Working with families following brain injury

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Abstract

It has been recognised for several decades that a moderate to severe acquired brain injury frequently causes a high level of psychological stress within the immediate family, who often provide long-term care and support. However, although there is an abundance of research evidence for family burden and stress following brain injury, research into the effectiveness of psychological interventions designed to support such families is relatively scarce. This paper will summarise some of the existing research literature and examine the clinical process of working with families following acquired brain injury. After a brief and selective review of the evidence for caregiver stress following brain injury, we will consider some theoretical models and concepts relevant to family work, and the existing research evidence regarding family interventions. We will then focus on our experience of working with families in clinical practice and our approach will be illustrated using a case study.

Keywords: family work, caregiver, psychological intervention, traumatic brain injury, acquired brain injury, systemic

The impact of acquired brain injury on families

Improvements in medical technology have resulted in more people surviving after an acquired brain injury (ABI), although often with permanent and complex disabilities. On discharge from hospital, it is often the case that the person with the brain injury returns home to live with their family, and the family play a pivotal role in the rehabilitation process (Jacob, 1988; Oddy & Herbert, 2003; 2009). However, supporting a person with a brain injury is a particularly challenging form of caregiving, and one that does not appear to become easier with time (Koskinen, 1998; Kreutzer, Rapport, Marwitz, Harrison-Felix, Hart, Glenn, & Hammond, 2009a). Furthermore, it is recognised that the quality of life and psychological well-being of the injured person often depends on the psychological health and coping skills of their family caregivers (Oddy & Herbert, 2003; Sander, Caroselli, High, Becker, Neese, & Scheibel, 2002; Gan, Campbell, Gemeinhart, & McFadden, 2006).

Over the past thirty years, the significant strain and burden that may be experienced by families of individuals with acquired brain injury has been extensively documented (see Oddy & Herbert, 2009 for review). Family members often have to provide long-term care and support for their injured relative. The family commonly experiences further changes in role in the household, employment and childcare domains as well as financial strain, social alienation and isolation (Hall, Karamark, Stevens, Englander, O’Hare, & Wright, 1994; Smith & Smith, 2000; Tyerman & Booth, 2001; Ergh, Rapport, Coleman, & Hanks, 2002). Numerous research studies have documented the psychological distress reported by family members caring for individuals following a brain injury (e.g., Kreutzer, Gervasio, & Camplair, 1994b; Marsh, Kercel, Havill, & Sleigh, 1998, 2002; Ergh et al., 2002). The literature suggests family caregivers frequently sustain some degree of emotional distress including increased levels of low mood, somatic symptoms, anxiety, anger, fatigue and stress. Recent prospective studies have reported clinically significant levels of psychological distress in approximately one third of adults caring for a person with a brain injury (Ergh et al., 2002; Kreutzer et al., 2009a).

There is now a longstanding and substantial evidence base exploring the different factors that influence burden and distress in family caregivers (Arango-Lastrupilla, Quijano, Aponte, Cuervo, Nicholls, Rogers, & Kreutzer, 2010; Hassan, Khaw, Rosna, & Husna, 2011). Many research studies have found that this type of caregiving does not get easier over time and that distress levels remain high, or increase, for years post injury (e.g. Koskinen, 1998; Oddy, Coughlan, Tyerman, & Jenkins, 1985; Kreutzer et al., 2009a). For example, in a multicentre study, Kreutzer and colleagues (2009a) found that depression, anxiety and somatic symptoms are common in family members at one, two and five years post injury.

Interestingly, severity of brain injury does not appear to be related to caregiver distress (Brooks & McKlnlay, 1983; Gervasio & Kreutzer, 1997; Gillen, Tennen, Affleck, & Steinpreis, 1998). However, it has been consistently reported that emotional and behavioural changes in the injured relative are a strong predictor of caregiver distress (Ergh et al., 2002; Oddy & Herbert, 2003; Ponsford, Oliver, Ponsford, & Nelms, 2005). Family members are often more distressed by these changes than by the level of physical care required by their injured relative (Anderson, Parmenter, & Mok, 2002; Douglas & Spellacy, 1996; Knight, Devereux, & Godfrey, 1998). In addition, levels of social support appear to be an important factor in relation to caregiver burden, distress and family functioning (Douglas & Spellacy, 2000; Ergh et al., 2002). For example, Ergh and colleagues (2002) found that, in the absence of adequate levels of social support, higher levels of caregiver distress were related to increased cognitive and functional...
Impairment and reduced awareness of deficits in injured relatives. Other factors that have been identified as determinants of caregiver distress include the injured relative having impaired functional status, high supervision needs, poor life satisfaction, and excessive alcohol use (Kreutzer et al., 2009a).

Research has also explored family-related factors that appear to influence caregiver distress and burden. For example, a recent study found that caregivers’ medical and psychiatric histories predicted higher levels of global distress (Davis, Sander, Struchen, Sherer, Nakase-Richardson, & Malec, 2009). The importance of the gender of the caregiver in relation to coping with caring for a relative with a brain injury has also been explored with some studies indicating that male caregivers may experience greater levels of distress than female caregivers (Sander, High, Hannay, & Sherer, 1997; Gervasio & Kreutzer, 1997). The impact of caring on the distress levels of parents and spouses has also been investigated. The findings in the literature are inconsistent, with some studies reporting higher levels of distress in spouses (Kreutzer et al., 1994a; Kreutzer et al., 1994b; Gervasio & Kreutzer, 1997), in parents (Douglas & Spellacy, 2000), and others reporting that caregivers have found distress levels are comparable (Pomfret et al., 2003; Kreutzer et al., 2009a). It has been suggested that focusing on quantitative relationship classifications may be too simplistic (Kreutzer et al., 2009a).

Research indicates that divorce and separation rates are not necessarily higher after traumatic brain injury than in the general population (Wood & Yundtakal, 1997; Kreutzer, Marwitz, Hsu, Williams, & Ridlack, 2000). However, although widely varying levels of marital stability have also been reported across the literature (Godwin, Kreutzer, Arango-Lasprilla, & Lehan, 2011). However, further research into the quality of marriages prior to, and following brain injury is needed. Greater marriage stability has been linked to longer pre-injury marriage, non-violent injuries, older people and those with less severe injuries (Kreutzer et al., 2007). With regards to parenting following brain injury, one study found that parents of children with a brain injury reported more concern for the future and pessimism than spouses (Knight et al., 1998). Until recently the needs of children who have a close relative with a brain injury have been largely overlooked in the literature (Webster & Daisley, 2007). However, it is now understood that child relatives experience psychological distress and have particular needs following a brain injury in the family (Kieffer Kristensen & Teasdale, 2011). It is important to highlight that many families demonstrate positive coping ability and resilience when challenged with a brain injury in the family (Godfrey, Knight, & Partridge, 1996; Koscieulek, 1994; Perlesz, Kinsella, & Crowe, 1999; 2000; Kreutzer et al., 2009a). Further research is needed to investigate the factors that contribute to positive adjustment, coping ability and resilience in families. As brain injury specialists, it can be easy to get drawn into a paternalistic approach, which is not necessarily what the family system needs. It is important to place the impact of the event, and the potential for change, within the control of the system.

A large number of studies have highlighted families’ need for information and education about the impact of brain injury, delivered at an appropriate time and in a helpful and memorable format (e.g. Morris, 2001). Brain injury is often underdiagnosed after head trauma (Deh, 1999), and the immediate medical focus on orthopaedic injury can result in a failure to appreciate the full impact of neuropsychological sequelae. This can often mean that survivors and families are deprived of early / timely psychological support. Instead, referrals for neuropsychological input tend to come at the point of relationship breakdown, system overload, or instances of high-risk behaviours. Lack of information and education can often result in families misunderstanding their relative’s difficulties, for example, blaming behavioural and emotional change on being deliberately difficult or intentionally lazy.

The empirical research described here and elsewhere clearly indicates that brain injury can result in long term unmet needs for the family. However, we do not know how early psychological intervention (or lack thereof) mediates these problems. One possibility is that engaging with the family system early in rehabilitation could improve wellbeing and foster realistic appraisals of the future neuropsychological residual effects, recovery potential, and deficit management.

The literature reviewed here provides unequivocal evidence of the significant psychological distress and burden experienced by families following acquired brain injury. This longstanding evidence indicates that the family, as well as their injured relative, would often benefit from access to psychological support and intervention. This paper will now examine the process of working with ABI families, by considering the concepts and models relevant to family work, the available evidence for the effectiveness of family interventions and our experience of working with families, which is then illustrated with a case study.

**Concepts and models relevant to family work**

Whilst the stress and burden of caring for a relative with an acquired brain injury has been recognised for several decades, it is only relatively recently that interventions designed specifically to meet those needs have been developed and documented. The various approaches to family work described in the literature are informed by and reflect a number of different psychological concepts and frameworks, some of which are considered in this section.

**The systemic model**

Recent developments in systemic ‘relational’ approaches to brain injury rehabilitation (e.g. Bowen 2007; Bowen, Yeates, & Palmer, 2010) are currently at the forefront of family intervention development in neuropsychological rehabilitation. These are founded on the Milan-based developments in systemic family therapy described in the 1980s (e.g. Boscolo, Cecchin, Hoffman, & Penn, 1987). Whilst relational approaches are influenced by, and in some cases directly represent the systemic models underlying family therapy, they do not necessarily involve the implementation of formal family therapy per se. An example is the emotion focused couples therapy (EFT) that has been used successfully with couples where one has a chronic illness, including couples where one partner had a traumatic brain injury (Chawla & Kafescioglu, 2012) and where one partner had aphasia following a cerebral stroke (Stell, Naaman, & Lee, 2007). Yeates and colleagues are also developing this work in the UK with couples following a brain injury (e.g. Yeates, 2013).

In essence, relational and systemic approaches to brain injury rehabilitation broaden the traditional focus on the person with the brain injury, so that the development and maintenance of difficulties can be understood in the context of relationships and interactions between the injured relative and other family members, and between the family and its wider context. Traditional neuropsychological approaches tend to view the injured person’s difficulties in isolation, as both direct symptoms of the brain injury and as the individual’s psychological and behavioural responses to those limitations. The circularity inherent in systemic thinking promotes an understanding of both the injured relative’s experience, the family’s reactions to the injury and the interaction of these.

Adopting a systemic approach allows practitioners to develop a broader contextual understanding of the situation, and an explanation for a larger proportion of the presenting difficulties, including the caregiver ‘burden’ and its impact. It also facilitates a non-blaming perspective and a formulation that can be shared with all members of the family or system. A systemic approach also allows interventions to be implemented at different points within the system. For example, interventions primarily intended to improve the psychological well-being of family members are also likely to have benefits for the relative with a brain injury, as has been demonstrated elsewhere (Singh, Lancia, Winton, Wahler, Singh, & Sage, 2004). Other authors have also reported that support for families produces benefits and greater gains in rehabilitation for the relative with a brain injury (Jackson & Haverkamp, 1991). Particularly promising applications of relational approaches to brain injury rehabilitation include the Brain Injury Family Intervention developed by Kreutzer and colleagues (e.g. Kreutzer et al., 2009b) and the family interventions developed at the Bouvier Centre in Australia (e.g. Charles, Butera-Prinzi, & Perlesz, 2007).

**Stress and coping models**

Models of stress and coping provide a framework for research that aims to identify mediators of resilience and coping in ABI family caregivers, as well as principles that can guide clinical practice. The predominant model, developed almost thirty years ago by Lazarus and Folkman (1984), centres on the concepts of cognitive appraisal and coping. Cognitive appraisal refers to the individual’s evaluation of the meaning and significance of ongoing events, whilst coping describes their capacity to meet the demands by planning and taking action. The model is transactional, involving the relationship between the individual and their environment. The model proposes that the severity of stress experienced cannot be understood in terms of the absolute nature of the events, as it depends upon the relationship between the individual’s perception of the demands being made and their (perception of) their ability to meet the demands. Appraisal processes (which are amenable to change) and coping (which is also amenable to change and include access to external sources of support) both mediate stress. Therefore, stress is never a direct response to a given situation. By
identifying different forms of coping (problem focused, emotion focused and avoidant coping), the model also identifies distinct routes to improved coping capacity, which can be implemented in stress management interventions.

In support of this type of stress process model, several caregiver studies have demonstrated that psychological well-being is mediated more accurately predicted by coping, appraisal and support variables than by the severity of the stressors involved per se. For example in a study of caregivers of people with dementia (Mausbach et al., 2012), the relationship between depression and stressors such as problem behaviour and role overload was significantly mediated by four distinct coping strategy and appraisal factors. In a similar study of ABI caregivers, a Perceived Stress Model of Burden, based on the Lazarus and Folkman framework, was derived from the empirical relationships between perceived stress, coping, social support and mental health outcomes (Chwalisz, 2006). In this study, social support was shown to have significant benefits, whilst different coping strategies were found to have varying relationships with perceived stress. Such studies provide strong support for the idea that coping and appraisal processes are critical determinants of the psychological impact of the stresses associated with family caregiving.

Grief and adjustment to loss

The concept of grief after brain injury provides a further important basis for our clinical practice. Conceptual models of grief, such as the model proposed by Kubler-Ross (1969), typically describe the psychological processes that occur after bereavement, and can help clinicians to understand responses at different times and to provide appropriate support. The stages are often interpreted as progressive and linear, leading to an eventual resolution and adjustment to the loss. According to the Kubler-Ross model, grieving involves experiencing and working through denial, anger, bargaining, depression and acceptance, a process that may take many months or years. ABI family work at the Bouvier Centre in Melbourne, Australia is guided by an ABI-specific Family Tasks Model based directly on this type of traditional bereavement model (Charles et al., 2007). It guides families in counselling through non-sequential processes of grieving, re structuring family roles and responsibilities, developing new identities and creating new meaning.

Grief has become an important concept in the brain injury family literature, and it is accounted for and measured increasingly in attempts to understand how families cope and function after brain injury (e.g. Zinner et al., 1997; Marwit & Kaye, 2006; Calvete & Arroyab, 2012). The concepts of loss and grief are also central to at least one psychotherapeutic approach adopted with brain injury survivors themselves (Cozert, 2006, 2013) and there are clear parallels between bereavement and survivors’ grief about their personal losses following brain injury.

There are, however, at least two important ways in which family grief following brain injury differs from grief following bereavement. The first is the ambiguity of the loss following brain injury. The injured relative is not dead but changed. The person known before may be present to some degree, or at some times, perhaps fleetingly. Their physical existence may act as a saddening reminder of the past, when relationships were more mutual and shared. There is often a loss of interpersonal connection, attunement and intimacy between partners after a brain injury, the injured partner may feel like a stranger or there may be a sense that their personality has died (e.g. Feigelson, 1993; Goslimg & Oddly, 1999; Bowen, Yeates, & Palmer, 2010). In some cases, relatives who have experienced initial elation (e.g. Humphrey & Utley, 1978), poor understanding of the situation may also sometimes reflect the family’s own denial of the severity, extent or permanence of the injury (Romano, 1974). In our own experience, relatives report in retrospect, that they had persisted at length in the belief that the injury would get better or that it was less severe in the first place. Denial by family members has been documented widely in the brain injury research literature (e.g. Oddly & Herbert, 2003). Whilst such beliefs and persistence may promote hope, and be helpful in earlier stages of recovery and adjustment, relatives can only function as resilient and effective long-term caregivers if they have a genuinely realistic appraisal of the nature of the injury and its prognosis. Family caregivers may need considerable support and encouragement to achieve this awareness, and facilitating this process can be an important part of our psychotherapeutic role.

Denial and avoidance

Whilst grief may be an important part of the family’s response to a brain injury, family members may also have reduced awareness of the consequences of their relative’s brain injury. Whilst this may reflect a lack of information provided either at all or at an appropriate stage (e.g. Humphrey & Utley, 1978), poor understanding of the situation may also sometimes reflect the family’s own denial of the severity, extent or permanence of the injury (Romano, 1974). In our own experience, relatives report in retrospect, that they had persisted at length in the belief that the injury would get better or that it was less severe in the first place. Denial by family members has been documented widely in the brain injury research literature (e.g. Oddly & Herbert, 2003). Whilst such beliefs and persistence may promote hope, and be helpful in earlier stages of recovery and adjustment, relatives can only function as resilient and effective long-term caregivers if they have a genuinely realistic appraisal of the nature of the injury and its prognosis. Family caregivers may need considerable support and encouragement to achieve this awareness, and facilitating this process can be an important part of our psychotherapeutic role.

Self-awareness and brain injury

A further source of isolation for the family after a brain injury is that, in a large proportion of severe traumatic brain injuries and cerebral vascular accidents, survivors have a significant lack of self-awareness about the impact of their injury on aspects of their functioning, including changes in their personality and behaviour (e.g. Petragno, 1997). Whilst poor self-awareness may protect survivors themselves from depression and grief (Carroll & Coetzee, 2011), it may heighten a sense of loss for the family.

Given that injured relatives tend to focus particularly on the loss associated with their physical symptoms and limitations, it is often difficult for the family to communicate openly with their relative about the loss they experience, or at least, to communicate about the whole picture. As family members tend to be more affected and burdened by the non-physical consequences of brain injury (Marsh et al., 1998; Wells et al., 2005), there is often a striking discrepancy between the survivor’s and their family’s perceptions of the losses incurred and their relative importance (Yeates, Henwood, Gracey, & Evans, 2007). However, as these authors have demonstrated, the means by which their ABI participants (who had reduced awareness of their executive function and social behaviour difficulties) made sense of change and disability were closely related to their pre-morbid identities and abilities, and strongly influenced by family and social relationships.
Evidence for the effectiveness of family interventions

As described above, there is substantial and longstanding evidence that highlights the psychological distress and burden experienced by families following acquired brain injury. Despite the recognition that many caregivers have significant needs, there is only a relatively small amount of theoretically motivated research evaluating family interventions (Oddy & Herbert, 2003, 2009). Concerns about the methodological rigour of the majority of existing studies and generalizability of findings have been highlighted in the literature (Boschen et al., 2007; Ramkumar & Elliott, 2010).

Studies exploring interventions for families following brain injury tend to focus on a combination of educational, psychological support, and skill development such as problem-solving, stress management or behaviour management. Two studies have focused on the provision of education to family caregivers through an information booklet (Morris, 2001) and a community-based educational group programme (Sinnakaruppan et al., 2005). These studies did not report any statistically significant change in psychological distress or avoidant coping. Three studies have focused on education and psychological support through a family support programme (Acorn, 1995), a social work liaison service offering telephone contact to carers (Albert, Im, Brenner, Smith, & Waxman, 2002), and tele-conferencing and face-to-face caregiver support groups (Brown, Pain, Berwald, Hirsch, Dechany, & Miller, 1999). The family support programme (Acorn, 1995) reported no significant changes in coping skills, general well-being, and self-esteem. However, caregivers evaluated the programme as helpful and continued to meet as a group following the conclusion of the study suggesting they found some benefit. The latter two studies reported significant improvements in distress levels (Brown et al., 1999), burden, satisfaction and mastery (Albert, 1995). Other studies have explored the effectiveness of skill development. For example, Carnevale and colleagues (2002) explored a community-based education and behaviour management programme for individuals with a brain injury and their caregivers. However, no significant improvement in burden or stress was reported.

An earlier study had investigated the benefits of a psychoeducational stress management programme for parents of children with brain injury, and reported significant reductions in depression and anxiety symptoms (Singer, Glang, Nixon, Cooley, Kerns, Williams, & Powers, 1994). Two randomised control trials have explored problem-solving interventions for families following brain injury (Rivera, Elliott, Berry, & Grant, 2008; Wade, Carey, & Wolfe, 2006a; Wade, Carey, & Wolfe, 2006b). Rivera and colleagues evaluated a face-to-face and telephone problem-solving training intervention for caregivers of adults with brain injury. They reported significant reductions in depression, health complaints and in dysfunctional problem solving styles. However, no statistical changes were observed in caregiver well-being, burden or constructive problem-solving style (Rivera et al., 2008). Wade and colleagues designed a family problem solving intervention for families with a child with a brain injury (Wade et al., 2004). The intervention involved an initial face-to-face visit with the whole family (including the child with a brain injury) and a telephone follow-up. The whole family then participated in a weekly online self-guided family problem solving session and a video conferencing session with the therapist. Following the intervention, parents reported reduced symptoms of depression, anxiety and global psychological distress (Wade et al., 2006a) and improved child self-management and compliance at follow up (Wade et al., 2006b). These studies indicate overall positive evidence of psychological benefits for caregivers undertaking family support and education programmes, perhaps particularly where the intervention contains a direct support component and/or training in problem solving.

A qualitative evaluation of a stress management group for family caregivers following brain injury based on Acceptance and Commitment therapy (Hayes et al., 2003; Noone & Hastings, 2009; 2011) found the approach was helpful; although challenging, for spouses in long-term caregiving roles (Williams, Vaughan, Huws, & Hastings, submitted). Caregivers were initially unaware of the severity of their stress and increasing their awareness was reported to be difficult and painful. Participants were encouraged to develop an acceptance of their emotional state and to consider changes that would improve their quality of life, with varying degrees of success. Although caregivers became less avoidant and more open to experiencing difficult emotions themselves, some felt unable to impose the consequences on their injured partners. Identified benefits were the support provided (including opportunities for long-term mutual support) and the opportunity to review their roles and coping strategies.

Although important, single and multi-component interventions focussing on education, support and development of skills may not meet the significant complex and diverse needs of some families following brain injury. Interventions may Need to take into consideration personal characteristics, current relationship issues, and family strengths and weaknesses (Ramkumar & Elliott, 2010). In addition, it may be useful at times for interventions to include the entire family system, rather than to focus on the relatives alone (Maiz & Sachs, 1995; Laori, 2000; 2003; Bowen, 2007). It has been proposed that professionals working in the brain injury field would ideally have knowledge of both neurorehabilitation and systemic approaches (Bowen, 2007).

The Brain Injury Family Intervention (BIFI) (Kreutzer et al., 2002; Kreutzer et al., 2009b; Kreutzer, Stejkska, Goodwin, Powell, & Arango-Lasprilla, 2010) is an example of a multi-component intervention guided by principles of family systems theory and cognitive-behavioural therapy. It is a 10-weeks long intervention process for families who include the person with a brain injury. It focuses on the family unit and uses family therapy techniques to strengthen family systems and integrates education, skills training and psychological support. Studies investigating the BIFI have found that participants report a greater number of met needs and perceive fewer obstacles to receiving services post-treatment (Kreutzer et al., 2009b). In addition, caregivers and patients viewed the BIFI as helpful and reported that the intervention facilitated the achievement of goals (Kreutzer et al., 2010). The investigators highlighted the importance of using qualitative, as well as quantitative methodology, so that participants’ experiences and perceptions can be included as part of the evaluation of interventions.

A further two studies have investigated the use of family therapy following brain injury. Perlesz and O’Loughlan (1998) described a preliminary family therapy study in which fifteen families following brain injury were followed over a two year period, including 12 months prior and 24 months post family counselling. A significant decrease in distress was reported for both individuals with brain injury and their carers, and a reduction in relatives’ burden and strain. In addition, family conflict reduced and family cohesion and adjustment increased. However, self-reported levels of anger and marital adjustment returned to original levels at 24 month follow up. The authors recommended that marital couples may have specific needs that require longer term counselling and that the issue of anger be further investigated (Perlesz & O’Loughlan, 1998).

In addition, Charles and colleagues (2007) described a pilot project exploring a multi-family group intervention for families where a parent had an acquired brain injury. Six families comprising 11 adults and nine children evaluated twelve sessions over six months. Each session consisted of parallel groups including parent/child, partner/person with brain injury and family time. Themes for sessions were derived from the Bouvier Family Tasks Model (Perlesz, Furlong, & McLachlan, 1992). Following the intervention, parents reported reduced levels of personal distress although high levels of marital and family dysfunction did not change over time. Families evaluated the group as useful and reported a range of positive changes including reduced feelings of shame and isolation, provision of mutual support, increased understanding of brain injury, sharing of difficult experiences and moving from blame to compassion.

It is recognised that UK brain injury services are often aware of the significant needs of families following brain injury and often provide services to meet this need (Bowen, 2007). However, this may not be as widely reported in the literature as it is included in clinical practice, and further documentation and research into this type of service related family work is needed (Oddy & Herbert, 2003). A number of UK service examples include the Community Head Injury Service in Aylesbury, which provides long term specialist services for individuals that include a family worker (Tyerman & Booth, 2001; Tyerman & Barton, 2007). In Oxford, Webster and Daisley (2007) have developed interventions that include child relatives following a brain injury in the family. Weatherhead and Newby (2008) have described and evaluated a parenting programme for fathers with an ABI in Cheshire, UK. The North Wales Brain Injury Service provides information, individual and group support for families.
processes that underlie their development and maintenance, and caregivers can be part of the solution, as well as part of the problem. Probably less closely linked to the litigation process.

Additional work or neuropsychological approaches to deal with the complexity of the dual role. Caseworkers are often closely involved with the families of their injured clients and typically come to know their client and the family very well. However, as the case management role is typically an open-ended relationship, supervision and care for their injured relative. The importance of addressing the needs of families in order that they can continue in this role cannot be overemphasized.

Whilst there is an urgent need for more research evaluating the impact of interventions for family caregivers following brain injury, we would guard against the recommendation that this evidence should be based exclusively on randomised control trials and similar quantitative methodologies. A requirement to acquire evidence via this 'gold standard' approach is likely to discourage clinicians who might otherwise participate in the research process, render the research less feasible, and confer a number of disadvantages over other naturalistic or less highly controlled approaches.

The UK's National Service Framework for Long Term Conditions (2005) includes the statement that 'RCTs and other quantitative methodologies are not necessarily best suited to research questions about quality of life'. In our view, this statement is directly applicable to caregiver intervention research, and reflects outcomes measurement issues, as well as ethical issues and concerns about clinical generalization. RCTs typically impose restrictive inclusion and exclusion criteria on participant selection, which means that samples may be highly unrepresentative of the population, and that the question about effectiveness in clinical practice may remain unanswered.

The random assignment of participants to the intervention conditions may also cause difficulties as participants can be assigned to conditions that would be considered unsuitable for them in a clinical (non-research) context. It may be that in order to achieve evidence-based practice, the evidence needs to be more practice-based (Mehl-Madrona, Leung, Kennedy, Paul, & Kaplan, 2010). For example, case studies based on heterogeneous samples selected from clinical practice can provide at least preliminary evidence of effectiveness. Critically important information about the acceptability and experience of interventions can also be achieved via qualitative and mixed methodology studies.

Our experience of working with families

The overarching aim of our approach is to engage families following brain injury in therapeutic interventions that will improve and to help maintain the psychological health and wellbeing of the injured relative and the whole family. Interventions involving the family, as well as their injured relative, can break negative cycles of stress and distress, and improve quality of life for all involved. We assume, on the basis of our clinical experience and the small amount of existing evidence, that working with the family is, in some cases, the most cost-effective way of supporting the recovery and rehabilitation of the injured relative, as well as helping the family members who provide care.

Case managers are often closely involved with the families of their head injured clients and typically come to know their client and the family very well. However, as the case management role is typically complex, multi-faceted and often closely linked to an ongoing litigation process, it is difficult for them to address the family’s psychological distress and the interactions occurring within the family without creating a compromising dual role. Case managers may not feel sufficiently trained in systemic family work or neuropsychological approaches to deal with the complexity of the dynamics involved and the role played by the brain injury. Additional support from clinical psychologists with specialist training in neuropsychology and family work can often be helpful. A psychologist’s input will also be less closely linked to the litigation process.

As we have illustrated, difficulties that arise following a brain injury are experienced by the whole family. Our work with families is based on a systemic understanding of those difficulties and on the premise that family caregivers can be part of the solution, as well as part of the problem. Problems and issues are understood in terms of positive and negative feedback processes that underlie their development and maintenance, and their application to the case management role is likely to discourage clinicians who might otherwise participate in the research process, render the research less feasible, and confer a number of disadvantages over other naturalistic or less highly controlled approaches.

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The random assignment of participants to the intervention conditions may also cause difficulties as participants can be assigned to conditions that would be considered unsuitable for them in a clinical (non-research) context. It may be that in order to achieve evidence-based practice, the evidence needs to be more practice-based (Mehl-Madrona, Leung, Kennedy, Paul, & Kaplan, 2010). For example, case studies based on heterogeneous samples selected from clinical practice can provide at least preliminary evidence of effectiveness. Critically important information about the acceptability and experience of interventions can also be achieved via qualitative and mixed methodology studies.
praisal by others. Furthermore, such difficulties can only be understood within these interactive social contexts (e.g. Yeates, 2009) and there is considerable evidence for circular and bidirectional relationships between influences within families with a brain injury (e.g. Moore, Stammbach, & Peters, 1993; Sander, Caroselli, High, Becker, Neese, & Scheibel, 2002). The cycle of stress and systemic model of the impact of caregiver support (see Figures 1 and 2) provide an illustration of this type of approach.

Recent social changes and changes in family structure have made families more difficult to define. Families are often a blend of more than one previous household resulting from separation and divorce, and the formation of new partnerships. Family relationships involving step-parents, step-siblings and half-siblings can be complex and challenging under optimally conditions and these challenges are often exacerbated by the occurrence of a brain injury in the family. Furthermore, people, who would not normally be defined as family members (e.g. close friends), may be involved in providing brain injury care at home, and there may be support workers and other paid caregivers with a high level of involvement. For the purposes of our work with families, the ‘family’ of the injured person may be defined as anyone who is closely involved with the injured person and continues to be affected by the brain injury.

Although the number of family intervention studies reported to date is small, and the result is a scarcity of evidence for the effectiveness of family interventions in brain injury rehabilitation, our approach is in line with interventions that have been found to benefit families (e.g. Kreutzer et al., 2009; 2010). It is also consistent with published guidelines for clinical practice, namely the Department of Health National Service Framework for Long-term Conditions (2005) and the Department of Health National Stroke Strategy (2007).

Ideally, our work with families in rehabilitation is proactive and preventative, and we aim to apply early intervention before severe problems develop. However, we more frequently find ourselves helping families who are already experiencing difficulties. The interventions we provide can be described under three main categories: psychoeducation regarding brain injury and its consequences, emotional support and psychological therapy, and behavioural management advice and support. These may not be presented as separate interventions or intervention stages, but as interwoven components of an integrated approach.

Psychoeducation and information for family members about the effects of the brain injury on their relative can cover a wide range of topics, often beginning with more factual information and moving towards a discussion of the impact on the family and management of difficulties. Topics include, for example, the physical and mechanical basis of traumatic brain injury, and why specific forms of injury result in specific changes in physical, cognitive and emotional function, personality and motivation etc. Similarly, the areas of the brain affected by a relative’s stroke can be described, with a view to understanding why some abilities are impaired specifically. It is often helpful to discuss the process of recovery and rehabilitation and to address the family’s expectations for future progress. It is also important to help the family to consider the emotional impact of the brain injury on the injured relative, possible changes in his or her sense of self and identity, and their adjustment to this. Encouraging the family to consider how the injury is affecting them, and how their responses, which are entirely normal and understandable, may be affecting their relative.

Emotional support often forms an important part of our work with families and overlaps to some extent with brain injury psychoeducation. It may involve psychotherapy for individual family members or meetings with the whole family. Commonly discussed topics include the emotional impact of the brain injury on relatives, their acceptance of and adjustment to the brain injury, and the family’s emotional reactions such as grief and anger. This work can be carried out with couples, parents, parents, siblings and children, or the wider family of a person with a brain injury.

Work with families often includes a behavioural approach to neuro-psychological rehabilitation, which has a strong theoretical foundation and a robust evidence base (Wilson, Herbert, & Shiel, 2003). This work might include a psychological assessment of problematic behaviour (for example, what the behaviour may communicate and the interactive effect of the family’s responses with the target behaviour), helping families to respond positively and consistently and providing strategies for the long-term maintenance of change (Vivisaker et al., 2003).

Another important component of working with families is the recognition of caregiver stress and the implementation of interventions designed to reduce it. Stress management interventions tailored for ABI family caregivers, especially when delivered to groups, can incorporate most, if not all, of the education, support and behaviour management components described above, as well as help relatives understand and reduce their own stress. This type of intervention may include psychoeducation about stress and its effects; recognizing stress, and practice with stress reduction techniques. Stress management approaches can also be included in individual work with relatives.

An important guiding principle in this area is that family caregivers can only provide effective long-term support for their injured relative if they are also able to look after themselves. However, as described earlier, helping caregivers to recognize and then attempt to reduce their own stress can be challenging, as they have often developed avoidant coping strategies by the time they obtain professional help. Frequently, the lives of family caregivers are so bound up with their injured relative’s difficulties and restrictions, they have often almost forgotten what it was like to consider their own well-being or happiness. When asked to think about themselves, the prospect of recognizing the extent to which their own needs are now unmet is very distressing and potentially threatening in relation to their own identity. On the basis of our own experience of running stress management groups for ABI family caregivers, caregivers find it difficult to acknowledge their stress and distress and so the first steps in stress management are often about recognizing and acknowledging their current unhappiness (Williams et al., submitted).

Our approach assumes that working with family members is a fundamental part of enabling and empowering a person with a brain injury to live as independent and meaningful a life as possible. Information and open discussion about the effects of brain injury can help families to understand their relative’s difficulties more clearly, change blame to compassion and empathy, and improve family functioning and quality of life for all concerned. Improving the emotional well-being of caregivers can have a significant positive effect on the well-being of the injured person as well as on the family. The family can be assisted to become more proactive in behaviour management and to facilitate positive cycles of behaviour that will be helpful for all concerned. Finally, stress management benefits caregivers directly and has indirect positive outcomes for individuals being cared for.

One final component of our work is to offer supervision and training to other psychologists and multi-disciplinary colleagues working in brain injury rehabilitation. Working with complex and severely injured clients and their families can often feel overwhelming and de-skilling. As Oddy and Herbert (2000) have pointed out, professionals often experience difficulties when working with families and there can be conflict between them. This may be based partly on families being misinformed and developing unrealistic expectations of professional input. The family is also relatively powerless and may struggle to contain their unaddressed, unresolved grief, distress and uncertainty. Anger, frustration and hostility may then be directed at the rehabilitation staff. Conversely, professionals, who may also be frustrated by slow progress may feel criticized by families and in turn may feel critical of the family’s behaviour, which may be seen by professionals as unhelpful. Developing collaborative systemic and psychological formulations of these difficult, sometimes ‘stuck’ situations can help other professionals as well as families to understand how alternative approaches and strategies might be useful. It is also possible to help other professionals to manage their own work-related stress more effectively and facilitate their emotional well-being.

The following case study, based on our own experience, illustrates some of the cycles of stress commonly encountered in work with ABI families. We will describe our attempts to intervene at different points in the system, to help family members to negotiate with each other and to come to terms with the brain injury and its effect on the family.

Case study

At the time of our involvement, Kate was in her late 20s. She sustained a very severe traumatic brain injury at the age of 13, when she was an unrestrained rear seat passenger in a serious road traffic accident. Kate also suffered multiple orthopaedic and internal injuries, and a depressed right parietal skull fracture. Neuroimaging showed bilateral temporal and frontal lobe contusions with a right intra-cerebral haemorrhage. Kate developed significant memory, cognitive, emotional and behavioural difficulties following the accident. In particular, in which had very severe memory problems and severe executive function impairments. As a consequence, Kate was unable to function independently in daily life and required frequent prompting and external monitoring. She had poor reasoning ability, and was inflexible and concrete. Kate’s behaviour was frequently disinhibited and inappropriate, and her social judgment was poor. She had a history of mood swings, verbal aggression and obsessive / compulsive behaviour. In addition, Kate developed epilepsy that had worsened progressively. Her
education and social development were disrupted, and she had never worked in paid employment after leaving school.

Kate was referred to neuropsychology because of concern about deterioration in her behaviour and family relationships. At the time of the initial assessment, Kate was living at home with her parents, Sarah and Phil. The frequency of Kate’s seizures had increased significantly over the past year, and this was having a negative impact on her functioning and independence. Sarah had recently resigned from her work in order to spend more time looking after Kate. However, Sarah described their relationship as volatile and was noticeably low in mood in the initial assessment. Phil worked away from home during the week. He had a positive relationship with Kate but was frustrated and upset by the conflict between his wife and daughter.

Kate was warm and personable, and it was easy to develop rapport and a relationship with her. She enjoyed cleaning, helping to prepare meals, watching television soap opera, listening to music and playing with her nieces and nephews. Kate wanted to be seen as a grown-up within the family and was clearly very sensitive to her younger siblings’ success. She resented her mother for restricting her independence, but at the same time wanted to be with her mother because she felt safe. She had been successfully participating in a voluntary work placement, but in recent weeks had stopped attending because of increased seizure frequency, and was at home with her mother most of the time.

Kate had been in a relationship with Neil for five years. Neil was in his late 40’s and similar age to Phil. Neil also had a severe brain injury, from a road accident in his late twenties. His sister had epilepsy, and whilst Kate and Neil both believed that he could manage and cope with her seizures, Sarah and Phil disagreed. They disapproved of Neil and did not understand why Kate was happy with him.

**Formulation**

The relationship between Kate and Sarah was markedly variable; it was frequently tense, with high levels of expressed emotion, but was also warm and loving at other times. An important early observation was that conflict between Kate and Sarah tended to reflect the quality of Sarah’s mood, and that this often created a negative cycle. Kate had a strong tendency to mirror the moods and behaviour of people around her, and this was particularly evident with Sarah. Sarah was frequently low in mood, particularly following the loss of her work and reduced social contact. An additional contributor was that Sarah stopped taking antidepressant medication as soon as she felt better and so was caught in a cycle of relapse and recovery from depression. It was also evident that spending five weekdays alone together at home added to Sarah and Kate’s difficulties.

Sarah found it difficult to act upon professional advice regarding behavioural management (e.g. ignoring unwanted behaviour), and often actively engaged in arguments with Kate, which might have been avoided. Part of the difficulty for Sarah was that she did not fully understand Kate’s cognitive and emotional limitations and often misinterpreted Kate’s problematic behaviour as intentional and provocative. This led to further blame on Sarah’s part and on-going conflict. Furthermore, in response to advice given about Kate’s behaviour, Sarah invariably reported that Phil, her husband, had already suggested the same idea. Sarah felt that she did not have the personal resources to follow the advice, whereas Phil could manage Kate’s behaviour more positively and they had fewer arguments. This became a further source of frustration and resentment for Sarah.

Kate’s verbal aggression and argumentative behaviour often reflected her frustration with the limitations imposed on her independence by Sarah. Although Kate usually spent weekends with her partner, the number of other nights she was allowed to stay with him was limited. Sarah believed that Kate needed to be at home to recover from having less sleep at the weekend and to reduce the risk of seizures triggered by fatigue. Kate wanted to live full-time with her partner and to manage a household with him, but her mother believed that this would have disastrous consequences for her epilepsy. Sarah also believed that Kate was too disabled and too vulnerable in other domains to live independently.

Long discussions with Sarah about Kate’s accident and the changes it caused revealed that Sarah had not accepted or fully understood the losses incurred. Kate was an intelligent and well-adjusted adolescent pre-injury, and as she and her siblings grew older, the gap between them widened progressively. Sarah had not yet allowed herself to grieve for these losses and Kate’s disrupted development, and found it difficult to acknowledge that Kate would not recover further.

**Intervention**

Two clinical psychologists were involved in work with Kate and her family. Both psychologists knew the whole family, but one developed a more direct relationship with Kate, whilst the other worked with Sarah. The joint appointments typically began with parallel individual sessions for Kate and Sarah, followed by a joint session. Occasionally, Sarah would be joined by her husband, Phil. The individual work with Sarah included an in-depth exploration of Kate’s injury and its effect on the whole family, helping Sarah to develop a clearer understanding of its consequences and their emotional impact. Reflecting on the losses incurred, and their meaning for Kate and Sarah, moved Sarah towards a greater acceptance of the situation and its limitations. It was then also possible to address Sarah’s considerable anxiety about Kate and her safety and to begin to consider options that were less restrictive for Kate. Sarah was also encouraged to continue her antidepressant treatment when her mood improved. The content of these sessions reflected a blend of psycho-education and therapeutic emotional support, with some discussion of behavioural management strategies as described above.

Sessions with Kate were primarily about gaining a clearer understanding of her perspective and the changes she wanted to make. This included her aspirations for independence, her frustration with her disabilities and the limitations on her life, and her distress and confusion about being different to others. As Kate had limited self-awareness of her cognitive, behavioural and emotional difficulties, some of the work with Kate was intended to help her to make more sense of herself. Although, as a result of Kate’s very severe memory problems, she was unable to recall information from her sessions, she valued these discussions and developed a strong therapeutic relationship with the psychologist. The work appeared to help Kate to feel better understood and to see herself as more adult-like than before.

The joint sessions provided Kate and Sarah with an opportunity to feed back limited aspects of their individual sessions to each other and to discuss issues more openly and safely. The psychological formulation was shared with them, and with Phil, with an emphasis on the circular relationship between their responses and understanding the situation without the need to blame. Although Kate was unable to understand the formulation fully, she appeared to benefit from the discussion. Sarah was able to accept the formulation gradually and to work more collaboratively with the psychologists as a result. The joint sessions also allowed Kate and her parents to begin to negotiate with each other and to plan some possible change.

With support, Kate was able to ask her parents for more independence, for their help in finding her accommodation, and for more time with Neil. Sarah and Phil were reluctant but eventually agreed that Kate could gradually move towards independent living. Sheltered accommodation close to her parents’ home was provided quickly by a local housing association, and Kate began a gradual transition to living there with Neil. This was a difficult time for Sarah and Phil, reflecting their anxiety about Kate’s safety. However, further psychological involvement allowed some compromises to be negotiated. For example, Kate began to spend every weekday morning at her brother’s and helped to look after the house. She then moved to Tom’s flat in the afternoon and joined Neil in town before spending the evening at home with him. Neil did their shopping, cooking and laundry, and Kate cleaned their house.

There was less conflict between Kate and Sarah, and when it arose, Kate could go home. She felt better for having a more adult lifestyle and identity. Sarah and Phil recognised that Kate’s dependence has been transferred to Neil, and found it very hard to let go of their role. Despite her parents’ misgivings, there were no serious incidents and the situation appeared to be sustainable.

The achievement of some distance between Kate and Sarah was critical in breaking the behavioural and emotional cycles they were trapped in, and that bound them together. This was followed by a renewal of contact between them that was more positive, and included an escape route. Kate and Sarah both reported a gradual increase in self-confidence and well-being. Kate felt more independent; Sarah felt she was supporting Kate but not at the expense of her own health & happiness.

**Conclusion**

This paper has considered some of the evidence for the psychological stress endured by the close relatives of people who survive a significant brain injury. A number of recently developed psychological interventions de-
signed to support families after a brain injury have also been considered, along with evidence for the impact that such interventions can have. We have also described our own experience of working with families in clinical practice and illustrated this with a case study.

References


