happens, because if I’m sick I start to cry before, to show my emotions that I do feel not well, um but otherwise I just suck it up and get on with it, but every since that happened it’s been like I’ve got a headache, quick, headache tablets, sit in a quiet room for a bit and sort myself, but if it’s ongoing mum will sort me out and that |
|     |  Relating reaction to personality |
|     |  Not surprised at reaction |
|     |  Keeping illness private |
|     |  Showing emotions - seeking support |
|     |  Dealing with illness |
|     |  Changes since illness |
|     |  Need for immediate reaction |
|     |  Measuring if support is needed |
|     |  But you took things... |
|     |  Being more serious |
|     |  Exploring significant events |
|     |  Support as significant in recovery |
|     |  Feeling supported |
|     |  Receiving cards - knowing you’re kept in

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<th>Page</th>
<th>Content</th>
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<tr>
<td>784</td>
<td>my friends in the school, um and obviously they've changed now but I still speak to the other ones that I met first of all, um I think the family has become...we were always a strong family but the family has become a bit stronger than it was, and the school was just like amazing with like letting me come a couple of hours to get used to it, and walking around and that, so it wasn't that bad</td>
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<td>790</td>
<td>E</td>
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<td>792</td>
<td>J</td>
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<td>801</td>
<td>J</td>
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<td>808</td>
<td>J</td>
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<td>809</td>
<td>J</td>
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<th>Page</th>
<th>Text</th>
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<tr>
<td>810</td>
<td>people saying what’s wrong I’ve heard about you, and that, I’d talk to them about it, um when first couple of months when I come back I had all my sisters friends, my friends, my mum’s friends, family members coming round we’d all talk about it, mum would tell them what happened. And for the first couple of months I don’t think I remembered anything until I think a couple of months afterwards mum started telling me what happened so I could understand because obviously I wasn’t myself for a couple of months afterwards, I still felt like I was ill, um and then all the pictures got put together and then I could tell my part of the story because I wouldn’t know if when I was being fed come first or me seeing my Nan come first or wouldn’t know which way round it went unless my mum had said the story.</td>
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<td>823</td>
<td>Yeah so you needed her bits to join up</td>
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<td>824</td>
<td>Yeah</td>
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<td>825</td>
<td>And now do you talk to your mum about it?</td>
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<td>826</td>
<td>If it came up in conversation I would but I wouldn’t bring it up out of the blue, because I know it was really emotional, so was everybody at the time.</td>
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<td>829</td>
<td>What do you think are the most important ways of coping with an experience like you’ve had?</td>
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<td>831</td>
<td>Um, I would say it was the hospital, my family and friends are why I’ve coped well with it</td>
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<td>836</td>
<td>I would have said it’s because I know my face swelled and I used to do modelling a lot and then I started just eating to comfort me and everything</td>
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<td>838</td>
<td>Wanting a narrative - asking for information</td>
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<td>Initial interest</td>
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<td>Curiosity of others- network of connection</td>
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<td>Collective sharing of information</td>
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<td>Needing mum to recount story</td>
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<td>Ongoing cognitive difficulties</td>
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<td>Not remembering</td>
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<td>Hearing the story</td>
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<td>Being someone else - not myself</td>
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<td>Ongoing illness</td>
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<td>Having only part of the story</td>
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<td>Confusing order of events</td>
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<td>Not knowing what happened- need scaffold for story</td>
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<td>Creating a coherent narrative</td>
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<td>Exploring the present</td>
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<td>Not feeling able to discuss</td>
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<td>Awareness of emotionality</td>
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<td>Awareness of others’ reactions</td>
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<td>Exploring coping</td>
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<td>Coping as based on others</td>
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<td>Reflecting on connectedness</td>
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<td>Looking different - attributing changes to visual features</td>
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<td>Change in body knock-on affect</td>
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<tr>
<th></th>
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<th>What were you comforting yourself about</th>
<th>Needing comfort - eating to comfort</th>
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<tbody>
<tr>
<td>849</td>
<td>J</td>
<td>I’m not too sure, I’d just eat if I could, if I wasn’t doing something</td>
<td>Eating to reduce boredom? Eating to do something</td>
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<tr>
<td>850</td>
<td>J</td>
<td>I’d eat just because I don’t know just felt like the right thing really at the time, um yeah</td>
<td>Eating to feel right</td>
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<tr>
<td>853</td>
<td>E</td>
<td>So you were doing modelling before..</td>
<td></td>
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<tr>
<td>844</td>
<td>J</td>
<td>Yeah modelling before then obviously meningitis happened, I was doing modelling since I was 10 or 11 and then meningitis happened and my face swelled and I’ve been eating so I didn’t feel confident about myself, I’d been listening to rock music but that changed and then my friends changed like my friends thought I was totally changing (interrupted by child crying), yeah I just didn’t feel myself anymore, everything was changing for me. It was like a chapter of my life had been taken out so I didn’t know if I’d changed during that and obviously I wanted to be more secure about when I get ill and stuff like that.</td>
<td>Meningitis stopped modelling</td>
</tr>
<tr>
<td>851</td>
<td>E</td>
<td>So it sounds like you’ve changed quite a lot, do you think you’ve gone back to who you were, or you are someone different or what?</td>
<td>Exploring the result of changes - on personality now</td>
</tr>
<tr>
<td>852</td>
<td>J</td>
<td>I feel like it’s somewhere in between, because obviously I don’t listen to the music as much, I don’t dye my hair. I was a bit like a little scene kid type thing, loved my gigs, now I’d see my friends, school work, being more serious than I was.</td>
<td>Not returning to old self</td>
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<tr>
<td>855</td>
<td>E</td>
<td>So some things have changed and some things</td>
<td></td>
</tr>
<tr>
<td>856</td>
<td>J</td>
<td>Yeah some things have stayed the same, some things have changed, some things haven’t.</td>
<td>Recognising stable features</td>
</tr>
<tr>
<td>857</td>
<td>E</td>
<td>So what advice would you give another kid who has gone through or is going through what you’re going through</td>
<td>Reflecting on emotional content</td>
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<tr>
<td>860</td>
<td>J</td>
<td>I would say like it is hard after, a couple of months afterwards and obviously you won’t feel yourself so it is just a time to sit back, relax, let everything go round you, and when you feel you can you</td>
<td>Not feeling yourself - needing to decrease pressure</td>
</tr>
<tr>
<td>869</td>
<td>stand up and go back to who you were or be who you want to be really. But not so, take things ever so slowly because otherwise things won’t get back to how they were. Be more serious about things because you never know what is going to happen now that’s happened.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>870</td>
<td>Needing space, relaxation</td>
<td></td>
<td></td>
</tr>
<tr>
<td>871</td>
<td>Wanting to return to normal</td>
<td></td>
<td></td>
</tr>
<tr>
<td>872</td>
<td>Going slowly</td>
<td></td>
<td></td>
</tr>
<tr>
<td>873</td>
<td>Needing time and slow pace to return to normal</td>
<td></td>
<td></td>
</tr>
<tr>
<td>874</td>
<td>Not knowing about future because of illness</td>
<td></td>
<td></td>
</tr>
<tr>
<td>874</td>
<td>E</td>
<td>That’s good advice. Is there anything else that I haven’t asked but is important for me to know.</td>
<td></td>
</tr>
<tr>
<td>875</td>
<td>J</td>
<td>No</td>
<td></td>
</tr>
<tr>
<td>876</td>
<td>E</td>
<td>Do you have any questions for me?</td>
<td></td>
</tr>
<tr>
<td>877</td>
<td>J</td>
<td>Not really.</td>
<td></td>
</tr>
<tr>
<td>878</td>
<td>E</td>
<td>Well that’s brilliant. Thank you for taking part.</td>
<td></td>
</tr>
</tbody>
</table>

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### Appendix 17: Example of developing categories and early memos

<table>
<thead>
<tr>
<th>Source Code</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>2-99-107</td>
<td>“the most scared I’ve ever been”</td>
</tr>
<tr>
<td>2-1-46-1047</td>
<td>S – It is the most scared I’ve ever been</td>
</tr>
<tr>
<td>2-1057-1058</td>
<td>Mum – And they moved him round to resus and that was terrifying going to that room because I knew what that room is for...</td>
</tr>
<tr>
<td>2-1129</td>
<td>Mum – when they moved him round to resus I honest thought he was going to die</td>
</tr>
<tr>
<td>5-58-59</td>
<td>Mum – it’s the worst thing that’s ever happened to me</td>
</tr>
<tr>
<td>6-55-58</td>
<td>Very personal statement – whilst illness was her son’s going to IC was for her really awful and affected her personally as well as affecting their family more generally.</td>
</tr>
<tr>
<td></td>
<td>Mum – When it was first mentioned to us just the words ‘intensive care’ it was like ‘oh god’ you know terrifying, absolutely terrifying. But when we actually go there, because it was so calm, so different, so...for us it wasn’t an unpleasant experience...</td>
</tr>
<tr>
<td></td>
<td>Both sides of the narrative seem to come out here – both being really scared and then feeling very calm – not sure what this is about here, but wonder if it’s also reflecting mum’s attempt to keep positive despite the fear she felt, and to relate it afterwards in a way which shows that she’s so tough.</td>
</tr>
<tr>
<td>4-253-257</td>
<td>Mum - She was never sick. Even on chemo and she had five anaesthetics and she was never sick. I was more sick I think, just from watching. Um and I remember you were quite sore when you woke up you had quite a headache I think after the operation.</td>
</tr>
<tr>
<td></td>
<td>Even when acknowledging discomfort it’s done with small words –sore rather than pain, and quite as a qualifier, and headache – which is a very everyday illness. Minimisation of the pain and discomfort – is it too difficult to contemplate anything else? This may also have been a coping strategy which helped F feel contained? (or she may have felt not-validated)</td>
</tr>
<tr>
<td>4-259-263</td>
<td>Mum – she gets quite distressed, the only time F does get distressed which is quite amazing cos nothing seems to bother you does it, in that way she’s very easy come. But the urine sample</td>
</tr>
</tbody>
</table>
| Distress at other's illness | 1 - 160-161 | R - It was good when they went obviously, um, but like when you see people coming in its not very nice  
Is this communicating the feeling of being left behind in misery? Discomfort at others illness  
R - And if something like on their monitor goes off and starts bleeping then you just worry or something and stuff like that  
Does this remind of her own mortality?  
Mum - so it's a bit daunting to then go to a whole room with, we think god there's quite a few children needing care and we're doing to just a few nurses or doctors  
Put this here as it seems the opposite to R's concern for the other children. For J's mum the concern is will my daughter get enough care with all these other children. No sense of connection with the other children, or even a sense that they were noticed beyond being a resource drain.  
Mum - I know we had a young lad, a very young boy, can’t remember how old he was, beside us, he had fallen and cut himself and the cut had become infected and he'd become really really ill through that, so mum and dad were very very very worried...  
Dad - We got two other kids... they want to see |
her as well we said no because I don’t want to take my younger kids to them to there because maybe it’s too much stress for them. I don’t want saw them my other daughter she is coming in this kind of condition probably so frightened of them because they never seen her like that she’s always happy chap, very very happy bunny when she isn’t in intensive care she always happy isn’t she.

| Unprocessed narrative | 1 – 55,57 | Mum- Stuff like that so I think maybe (trails off) R – Stuff like that...yeah...I know Not able to finish sentences – where does this fit with social constructivism? Not able to construct narrative even given the frame
Dad - We actually finished up, got up in the morning this side of his face was normal, that side of his face was like an orang-utan. Still to this day we don’t know what happened. We think he was bitten, um...

| Or Incomplete narratives | 6-120-126 | Mum - Stuff like that so I think maybe (trails off) R – Stuff like that...yeah...I know Not able to finish sentences – where does this fit with social constructivism? Not able to construct narrative even given the frame
Dad - We actually finished up, got up in the morning this side of his face was normal, that side of his face was like an orang-utan. Still to this day we don’t know what happened. We think he was bitten, um...

| Reflecting on coping being situation dependant | 2-1354-1361 | Mum – we would handle it differently....but then it’s so hard to know how you’ll feel at the time, but yeah we did handle it very badly and I think we did a lot of harm to S and we felt terribly guilty and it was so unfair...
Guilt and fearing ‘doing harm’ sense that it was their fault when actually no one could know [if it was cancer returning or just an infection] without the medical intervention which needed to be fast and through – and it was the doctors who made those calls not parents. However perhaps I don’t know full story of how they reacted to him or this scare or what they did that was ‘doing harm’ to him.
Mum – I mean, I say part of the blessing was that it was in the summer holidays. If it had been time off school when I should be picking her up, taking her to school, picking her up from school and doing whatever it might have been different and she probably would mind if I’d said, but the fact is she was having a whale of a time.

| Coping by avoidance or forgetting | 3-697-703 | J - you know like someone has a cough you back away a bit, someone being sick you back away, you know if one of my friends was ill I would go round and see if they’re ok but now if they’re ill I’d make sure they were ok but not getting near them because I’m scared of getting ill, scared that it will happen again
Mum – your body is amazing – it makes you forget the bad bits. When we lie in bed

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sometimes and suddenly I’ll go to you
remember when we were measuring F’s wee
and her poo and you know remember when
she couldn’t eat for five months and its like;
step-dad – you do forget you forget, you get
photographs out and you think my god is how it
was.; Mum – your body makes you forget.
Mum - Some of the things they [staff] see. I
dread to think. Some of the things. They were
funny...cos I guess they’ve got to be
This is here because it seems mum doesn’t
actually want to think about how awful PICU
really is
Dad- Yeah but normally you’re a complete
mess; Mum – totally; Dad- you’re sitting
outside somewhere and I’m in there dealing
with him; Mum – I can’t deal with it; Dad –
she’s not actually in there to be perfectly
honest; Mum – ...because of his fit [dad] said
you don’t want to see this; Dad – I sent her out;
Mum – He sent me out because he sent me out
of the room which is obviously for my own
good and I didn’t see his head banging because
I no totally, scary...

Mum – Cos we got close to quite a lot of people
really
Detail on people they knew with similar
experiences
Mum – so it was nice because you ended up
building up quite a good relationship with him
as a family friend which he is now
Details of forming relationship with doctor
?Building positive relationships so they will save
your daughter. This family (1) are very good at
creating and maintaining connections.
Mum – he hates being in hospital cos of we’re
not around all the time...
Put this here as perhaps he would cope better
if they were around all the time. However they
don’t feel they can be around all the time
because then they can’t cope with the
recovery. So a short term coping strat for them
is to be absent, go home and get space, which
charges them up for the long term recovery
period.
Appendix 18: Examples of Memos

Memo: Writing their stories

It seems that parents struggle to know how to construct their PICU admission. Whilst being every parents' worst nightmare, which they are living, faced with the fact their child might die, they are also struck by the support from staff and recognise that they have freedom when their child is on PICU which is not available when they are on a ward. This way of constructing the experience as having both positive and negative facets is important as it provides information about the narratives parents have developed for their families after a PICU admission.

There is something interesting about the need to tell the story of the PICU admission in such depth, despite me only wanting to hear briefly about the experience. Once I am with a family I feel it is important to give space to whatever they want to say, inevitably making the interview process longer (2.5 hours instead of the maximum one hour I was planning initially). Why is it that families need to tell this part of the story? It is like they need to provide me with a context for their recovery, which is not possible until I know the whole story.

Research into narratives after a distressing event note that there are both 'social' and 'self' functions of sharing the story (Baddeley & Signer, 2008). The 'self' functions include 'emotional expression, validation [and] insight' (p.422) and it seems that both were happening here – that the participants wanted validation of their experience by me (social-function of telling the story), and the chance to just express it was part of self-validating (self-function). The chance also to name their feelings and have them contained and normalised by me seems vital. However they also seemed to be looking at it afresh in the interview and creating something new. This is seen in family 3 when J is trying to use her mothers' story to create her own. This is where social constructivism can be seen to be occurring tangibly – through our conversation we are creating what live was and is like for them. I am coming to understand this, and participants are learning about their experiences through sharing them.
However the narratives that are told depend on both the autobiographical memory for the events and it seems also how much they have been thought about since the event. Family 2 struggled to talk about what had happened because it seemed their narrative was so unrehearsed. Many writers reflect on the balance which needs to be struck when dealing with painful memories from a traumatic event (Peebles-Kleiger, 2000; Herman, 1998). Not engaging with intrusive thoughts and flashbacks must be tempered against the danger of complete avoidance as a defence mechanism. This is similar to Stroebe and Schut’s (1999) model of bereavement where the balance between being sad and getting on with life is one which grieving individuals must negotiate. In this study some families seem to still be an avoidance phase and have not yet managed to tackle the experience in order to create a narrative. There is some kind of stalling in the creation of narrative which means the family are still stuck in the distress of the experience without being able to move on from it.

This suggests that some kind of thinking about the narrative, and returning to the traumatic event must occur in order to create this story, This relates to Herman’s (1998) model where stage two is ‘recalling, examining and understanding the trauma’ (p. S2).

Memo: Seeking Normality

All the families so far have talked about seeking normality after their admission. This seems to be their goal when they are first discharged, and it seems that families think this will be easy at the start. For example S talking about expecting to go back to school and other activities because he was better and no longer on treatment. I wonder if this occurs because people return home and therefore assume (even without thinking) that things will be as they were. This means there is safety because they are returning to something familiar and where they have control, having had unfamiliar and no control when in hospital.

Hospital fundamentally changes the family roles and dynamics. For example Graham et al. (2009) talk about parental roles of primary protector and decision maker being fundamentally changed and hospital staff assuming some of these roles. The child too is fundamentally changed. I am also reminded of the way
Dunmore (2002) describes a child coming through a hideous food-shortage, and the dawning realisation that when he asks the adults for food they cannot provide. Similarly the child post-PICU knows the limits of adults' power, realising, perhaps for the first time that their parents cannot always make everything better, make the pain go away, or stop themselves from showing their own distress at times. Further beliefs about the worlds as a safe and benign place may also have been shattered for both parents and children, particularly in the context of seeing other very very sick children, some of whom have died whilst they were in PIUC.

Given this it is therefore unsurprising that families do struggle with ‘normality’ when they return home. Things can never go back to the way they were before because the children and parents are now different people. It seems important to note that we are all shaped by our experiences so these families would have been changed even without a PICU admission. However such a monumental experience as a PICU admission seems to change things more than the ‘normal’ (there’s that word again!) pace of change – for example children tend to grow up very quickly and mature beyond their years (discussed by families 2&3).

![Old Normal](Old Normal) [PICU admission/post-discharge] [New Normal]

**Additional note**

Now I have interviewed the parents of children with a learning disability this memo requires further thought. These families all talked about returning to normal more quickly. It was not instant, but the recovery process seemed to occur in a smaller space of time. Families with a child with an ongoing developmental diagnosis talked about the time of diagnosis as the really difficult time, and that from then on life has no longer been ‘normal’. Their trajectory as a family is very different from families without children with a disability (am struck here by the parallel as the non-LD families also have a different trajectory from ‘well’ families). So it seems that ‘old normal’ was lost when families first found out about their child’s difficulties, and thus after a PICU admission they already know
life is going to be different and are more prepared. These families also had more experience negotiating their journey so even thought the PICU admission was challenging, different and traumatic (in most cases) it was easier to cope with and less unusual than for the ‘sick’ families. So overall it seems these families do still conform to the same pattern, but do progress between the two stages quicker. Graham et al. (2009) noted that ‘children with severe antecedent disabilities and their parents are inextricably linked with critical care services’ (p.2064) and noted that clinicians needed to work to understand this unique sub-section of the population. Therefore in relation to this study in the recommendations it might be important to consider how parents in this situation both differ and have similar needs compared with other parents.

Memo: Struggling with a changed identity

This is coming up as a significant theme in a number of interviews. There seem to be two aspects. One is the experience of being in hospital and how this challenges your known identity. For example in interview 3, S talks about not wanting people to see him as ill and pity him. His mum talked about the difficulties of wanting to be with him all the time, being his mother and the difficulties because he didn’t want her there. All this challenged her understanding of her own parental role.

Additionally people have talked about their identity when they leave hospital. There seems to be a realisation that they are not quite the same person as they were before, and this is challenging for people to accept. This was shown most with the young people who struggled to discover their identity having realised it had changed so much. Parents sought more to maintain the status quo, although on reflection were able to talk about the challenges to their identity and that of the family and relationships within it.

People talked both about self-identity (i.e. how they see themselves) and role identity (where they are positioned in relation to others and the word, mother, son, cook etc).Regber & Berg Kelly (2007) argue that childhood and adolescence already involve changes to the sense of identity because of changing physical and emotional characteristics as well as shifting responsibilities and expectations.
Having a serious illness can result in identity shifting further, and children can then find it difficult to express their identity, because they first need to explore the new person they have become. Earle and Eiser (2007) noted that Children aged five to fourteen appear to find it difficult to cope after a diagnosis of cancer, withdrawing socially and becoming more concerned with their illness and appearance which seems to mirror my findings: that the illness and hospitalisation cause young people to focus even more on their identity. However children’s identity needs also to be considered in the context of relationships, as they cannot live alone and therefore will always have significant relationships with care-givers. The model developed by Pynoos et al. (1995) highlights the importance of family or community circumstances and the integrity of the child’s environment is also taken into account. A child’s interactions will exist within a system that most commonly includes their parents, siblings and extended family, as well as interacting with wider systems at school and in extracurricular activities. And the formation of a new identity (or recovery of an old one) will occur in this context too.

In relation to serious health problems everyone in the family is likely to be affected with disruptions to routines, parent’s availability and potentially living standards if parents have to give up their job to care for a sick child. This will therefore challenge parent’s existing identity conceptions as they take on a different role in relationship to their child and re-evaluate what is important to them. It is also noted that how parents respond to the child’s admission and diagnosis will influence how the child reacts (Eiser et al., 2000). Therefore it is possible that the parent feels unable to explore the new identity or has to repress a part of themselves to be with their child. This also will be instrumental in the development of their new identity as they are/are not able to manage their own emotional reaction in addition to being an appropriately containing parent and providing for the emotional needs of their child.

This emerging theme seems to tie in with the idea of normality. The old identity is constructed as ‘normal’ and is initially a goal to get back to. However over time people seem to accept that they have fundamentally changed because of their...
PICU experience and then they seem to work towards understanding the new identity and accepting it.

Memo: Developing Coping strategies

All families have talked about the ways that they coped when they were discharged (and even whilst in hospital). These coping styles seem to be most important straight after discharge. At these times parents and young people talked about needing coping strategies just to manage the transition, and the early realisation that things were not back to normal. Coping styles seem important for a long time during recovery, but the need for them appears to diminish as families come to understand their recovery more. For example in interview 4 when they came out of hospital F was still very ill and her parents were struggling to cope with everything, employing strategies like just getting through each day and using the outside support available to them. However as F has got better the family started to talk about then being able to look back over what has happened to them and evaluate.

Hodge et al. (2006) describe 3 styles of coping:

- Task focused coping
- Emotional focused coping
- Avoidance focused coping

These three types all seemed to have come up as ways that people manage the early period post-discharge. In this study it seems that having any kind of coping strategy or style was important and families that were able to ‘cope’ in the short term were then able to move forward and really engage with their experience later on. To date all of the families have had coping strategies, although some of them seem not to be helpful in the long term (such as taking up smoking, over eating).

I wonder if the families with greater resilience were able to develop helpful coping strategies, and to move though this stage more comfortably. Waugh et al. (2008) describes resilience as the capacity of people to ‘thrive despite their difficult experiences’ (p.1032). It depends how ‘thrive’ is defined but none of the families
in my study seemed to be ‘thriving’. Many were managing and had moved forward, but all had experienced a very difficult time which had challenged them significantly. Some are still stuck in the distress of the PICU experience or are still trying to understand what has happened to them.

Memo: How people create their stories when recovering

As I write memos it seems clear that families are at some point having to return to their PICU experience and come to understanding it, with the extra knowledge they have gleaned in the time since discharge. In a memo on narratives I wrote after 3 or 4 interviews I reflected on the way people were compelled to tell me their story from beginning to end, often in a lot of detail and that the PICU admission and the illness were central to this narrative. Only when families had this were they then able to move onwards with their recovery journey. For example family 2 did not seem to have a coherent admission experience and this family experienced a great deal of distress when talking about aspects of the time in hospital. It seemed that without this narrative they are also unable to create a model of recovery. This is also shown in interview 4 where her mum has a model of recovery (borrowed from her own understanding of coping with bereavement) but J does not have a model of recovery, as she does not yet have a processed narrative and is still unsure how to tell the story. Processing what has happened in order to create a narrative therefore seems a key process in people being able to recover.

The link between processing and the narratives is held out by the literature. The way a traumatic event is responded to by others can have an impact on how it is
processed. For example a listener may find it more acceptable to hear about a traumatic car accident than to listen to a narrative about sexual assault. When negative reactions are perceived by the victim this may result in increased distress or avoidance of talking about the topic. In the context of health-related traumatic events it is noted that ‘secrecy, bad communication and patients’ suspicions...can contribute to fear and anxiety’ (BMA, 2001, p.5). This highlights the social nature of processing, and also reflects on perhaps the fact that processing can be both conscious and unconscious. This links to what the mother in family 5 said when she talked about crying for no reason, or her body shutting down when F was better in order to give her (the mother) time to process or recover. S’s mother also talked about unconscious and conscious processing – talking about things which affected her even though she didn’t expect them to, and also consciously thinking about the PICU admission and going over and over her memories.

Children who have been traumatised appear to show a unique pattern of comorbidity with other mental health problems or difficult behaviours (Margolin & Vickerman, 2007). These include risk taking behaviours such as substance abuse or risky sexual behaviours. Using my data so far I wonder whether this happens because children are unable to process their experiences and thus are left with the traumatic memories and no structure to place them in. In my study young people seemed to find it harder to create a narrative because they were so unwell at the time, and people avoided talking about it with them subsequently.

Memo: Beyond physical recovery - Biospsychosocial models

An emerging theme in my data is the biospsychosocial nature of the recovery process. In the interviews participants have talked about early priorities being related to physical recovery, particularly recovering their strength and stamina. That this took time was a surprise to most participants who had not expected to still be recovering when they left hospital. Once physical recovery was progressing enough that participants (and therefore their families) could start to go out, social recovery then began. This involved different things for different families, but includes going to BBQs at friends houses (F’s family), going to a youth club (J) and returning to school or work to see friends and colleagues (S, S’s mum, R).
Participants also talked about these social occasions as a way of recognising where they were in their recovery journey, and what had changed, as they compared themselves with others, and others compared them with the person they knew before. It seems to be emerging from the data that at this point families then begin to reflect on their journey and process their experience more. Before that they were so busy with the process of healing and just coping with the adjustment involved with coming out of hospital that really thinking has not been possible.

Löf et al. (2007) describe that after three months emotions about the ‘critical illness were extensive, detailed and strong’ (p.108). I wonder if this is because they have not yet been processed because life has been moving too fast to do this. It seems that the emotional or psychological recovery does not begin until after physical recovery has been mastered to a degree. In the same study participants described that after a year ‘unpleasant emotions were less intense and had less prominence’ (p.108) which leads me to wonder if participants are more processed at a year and therefore have not only physically recovered, but have recovered biopsychosocially. This does not take away what happened in PICU, but allowed them just to feel more in control of the emotions, and to prioritise life sometimes over remembering the admission. This hypothesis matches Stroebe & Schut’s (1999) model, but it will need checking with participants before I can be sure this is indeed what is happening. Importantly Löf et al.’s study was carried out with adults after ICU so it may not be possible to draw comparable conclusions, and the inter-relational nature of both a PICU admission and this research may mean that many more factors are coming into play here.

Memo: Choice and control for children & young people

This was also an issue for parents, but here are some reflections on the role for children.

When children are taken ill their needs for support, containment and understanding must still be balanced with their rights to be independent in
expressing their opinions and making decisions. Here parents and professionals are required to work together in a unique way under challenging circumstances. Complexity is created when professionals need to balance these needs given that two children of the same age may differ significantly in terms of their cognitive abilities or emotional maturity. Often parents and staff attempt to protect children from distressing information or underestimate how able a child is to process complex information about their health (BMA, 2001). In interview children talked about not always knowing what was happening and parents talked about getting information from the doctors. Children were therefore not party to many of the discussions, even in later adolescence.

When adults are admitted they are, in most cases, assumed to have capacity to understand what is happening to them and to consent as necessary to their treatment. Despite this there remains a somewhat paternalistic attitude in many local hospitals, where medical and nursing staff have a tendency to assume they know best and will make decisions for the patient. However if the patient has a problem with their treatment or wishes to disagree with the professional staff then they also have the vocabulary to do so and some understanding of the social conventions and practical avenues to provide feedback. Relatively recent rulings have meant that children’s rights to information and to make decisions about medical treatment have been enshrined in British law. As long as a child is determined to be Gillick competent they have a legal right to consent to treatment (Mayall, 2003) even if they are under 16 years old. Gillick competency applies to children ‘providing they can demonstrate sufficient maturity and intelligence to understand and appraise the nature and implications of the proposed treatment including risks and alternative courses of action’ (Wheeler, 2006, p.807).

However, despite this being a legal and ethical right, children are often assumed not to have capacity and, in line with dominant discourses, are ‘not trusted...they cannot be allowed to chose; rather they must be given clear direction’ (Hendrick, 2003, p.253). Evidence of this comes from a recent study showing that junior doctors, often the first point of contact for families arriving in hospital, had poor knowledge of vital legal concepts and their implementation (Ashtekar et al., 2007). In my interviews this was clear – children were not being given the sense of
choice or control, and when they were later recovering they had to work hard to understand what that meant about them as people (identity) and how they related to others (role) and finally how they could construct a story without having all the information.

Additionally with so many pressures on medical and nursing staff to attend to the immediate medical needs of a child may mean that a child’s rights for information and choice may sometimes be given second place, particularly when the child is so unwell they require a PICU admission. This disempowering context coupled with fewer avenues than adults where they can redress the balance when they are recovering can potentially make hospital admission very traumatic for children, and thus for their families.

Despite these conflicting pressures many specialist staff, particularly in specialist paediatric settings work hard to attend to a child’s psychological need for information as well as their medical needs and most young people said they valued the way the staff hard worked with them. In this study the experiences and understanding of children is highly valued. What they have to say about their admission to the Paediatric Intensive Care Unit (PICU) and how they have negotiated their physical and psychological recovery post-discharge is vital as a reflection of who they are and the journey they have travelled. It aimed to give them back some of the choice and control which has been lacking. However this study also recognises that children are living in a social world and thus their parents also have a valuable contribution to make to our understanding of their children's reported experiences. Indeed from the interviews it seems that parents are key in this process because they become the only source of information on the PICU admission from whom children can being to create a narrative.

References

These are the additional references which are not in the original reference list.


**Appendix 19: Summary themes table**

<table>
<thead>
<tr>
<th>AXIAL CODING – RELATES CATEGORIES TO SUBCATEGORIES, SHOWS LINKS BETWEEN CATEGORIES. ANSWERS QUESTIONS SUCH AS WHEN, WHERE, WHY, WHO, HOW AND WITH WHAT CONSEQUENCES</th>
<th>FOCUSED CODING – MOST SIGNIFICANT OR FREQUENT CODES – MAKE MOST ANALYTIC SENSE TO CATEGORISE DATA INCISIVELY AND COMPLETELY</th>
</tr>
</thead>
<tbody>
<tr>
<td>Major theme</td>
<td>Are there any themes that were consistently found across the data?</td>
</tr>
<tr>
<td><strong>EMOTIONAL/PSYCHOLOGICAL</strong></td>
<td>Enormity</td>
</tr>
<tr>
<td></td>
<td>Death/remission anxieties</td>
</tr>
<tr>
<td></td>
<td>Unfairness/anger/Feeling punished</td>
</tr>
<tr>
<td></td>
<td>Parallel traumas/other difficult events/multiple stressors</td>
</tr>
<tr>
<td></td>
<td>&quot;the most scared I've ever been&quot;</td>
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<td></td>
<td>'The intensive care fiasco'</td>
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<td>Torture</td>
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<td>Feeling contained</td>
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<td>Ambivalence or Minimising effect on child</td>
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<tr>
<td><strong>SOCIAL</strong></td>
<td>Comfort seeking</td>
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<td>Being entertained</td>
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<td>Distress at other’s illness</td>
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<td>Promoting altruistic motives</td>
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<td>Worrying about others – expressing distress</td>
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<td>Shared journey</td>
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<td>Struggling with isolation</td>
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<td>Staff -valuing -attitudes</td>
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<tr>
<td><strong>PHYSICAL</strong></td>
<td>Dynamic experience -constantly changing</td>
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<td></td>
<td>Physical experience</td>
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<td></td>
<td>Being highly managed</td>
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<tr>
<td><strong>ENVIRONMENTAL – HOSPITAL AS CONTAINMENT</strong></td>
<td>Eulogising about IC</td>
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<td>Valuing the service</td>
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<td></td>
<td>Downward comparison</td>
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<td>Enforced confinement</td>
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<td>Choosing to stay. Rationale for choice</td>
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<td></td>
<td>Missing home comforts</td>
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<td></td>
<td>Needing personal space</td>
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<tr>
<td><strong>TIME RELATED ASPECTS OF ADMISSION</strong></td>
<td>Time logged related to diagnosis &amp; treatment</td>
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<tr>
<td></td>
<td>Perception of length of time</td>
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<td><strong>SEEKING NORMALITY DURING ADMISSION</strong></td>
<td>Desiring normality</td>
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<tr>
<td></td>
<td>Trying to achieve normality in hospital</td>
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<td>Disruption</td>
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<td>Treatment being ‘not normal’</td>
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<td>Links with specialness?</td>
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<td>Noticing non-normality</td>
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<td></td>
<td>Developmental cusp</td>
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<tr>
<td>CHOICE AND CONTROL</td>
<td>Also an issue post-admission</td>
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<td>-----------------------------------------------------------------------------------</td>
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<tr>
<td>Relationship with control over destiny</td>
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<tr>
<td>Recognition of mortality</td>
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<td>Feeling intruded upon</td>
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<tr>
<td>Feeling out of control</td>
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<tr>
<td>Not having any options or choices</td>
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<tr>
<td>“there was nothing I could do...”</td>
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<tr>
<td>Physically out of control</td>
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<tr>
<td>Choosing or rejecting choice and control</td>
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<tr>
<td>Taking back control</td>
<td></td>
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<tr>
<td>Gathering and using Medical terminology</td>
<td></td>
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<tr>
<td>Out of control/ out of this world</td>
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</table>

<table>
<thead>
<tr>
<th>RELATIONSHIPS</th>
<th></th>
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<tbody>
<tr>
<td>Different perspectives on same experience</td>
<td></td>
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<tr>
<td>Contrasting/Incongruent narratives</td>
<td></td>
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<tr>
<td>Disconnecting - ‘Double blow’ — being cut off from outside world</td>
<td></td>
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<tr>
<td>Enormity of experience leads to disconnection</td>
<td></td>
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<tr>
<td>Not talking about experience</td>
<td></td>
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<tr>
<td>Also relates to individual and family identities and beliefs about talking about things</td>
<td></td>
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<tr>
<td>Wanting to talk but not having space to be heard – avoiding in an attempt not to upset you</td>
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<tr>
<td>Links with not talking about experience in this category</td>
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<tr>
<td>Needing to tell story</td>
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<tr>
<td>Working as a family</td>
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<td>Downward comparisons</td>
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<tr>
<td>Upward comparisons</td>
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<tr>
<td>Parenting a child with a LD</td>
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<table>
<thead>
<tr>
<th>IMPACT ON IDENTITY</th>
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</thead>
<tbody>
<tr>
<td>How the illness affect identity/who you are</td>
<td></td>
</tr>
<tr>
<td>Impact on parent</td>
<td></td>
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<tr>
<td>Maternal role links here. Also in identity</td>
<td></td>
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<tr>
<td>How others see you — Links with connectedness</td>
<td></td>
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<tr>
<td>Identity — how you see yourself</td>
<td></td>
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<tr>
<td>Including loss</td>
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<tr>
<td>Related to developmental milestones</td>
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<table>
<thead>
<tr>
<th>STRIVING FOR NORMALITY FIRST STEPS IN RECOVERY</th>
<th></th>
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<tbody>
<tr>
<td>PHYSICAL &amp; PRACTICAL</td>
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<tr>
<td>Trying to achieve normality once out of hospital</td>
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<td>Physical limitations to normal activities</td>
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<td>Struggling with routine</td>
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<tr>
<td>DEVELOPMENTAL L Y</td>
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<tr>
<td>Not having normal developmental experience</td>
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<tr>
<td>Achieving normal milestones</td>
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<tr>
<td>COMPARISON OF PRE- AND POST- NORMALITY</td>
<td></td>
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<tr>
<td>Being normal before diagnosis</td>
<td></td>
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<tr>
<td>Normal being different to before</td>
<td></td>
</tr>
</tbody>
</table>
Major Research Project (Appendices)

| EMOTIONALLY/PSYCHOLOGICALLY | Specialness  
|                           | Normal post-illness being more than normal before  
|                           | Put here because this relates to recovery – cognitive dissonance between special treatment necessary because of illness and therefore to construct as special anyway makes that easier to understand.  
|                           | Relates to processing  
|                           | Being unsure about normality  
|                           | Returning to normality (Easy return to normality)  
|                           | Striving for emotional recovery (return to normality)  
| EMOTIONAL PROCESSING | Emotional processing  
|                        | Connecting with emotional experience  
|                        | Coping with trauma  
|                        | Not wanting to remember  
| COGNITIVE PROCESSING | Lucky escape  
|                      | Focusing on small details (rather than bigger picture)  
|                      | Factual story telling  
|                      | (Lack of emotional content)  
|                      | (Recalling admission details not illness details)  
|                      | Being disconnected with the experience  
| PROCESSING THE EXPERIENCE | Telling the whole story  
|                          | Unprocessed narrative  
|                          | Or Incomplete narratives  
|                          | Building a narrative over time  
| PROCESSING THROUGH NARRATIVES | Narrative of contamination This is a theory driven code be aware of this in terms of GT coming from participants  
|                           | Considering alternative narratives  
|                           | Predicting future outcomes  
|                           | Or trying to predict or find reasons for things  

Unconscious and conscious awareness

| COPING STRATEGIES | Features of coping  
|                   | Reflecting on coping being situation dependant  
|                   | Not coping  
| Avoidance strategies | Autopilot  
|                     | Detaching  
|                     | Hiding emotions  
|                     | Coping by avoidance or forgetting  
| Control strategies | Constant battling/ keeping fighting  
|                     | Planning for worst eventuality  

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### Mastery strategies – taking control of the situation
- Seeking and demanding information
- Over compensation

### Coping through relationships
- Seeking support
- Closeness & Forming of relationships
- Staying safe
  - ‘talking in non verbal ways’
- Taking time out of the relationship
- Finding and sharing joy
- Trusting professionals

### Coping through the self
- Being positive
- ‘Buckling down’
- Comfort eating
- Being hard on self/Judging self
- Personal strategies
- Narrative of coping – internal strengths
- Becoming de-sensitised

### Lack of model of recovery – living with uncertainty
- Shifting concept of wellness
- Ongoing health problems/scars
- Ongoing vulnerability
- Recovery during illness
- Supporting physical recovery
- Needing a known or familiar environment

### Ambivalence about recovery - Treatment as ‘safe’
- Models of recovery – anxiety/fear
- Unstable/unable to be relied upon
- Feeling secure and content

### Effect of experience on personality
- Bouncing back (to ‘old self’)

### Being contained
- Pressure on family
- Educating others
- Reconnecting
- Difficulties with reconnection
- Normal models of recovery (for ‘normal’ people) - For comparison
- Needing space to talk
- Parental Role
- Being available
- Working together – as a couple
- Developing own understanding from personal
Major Research Project (Appendices)

<table>
<thead>
<tr>
<th>Understandings</th>
<th>Experience</th>
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<td>Developing a model of recovery by looking at experience</td>
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<td>Unusual experiences contributing to recovery</td>
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<td>Slowness of recovery</td>
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<td>Changing perspectives</td>
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<td>Relates to normality in that some families seek returning to previous place whilst some acknowledge that perspectives have been changed forever</td>
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<td>A journey</td>
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<td>Rebuilding</td>
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<td>And reprocessing with time</td>
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<td>Changes over time</td>
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<td>Reflecting on life – philosophical questions</td>
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<td>Developing resilience</td>
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<td>Acceptance</td>
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<td>Living life to the full, achieving, pushing self</td>
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<td>Giving personal space to recover</td>
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<td>Staged model of recovery</td>
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<td>Valuing recovery</td>
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<td>Learning from experience</td>
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<tr>
<th>Changes/ongoing-ness</th>
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<tr>
<td>Being realistic about what can be achieved</td>
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<tr>
<td>Goal setting</td>
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<tr>
<td>Returning to school</td>
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<tr>
<td>Support from school</td>
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</table>
Appendix 20a: Seeking feedback from participants

Dear [Parent’s name/Child’s name]

PROJECT TITLE: The experiences of children & families following discharge from Paediatric Intensive Care Unit (PICU)

Thank you for participating in this project, and giving up your time to be interviewed. The information gathered has been invaluable.

Attached is a summary of the results with a feedback sheet. It would be really helpful if you could read the summary and then give some feedback about the results. This is so that we can make sure that the results really reflect people’s experiences.

Please send the feedback sheet in the stamped addressed envelope. It would be helpful if feedback sheets could be sent by 10th April 2010.

In the next few months we shall be completing the project and writing a full report. If you would like a copy of the report please tick the box at the bottom of the feedback sheet.

Best wishes,

Ellie Atkins
Researcher, University of Surrey
Email: e.atkins@surrey.ac.uk
Summary of results – Recovery after paediatric intensive care admission

The PICU and hospital experience

All the families told me extremely moving stories of the illness and hospital admissions. Many families had a number of interesting and insightful reflections to make about their intensive care admission. People talked about ‘the enormity’ of being that unwell, although this was truer for parents than for young people. Many young people were less aware at the time, but afterwards would look back and be shocked by what they had been through.

The affect on your identity

All the parents and young people talked about the affect of the serious illness and their hospitalisation had on them personally. Whilst in hospital people felt they had little choice or control and this was difficult. After discharge people highlighted how the experience made them reassess their priorities. For young people it seemed that they had matured as a result of their experience, and they could see the differences between them and their friends. However some young people had also missed key experiences which were important for their development and this was something which needed to be overcome. Parents reported getting more perspective on life generally and needing to develop strength to endure the experience and cope with the recovery period.

Trying to get back to ‘normal’

It seemed that people assumed that being discharged meant things would go back to ‘normal’ – i.e. that things would return to what they had been like before. However often people described how in reality their experience wasn’t that smooth. People talked about how long it took to return to school or work and how they were not able to do things they could do before. Additionally after discharge people began to realise the ‘enormity’ of what had happened to their family and this took some time to get over.

Reconnecting

Most people described the illness as very isolating. For young people this meant being cut off from school, their friends and their normal activities. For parents they felt disconnected with the world.

Parents and young people described the importance of family connections and emphasised how important this support was, both during admission and after discharge. Families talked about having to re-connect with life
after the isolation of hospital and being ill. It seemed that it was easy for families to reconnect with those who were close to them, but reconnecting with others was harder. Sometimes this was because people did not know how to talk to others about their experiences in hospital. Reconnection seemed to happen eventually, but sometimes it took time to achieve.

Coping strategies

Coping strategies seemed to be used by people after discharge to cope with all that they had been through and to start to return to their normal life. There was a range of different coping strategies described, and these included being positive, hiding your feelings, seeking support from others, comfort eating, going on to ‘autopilot’ and many others.

Ideas about recovery

It seemed that over time families moved from just ‘coping’ to ‘recovering’. Both parents and children had many ideas about how ‘recovery’ would work and what was personally important for them. For example one young person described getting his social life back together as top of his priority list. In another family one mum described the importance of taking time to process what happened to you. Many people talked about the fact that their priorities and goals for life were different than they would have been before this experience. This meant ‘recovery’ wasn’t about returning to where they had been before, but was about choosing a new direction and heading there instead. Parents and young people described how recovery was slow and took time. They noted that the child just has to work through their emotions, and need the support of their parents and others to help them do this.

Processing the experience

Throughout the interviews it seemed that people were telling a story which they had thought about and tried to understand. People were able to reflect that sometimes they hadn’t been able to talk about the experience of being in intensive care because they didn’t want to upset others. Often people said that it was helpful to talk but they were often not sure how to do this or who to talk it through with. People also talked about the different ideas that might exist in the family, for example the comparison between what the child or young person had taken from their admission, compared with how this was understood by the parents. People sometimes would describe their experience very factually, with little emotion. This was a helpful way to be able to think about the enormity of what had happened. At other times people connected with their experiences more emotionally, describing how they had felt at the time and how they feel now that they are in a different place.
Feedback sheet

Please use this sheet to give any feedback about the summary of results above. In your feedback try to answer the following questions:

- In what ways do these results match/not match with your personal experiences?
- What are the important points which these results highlight?
- What is missing from these results that is important to include in a project about recovery after Paediatric Intensive Care?

Please send just this page in the stamped addressed envelope provided – please send by 10th April 2010.

Thank you for your input. We will use these results to help families who experience PICU admission in the future.

If you would like a copy of the final report when it is finished please tick here
Appendix 20b: Seeking feedback from participants (child-accessible -version)

Dear [child's name]

Thank you for talking with me about your experience of being in hospital and about your life since you were discharged. It was very interesting to talk to you. I also really liked the drawings you did for me which told me more about your life.

Here is a summary of the results from all the people I talked to. Please can you let me know if what I have written is right or tell me if I've got it wrong?

Please read the next page and then tell me what you think in the box below.

This is what I think about the results:
What I found out from talking to people:

1) How being in hospital changes you
   People told me that they had to be strong to
   be in hospital, and that they learnt lots of
   things about how to cope with life

2) Getting back to normal
   People told me that they expected to get back to
   normal once they left hospital, but things were
   different and it was difficult to find 'normal' again.
   Getting back to where they wanted took a long time.

3) Building relationships
   Being in hospital was like being separate from
   everyone. It was hard to re-connect with
   people, especially because things were
   different for you. For example you found it
difficult to go places and see people because
there was always food there and you couldn’t
eat anything.

4) Coping and recovering
   It took everyone a long time to recover from being in
   hospital. It took mums and dads a long time too,
even though they weren’t the ones who were ill.
   Everyone said that it was slow going and they
   had to work hard to get back into life again.
   People also found that they were different than
   they had been before their illness.

5) Understanding the experience
   People had to think a lot about what had happened
   to them so they could understand it. When they
   understood it they realised why they were upset and
could talk about it more easily.

Now tell me what you think. Have I got it right? Is there something I
missed?

You can write in the box on the first page, or get someone to write for you.
Please send me that page back so I can see what you think.
I hope everything is going well for you.
Take care

Ellie Atkins
Researcher, University of Surrey
Email: e.atkins@surrey.ac.uk
Appendix 21: Examples of feedback from participant

Feedback sheet

Please use this sheet to give any feedback about the summary of results above. In your feedback try to answer the following questions:

- In what ways do these results match/not match with your personal experiences?
- What are the important points which these results highlight?
- What is missing from these results that is important to include in a project about recovery after Paediatric Intensive Care?

These results reflect my personal experience in many ways. The important points that these results highlight is how the whole experience affects you and your family and how difficult it is to return back to normality. The missing point from the results is that going through this experience can have a positive effect on people. It can make you stronger as a person and to appreciate the smaller things in life. In your recovery, you look back and realise what you’ve overcome.

Please send back this page in the stamped addressed envelope provided - please send by 10th April 2010.

Thank you for your input. We will use these results to help families who experience PICU admission in the future

If you would like a copy of the final report when it is finished please tick here.

Please contact me with any questions at e.atkins@surrey.ac.uk

Participants feedback information 1/2/10
Feedback sheet

Please use this sheet to give any feedback about the summary of results above. In your feedback try to answer the following questions:

- In what ways do these results match/not match with your personal experiences?
- What are the important points which these results highlight?
- What is missing from these results that is important to include in a project about recovery after Paediatric Intensive Care?

I find the results very interesting, having felt my experiences were unique, so it is clear that others have similar stories. Thank you for compiling this.

Please send just this page in the stamped addressed envelope provided – please send by 10th April 2010.

Thank you for your input. We will use these results to help families who experience PICU admission in the future.

If you would like a copy of the final report when it is finished please tick here.

Please contact me with any questions at e.atkins@surrey.ac.uk.
Feedback sheet

Please use this sheet to give any feedback about the summary of results above. In your feedback try to answer the following questions:

- In what ways do these results match/not match with your personal experiences?
- What are the important points which these results highlight?
- What is missing from these results that is important to include in a project about recovery after Paediatric Intensive Care?

These results do mirror my own personal experience.
The important points reflect how hard it is to get back to a normal life! Or moving on from an experience like this.
What I think is missing is that there is no mention of anyone getting any professional help or counselling on the road to their recovery!!!

Please send just this page in the stamped addressed envelope provided – please send by 10th April 2010.

Thank you for your input. We will use these results to help families who experience PICU admission in the future

If you would like a copy of the final report when it is finished please tick here

Please contact me with any questions at e.atkins@surrey.ac.uk
**Appendix 22: Example of feedback from professional**

From: Name [Name@meningitis-trust.org]
Sent: 25 February 2010 16:18
To: Atkins EK Miss (PG/R - Psychology)
Subject: re presentation

Hi Ellie

I just wanted to say again how much I enjoyed your presentation. It really does illustrate many of the problems we hear from families on a regular basis following discharge from PICU. We have put together a discharge leaflet to help, please see attached.

I would be very grateful if you could send me a copy of your presentation. I would also be interested to hear your findings when your study is completed and also any information that you produce for families as a result of your research.

If you are ever in our area (Gloucestershire) and would like to visit us at the Meningitis Trust, just let me know, you would be very welcome.

Kind regards
Name

Name
Community Services Nurse Manager
Meningitis Trust
Direct Dial: 01453 769075
Reception: 01453 768000
Fax: 01453 768001
### Appendix 23a: Peer Checking (Validity check)

**Axial codes**

<table>
<thead>
<tr>
<th>AXIAL CODING</th>
<th>QUOTES</th>
<th>MATCH TO MY CODING</th>
</tr>
</thead>
<tbody>
<tr>
<td>Experiences during admission</td>
<td>“And I thought this is where children come to die (cries).” (Mother, 3)</td>
<td>✓</td>
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<tr>
<td></td>
<td>“When I was in hospital my little sister was like really scared...and it was a bit weird for them to see like tubes in my arms and everything...my face being swelled up...it was a bit shocking for them” (Young person, 4).</td>
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<td></td>
<td>“It’s one of those things that’s absolutely terrifying and um yeah we did think we were going to lose her and it’s very hard...” (Mother, 4)</td>
<td>✓</td>
</tr>
<tr>
<td>Seeking normality during admission</td>
<td>“You feel pretty rotten as it is, because you can’t keep normal life going, do the things you would normally do...” (Father, 5)</td>
<td>✓</td>
</tr>
<tr>
<td>Choice and control</td>
<td>“I think I like to be very independent and I like to be in control...which were two things I couldn’t have when I was ill, which was really hard.” (Young person, 3)</td>
<td>✓</td>
</tr>
<tr>
<td></td>
<td>“You can’t do anything, you can’t make any decisions...I did often feel like a spare part. I couldn’t do, I couldn’t take the pain away, I couldn’t make her feel any better...I couldn’t get nothing right sometimes” (Mother, 2)</td>
<td>✓</td>
</tr>
<tr>
<td>Relationships</td>
<td>“When I was in hospital my little sister was like really scared...and it was a bit weird for them to see like tubes in my arms and everything...my face being swelled up...it was a bit shocking for them” (Young person, 4).</td>
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<td></td>
<td>“It was very much detached...I didn’t really know what to say to anyone else (young person, 3)</td>
<td>✓</td>
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<tr>
<td></td>
<td>“You can’t do anything, you can’t make any decisions...I did often feel like a spare part. I couldn’t do, I couldn’t take the pain away, I couldn’t make her feel any better...I couldn’t get nothing right sometimes” (Mother, 2)</td>
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<td></td>
<td>“I mean we don’t really know, we bounce off each other, but no really know what to say I mean...we don’t really know how to answer that you know because we sort of say, we don’t know what to say.” (Father, 5)</td>
<td>✓</td>
</tr>
<tr>
<td>Impact on identity</td>
<td>“It’s definitely a character building experience, and obviously not one that I would recommend, but having had to have it, it’s um character building”</td>
<td>✓</td>
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<tr>
<td>Major Research Project (Appendices)</td>
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<tr>
<td>because before well I wasn’t too happy with who I was anyway and that reputation sort of wiped clean anyway because I got ill...&quot; (Young person, 3). “I’d been listening to rock music but that changed and then my friends changed, my friends thought I was totally changing, yeah I didn’t feel myself anymore, everything was changing for me. It was like a chapter of my life had been taken out so I don’t know if I’d changed during that...” (Young person, 4)</td>
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<td><strong>Striving for normality (after discharge)</strong></td>
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<td>“It’s weird though, it’s weird doing normal things again because we didn’t do normal...” (Mother, 5)</td>
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<td><strong>Processing the experience</strong></td>
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<td>“I don’t remember much, it’s from like my sister, my mum, my mum’s boyfriend, my dad, it all blends in and makes more sense now...over the year I’ve found out more and more and it makes, it puts the picture together. “ (Young person, 4) “It’s nothing out of the ordinary for him...it’s just another thing that’s happened.” Mother, 6) “you just sort of go on autopilot in those situations but it’s hard because it wouldn’t sink in for quite a while...” (Father, 5)</td>
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<td>“you just sort of go on autopilot in those situations but it’s hard because it wouldn’t sink in for quite a while...” (Father, 5) “I mean we don’t really know, we bounce off each other, but no really know what to say I mean...we don’t really know how to answer that you know because we sort of say, we don’t know what to say.” (Father, 5)</td>
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<td><strong>Ideas about recovery</strong></td>
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<td>“...the important points that these results highlight is how difficult it is to return back to normality” (Young person, 2, written feedback) “I also knew that she needed to space to do or not to do what it was so she could go through what she needed to so she could get her head straight and things. Get back on track, um, and you know, realise she’s got a future and you know she can do what she wants” (Mother, 4).</td>
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### Appendix 23b: Peer Checking (Validity check)

**Open Codes**

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<td>&quot;the most scared I've ever been&quot;</td>
<td>8. Mum - When it was first mentioned to us just the words 'intensive care' it was like 'oh god' you know terrifying, absolutely terrifying. But when we actually go there, because it was so calm, so different, so...for us it wasn't an unpleasant experience... 13. Mum - And they moved him round to resus and that was terrifying going to that room because I knew what that room is for...when they moved him round to resus I honest thought he was going to die</td>
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<tr>
<td>Ambivalence or Minimising effect on child</td>
<td>12. E - what was that like?; Mum - scarier for me than for her. I was saying to E that nothing seems to bother her. 1. Mum - we just did the normal stuff we did in hospital, because as I say it wasn't an emergency admission. It made a difference. Emergency is different to a long term condition so we just go on with it.</td>
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<td>Distress at other's illness</td>
<td>2. Mum - I know we had a young lad, a very young boy, can't remember how old he was, beside us, he had fallen and cut himself and the cut had become infected and he'd become really really ill through that, so mum and dad were very very very worried.... 3. Dad - We got two other kids...they want to see her as well we said no because I don't want to take my younger kids to them to there because maybe it's too much stress for them. I don't want saw them my other daughter she is coming in this kind of condition probably so frightened of them because they never seen her like that she's always happy chap, very very happy bunny when she isn't in intensive care she always happy isn't she.</td>
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<td>Unprocessed narrative Or Incomplete narratives</td>
<td>5. Mum - Stuff like that so I think maybe (trails off) R - Stuff like that...yeah...I know 9. Dad - We actually finished up, got up in the morning this side of his face was normal, that side of his face was like an orang-utan. Still to this day we don't know what happened. We think he was bitten, um...</td>
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<td>Reflecting on</td>
<td>6. Mum - we would handle it differently....but then</td>
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| Coping being situation dependant | it’s so hard to know how you’ll feel at the time, but yeah we did handle it very badly and I think we did a lot of harm to S and we felt terribly guilty and it was so unfair...  
11. Mum – I mean, I say part of the blessing was that it was in the summer holidays. If it had been time off school when I should be picking her up, taking her to school, picking her up from school and doing whatever it might have been different and she probably would mind if I’d said, but the fact is she was having a whale of a time. |
|---|---|
| Coping by avoidance or forgetting | 4. Mum – your body is amazing – it makes you forget the bad bits. When we lie in bed sometimes and suddenly I’ll go to you remember when we were measuring F’s wee and her poo and you know remember when she couldn’t eat for five months and its like; step-dad – you do forget you forget, you get photographs out and you think my god is how it was.; Mum – your body makes you forget.  
10. Dad- Yeah but normally you’re a complete mess; Mum – totally; Dad- you’re sitting outside somewhere and I’m in there dealing with him; Mum – I can’t deal with it; Dad – she’s not actually in there to be perfectly honest; Mum – ...because of his fit [dad] said you don’t want to see this; Dad – I sent her out; Mum – He sent me out because he sent me out of the room which is obviously for my own good and I didn’t see his head banging because I no totally, scary... |
| Closeness Forming of relationships | 7. Mum – Cos we got close to quite a lot of people really  
14. Mum – so it was nice because you ended up building up quite a good relationship with him as a family friend which he is now |
### Appendix 24: Literature review tables

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### Major Research Project (Appendices)

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336
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Appendix 25: Detailed recommendations

During admission (both on PICU and afterwards on the wards)

→ Medical staff should:
  - Have awareness of the issues around choice and control which families struggle with.
  - Provide choices and discussion whenever possible – obviously difficult in life threatening situations, but as appropriate medical staff could try to discuss possible outcomes and actions beforehand or provide opportunities to discuss what happened after the event.
  - Familiarise themselves with recovery journey and be prepared discuss if parents ask
  - Signpost families to psychology services for further discussion or if there are concerns
  - Model/suggest short-term coping strategies whilst families are in hospital which can be transferred to the period directly after discharge (This includes sleeping and eating, keeping clean, reading, having time out, talking about what is happening, gathering information if desired)
  - Support both young person's and parents identity whilst in hospital – e.g. encouraging young person to do things they like or facilitate this if they are very unwell (such as providing a DVD they enjoy); e.g. encouraging parent to act in parental role which if possible is age appropriate
  - Be containing and supportive to parents, modelling this to help parents know how to behave towards their child
  - Provide information about the medical condition and procedures as required and as age appropriate. This information can be used later as families begin to process their experiences.

→ Psychologists should:
  - Give out information (e.g. the leaflet discussed in section 4.7.1) to all families in PICU, as at discharge it is difficult to tell which families will struggle with the recovery process.
• Offer appropriate ongoing psychological support to families who are overwhelmed by their emotional reactions or need a space to explore their experiences
• Use time with parents and children to discuss how families will talk about their experience between themselves and with others when out of hospital
• Model/suggesting short term coping strategies whilst in hospital which can be transferred to the period directly after recovery
• Support both young person’s and parents identity whilst in hospital, by making space for each of them to be themselves and exploring their sense of identity in the context of their illness (and to make further referrals e.g. to play therapists to support this as required)
• Prepare families for life being different after discharge, and help them to recognise that life would not have remained static even without the admission (being mindful of the need to provide a balance and not be overly negative)
• Train and consult with medical staff and allied health professionals, particularly in the context of the ongoing recovery process, and to consider inpatient factors (such as choice and control) which might impact on this.

After discharge

→Medical staff

• Any medical follow up (out-patients appointments and clinics) should include a recognition that physical recovery is only part of the model. Doctors and other staff will need to hold in mind a biopsychosocial model of recovery.
• Medical follow up, particularly that which happens later in the journey (i.e. after some time has passed since discharge) should be prepared to provide more information on the condition and what happened whilst the child was in hospital. This will need to be sensitively provided when families are ready to hear it

→Psychologists should:
• Offer follow up sessions to all families where the child has been in PICU, using the evidence that those families who need it will access this service (Colville et al., 2010)

• Be prepared to help families with processing of their experience and support the creation of a narrative. Alternatively it might be more appropriate to help families simply find the tools to do this at home

• Consider linking up families who have had similar experiences for mutual support and normalising. This aims to de-pathologise the experience post-discharge.

• Provide scaffolding to create a model of recovery which is appropriate for their family, and to accept and integrate the story into their personal and family identities.

Commissioners should

• Recognise the biopsychosocial nature of recovery following a PICU admission and therefore provide a range of provision for families which does not just focus on their medical or physical health needs

• Ensure there is adequate provision for psychologists to meet the needs of young people and their families, both during their admission and post-discharge.

• Note the time that recovery can take and therefore ensure that ongoing support is available and allow families to access support some time after their admission if they require further support

Recommendations for families

As parents and young people will read this report and were integral in its development it is important to highlight what this research suggests they do to support their own recovery.

Generic (for both parents and young people)

• Remember that it is ok to feel sad about your experiences, but that it is equally ok to not think about them and get on with your life. Both of these are important. The journey of recovery will have ups and downs and as you go on there will be more ups than downs.
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- Talking about your experiences will help. Remember your family will have been through it too – when you feel ready start to talk about what you remember and see if you can create a story about your experience of serious illness.

- Look back and notice how things have changed – some of these changes will be for the better, and others may be more difficult to come to terms with. Remember that life changes all the time anyway, whether or not you have a serious illness. Noticing the positives and accepting that the negatives are a part of life too may help.

- Think about how you have managed to get this far – what has helped you to manage? Use these things (if they are positive strategies) to get you through and think about how they will help you in the future.

- Remember that this experience is only one part of you and you are so much more than just the illness or the hospitalisation. Sometimes it can be hard to see this straight afterwards, but with time this will be easier to remember.

- Look after yourself and your family. You have been through some difficult times. Allow time to mourn the losses you have experienced and time to be together as a family to do enjoyable activities or do things unrelated to the illness or recovery

→Parents

- Going into hospital challenges everyone’s sense of who they are. You will be important in helping your child understand their identity as they recover. This involves working to create a balance between keeping things the same and providing growing and changing space – and also acknowledging that things have changed and being ok about this

- You will need to model talking about the experience so your child knows it is ok to talk about it.

- Knowing it’s ok to struggle, to feel sad, to not understand, and being able to let the child know this too

- Your child will need general, non-specific support and will need to feel very loved and safe. This includes setting boundaries appropriate to their age
Major Research Project (Appendices)

(e.g. related to bedtimes, behaviour, school work) which they may not have had whilst they were ill

→Young people

- Remember you are on a journey that has ups and downs
- Recognise that recovery doesn’t just mean getting physically better, but also thinking about what happened and being ok with that
- It’s ok to feel sad or confused sometimes – this won’t last forever
- Coping strategies that might help:
  - Notice when you make progress – celebrating the positives
  - Talk about it with others who you feel safe with - parents often good as they were there too, but other family, friends or teachers may also be good.
- Lots of people noted that they had grown and changed as a person because of their experiences – for example becoming more mature or empathetic – what positive changes have you noticed?
- Knowing who you are can be difficult after a serious illness. That’s ok, because with time you’ll come to a stage where you feel like you do know this again - One person talked about how great it was to be able to ‘rewrite’ his identity. Think about who you want to be, and go for it – there’s no reason you can’t achieve your dreams.
### Research Log Checklist

<table>
<thead>
<tr>
<th></th>
<th>Description</th>
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<tbody>
<tr>
<td>1</td>
<td>Formulating and testing hypotheses and research questions</td>
<td>✓</td>
</tr>
<tr>
<td>2</td>
<td>Carrying out a structured literature search using information technology and literature search tools</td>
<td>✓</td>
</tr>
<tr>
<td>3</td>
<td>Critically reviewing relevant literature and evaluating research methods</td>
<td>✓</td>
</tr>
<tr>
<td>4</td>
<td>Formulating specific research questions</td>
<td>✓</td>
</tr>
<tr>
<td>5</td>
<td>Writing brief research proposals</td>
<td>✓</td>
</tr>
<tr>
<td>6</td>
<td>Writing detailed research proposals/protocols</td>
<td>✓</td>
</tr>
<tr>
<td>7</td>
<td>Considering issues related to ethical practice in research, including issues of diversity, and structuring plans accordingly</td>
<td>✓</td>
</tr>
<tr>
<td>8</td>
<td>Obtaining approval from a research ethics committee</td>
<td>✓</td>
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<tr>
<td>9</td>
<td>Obtaining appropriate supervision for research</td>
<td>✓</td>
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<tr>
<td>10</td>
<td>Obtaining appropriate collaboration for research</td>
<td>✓</td>
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<tr>
<td>11</td>
<td>Collecting data from research participants</td>
<td>✓</td>
</tr>
<tr>
<td>12</td>
<td>Choosing appropriate design for research questions</td>
<td>✓</td>
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<tr>
<td>13</td>
<td>Writing patient information and consent forms</td>
<td>✓</td>
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<tr>
<td>14</td>
<td>Devising and administering questionnaires</td>
<td>✓</td>
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<tr>
<td>15</td>
<td>Negotiating access to study participants in applied NHS settings</td>
<td>✓</td>
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<tr>
<td>16</td>
<td>Setting up a data file</td>
<td>✓</td>
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<tr>
<td>17</td>
<td>Conducting statistical data analysis using SPSS</td>
<td>✓</td>
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<tr>
<td>18</td>
<td>Choosing appropriate statistical analyses</td>
<td>✓</td>
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<tr>
<td>19</td>
<td>Preparing quantitative data for analysis</td>
<td>✓</td>
</tr>
<tr>
<td>20</td>
<td>Choosing appropriate quantitative data analysis</td>
<td>✓</td>
</tr>
<tr>
<td>21</td>
<td>Summarising results in figures and tables</td>
<td>✓</td>
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<tr>
<td>22</td>
<td>Conducting semi-structured interviews</td>
<td>✓</td>
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<tr>
<td>23</td>
<td>Transcribing and analysing interview data using qualitative methods</td>
<td>✓</td>
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<tr>
<td>24</td>
<td>Choosing appropriate qualitative analyses</td>
<td>✓</td>
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<tr>
<td>25</td>
<td>Interpreting results from quantitative and qualitative data analysis</td>
<td>✓</td>
</tr>
<tr>
<td>26</td>
<td>Presenting research findings in a variety of contexts</td>
<td>✓</td>
</tr>
<tr>
<td>27</td>
<td>Producing a written report on a research project</td>
<td>✓</td>
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<tr>
<td>28</td>
<td>Defending own research decisions and analyses</td>
<td>✓</td>
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<tr>
<td>29</td>
<td>Submitting research reports for publication in peer-reviewed journals or edited book</td>
<td>✓</td>
</tr>
<tr>
<td>30</td>
<td>Applying research findings to clinical practice</td>
<td>✓</td>
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</tbody>
</table>
Appendices to the Research Dossier

Published Work and Conference and Poster Presentations

Years One-Three

September 2007-September 2010
MATERIAL REDACTED AT REQUEST OF UNIVERSITY
Appendix Three: Presentation at Conference

Ellie Atkins
Doctorate Course for Clinical Psychology
The Psychology Department
University of Surrey,
Guildford,
Surrey
GU2 7XH

Dear Ellie

Re: Children with complex health needs: Managing the Journey 23rd-24th February 2010

I am writing to thank you so much for coming to speak at the above conference. Your presentation was hugely successful. I was very disappointed not to be able to attend your workshop session but feedback from my colleagues was that it was extremely informative, thought provoking and well executed.

In terms of the feedback – 8 people rated your presentation as ‘excellent’. 9 as ‘above average’ and 1 as ‘average’.

Once again, many thanks for your participation and do stay in touch.

With very best wishes
Yours sincerely,

Jenny Smerdon
Clinical Psychologist
Tel: 01225 731624
e-mail: lifetime@banes-pct.nhs.uk
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Appendix Four: Presentation at teaching day

PICU PSYCHOLOGISTS MEETING
21/5/10
TR 27 Level 5 Hunter Wing
St George’s Medical School

12-12.30 Introductions – All
12.30 -1 Clinical work on PICU - Gillian Colville
1-1.30 Using EMDR with traumatised parents - Victoria Samuel
1.30 - 2 Psychological recovery in families over the year post PICU discharge
   - Ellie Atkins (Surrey Trinice Final Year Research Project)
2- 2.45 Research on outcomes and follow up - Gillian Colville
2.45-3.30 Discussion re unique challenges, collaborations, future meetings - All
Appendix Five: Presentation at CAT conference

28th May 2010

The practice of
Cognitive Analytic Therapy
with people
with Learning Disabilities

PROGRAMME

Event Chair || Val Crowley
9.30 Arrival and registration
10.00 - 10.40 Introducing CAT in Services for People with Learning Disabilities || Val Crowley
10.40 - 11.20 The Psychotherapy File as Dialogue – Adaptations and Modification of the Psychotherapy File when working with People with a Learning Disability || Ann Bancroft
11.20 - 11.35 Coffee
11.35 - 12.15 A CAT Approach to Working with Carers || Julie Lloyd
12.15 - 12.55 The Problem of being Cared for || David Wilberforce
12.55 - 13.45 Lunch
13.45 - 14.25 The Common Themes and Reciprocal Roles when Working Therapeutically with Learning Disabled Offenders || Nicola Murphy
14.25 - 15.05 Bullying to Bullied Group Work: working with the Bullying <-> Bullied reciprocal role in a group for men with a learning disability || Ellie Atkins
15.05 - 15.20 Coffee
15.20 - 16.00 "The whole is greater (other) than the sum of the parts". The benefits of sharing Cognitive Analytic Therapy formulations with staff teams in secure settings for people who have a learning disability and who have offended || Michelle Anwyl, Phil Clayton, Pam Mount
16.00 - 16.30 Conference forum for questions and discussion with panel
Appendix Six: Presentation at BABCP conference

Presentation at the BABCP conference, and short listing for BABCP new researcher award.

From: Rebecca Kelly
[mailto:Rebecca.E.Kelly@manchester.ac.uk]
Sent: 23 June 2010 11:01
Subject: BABCP 2010 - Shortlisted for Excellence Award - Please confirm eligibility
Importance: High

Dear all,

I am emailing because your open paper presentation has been shortlisted for an Excellence Award.

Three Excellence Awards will be awarded at the conference: one for an open paper, one for a poster, and one for a case report poster. The winners will receive complimentary registration for next year's conference, and an invitation to present at the next conference.

To be eligible for a New Researcher Award you must have completed your most recent qualification (MA, PhD, DClinPsy, etc) within the last 2 years.

Please could you reply to this email to confirm you are eligible for this award? If you have any queries about your eligibility, please email or telephone me, my contact details are below.

Best wishes,
Rebecca Kelly
BABCP Conference Assistant & Research Assistant/ PhD student - EROS project

School of Psychological Sciences
112a, 1st Floor Zochonis Building
University of Manchester
Brunswick Street
Manchester M13 9PL
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Appendix Seven: Presentation at BPS conference

Paper to be presented at Faculty for Children and Young People Annual Conference, 7th September 2010.

From: The British Psychological Society [confsub@bps.org.uk]
Sent: 13 May 2010 11:02
To: Atkins EK Miss (PG/R - Psychology)
Subject: Faculty for Children & Young People Annual Conference 2010 - Submission

Dear Miss Ellie Atkins

CYP100003-00005288
Adjusting to a new reality after serious and life-threatening illness: Families experiences of recovery in the year after a paediatric intensive care admission.

I am pleased to inform you that your submission has been accepted as a paper presentation at the forthcoming Faculty for Children & Young People Annual Conference.

We have allowed a maximum of 40 minutes for each presentation, including time for questions.

The electronic abstract you submitted will be included in the Conference Abstract Book and BPS Conference proceedings. If the presenting author is not the first person on the list of authors, please email cypconf@bps.org.uk indicating who to highlight as presenter on the programme. A provisional programme will shortly be available on the Conference website, www.bps.org.uk/cyp2010 where you will find your allocated date and time slot.

The Faculty is offering ONE complimentary day attendance for paper presentations. ALL additional contributors will be expected to register at the appropriate rate. Please mark clearly on the registration form if you are taking the complimentary place on the day of your presentation.

If there is anything further you would like to know please do not hesitate to contact us. It would be helpful if, in any correspondence, you quoted the reference number given at the top of this email.

Thank you again for your submission and we look forward to seeing you at the Conference.

Yours sincerely
Mandy Hemsill
Conference Organiser
On behalf of the CYP Conference Organising Committee

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Appendix Eight: Poster Presentation at Health Psychology, BPS conference

Poster Presentation at Faculty for Health Psychology Annual Conference, 16th/17th September 2010.

From: The British Psychological Society [confsub@bps.org.uk]
Sent: 29 June 2010 15:42
To: Atkins EK Miss (PG/R - Psychology)
Subject: Division of Health Psychology Annual Conference 2010

Dear Ellie Atkins

Re: Abstract submission for the BPS DHP Annual Conference, 15th - 17th September 2010, Queen’s University, Belfast

Adjusting to a new reality after serious and life-threatening illness: Families experiences of recovery in the year after a paediatric intensive care admission.

Thank you for your submission to this conference. This year 77 abstracts were submitted and considered by the Conference Scientific Committee at the June meeting. All submissions were blind reviewed by the CSC. We are pleased to accept your submission as a poster presentation. This year there are two hour-long poster sessions that all presenters and delegates are encouraged to attend, one on Thursday 16th and one on Friday 17th. Those presenting on Thursday can put their posters up anytime during Wednesday or as soon as they arrive on Thursday. Those presenting on Friday should put their posters up after the poster session on Thursday. In July you will be emailed with information on which day you are presenting and details of the poster format.

The electronic abstract you submitted will be included in the Conference Abstract Book and BPS conference proceedings. If the presenting author is not the first person on the list of authors, please email kerry.wood@bps.org.uk indicating who to highlight as presenter on the programme. A provisional programme is available on the conference website (www.bps.org.uk/dhp2010).

Registration is available via the website. We would encourage you to register early, as the conference fee increases at the end of July. All those presenting at the conference must register.

Thank you again for your submission. We look forward to seeing you at the conference.

Best wishes,

Dr Caroline Henderson, DHP National Conference Organiser
Dr Diane Harcourt, DHP Chair
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