

Taking a developmental and systemic perspective on neuropsychological rehabilitation with children with brain injury and their families

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Abstract

This paper reviews current approaches and models in the neuropsychological rehabilitation of children following Traumatic Brain Injury (TBI) and cites a large evidence base for a developmental and family systems perspective to neuropsychological rehabilitation of children post-TBI. The paper describes the application and efficacy of a systemic and developmental perspective to rehabilitation of children with TBI, with a clinical case example of this approach. The paper describes the development of a community-based child neuropsychology rehabilitation service integrating applied developmental neuropsychology and systems ideas as a way of working effectively with children with TBI and their families.

Keywords

children, family systems, neuropsychological, rehabilitation, traumatic brain injury

Introduction

The impact of Traumatic Brain Injury (TBI) in children

TBI is recognized to be the primary cause of neurological disability in childhood, with 1 in 30 children suffering a TBI before the age of 16 years. Reported incidence varies between 100–300 per 100,000 per year for children and young adults (Cassidy et al., 2004; Hawley, Ward, Long, Owen, & Magnay, 2003; McKinlay et al., 2008; Middleton, 2001).

The range of severity is broad, from concussion through to persistent vegetative state. Those children who suffer moderate to severe TBI are at a high risk of developing negative sequelae, although

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notably research also highlights that mild TBI can affect neurobehavioural and neuropsychological functioning in children (McKinlay, Dalrymple-Alford, Horwood, & Fergusson, 2002; McKinlay et al., 2008; Yeates & Taylor, 2005). The literature shows that children with severe TBI show neuropsychological, psychiatric and behavioural, and social and academic problems (Catroppa et al., 2007; Max et al., 1997, 1999, 2000; Schwartz et al., 2003; Taylor et al., 2002; Yeates, 2000; Yeates et al., 2004). In addition, findings from longer-term follow-up of children with TBI suggest that even with resolution of cognitive impairment, other problems persist over time (Jaffe, Polissar, Fay, & Liao, 1995; Kinsella, Ong, Murtagh, Prior, & Sawyer, 1999; Klonoff, Clark, & Klonoff, 1993; van Heughten et al., 2006), particularly behavioural and social difficulties (Fay et al., 1994; Fletcher, Ewing-Cobbs, Miner, Levin, & Eisenberg, 1990; Schwartz et al., 2003; Yeates et al., 2004), and that these problems are likely to become more pronounced as academic and social demands increase (Taylor et al., 2002).

It is notable that these sequelae are not characteristic of all children with TBI and the literature documents a great deal of variability in long-term outcomes, even with children with severe TBI (Yeates et al., 1997). Severity of TBI is a consistent predictor of long-term outcome (Jaffe et al., 1995; Klonoff et al., 1993). However, the literature suggests that injury severity alone is insufficient for predicting long-term outcomes of TBI, and that neuropathological and environmental factors also need to be considered, such as higher levels of reported pre-injury behaviour problems (Max et al., 1997, 1998), greater cognitive impairment post-injury (Bloom et al., 2001) and lesser family social advantage (Anderson et al., 2006; Kinsella et al., 1999; Schwartz et al., 2003; Taylor et al., 2002; Taylor, Wade, Yeates, Drotar, & Klein, 1999). In addition, there is evidence from the literature that TBI earlier in childhood is associated with worse long-term neuro-cognitive and psychosocial outcomes than those whose injuries were sustained in later adolescence (Anderson & Moore, 1995; Anderson, Catroppa, & Morse, 2005; Anderson, Morse, & Klug, 1997; Donders & Warschausky, 2007). This supports theories that early brain injury onset interferes with the development of rapidly evolving skills and may be associated also with magnification of deficits in later development (Reed & Warner-Rogers, 2008).

The impact of childhood TBI on the family

There are a plethora of articles in the literature describing the impact of childhood TBI on the family (Anderson et al., 2006; Gan, Campbell, Gemeinhardt, & McFadden, 2006; Lezak, 1988; Testa, Malec, Moessner, & Brown, 2006). The literature documents increased family strain, depression, psychological distress, burden, anxiety, social isolation and loss of income (Rivara et al., 1992, 1996; Wade et al., 2001; Wade, Taylor & Drotar, 2002; Wade, Taylor, Drotar, Stancin, & Yeates, 1998; Gan et al., 2006). To date the majority of the literature has focused on the primary caregiver, however, there is a growing recognition that the effects of TBI extend beyond the injured person and the primary caregiver (Gan et al., 2006) and that siblings and children of individuals with TBI are likely to experience clinically significant levels of distress (Orsillo, McCaffrey, & Fisher, 1993). There is an emerging evidence base on the psychosocial effects on siblings including increased behavioural problems, mood disturbance, relationship difficulties, illness-related fears, loss of milestones, self-blame, anger and guilt (Butera-Prinzi & Perlesz, 2004; Daisley, 2002; Pessar, Coad, Linn, & Willer, 1993). In addition, siblings report feelings of neglect by parents, the need to take on more responsibility at home and increased awareness about the changes in the injured sibling and relationships with family members and friends (Gill & Wells, 2000; Rivara et al., 1992). The research so far has tended to emphasize the negative impact, although the literature also describes positive outcomes, including reports of increased responsibility, maturity, independence, and opportunities to spend more time with the injured relative (Adams, 1996; Smiton, 2005).

Although the extent to which families influence the overall outcome of recovery is still unknown, the child literature provides evidence of a correlation between both pre- and post-injury family function and outcome (Anderson, Catroppa, Haritou, Morse, & Rosenfeld, 2007; Schwartz et al., 2003; Taylor et al., 1999, 2002; Yeates et al., 1997), with Taylor and his colleagues suggesting a “double hazard” effect where greater injury severity and psychosocial disadvantage together predict the poorest outcome (Schwartz et al., 2003; Taylor et al., 2002).

In terms of pre-injury factors, there is evidence of the moderating influence of environmental factors on the outcome of children with TBI, with more marked behavioural and adaptive difficulties found in children from more dysfunctional or disadvantaged backgrounds (Kinsella et al., 1999; Taylor et al., 1999, 2002). Yeates et al. (1997) found that pre-injury family environment was more closely related to behavioural outcomes than to cognitive outcomes. In addition, deficits in memory and adaptive functioning were buffered by above-average family functioning and exacerbated by below-average family functioning. Moreover, children with severe TBI whose families were functioning poorly displayed less rapid recovery over time and lower functioning at 12 months post-injury, than children whose families were functioning well. Stancin et al. (2002) reported on a longitudinal study looking at behaviour and achievement in children with severe TBI, moderate TBI and a control group (consisting of orthopaedic injuries not involving brain injury). He found that families who had stressful lives prior to the injury, perceived burdens arising from the injury as more stressful than those families who had few stressors before the TBI occurred.

The relationship between injury and family function seems to be bi-directional. Investigators have speculated that initial cognitive impairments and behaviour changes in the child adversely affect parent adjustment and parent-child interactions. In addition there is increasing evidence of a reciprocal relationship between long-term child outcome and family adjustment (Taylor et al., 2001; Wade et al., 2003). Taylor and his colleagues conceptualized these reciprocal bi-directional influences as a “negative spiral” in which the “initial post-injury impact of TBI on the child’s behaviour threatens family adjustment, and problems in family adjustment, in turn, make it difficult for parents to deal effectively with the child’s behaviours” (Taylor et al., 2001, p. 762). Specifically they argue that the initial child and family sequelae may develop from various sources such that different behaviour problems originate from the brain insult, and family burden and distress are reactions to the traumatic incident and worry about the child. However, over time, the child’s behaviour problems may themselves contribute to family burdens and distress which sets in motion a pattern of mutual influence between child behaviour and family adversity.

There is research indicating that the impact of TBI on family members is enduring and extends well beyond the acute phase of recovery and the end of formal rehabilitation when traditionally professional support substantially decreases. Wade Wolfe, Maines Brown, & Pestian (2005) followed children with severe TBI, moderate TBI and orthopaedic injuries at six time points from baseline to six years post-injury. They reported that the severe TBI group reported higher injury-related burden over time after injury than the other groups. In addition, the literature reports that neurobehavioral sequelae associated with severe TBI, rather than injury severity per se, is related to family dysfunction (Max et al., 1998). Anderson et al. (2007) also suggests that as physical and cognitive recovery stabilizes, psychosocial and behavioural difficulties tend to emerge. With this shift, the family focus moves from rehabilitation concerns to the ongoing stresses that the child with TBI places on family relationships and activities.

The limited research documenting the needs of a family following TBI (in terms of self-report measures including symptoms of distress or burden or post-injury changes) suggests that quality of life diminishes over time for the caregiver (Kolakowsky-Hayner et al., 2001) and child (Stancin et al., 2002, Limond et al., 2009), and that the quality of life of the child affects the family’s quality

of life, and vice-versa (Stancin et al., 2002; Taylor et al., 2001; Wade, Taylor, Drotar, Stancin, & Yeates, 1996). In addition, families report an increasing number of unmet needs (e.g. for medical information, professional support, community support, involvement in their child's care) as time since injury increases and that the importance of these needs change (Armstrong, 2000; Kreutzer, Serio, & Bergquist, 1994). Therefore there is a recognition that as rehabilitation progresses, the needs of families change, and that the focus may shift from medical to more community-based needs (Stebbins & Leung, 1998).

The impact of family intervention

The reciprocal relationship between long-term child outcome and family adjustment yields support for the hypothesis that the success of intervention programmes designed to assist families in their adjustment may also improve child outcome. And in fact, there is a growing body of research and clinical evidence of the relationship between the family's ability to cope with and adapt to the trauma of TBI and the child's success in rehabilitation (see review by Ylvisaker et al., 2005).

Singer, Glang and Nixon (1994) found that explicit stress management was more effective in reducing symptoms of depression and anxiety than participation in family information sharing groups. Wade and colleagues reported that parents and siblings of children with TBI expressed high levels of satisfaction with a web-based intervention designed to teach families collaborative problem-solving strategies (Wade et al., 2005) and parenting skills (Wade, Oberjohn, Burkhardt, & Greenberg, 2009). Indeed, Drotar (1997) in his review of interventions across several paediatric populations revealed evidence that intervention focused on problem-solving and stress management improves family outcome.

In addition, in recent large review studies of neuropsychological rehabilitation with children, there is an acknowledgement of the variability of the type, diversity and intensity of treatment received by children with TBI (Laatsch et al., 2007; Limond & Leeke, 2005). There is a growing recognition of the need to include the family in the rehabilitation programme, in terms of psychoeducation at an early stage for the family, and support and inclusion of the family as active providers in the treatment plan (Laatsch et al., 2007; Ylvisaker et al., 2007), and the efficacy of a family-focused approach has been demonstrated (Hostler, 1999; Semlyen, Summers, & Barnes, 1998; Swaine, Pless, & Friedman, 2000). What is less clear from the literature is how far services in the UK are able to provide a comprehensive service of working effectively both with children with TBI and their families, despite the models of provision that have been advocated (e.g. Muir, Rosenthal, & Diehl, 1990; National Service Framework for Children, Young People & Maternity Services, 2004). Bowen, (2007) suggested that the need for professionals to acquire concurrent competencies in neuro-rehabilitation and family therapy might be one barrier to service provision.

In terms of family-focused rehabilitation, Ylvisaker and his colleagues have emphasized the value of a *context-specific*, interactive approach in which the child, family and professionals work together to achieve the best outcome (Feeney & Ylvisaker, 1995, 2003, 2006; Ylvisaker, 2003; Ylvisaker & Feeney, 1998; Ylvisaker et al., 2001). This approach argues that knowledge and skills acquisition within the context of the settings, activities and content to which the knowledge and skills apply, is more effective than acquisition outside of the routines of everyday academic, social and familial life. Therefore in terms of childhood neuropsychological rehabilitation, the best form of rehabilitation is that which integrates therapy (i.e. cognitive and cognitive behavioural interventions) into the child's everyday activities of daily life (ADLs) and routines at home, school, work and community life. In addition, in this approach, the role of the therapist after the initial period, is to act as a support system and for day-to-day therapy to be maintained by familiar people in the life of the child, such as parents and teachers (Feeney, Ylvisaker, Rosen, & Greene, 2001; Feeney &

Ylvisaker, 2003). The effectiveness of this approach in terms of the superiority of indirect, family-supported and professionally integrated intervention over conventional multi-disciplinary, clinic-based direct intervention, has since been replicated in larger randomized control studies (Braga, Da Paz, & Ylvisaker, 2005; Wade et al., 2005).

The impact of TBI on development

Severe TBI affects multiple neural systems and causes sudden disruption of children's developmental processes, in many cases across cognitive, academic and social domains. Keith Yeates and his colleagues have argued for some time that the impact of TBI is best understood in terms of its consequences for subsequent development, rather than in terms of outcomes at any particular point in time post-injury (Yeates et al., 2005, 2007). There is an ever increasing emphasis in the literature on the interaction between development and brain injury and its association with outcome in childhood TBI, with a particular focus on the timing and nature of the injury and the stage of skills development (Anderson, Northam, Hendy, & Wrennal, 2001; Eslinger, Biddle, Pennington, & Page, 1999; Schwartz et al., 2003; Ylvisaker et al., 2005).

With a focus on understanding the effect of brain injury at various developmental/neuropsychological stages, neuropsychological rehabilitative intervention is increasingly attempting to put in place strategies to facilitate development to the next stage. For example, there is a growing literature on the critical role of the frontal lobes on behaviour, with an emphasis on the interaction between childhood development and frontal lobe damage when designing and implementing behavioural programmes for children with behavioural disturbance following TBI. Traditional behavioural management methods require the capacity to learn efficiently from consequences. The ability to learn in this way is reduced significantly by frontal lobe injury (Rolls, 2000; Schlund, 2002). In recent years, the research has suggested that *positive behaviour supports* are the most appropriate strategies to manage behaviour of children with TBI, as they focus more on managing the environment (e.g. preventing triggers to behaviour) rather than trying to shape and change behaviour. There is mounting evidence of their efficacy at home (Feeney & Ylvisaker, 1995; Ylvisaker, 2003) and school (Pressley, 1995; Sweet and Snow, 2002; Ylvisaker et al., 2001). In addition, it is recognized that children with damage to the frontal lobes as a result of brain injury have particular difficulty with planning and organizing. Positive behaviour supports can be used by the young person to compensate for these difficulties, for example, by encouraging the young person to use graphic organizers and mobile telephones and other specific organizational strategies, and through the provision and implementation of predictable and paced daily routines. Again, there is evidence of the efficacy of these types of intervention (Feeney & Ylvisaker, 1995, 2003, 2006).

Another example of the interaction between childhood development and brain damage is the difficulty that many children demonstrate in the social domain following TBI (Tonks et al., 2009; Turkstra, Williams, Tonks, & Frampton, 2008; Yeates et al., 2004). Neural substrates of social cognition (i.e. social information processing and the regulation of social behaviour) have been implicated in a network of predominantly frontal and anterior temporal brain regions (Adolphs, 2001; Grady & Keightley, 2002). There is a lot of evidence in the literature that children with TBI display impaired social-affective functioning (Dennis, Barnes, Wilkinson, & Humphreys, 1998; Dennis, Purvis, Barnes, Wilkinson, & Winner, 2001), are frequently less skilled at social problem-solving (Janusz, Kirkwood, Yeates, & Taylor, 2002) and are rated as less socially competent and lonelier than their peers (Andrews, Rose, & Johnson, 1998; Kendall & Terry, 1996; Max et al., 1998). Moreover these difficulties can persist and become more pronounced as academic and social demands increase (Taylor et al., 2002; Yeates et al., 2004). Recent literature has attempted to

combine social neuroscience models with models of social cognition and social development (Yeates et al., 2007). Although sparse, there are also attempts in the literature to identify the contribution of brain dysfunction on the development and expression of social skills in children with TBI (Janusz et al., 2002; Warschausky, Argento, Hurvitz, & Berg, 2003; Yeates et al., 2007). However, clinical application is lacking, both in terms of more sensitive measures to target children with poor social outcomes for further intervention, and in the refinement of a “multilevel, integrated causal model” (Yeates et al., 2007) of social cognition following TBI.

Models to help understand adaptation in child neuropsychological rehabilitation

Family systems models A family systems perspective views the family as a group with definite structure, operational rules, communication patterns and ways to solve problems and negotiate with one another (Carr, 2000; Goldenberg & Goldenberg, 1985). Therefore family therapy treatment aims to work towards a change in the family’s organization, structure, or communication patterns, rather than simply to educate and/or support a family. A systems perspective suggests that healthy family functioning is dependent upon the functioning of each individual within that family system and therefore it is important to consider the entire family system, as family members interact with one another and influence its overall functioning.

One idea held within the family systems approach is that disruptive life events impact the whole family, and in particular that stress can be triggered in a family by the need to adapt, restructure and accommodate to new situations (Vetere, 2001). TBI is an unexpected and sudden intrusion and according to DePompei, Zarski and Hall (1988), immediate family reactions are often based in anger and feelings of injustice at what has occurred. Over time, families tend to begin to respond most often with behaviours that reflect coping strategies consistent with previous organizational patterns in the family. Responses to TBI by families are varied and reflect a number of previously established operational patterns in the family, including previous responses to a given crisis, communication styles (Satir, Stachowaiik, & Taschman, 1975), and family organizational patterns (Maitz & Sachs, 1995; Minuchin, Montalvo, Guerny, Rosman, & Schumer, 1967). Other wider contextual factors have been identified as associated with family responses to TBI, including cultural and ethnic background (McGoldrick, Pearce, & Geordano, 1982), their stage in the family life cycle (Maitz, 1991; Rolland, 1988a, 1988b, 1994; Wade et al., 2002) and the availability of, and the family’s willingness to access community resources (Williams, 1993). In addition, the age of the family member with TBI is significant with DePompei and Williams (1994) arguing that parental dyads, siblings and extended family members have different issues when a child or adolescent is involved, compared to an adult.

Carter and McGoldrick (1988) proposed a model of expected family life cycle stages as including: marriage; birth of children; raising of young children; raising adolescents; launching and moving on of children; middle age; retirement. When a family experiences TBI, it can significantly affect the family life cycle such that a stage is prolonged – for example, a family that was about to move into retirement has to continue in work to provide financially for the family – or a stage is revisited – for example, an adolescent child who was moving towards independence, becomes completely dependent on their parents for care again. It has been hypothesized that as a family goes through various transition periods this can lead to persistent worries by parents about their child’s future and contribute to greater parental burden and family conflict (Silverberg, 1996). In addition, when expected transitions do not occur, or are perhaps occurring in the peers of the child with TBI, and their families, it is a reminder to the parents of what their child should/could be doing and may trigger a loss/grief reaction in the family.

As an adjunct to the life cycle model, Rolland (1988a, 1988b, 1994) developed a model to describe the effect of chronic illness on the family suggesting that one needs to consider not only key family life cycle issues, but also the psychosocial dimensions (onset, course of progression, outcome, incapacitation, level of uncertainty) and time-related stages (crisis or diagnosis, chronic, terminal) of illness. The life cycles transition model and Rolland's model of the life cycle of chronic illness can be useful frameworks to apply to therapeutic work with children with TBI and their families.

Loss and grieving models. Lezak (1986) provided a bereavement model of family adaptation following TBI. She proposed that families need to go through a similar process of accommodation to loss after a TBI, as after a death, that is, as in Kubler-Ross's (1969) linear model of grief in which individuals proceed through a series of stages of denial, anger, bargaining, depression and acceptance. In addition, Lezak recognized the specific difficulties of this process when the person is still alive but their personality has changed (Lezak, 1978), making the process of mourning difficult and uncertain. Williams (1993) supports the idea that in the process of adjustment to TBI, families may experience Kubler-Ross's stages of grief in a non-linear and unpredictable manner.

Coping models. A well-known approach put forward by Lazarus (1991) separates problem-focused coping (which involves attempts by the individual/family to deal with stress by acting on the environment or the self) from emotion-focused coping (which involves a reappraisal of the problem and requires a change in the perceived meaning of the problem). Oddy and Herbert (2003) argue that this coping model can be a useful framework for analysing coping resources available to a family, identifying who is most vulnerable to stress and helping family members to practically problem-solve as well as identifying the role of attributions in the development of stress. Another coping model that has been helpfully applied to families with TBI is the construct of internal (reliance on self) and external (seeking help from others) locus of control (Man, 2002a, 2002b). TBI poses many unique ongoing stressors that might contribute to greater longer-term parental burden and distress than other injuries not involving the Central Nervous System, including emerging behaviour problems and concerns about the child's ability to function independently (Schwartz et al., 2003). These stressors may tax parental coping and deplete family resources thereby contributing to deteriorating function over time.

Oddy and Herbert (2003) proposed that a cognitive adaptation model should be included within a conceptual framework of coping and family adaptation to TBI. Such a model attempts to emphasize the strengths and resiliencies of a family and focus on the positive aspects of how families cope with adversity (Antonovsky, 1993; McCubbin & McCubbin, 1991). Taylor (1983) reports the importance of feelings of "mastery" and "meaning" to enhance coping and self-esteem. This may include being able to appraise negative events as a challenge rather than a threat and make active attempts to alter stressful situations. Taylor and Armor (1996) went as far to say that "cognitive illusions" such as these and others, including self-aggrandizement, unrealistic optimism, and exaggerated perceptions of control, are associated with successful adjustment to stressful events, including conditions of extreme adversity. Specific positive coping strategies have been identified in families with an adult with TBI. Strategies include the ability to see the impact of brain injury as manageable and meaningful (Kosciulek, 1997), the ability to positively reframe events and seek out spiritual guidance (Minnes, Graffi, Nolte, Carlson, & Harrick, 2000), and the ability not to attribute all family problems to brain injury, and developing a realistic but optimistic outlook (Willer, Allen, Liss, & Zicht, 1991).

The development of a community-based child neuropsychology rehabilitation service

Currently we are developing a specialized neuropsychology rehabilitation service in order to effectively meet the needs of children with TBI and their families. The service we provide has been heavily influenced by the findings from research literature summarized in this paper. We recognize from this large body of research and growing evidence base that we need to take both a systems and developmental perspective in order to provide best practice for children with TBI and their families. We have integrated applied developmental neuropsychology and systems ideas, grief and coping models, and behavioural and cognitive behavioural therapy models in our approach.

We recognize that whether a child receives rehabilitation or not, it is the family who often fulfils the vital role of caring for their child following a TBI, and that over the longer term the major responsibilities of caring for the child falls predominantly on parents. We therefore apply Ylvisaker and colleague's (Braga et al., 2005; Feeney & Ylvisaker, 1995, 2003, 2006; Ylvisaker, 2003; Ylvisaker & Feeney, 1998; Ylvisaker et al., 2001) ideas around context-sensitive therapy and as far as possible encourage the inclusion of family members in the rehabilitation process. In addition, we apply a community-based model of rehabilitation, with a focus on the systems around a child or young person, including the family system, the education system, the child's peer group and his or her carers. Our experience is that there is the need to work directly with these systems in order to produce change and to provide optimum recovery and development. In addition, the rehabilitation programme is set up and runs within the home setting (and as appropriate includes other community-based systems such as school), rather than in an institution away from the home.

We explicitly use a developmental approach (Yeates et al., 2005, 2007; Ylvisaker et al., 2005) to rehabilitation. We have developed a model called PEDS to explain our approach. The P stands for physical brain development and includes factors such as the influence of diet, sleep and activity on healthy brain development. The E stands for executive function. We try to understand how executive function development has been affected by the brain injury. The implications from this are to provide environmental and systems level support to compensate for executive weakness. The D stands for development and encompasses understanding the impact of the brain injury on the individual child's development. This includes cognitive, behavioural, social, emotional and physical development. The S stands for understanding the impact of the injury on the systems that surround the child.

We recognize that TBI impacts the entire family (Anderson et al., 2006) and is likely to affect the family's and the child's quality of life (Kolakowsky-Hayner, Miner, & Kreutzer, 2001; Limond, Dorris, & McMillan, 2009; Stancin et al., 2002; Taylor et al., 2001; Wade et al., 1998, 2001, 2002). Our assessment and intervention focus specifically on maintaining and where possible improving the quality of life of the child and family.

We recognize that there is often the need to work with families on a long-term basis, due to the longer-term effects of TBI on family functioning (Taylor et al., 2001; Wade et al., 2003), developmental changes and life cycle transitions in the child and family (Maitz, 1991; Silverberg, 1996; Wade et al., 2002) and the likely emergence of psychosocial and behavioural difficulties over time (Anderson et al., 2007; Fay et al., 1994; Fletcher et al., 1990; Schwartz et al., 2003; Yeates et al., 2004). We are fortunate in the private sector that there is greater opportunity and resources available to work for a prolonged period with children and their families.

It is our practice to co-work a case, such that one psychologist assesses and works with the child with TBI and the other assesses and works with the family. We found that we were unable to

effectively meet either the child's or the family's needs when one psychologist attempted to work with both the child and family.

Assessment

The family assessment includes standard and non-standard measures (i.e. Lichter scales, Visual Analogue Scales) of family functioning; looking at family communication and coping styles, family roles and quality of life. Views of parents and siblings are incorporated, in addition to putting no limits on who might be considered to make up the family unit and participate in the assessment. We are aware also in thinking about the needs of the family that we must incorporate non-injury-related stressors in our assessment of family adjustment to and coping with TBI. More in depth emotional assessment may be appropriate including specific assessment of anxiety, depression and Post-Traumatic Stress Disorder (PTSD).

Typically, the child assessment gathers information about the child's history, cognitive, academic, social behavioural and emotional functioning via neuropsychological testing, standard and non-standard assessment measures, interviews with family members and individuals in statutory and non-statutory services, and observations in the home and school settings. The assessment may also include specific assessments of behaviour (functional assessments), and assessment of trauma and emotional functioning, especially anxiety and depression.

From this collated information, we provide a report with recommendations for ongoing work with the child and family.

Intervention

In terms of intervention for children, where appropriate we address the behavioural sequelae of TBI in children via the application of traditional behavioural intervention such as behavioural contingency programmes, alongside Ylvisaker's and colleagues ideas around context-sensitive rehabilitation, that is, integrating therapy into the child's everyday activities in daily life (Feeney & Ylvisaker, 1995, 2003, 2006; Ylvisaker, 2003; Ylvisaker & Feeney, 1998; Ylvisaker et al., 2001). We provide *positive behaviour supports* to compensate for executive difficulties (Feeney & Ylvisaker, 1995; 2003, 2006; Pressley, 1995; Sweet and Snow, 2002; Ylvisaker, 2003; Ylvisaker et al., 2001). Cognitive remediation for neuropsychological difficulties may be appropriate. We also provide emotional support, in terms of cognitive behavioural therapy, for anxiety, depression or PTSD (presented in a format appropriate for the child's neuropsychological and developmental stage). We may choose to apply family therapy ideas involving the whole family to facilitate change for the child with TBI and their family (DePompei & Williams, 1994; Maitz & Sachs, 1995; Silverberg, 1996). Finally, in acknowledgement of the likely social sequelae of TBI (Dennis et al., 1998, 2001; Janusz et al., 2002; Max et al., 1998; Taylor et al., 2002), we provide specific intervention to facilitate social development in terms of behavioural intervention and modelling, modification of the environment to promote social interaction, and liaison with school (or other relevant settings). We provide advice with regards to the development of social skills via role-playing, group work and reflection and feedback from family and friends (i.e. buddy schemes at school).

In terms of family intervention, any intervention with children will always include education and support for the family (Laatsch et al., 2007; Ylvisaker et al., 2007), and where needed more formal family therapy, particularly where there are issues around adjustment, grief, poor quality of life and emotional functioning. The authors tend to apply a Structural and Narrative frame around this work, acknowledging the impact of TBI on power, roles and hierarchy in the family (DePompei

& Williams, 1994; Minuchin et al., 1967; Maitz & Sachs, 1995), and acknowledging that a family's identity is shaped in part by the stories they hold about TBI and its effect on the individual and family, and that some of these stories may be quite negative and unhelpful (Morgan, 2000; White, 2000). We also value family systems ideas around life cycle transitions and how these may be influenced by TBI in the family (Maitz, 1991, Silverberg, 1996; Wade et al., 2002). More circumscribed pieces of sibling or couple work may be deemed necessary. In addition, families may need advocacy and support in accessing other services, either for themselves or on behalf of their child.

Case illustration

The following case is an example of the work we undertake in our service. The names and details have been changed to protect the family's identity.

Background

In March 2004, at the age of 15 ½ years, Simon was involved in road traffic accident where he was a passenger in a car. He sustained a severe brain injury including extensive contusions and haemorrhage essentially involving the brain stem, basal ganglia and left frontal and temporal areas. He had an initial Glasgow Coma Scale of 3 out of 15 and was in a coma for 2 weeks. He regained consciousness and made gradual progress in the acute hospital setting. In May 2004, he was transferred to a specialist residential centre to continue with intensive rehabilitation. He was discharged home in March 2005 with cognitive, social and emotional, speech and language, physical (left-sided hemiparesis) and mild behavioural difficulties.

Initial assessment

In April 2005, a solicitor, acting on Simon's behalf in a medico-legal case for compensation, requested a Rehabilitation Assessment with recommendations for intervention for Simon and his family. The assessment outlined Simon's current levels of functioning and indicated that physically the left-sided hemiparesis affected his mobility and also the use of his left arm. In terms of self-care, Simon was able to get dressed with help from his mother, and to shower, brush his teeth and shave. Cognitively, he showed average reading, mathematical and verbal intellectual ability (which was suggested to be due largely to his pre-morbid learning). Simon had difficulties with memory and executive functioning in terms of problems with initiating, planning ahead, thinking flexibly and self-regulation (of mood, sleep, temperature and energy). Socially and emotionally, Simon was more disinhibited than before the accident and he had difficulties regulating his mood, being emotionally labile and irritable. In addition he showed signs of fluctuating depression, with low mood occurring in the context of statements about "being disabled" and "less independent" than prior to the accident. At that time, his weekly routine included attendance at school for less than three hours per week to study Art. He also had Therapy input at home from Community Services including weekly physiotherapy, fortnightly speech and language therapy, occupational therapy and hydrotherapy. With a high level of support from family members, Simon was also being reintroduced to some leisure activities including sailing with his father and finishing his Silver Duke of Edinburgh Award.

In terms of family functioning, it was acknowledged that following the accident, Simon's parents had had to take a year out from normal activities in order to be with Simon. His mother left her job, and his father spent significantly less time running the family business. Once he returned home, they provided the majority of his daily care, and were available to assist and support Simon 24

hours a day. They showed a high level of insight into how to manage Simon's disinhibition and low irritable mood. In addition, they were committed to and supported Simon's ongoing recovery and rehabilitation. They were the main motivating forces in organizing activities and events and supported Simon during his participation of them. However, they acknowledged that their organization of activities was often motivated by their longing to reintegrate him into the world that he occupied before the accident, and they found it difficult to consider the possibility that the opportunities open to Simon might be different following the brain injury. In addition, although they recognized the impact of Simon's accident on them as a family, they found it difficult to think and talk about it. Simon's mother also spoke about the "pain" she felt as she thought about her son and "how his life was, and is now", and that she tries to keep these feelings "locked away" for fear that they will overwhelm her. Simon's parents described their extreme tiredness, feelings of anxiety and depression and "not coping", in addition to changes in their own marital relationship and social network.

Formulation

The nature and timing of the injury was considered in understanding Simon's current level of functioning (Eslinger et al., 1999; Ylvisaker et al., 2005). His difficulty with executive functioning (including memory retrieval) was likely to reflect not only damage to the left frontal lobe as a result of the accident, but also disruption to the development of these areas. We argued that any rehabilitation programme would need to include specific strategies to facilitate development of executive functioning (Feeney & Ylvisaker, 1995, 2003, 2006), in addition to social and emotional development (Janusz et al., 2002; Yeates et al., 2007).

From analysis we found a relationship between Simon's mood and fatigue levels, with dips in mood occurring with increased fatigue levels. Furthermore, the strongly held family belief around the need for "goals" to provide meaning and motivation impelled Simon's parents to provide, and take hold of, opportunities for Simon, often at the expense of his fatigue levels. The rehabilitation programme would need to consider how to manage Simon's environment and support the parents, to provide as far as possible a paced, structured lifestyle (Feeney & Ylvisaker, 1995, 2003, 2006).

Simon's parents experienced increased burden, psychological distress including feelings of intense anxiety, stress and depression, social isolation and loss of income as a result of Simon's brain injury. These issues were likely to impact on how effectively Simon's parents could continue to support and care for Simon in the future (Anderson et al., 2006; Gan et al., 2006; Wade et al., 1998, 2001, 2002), and on their quality of life (Stancin et al., 2002; Taylor et al., 2001; Wade et al., 1996).

We recognized the stress of Simon's brain injury on the family, and the high level of ongoing family adaptation and restructuring required by Simon's parents in order to support Simon effectively and to cope as a family (DePompei & Williams, 1994; DePompei et al., 1988; Schwartz et al., 2003). However, we also acknowledged the family's competence and resilience thus far and recognized the importance of increasing their awareness of how they were managing as a family. There was a need to help Simon's parents to identify the resources within and around them, and enhance coping skills as appropriate (Drotar, 1997; Lazarus, 1991; Wade et al., 2005).

In terms of emotional functioning, life cycle transitions are significant triggers to feelings of loss, grief, anxiety and depression (Lezak, 1986; Rolland, 1994; Silverberg, 1996). Simon's parents had frequent reminders of what Simon should be doing as part of the transition from adolescence to young adulthood – for example, studying for A-levels, making plans to go to university, having a girlfriend. We recognized that any intervention with Simon's parents would need to hold in mind the life cycle transition framework in understanding the family's emotional functioning and adjustment over time (Maitz, 1991; Silverberg, 1996; Wade et al., 2002).

Treatment

We used Ylvisaker and colleague's (Feeney & Ylvisaker, 1995, 2003, 2006; Ylvisaker, 2003; Ylvisaker & Feeney, 1998; Ylvisaker et al., 2001) ideas about *context-sensitive rehabilitation* as our framework for delivering Simon's rehabilitation. We emphasized the need for rehabilitation to occur within the context of ongoing, everyday activities delivered in structured way. A coherent weekly timetable was drawn up with therapeutic one-to-one time planned into the timetable. We stressed also the need for regular coordination meetings with the therapists involved in Simon's care to plan and communicate clear therapy goals that could be carried out by Simon, his parents or any carer working with him.

We also applied Ylvisaker and colleague's ideas around *positive behaviour supports*, and included the employment of support workers to facilitate adherence to the timetable by providing planned structured activities. In addition, in the context of the relationship between Simon's mood and fatigue levels, rest times were planned into the timetable, in order to facilitate as far as possible a rhythm or pace to Simon's day. We also provided advice and support around sleep hygiene emphasizing routine and relaxation at bedtime.

To maintain and where possible improve Simon's quality of life, we drew up a list of activities that Simon found meaningful and/or that gave satisfaction and enjoyment. Simon's special interest in photography, and his enjoyment of sport, exercise (at the gym) and regularly meeting friends socially, was acknowledged and there were regular opportunities to engage in these and other activities that promote quality of life within the rehabilitation programme.

The work with Simon also included regular fortnightly/monthly sessions with a psychologist providing emotional support to facilitate insight of and adjustment to the effects of his brain injury. Due to his poor memory and difficulties with flexibility of thinking, a modified cognitive framework was applied, with repetition of concrete ideas and strategies. In addition, the individual sessions provided a forum for Simon to articulate his views about the rehabilitation programme to, as far as possible, empower Simon and involve him in the therapy process, and to advocate on his behalf, as appropriate.

The work with Simon's parents occurred on a regular basis providing support within a systemic framework, and utilizing also techniques from the Cognitive and Cognitive Behavioural models for anxiety and depression. A large part of the work has been in supporting Simon's parents as they adjust and adapt to the changes in their family since Simon's accident. Using approaches advocated by Structural and Narrative Therapy, we "storied" the accident and its effects on them as individuals, on their relationships, and on family structure and organization. The life cycle transitions model has been an important framework enabling conversations about the parent's expectations for Simon and for the family, normalizing their experience of "not wanting to accept and adjust", in addition to exploring possible ways of negotiating transitions effectively as a family. We looked at patterns of coping, offering advice, validation and encouragement, as appropriate. We looked at their styles of communication, not only in the family but with the wider network of professionals around them. We facilitated as far as possible effective communication via their inclusion in regular Case Review meetings. There have been many opportunities for Simon's parents to talk about thoughts and feelings frequently avoided. Using cognitive behavioural ideas, we provided strategies to manage their symptoms of anxiety and depression. The work has also included provision of advice on behavioural management of Simon's fluctuating mood and disinhibition. Finally, throughout this piece of work, we have been mindful of Simon's parent's quality of life and have attempted to support them in making changes that improve their well-being.

Outcome

Simon had a structured timetable which was accepted, along with the need for support via a Support Worker team. Individual psychological support was important in helping him adjust to his disability and to accept the need for support from others. Simon attended school with support and completed an A-S Level in Photography achieving an A-grade. He maintained a social network and went out on a weekly basis. In addition, he has been on weekend breaks to Europe with his Support Worker and without his parents. Simon actively pursued photography as a hobby and gave frequent highly acclaimed talks in conjunction with the Emergency Services on road safety to teenagers. There were regular Team Reviews where Simon prioritized goals which were achieved. Finally, Simon's mood, as measured by rating scales completed by the Support Worker, was stable and was higher than at the beginning of therapy. In addition, his behaviour and levels of fatigue were stable.

Simon's parents applied information provided about Simon's brain injury to modify their interactions with him and to support the rehabilitation programme (including pacing of his day and week; regular rest times; relaxation at night-time; distraction and management of fluctuations in mood). They acknowledged that the support "gave them insight and understanding of Simon's problems" and an opportunity to "reflect on their reactions to Simon's problems". Simon's parents described an increased openness to talking about their feelings, and for both of them, it was important to hear the other partner express their feelings. They both showed objective signs of adjustment in terms of reduced tearfulness in session, increased ability to express realistic expectations about their son, and acknowledgement of the family's strength to cope. In addition to the application of coping skills to particular situations they both felt that they have adjusted and adapted to some extent to Simon's brain injury. As Simon's mother remarked, although "it was hard to listen to things you don't want to accept and face realities ... it is helping me to understand and adapt to my feelings with advice". Support enabled them to reflect on their communication, and they have modified how they relate and react to one another and to professionals in the wider system. In addition, they applied cognitive and behavioural strategies to manage anxiety/worry and low mood (although not consistently) and described the sense of control that this provides when it is used.

Their quality of life remains quite low, with high scores on all scales of the PedsQL Family Impact Module (Varni et al., 1999). As indicated in the research, quality of life tends to diminish over time for carers of individuals with TBI (Kolakowsky-Hayner et al., 2001). Simon's parents recognize in themselves a degree of adjustment, adaptation, and mastery of overwhelming thoughts and feelings. However, they continue to be heavily involved in Simon's care, and frequently experience a deep sense of sorrow and grief, frequently triggered by meeting someone from their own or Simon's peer-group who describes what they, or their child, are now doing, which is usually starkly different from their own and Simon's experience. In addition, Simon is moving into a significant transition period whereby he will move into independent living. This is causing high levels of worry and anxiety for Simon's parents as they consider how he will manage in the future.

Conclusions

We have summarized the literature on the impact of a child TBI on family and development. We have described the development of a specialized community child neuropsychology service that integrates applied developmental neuropsychology and systems ideas in order to provide best practice for children with TBI and their families. We have reported a case study that uses this approach. Despite the strong evidence base for the need of this type of approach, and our anecdotal evidence of the success of this approach, we recognize that there is little direct and systematic experimental

evidence concerning its efficacy. This is something we would like to begin to rectify through systematic collection of outcome data over time.

We acknowledge also that in order to optimize intervention for children with TBI, there is so much that we still need to understand in terms of the interaction between development and brain injury (particularly in relation to the timing and nature of the injury and the stage of skills development), and its association with outcome in childhood TBI. In addition we need to understand the factors that influence outcome in families, for example, the longer-term changes in the family, implications of role changes, unique stresses, effective and non-effective coping methods, and various strategies that families have adopted to help them cope with the demands of a child with TBI.

It is our hope that we can continue to develop and apply this approach to our work with children with TBI and their families.

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