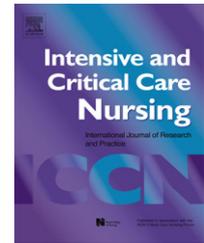




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ORIGINAL ARTICLE

# A 'biopsychosocial' model for recovery: A grounded theory study of families' journeys after a Paediatric Intensive Care Admission

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## KEYWORDS

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Intensive care;  
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**Summary** Paediatric intensive care has a significant impact on the children and families who experience it. This effect continues post-discharge as the family attempt to recover from their ordeal. This article begins with an exploration of what makes a Paediatric Intensive Care Unit (PICU) admission potentially so traumatising and then examines current models for recovery which exist in the literature. These remain sparse and do not provide a coherent model for recovery after PICU. This paper therefore presents research which aimed to develop a model to understand the recovery journey for families. Children who had been PICU patients and their parents were interviewed and the transcripts analysed using grounded theory. Participants highlighted the importance of physical, psychological and social recovery and these have been integrated into a biopsychosocial model of recovery. Finding and accepting a 'new normal' were the culmination of this biopsychosocial journey. This paper concludes that an integrated approach to recovery is necessary and makes some recommendations for further research and clinical practice.

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## Introduction

An admission to a Paediatric Intensive Care Unit (PICU) can be significantly traumatic for both young people and their families. The challenges continue beyond the hospital (Bronner et al., 2010), as families then have to negotiate

the complex recovery period and simultaneously manage their feelings about the admission. Whilst a great deal is now known about the admission experiences we still lack an in-depth understanding of how children and parents' negotiate recovery following PICU discharge (Colville et al., 2009).

## The nature of PICU admission

Over 15 000 children (aged 0–15) per year are critically ill and require intensive support during their hospital admission (Draper et al., 2008). A PICU caters for the most seriously

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ill babies and children providing a high level of observation and intensive medical care.

PICU admission can have a large psychological effect on children. Reasons for this include 'The highly invasive technological interventions, lack of control over events, severity of illness, and high levels of parental distress...' (Rennick et al., 2008, p.252). Close proximity to parents can be unusual for older children, whilst for younger children separations from parents during procedures can be equally distressing. Other reasons include displacement from home and friends and witnessing the distress of other children and families.

However, whilst the experience is traumatising for a large number of children, for others who experience an admission there is no evidence of trauma (Colville et al., 2009). For some children the support from nurses 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.

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; Bronner et al., 2009; Colville, 2001). Parents worry about the level of pain their child is experiencing and the potential for a poor outcome, both physically and psychologically (Salisbury et al., 2007). They also report difficulties after seeing other children dying or in considerable distress (Colville et al., 2009). Further, they find the highly technological environment of PICU overwhelming, but do welcome knowing that they are in the right place. No correlation has been found between the child's illness severity and maternal distress (Balluffi et al., 2004; Bronner et al., 2010; Colville and 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.

### Models of recovery for children

To date there are few models which examine children's psychological recovery after health-related trauma or any models which look systemically at family recovery. However, there are theories within the field which are helpful in providing a framework for our understanding. Salmon and Bryant (2001) consider the developmental issues following exposure to trauma and propose that cognitive theories must include the differing knowledge, language development and emotional regulation skills of the child.

Finkelhor and Browne's (1985) model highlights key influences of trauma on psychological functioning, such as the impact of powerlessness and betrayal. Their paper considers how these might influence a child's ability to recover. Although their model was designed specifically for children who had been sexually abused, Stevenson (1999) noted that it could be useful for other types of trauma. For PICU admission powerlessness would appear to be particularly poignant

as children have so little control over their bodies (e.g. causing them pain) or what others do to them (e.g. invasive medical procedures). If parents are perceived to do nothing to prevent painful experiences or are seen to actively endorse them then children may also feel betrayed. Glaser (1991) later added further components to this model, including the recognition of extreme fear and isolation which could also be present for children in PICU, who are removed from their peers and aware that something was seriously wrong with them.

### Models of physical recovery

In healthcare a 'dualistic thinking' mindset (Sperry, 2006, p.26) can be the dominant perspective with the result that there is a lack of integration of the mind and body. This still exists in contemporary medical practice (e.g. Levant, 2005; Sperry et al., 2008) and results in 'the supremacy of the bio-medical model' (Sperry, 2006, p.26). In paediatric work medical staff are noticeably more psychologically minded and will consider referrals to psychological services when a psychological element to an illness is detected. However, this often remains as an adjunct to treatment rather than being an integrated part of the holistic management of the child's presenting difficulties from the outset.

Although the biopsychosocial model (Engel, 1977) is recognised theoretically, operationally it remains on the periphery of clinical practice in acute medical settings. The acknowledgement of social and psychological factors impacting on overall health and wellbeing in a comparable way to biological or medical factors is necessary to provide an understanding of children's complex responses to physical injury. Whilst the biopsychosocial model provides a framework for 'assessment, diagnosis, treatment and prevention' (Sperry, 2006, p.26) there is little evidence it has been applied to recovery either in physical or in mental health settings, despite the finding that families describe their experience in psychological and social terms as well as highlight physical difficulties (Shudy et al., 2006). Perhaps the explanation for this lies with the thinking that the model is 'primarily descriptive in function, rather than explanatory' (Vetere, 2007, p.5).

### Cognitive or emotional models

Most other relevant models tend to focus on either cognitive or emotional appraisals and subsequent strategies for recovery following trauma and leave out the physical or biological elements. For example the concept of locus of control reflects the way an event is interpreted as the precursor to either recovery or ongoing mental health difficulties (Capps and Bonanno, 2000; Weiner, 1992). Models of coping categorise people in a number of ways, including as 'sensitisers or repressors' (Field et al., 1988) or as task-focused, emotion-focused or avoidance-focused (Hoge et al., 2007). These models do not take account of coping mechanisms being situation-dependant or that people may employ a number of strategies rather than relying on just one way of coping.

## Aims

This research aimed to investigate how families (parents and young people) came to understand their recovery following their child's admission to PICU. Using grounded theory it sought to establish whether there was a more holistic model of recovery which was person centred and did not simply gather a record of symptoms. Thus by being grounded in the participants' experiences it aimed to gather an understanding of the nature of recovery after serious illness, particularly focusing those aspects which were important to children and their parents. Finally it aimed to develop a model which would be helpful to practitioners working in this arena.

## Method

### Research challenges

Undertaking research in this area is challenging owing to the nature of the injury, subsequent potential distress, the life expectancy of participants and the location of the medical units and the geographical spread of families. Furthermore a lay perspective exists, believing that children will not want to share their experiences and that discussion will be emotionally unhelpful if it is distressing despite the substantial evidence to contradict this position (Newman and Kaloupek, 2004).

### Methodology

This study was carried out using the qualitative method of grounded theory (Charmaz, 2006). The approach allowed the individual voices of each child or parent to be 'heard' and valued and recognised that the context and system around the participants also influenced what they understood about their experience and what they chose to share in an interview (Dallos and Draper, 2000). Unlike other qualitative methodologies grounded theory moves beyond individual case studies (Smith and Eatough, 2007) and through rigorous analysis allows the genesis of a model or theory with explanatory power. In this study a constructivist method, seeing analysis as 'created from the shared experience and relationships with participants' (p.130) was adopted (Charmaz, 2006) The process of data collection and analysis in grounded theory has been described as involving 'spiral patterns of activity' (Payne, 2007, p.73) where data was collected and analysed, feeding into the focus of further data collection.

### Detailed method

Ethical approval for this study was received from the National Health Service (NHS) Research Ethics Committee and the NHS Research and Development Committee for the research site. The methodology was developed using advice from parents with children within the age-range. These participants guided the development of the interview schedule. A pilot interview was then carried out with a family who had experienced a PICU admission and their feedback integrated

into the schedule. This piloting process also highlighted the systemic nature of the admission and thus a large role was given to interviewing parents as well as young people to ensure this was adequately captured.

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.

General practitioners (GPs) of the 48 families who met the inclusion criteria were contacted to gain consent to contact families. Consent was given in all but four cases and was refused only if the child had died or continued to be seriously unwell. Then families received a letter inviting them to participate. Eight families agreed to participate in the research with a further family recruited to check the emerging model. The researcher met with each family at their home at a time suitable to them. A semi-structured interview schedule was used which consisted of open-ended questions and relevant areas which the participant raised were explored in more detail. Children were interviewed with or without their parents depending on their wishes. Interview length ranged from 1 hour to 2.5 hours and although the option of a break was offered to all participants, none felt it was necessary. All interviews were taped and later transcribed. A summary of participants can be seen in Table 1. There were a large number of families from ethnic minority backgrounds in the sampling pool but the participants consisted of 8 families who defined themselves as white British and one as Asian British.

### Analysis

The analysis was conducted in line with Payne's (2007) view of data analysis. Initially repeated readings of the transcripts were carried out to highlight meaningful units. These were labelled in the initial coding stage by all three authors. The aim of this stage of analysis was to 'capture the details, variation and complexity of the source data' (Payne, 2007, p.79).

The interview schedules were adapted as initial codings emerged. Further interviews were then carried out and the resulting data was coded by one researcher (EA) in an attempt to identify both the same categories and any new meaningful ones. This process was repeated a number of times with new interviews being dependant on the themes highlighted by participants in previous interviews. Following this definitions of the categories were created and reconsidered to produce 'more conceptually refined codes' (Payne, 2007, p.80). Finally the categories were examined for relationships and hypotheses were tested against the data. This led to 'theoretical integration' where core categories were identified which had major explanatory power.

The approach requires that participants are given an opportunity to comment on the emerging theory and judge whether they think the data and its interpretation matches their views. Therefore participants were sent a summary of

**Table 1** Participant information.

Case	Age of child (years)	Reason for PICU admission	Participants		
			Child	Father	Mother
1	5	Osteomyelitis	✓	✓	
2	17	Leukaemia	✓		✓
3	16	Leukaemia	✓		✓
4	8	Brain tumour	✓	✓	✓
5	5	Status epilepticus		✓	✓
6	7	Status epilepticus			✓
7	15	Meningitis	✓		✓
8	10	Bowel surgery		✓	✓
9	6	Orthopaedic surgery		✓	✓

the research findings and given an opportunity to respond. This was provided in both an adult and a child-friendly version. Six participants returned feedback forms (four parents and two young people). Additionally one family was recruited to discuss and explore the emerging model and to comment/suggest changes as appropriate. This stage enabled verification of the model and ensured that the analysis and conclusions represented the families' experiences.

## Results

In this section only codes relating to the biopsychosocial recovery following a PICU admission are discussed. Analysis and discussion of other findings can be found in (Atkins et al., submitted for publication).

### The 'bio-' in biopsychosocial: physical recovery

Following discharge families focused on their physical recovery, placing this as their first priority. Milestones in this early period were 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)

People noted how long physical recovery took and their surprise that being out of hospital did not mean they were well.

'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)

Because the child or young person was not physically recovered immediately following discharge, other aspects of recovery were more difficult and were delayed until some physical recovery had been achieved. Participants could not recover their social lives and return to activities because of the physical limitations. Whilst it is the child who has been ill a PICU admission has a significant physical toll on parents as well, particularly in terms of poor sleep and inadequate nutrition and exercise.

'I used to sleep on 3 or 4 kitchen chairs pushed together ... and it was probably the most uncomfortable I've ever been but I was so exhausted' (Mother 5)

Parents and other close family members therefore also had to achieve physical recovery.

Focusing on the physical health aspects precluded much emotional engagement with their experience, thus delaying families' psychological recovery. However, families were clear that physical recovery was not the only hurdle they needed to manage.

'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).

### The 'psycho-' in biopsychosocial: psychological recovery

Interviewer: '...once you're out of hospital what are your priorities for [your son]?'

Mother 7: 'Making him happy again, getting him back to his lively self...'

Psychological recovery was vital to families after discharge and as their physical health improved they began to recognise the enormous emotional toll of PICU admission. Coping strategies were initially 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.

'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)

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.

'I would say it's hard after, a couple of months afterwards and obviously to start with you don't feel yourself, so it is just time to sit back, relax, let everything go round you

and when you feel like you can stand up and go back to who you were or be who you want to be really. But you must take things ever so slowly because otherwise things won't get back to how they were' (Young person 7)

'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 you 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)

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).

Psychological recovery involved developing a narrative about the experience. This is discussed in more detail in [Atkins et al. \(submitted for publication\)](#). Participants needed to use the stories from others in the family to build their narrative and tended to think about it a great deal in an effort to understand what had happened.

'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).

It was clear that this working through the experience and producing a narrative engendered movement. As families created a story of their experience they 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)

### The 'social' in biopsychosocial: social recovery

Social recovery began with integration back into the family home and whilst physical recovery was occurring little other social contact was achieved. However, as the young person's health improved wider social recovery was possible.

One of the challenges of social recovery was knowing how to talk to people about the experience, as participants often found their wider family and friends were unsure about how to raise the topic.

'I've never really told 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 4: 'I would like to but it's hard to explain it and stuff...'

Social recovery also involved reintegrating back into the world after having been so isolated and disconnected during the admission. As time passed reintegration with the wider social network became possible (partly due to improving physical health). Young people returned to school and their friends and parents began 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 every day and once I started it dropped right back down to once a week'  
(Mother 3).

The young people's experience of illness and their PICU admission had a significant impact on their social identities, meaning that social recovery often involved social change (such as a new job for parents or a new school or different groups of friends for young people).

'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...'  
(Young person 4)

Parent's roles changed, as during the admission they had been required to provide round-the-clock parenting for a child who was previously very independent. This involved physical and practical help for the child as well as providing emotional support and entertainment. Parents 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 another change in relationships and roles as the child recovered.

### Working towards a 'new normal'

Normality was a reoccurring theme in each of the bio-, psycho- and social areas. It was craved by all families, but during psychological recovery 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. This was an important milestone in recovery and once acknowledged families were able to recognise that '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.

## Discussion

### An integrated model of recovery

As can be seen within the results, families identified a number of strands which together constituted their 'recovery'. Whilst *physical* recovery seems to be people's first priority

it was only one element of the overall progress. Participants emphasised that although it was important and took longer than expected the *social* and *psychological* or *emotional recovery* were all vital parts of their journey.

Fig. 1 focuses on families' experiences after discharge, looking at three concurrent strands of physical, social and emotional/psychological recovery. It draws together how at the start families focus on physical recovery and concurrently, are still feeling quite socially 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 an active 'coping' stage where they are just trying to get through each day and with the aim of getting back to normal.

Fig. 1 highlights that the recovery journey was not linear or dependant on one set of cognitions or coping skills. Instead the process was constructed by participants as biopsychosocial (Engel, 1977) in nature. The circles on the far right of Fig. 1 represent the 'new normal' and include many elements that make 'new normal' different from 'old normal' for families.

The findings indicate that the biopsychosocial model of illness has relevance within the recovery phase and moves the model beyond simply informing areas such as health promotion, assessment and treatment (Sperry, 2006) These findings underscore that explanatory frameworks need to be 'integrative, comprehensive and systemic' (Sperry et al., 2008, p.370) if they are to truly represent the experience of families.

### Roadblocks to recovery

Fig. 1 provides a model which illustrates the pathway to recovery as described by families who have experienced it. However, whilst for some families this process was smooth, for many there were 'roadblocks' which prevented them moving through the various stages to achieve and accept a new normal.

### Pathologising recovery

Many families were ambivalent about talking and thinking about the PICU admission and their reactions to it. However, to repress their thoughts and refuse to talk about the experience resulted in neglect of the psychological and socio-emotional aspects of recovery. The fear that they are doing something wrong often engenders anxiety which paralyses thinking and thus prevents moving on from the PICU experience. Societal expectation played a role in shaping families ability to reflect and process the experience, feeling because they were expected to be happy that the child was physically better and out of hospital. PICU admission is so rare meaning 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, impacting on the family's social recovery. 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 social and psychological recovery appeared to be stalled.

### Medicalisation of recovery

It was striking how confusing the messages were from the medical staff. Despite the acknowledgement of biopsychosocial factors (Davidson et al., 2006) being important physical aspects of recovery and an absence of disease were emphasised and prioritised. This focus may lead to families struggling to hold in mind the multiple elements let alone integrate them with their views of wellbeing. 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.

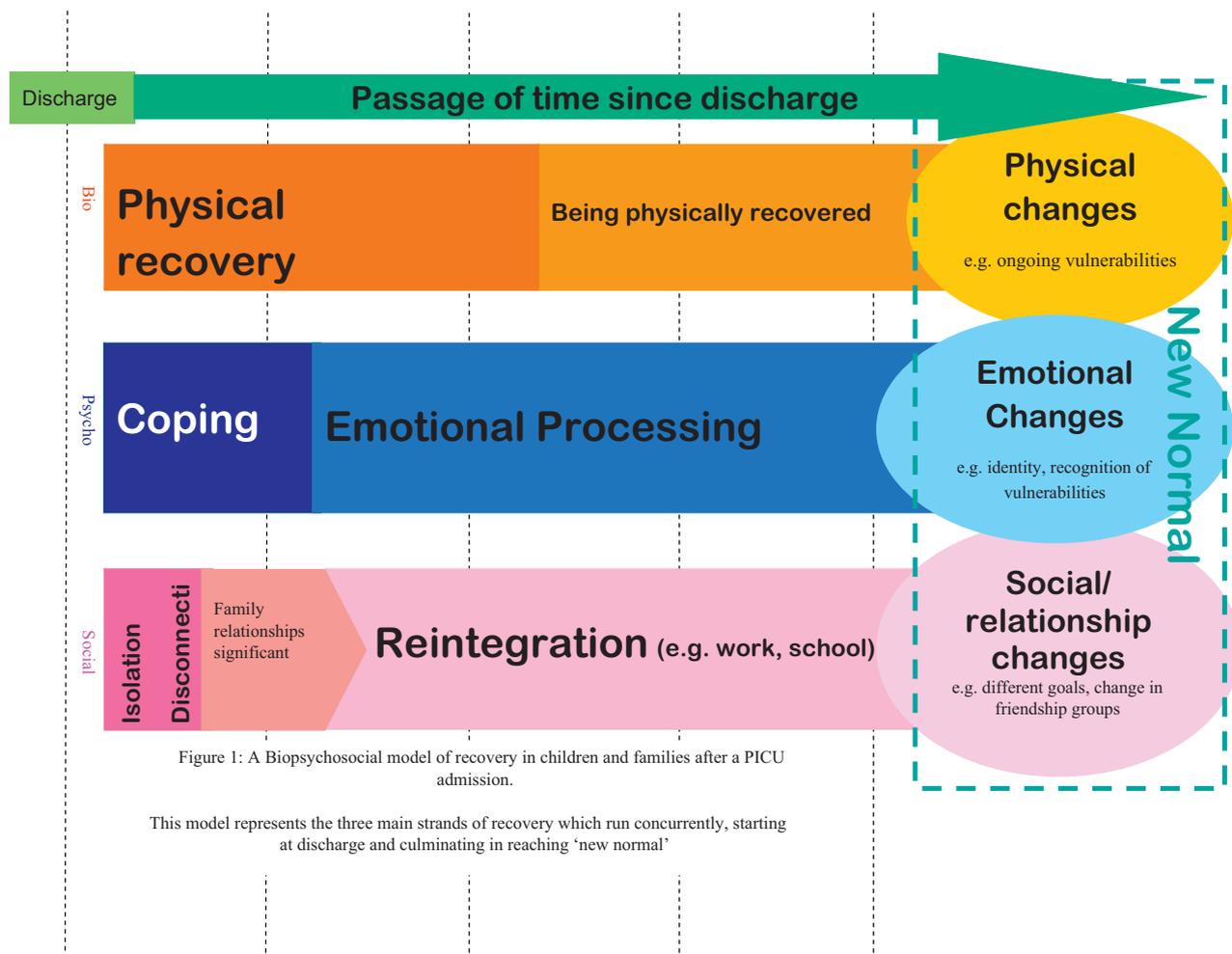
### Making links with the recovery model

The present research has a great deal in common with both the ideology and the outcomes of the 'recovery' movement. Having originally come from the physical health paradigm the word 'recovery' was reclaimed by services users and researchers in mental health. They attempted to shift the narratives from symptom reduction to a focus on overcoming difficulties and living more meaningful lives (Anthony, 1993). Andresen et al. (2003) identified a number of key themes in recovery including 'finding home; re-establishing identity and taking responsibility for one's own recovery' and developed a five-stage model of the recovery process following a serious or enduring mental health difficulty. The model attempted to be person-centred and move beyond psychiatric diagnoses or indicators of 'illness' and 'health'.

This research has taken a similar ideological stance by listening directly to the stories of people with 'lived experience' of PICU and using their understanding to develop a picture of the true nature of the post-PICU recovery experience. Additionally many aspects of the model presented in this paper map onto Andresen's stage model of the 'recovery process'. Following life-changing circumstances families in this study discussed their new goals (Davidson and Roe, 2007) and need to explore their experiences and rebuild their both individually (psychological recovery) and with others (social recovery). Further families discuss the need to 'live with' what has happened to them rather than being able to revert to their previous version of 'normal life' following a return to physical health.

This paper presents a biopsychosocial model of recovery, adapting Engel's (1977) original model which he developed for the physical health arena. The overlap which has been identified between 'the recovery model' and the present research is therefore interesting as it highlights the applicability of the recovery model beyond mental health settings and within settings which remain largely medicalised and physical-health focused.

However, there are also differences between the present model and that presented by Andresen and others. Mainly there is a separation between the different elements of recovery, rather than proposed a multifaced, biopsychosocial recovery model and little focus is given to each of the three strands discussed in this paper. Further research will be vital in developing an understanding of how each model can be applied in the others' contexts.



**Figure 1** A biopsychosocial model of recovery in children and families after a PICU admission. This model represents the three main strands of recovery which run concurrently, starting at discharge and culminating in reaching 'new normal'.

## Clinical implications

The findings from this research suggests that families should be advised about what they can expect from a biopsychosocial recovery experience when being discharged and be prepared for the time it will take to reach a place where things feel '(new) normal'. This advice is most appropriately given once the child is out of danger and alert: the results suggest that both child and parents are more able to engage in discussions at this point. Here, a balance must be struck between creating unnecessary anxiety about what families will face in the future and making them aware of the paths which lie ahead. Knowing about the multifaceted nature of recovery may help families normalise their experiences, rather than worrying when they are not completely 'recovered' despite being physically well. It would also provide the family with a set of parameters to construct their own framework around.

This framework could be supported by post-discharge follow up clinics, such as those offered in adult settings (Griffiths et al., 2006). At such clinics medical staff should hold in mind the broader based biopsychosocial model of illness (e.g. Ogden, 2000) and wellbeing and 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 of their experience. Commissioners need to consider funding practitioners who can deliver evidence based interventions in a creative unique manner to address this client groups' distress and look beyond just their physical needs.

## Critique and further research

As families self-selected to participate in the research 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. If this criticism is taken into account it still suggests that there is a significant need for ongoing psychological intervention. 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) and how services are utilised (Bhattacharya et al., 2010). This has been previously highlighted by Shudy et al. (2006) who also identify that further research into non-white/non-British families is necessary.

Further research is needed to explore these findings across a wider sample, particularly focusing on those groups underrepresented in the present study. 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, this research only investigated families who had a PICU admission and thus it is unclear whether it applies to all families who experience a serious or life-threatening illness or long-term hospitalisation. Clinical experience suggests that the model is applicable in these other contexts but research to confirm this and highlight any differences would be valuable.

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