In Practice

Maintaining and developing friendships following severe traumatic brain injury: Principles of occupational therapy practice

Libby Callaway,1 Sue Sloan2 and Dianne Winkler3

1Neuroskills Pty Ltd, Highett, 2Osborn Sloan & Associates, Kew and 3Monash University, Frankston, Victoria, Australia

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Introduction

Numerous outcome studies have found that loss of friends and social isolation are common outcomes of traumatic brain injury (TBI) (Burleigh, Farber & Gillard, 1998; Eames, Cotterill, Kneale, Storrar & Yeomans, 1996; Olver, Ponsford & Curran, 1996; D. Winkler, unpublished data, 2002). Traditional therapy programs, such as social and conversational skills training (McDonald, 2003) and life skills development (Ylvisaker & Feeney, 1998), aim to reduce activity limitations arising from cognitive-behavioural impairments and may indirectly lead to improved behaviours and increased social contact. However, friendship as an occupational role, and the maintenance and development of natural social networks following TBI, has not been a major focus of occupational therapy intervention to date (Burleigh et al.). This paper explores the role of occupational therapists, and describes principles of practice, in supporting and fostering friendships following TBI. It aims to highlight the importance of the area of friendship maintenance and development and, drawing on the clinical experience of the authors, provides practical strategies to facilitate friendships.

Friendships are voluntary relationships involving reciprocal interaction and requiring some degree of affective involvement from each partner (Matthews, 1983). The friendship bond is fragile because unlike marital, family or work relationships, there are no formal ties (Wiseman, 1986). Friendships are maintained through volition, change over the lifespan and are vulnerable to termination following a major life change, such as TBI.

Traumatic brain injury is an insult to the brain, caused by an external physical force that may produce a diminished or altered state of consciousness, and results in impairment of cognitive abilities or physical functioning. Disturbance of behavioural or emotional functioning can also occur (Fortune & Wen, 1999). The majority of people who sustain TBI are young males (15–24 years; Fortune & Wen), in a period of life when people tend to value friendships highly, have a large number of friends and spend much of their time with them (Hartley, 1994). Given the importance of social relationships to most young adults, friends as well as family should be included in education programs and the rehabilitation process. In the early stages following TBI, the individual is usually focused on physical recovery; however, several years post injury, people are more aware of reduced community integration, social isolation and boredom — long-term issues that may worsen over time (Burleigh et al., 1998; Ponsford, Sloan & Snow, 1995).

Community integration is defined as the inclusion of people with activity limitations in the common life of their local community, a part of which is having a network of family, friends and acquaintances (D. Winkler, unpublished data, 2002). Outcome studies show that following a severe TBI, people are often located in the community, however, they are not an integral part of their community (Burleigh et al., 1998; D. Winkler, unpublished data, 2002). In particular, severe TBI frequently results in isolation from social contacts (Olver et al., 1996) and the loss of multiple life roles (Davies Hallett, Zasler, Maurer & Cash, 1994). Olver et al. reported that, 5 years post injury, 50% of a
follow-up group of people with TBI said they had lost friends. Eames et al. (1996) found that 71% of their sample had ‘no social life except that arranged by family (p. 645),’ and a further 15% reported a marked reduction in social activity. D. Winkler (unpublished data, 2002) found that 54% of participants reported their relationship with friends had changed substantially, and the range of occupations they shared was restricted. In addition to losing friends, people with TBI experience significant cognitive-behavioural impairments (McDonald, 2003; Ponsford et al., 1995), which impact on their ability to develop new friendships. Over time, social isolation and dissatisfaction with social networks tend to increase, and may lead to the development of secondary psychological sequelae (Burleigh et al., 1998).

Given the impact of TBI on friendships and social networks, it is vital that interventions are developed to stem the loss of friends and facilitate the development of new friendships (Burleigh et al., 1998; Eames et al., 1996; Olver et al., 1996; D. Winkler, unpublished data, 2002). However, to date, research to elucidate the issues and direct clinical practice is limited, and tends to focus on social skills training (McDonald, 2003) or the development of formal support networks (Johnson & Davis, 1998; Kuipers, Kennedy & Smith, 1999; Rowlands, 2002). While social and communication skills training can be an adjunct to friendship development, it only offers intervention for the individual with TBI and does not consider the barriers friends may experience in maintaining a relationship with the injured person. Furthermore, although research indicates the potential for positive behavioural change within the training setting (McDonald), there is limited evidence of generalisation of social skills to real-life situations. Formal support networks, including matched social contacts (Johnson & Davis) and circles of support (Kuipers et al.; Rowlands) offer mechanisms for increasing social contact. However, follow-up studies show that the maintenance of relationships developed may be limited to the life of the structured program (Johnson & Davis). The principles of practice described in this article address the limitations of these more traditional interventions by directly targeting the reciprocal relationship that is friendship, providing individualised input with both the person with TBI and their existing or potential new friends in naturally occurring settings.

Assessment

Given the personal and individual nature of friendship, a thorough understanding of the person and their social context is essential prior to intervention. Areas of assessment may include: the person’s social networks and shared interests prior to their injury; current interests and friendship networks and level of satisfaction with these; as well as personal beliefs regarding future friendship requirements (such as frequency of contact and size of friendship group) and valued life roles. A comprehensive understanding of personal strengths, cognitive-behavioural, physical and communication abilities and level of independence in everyday activities is required. There may also be a need to separate the individual’s friendship needs and desires from those of significant others. For example, family members may not welcome renewed contact with some of the person’s pre-injury friends.

Occupational therapy practice

Client-centred practice is imperative within the area of friendship development as it recognises the strengths individuals bring to therapy, the need for client choice and the benefits of client–therapist collaboration (Law, Baptiste & Mills, 1995). Intervention in this area may be confronting, highlighting areas of grief or loss for both the individual and their friends (B. Easton, unpublished data, 2001). Often, a conservative approach is required because of potential conflict between the individual, their family and friends. For example, family members may hold some resentment towards friends who have made little contact since the injury, resulting in barriers to the maintenance or re-establishment of these friendships. It is important to ensure that intervention does not do more harm than good, not only for the individual but their existing social and family network (Willer & Corrigan, 1994). Goals for, and expectations regarding, intervention within this area must be clearly defined to ensure that all parties have a realistic and consistent understanding of the aims, desired outcomes and timelines for intervention.

Occupational therapists are ideally placed to assist with the development and maintenance of the individual’s social network at each stage of the rehabilitation process (Burleigh et al., 1998). While the emphasis in the acute stage will be on maintenance of existing friendships, the community reintegration stage offers scope for interventions focused on developing new friendships. At each stage, success will depend on the formation of collaborative relationships between the therapist and key people including the individual, their friends and family members. Supporting and strengthening natural existing community-based friendships may not only enhance long-term psychosocial outcomes, but also reduce dependence on paid supports for social contact.

Interventions

Following is an outline, from the authors’ clinical experience, of potential areas of intervention that may
be offered in order to stem the loss of friends following TBI and foster the development of new friendships.

**Education**

While rehabilitation facilities frequently provide comprehensive education and support to family members, the information provided to friends is often limited. With the individual's consent, it is important that people within their social network develop an understanding of the cognitive-behavioural, physical and communication sequelae of the brain injury and are helped to identify strategies to facilitate engagement in activities and relationships. Welcoming friends to the rehabilitation facility and involving them in therapy activities provides the opportunity to role model practical skills (e.g. how to operate a wheelchair) as well as more complex interventions (e.g. managing challenging behaviours). Although in the early stages of rehabilitation, actively engaging friends in the rehabilitation process may not seem important, given the other demands on the therapists' time, the provision of education and support to stem the loss of friends at this stage is likely to be far more effective and efficient than attempting to re-engage friends or develop new friends several years post injury (D. Winkler, unpublished data, 2002). Re-engaging the individual in social situations will often involve some level of risk taking, and it is important that friends are helped to manage such risks and to understand any definite boundaries within social activities (e.g. alcohol consumption). Paid support staff also require education to ensure they understand their role, particularly the importance of professional boundaries when engaging with the individual and their friends. Training may be required to increase the understanding of grading or withdrawing support as natural relationships develop.

**Communication channels**

Following severe TBI, the individual’s changed circumstances and abilities usually necessitate a restructure of communication channels with friends and, particularly in the early stages post injury, direct assistance may be required to ensure contact is maintained. Collecting contact details of friends is a vital first step and may be achieved by placing a visitor’s book in the individual’s room or identifying a key person to gather, and regularly update this information. Therapists may access these resources to assist the individual to make contact with friends, such as sending thank you cards or emails. In the longer term, a contact list may provide the mechanism for re-engaging friends at a later time post injury when the individual’s awareness of their social isolation is typically heightened (Burleigh et al., 1998). Establishing communication channels between friends and family members will assist in maintaining their engagement when therapists are no longer involved.

**Shared occupations**

Contact with individuals who have shared interests can lead to friendship development (Hartley, 1994). The maintenance of past, or the facilitation of new, meaningful occupations that can be shared forms the basis of social network development and is a key area for occupational therapy intervention.

A reduction in the range of shared occupations can lead to loss of existing friendships (B. Easton, unpublished data, 2001; D. Winkler, unpublished data, 2002). Occupational therapists can work with friends to identify, and support them to participate in suitable shared occupations from the earliest stages of rehabilitation (B. Easton, unpublished data, 2001). Initially, these occupations may be as simple as listening to music together, looking through a photo album or having a coffee at a local café. However, supporting friends to find shared occupations that make social contact more rewarding for both parties may foster the maintenance of friendship in the long term. Intervention may include distributing a newsletter regarding the person’s progress and suggestions regarding activities that could be undertaken together. The development of social routines with existing friends will assist in regular contact (e.g. celebrate the person’s birthday on the actual date so friends know to keep it free). In the longer term, the person with TBI can be assisted to consider the activities they previously undertook with friends and re-engage with them through these shared occupations.

Working with the individual to develop interests in regular community-based activities may offer natural opportunities for social contact and the potential for development of new friendships. For example, an interest in competitive sport may lead to the development of skills in archery and, with appropriate support, participation at a local archery club. Routine participation in this activity will offer regular contact with other club members.

Being present in the community is the first step towards integration, but does not always lead to community inclusion or expansion of social networks. Sometimes, although the person is actively involved in community-based groups, friendships do not occur naturally and may need to be fostered. Acquaintances, who share common interests but have a more distant relationship with the individual, may be encouraged to take on a closer friendship role through active social planning by the person with TBI, supported by the therapist. For some people with TBI, the development of an acquaintance relationship into friendship will be difficult. Despite this, there is considerable value
in increasing a person’s social contacts and the number of community locations in which they are valued and accepted (McLeod, Stewart & Robertson, 2002).

Skill development
Therapists play a valuable role assisting the person with TBI to develop the skills to participate in shared occupations. Most importantly, the individual needs to be equipped to manage their behavioural responses within community settings (D. Winkler, unpublished data, 2002). Thorough assessment will lead to the identification of residual strengths that can be utilised in the acquisition of specific cognitive-behavioural, physical, communication and independent living skills (e.g. anger management, conversational skills, money handling).

Conclusion
Friendship is an occupational role often neglected in the rehabilitation of adults with TBI. Outcome studies indicate that, over time, numbers of friends dwindle and social integration tends not to improve or may even worsen. The loss of friends has been found to be consistently associated with high levels of psychological distress. Early intervention is required to support and maintain friendships following TBI. Occupational therapists are well placed to work with individuals to address this complex area, providing education to family and friends, identifying and structuring communication channels for friendship, developing participation in shared activities, and promoting acquisition of skills that underpin role performance. The principles of occupational therapy practice outlined in this paper stem from clinical experience. They require further development as well as empirical evaluation of their effectiveness in helping people with severe TBI to become an integral part of their community, rather than just being located in the community.

References


Just as two people are not exactly alike, no two brain injuries are exactly alike. Therefore, approach to neurological rehabilitation and physiotherapy post-traumatic brain injury should observe neuroplasticity, motor learning, and motor control principles as well as the patient-centred approach with an The first priority in traumatic brain injury (TBI) is complete and rapid physiologic resuscitation. Special considerations for isolated communities without neurosurgical support Moderate/severe TBI Behavioral therapy is a well-accepted and widely used therapy for TBI; it acknowledges that behavioral problems are always multi-factorial and therefore should consider medical, neurosurgical, neurological, psychiatric, environmental, and psychosocial issues. These should be trialed within a rehabilitation therapy program by physical therapists, occupational therapists and speech-language therapists, to determine which tools are most suitable for individual cases. Psychological/Educational Interventions.