1 Seeing the Bigger Picture: Using Clients' Experiences to Shape Clinical Practice

Chapter objectives

- Discuss the impact of brain, injury on the lives of individuals and their families, highlighting the changes that clients experience over time and the subsequent need for long-term services and supports, particularly during times of transition between services.
- Outline requirements for effective collaboration with clients and caregivers, including principles and practices the clinician can adopt to ensure client-centred service provision that promotes clients' and caregivers' long-term quality of life.

Abbreviations

ABI	Acquired brain injury
CP	Cerebral palsy
TBI	Traumatic brain injury

1.1 Appreciating the client's experiences

To ensure that neurorehabilitation, or any other aspect of service provision, is effectively targeted and contributes to positive outcomes for clients in their life contexts, the clinician must step back and appreciate the wider picture of what occurs in the lives of individuals and their families after brain injury. Health professionals may, at times, feel that they have limited control over the organisational context and practical constraints (e.g. funding mechanisms, staffing levels, resource availability) within which they are working. Indeed, service evaluation, long-term research and government lobbying is often required to drive positive change in service provision models, availability and quality. Nonetheless, the individual clinician usually has some control over *how* he or she practices – what is emphasised and prioritised in encounters with the client and family, which clinical skills are developed and refined, who the client will be referred to after this clinical service has ended, and the communication that will occur with the client and family, as well as with subsequent service providers.

Therapy services are typically categorised according to the amount of time post-injury, the service purpose (acute care, rehabilitation, long-term community-based services, residential care) or a specific client age range (children and youth, adults, older people). Therefore, each clinician will be involved for only part of the client's story. Smoothing the pathway from one phase of service provision to the next requires a broader appreciation of the client's rehabilitation journey outside the clinician's own immediate service context.

To gain this broader perspective, the clinician can consider what has been learned from research into the experiences of clients and caregivers post-injury and their perceived long-term service needs. Although a variety of different factors come into play when working with clients with different diagnoses, research into chronic disability due to brain injury suggests some common themes across stroke, traumatic brain injury (TBI) and cerebral palsy (CP). Awareness of these 'big picture' themes can help clinicians develop practice habits and skills that support the client's quality of life and promote positive long-term outcomes. Research findings suggest that the following themes are important in guiding service provision.

1.2 Providing or assisting access to long-term services

1.2.1 What are the needs?

It is clear that quality acute care supports better outcomes for people with acquired brain injury (ABI). This is illustrated by the variation among stroke outcomes in different European countries depending on the resources devoted to the acute phase of treatment [1]. It has further been suggested that, in addition to advances in brain stimulation techniques and pharmacological interventions, early provision of intense interdisciplinary neurorehabilitation contributes

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substantially to better stroke outcomes [2]. In relation to children with CP, substantial progress has been made over the past two decades in developing coordinated interdisciplinary rehabilitation services [3] and research into related interventions has focused on provision of services early in life and throughout childhood [4].

Despite a concentration of resources within the acute and early rehabilitation phases of intervention, a growing body of research across different diagnostic groups indicates that people with brain injury continue to have therapy needs on a long-term basis, often for the duration of their lifetimes [5]. In a study of 60 people with TBI who were interviewed one year after their injuries, 38% identified significant restrictions to their lifestyle and work capacity and 15% were unable to care for themselves [6]. In a UK study of 1251 people ranging from one to five years post-stroke, approximately half of the participants reported a reduction in work activities and two thirds participated in fewer leisure pursuits than before their strokes [7]. In a comparison of the quality of life between people with recent (1 – 5 years) and extended (more than 5 years) brain injuries, the extended group reported more difficulties with instrumental activities of daily living, such as household tasks and community activities, indicating the need for continuous community living skills training [8].

As people with CP live longer, there are indications that atypical tone increases with age and secondary conditions, such as contractures and degenerative arthritis, are having lifetime effects [9]. In a review of long-term outcomes for adults with CP, Kembhavi *et al.* [4] identified that ambulation skills commonly deteriorated in adulthood and that joint deformities occurred regardless of mobility status or severity of the condition. Co-morbid diagnoses, such as stroke, multiple sclerosis and Parkinson disease, are not uncommon in adults with CP [9]. The recognition of these long-term issues within this client group has led to increased research into the impact of pain and fatigue on their participation in daily life activities [4].

In addition to these ongoing physical and rehabilitation needs, it is clear that emotional and psychosocial issues continue to be evident over time across all diagnostic groups. In a large UK study, one third of participants who had had a stroke between one and five years previously reported emotional problems [7]. Similarly, in a sample of French participants, two thirds of whom were more than one year post-stroke, depression was more common than in matched controls, and levels of both depression and difficulties in social interaction increased over time post-stroke [10]. Comparable difficulties were found in a study of people with TBI [11]. For people with stroke, emotional and social issues were more marked for those who had hemiplegia or were unemployed [10]. As such needs have become more recognised, it has become evident that promoting quality of life among people with ABI requires ongoing support of emotional and social role functioning, daily life activities and participation in enjoyable activities [12]. A similar breadth of needs can be identified for people with CP. Studies suggest that adults with CP commonly live isolated lives [13] and that those aged over 40 have been assessed to be lonelier than other adults [14]. Mental health issues, such as depression, are not uncommon in this population [9]. At a consultative clinic for adults with CP in New South Wales, Australia, while the main areas of need are neurological and musculoskeletal, depression and anxiety are also being identified [3].

Collectively, this research suggests that the service needs of people with brain injury change and increase over time and that services need to be responsive to these changes [5,15]. It is further suggested that the degree to which these service and support needs are met will significantly impact clients' long term quality of life, psychological adjustment and participation in meaningful life roles [16 – 18]. The importance of ongoing service provision for adults with TBI is highlighted by the finding from one study that, for some people, the hope of continuous improvement over time played a critical role in developing a "new self" [6] (p.414). For example, one participant commented that "I'll keep improving, with hard work of course, for the next … 10 years, or 20 years, no matter what … " (p.413).

1.2.2 Are the needs being met?

Despite increasing acknowledgement of long-term service needs, current service availability and access is falling short of the expectations of clients and families. Half of the participants in a UK study of people post-stroke reported unmet needs in relation to clinical services and information provision [7], while an Australian survey of carers of adults with TBI found that only 33% reported access to therapy services following hospital discharge [5]. In another study focusing on the transition of people with ABI from hospital to home, the services that were provided (even during inpatient rehabilitation) were considered insufficient in terms of timing, intensity and duration [15]. Adults with chronic lifelong disabilities have reported difficulty accessing services in the adult health system equivalent to those available when they were children [19]; similarly, young people with CP experience a marked reduction in rehabilitation services once they finish school [3]. People living in rural areas and those with non-compensable injuries also face restrictions to service access in some countries [15].

While limited resources are likely to be partly to blame for unmet service needs, some studies indicate that the attitudes of service providers were unhelpful and they reduced access to further services. In a Swedish study, people with TBI and their relatives reported feeling avoided and misjudged by health service personnel [20]. They relayed their experiences of professionals evading their questions about further service provision and making decisions about their care without consulting them or allowing their families to have meaningful input. Dennis [21] provides a vivid account of similar experiences after her mother had a stroke and service providers decided that rehabilitation was not warranted due to the severity of the stroke's effects. Dennis perceived that once this decision is made by health professionals, care and therapy ceases, causing further negative impact on the quality of life of people with more severe disabilities. Adults with CP have also reported that, while their experience of dealing with health professionals was generally positive, barriers to accessing health care included lack of interest and time provided to them by some health professionals [13] and a lack of specialist knowledge and professional training [4,22].

It may be difficult for individual clinicians to effect significant organisation- or health care system-wide changes to service access. However, the research outcomes described here can be used constructively to develop one's own practice style and principles, focusing in particular on developing a client-centred approach to service provision and a personal attitude of compassion.

1.3 Initiating and supporting transitions from one service to the next

1.3.1 How is transition experienced?

The process of transitioning from one service context or stage to another is another theme identified as important by clients and caregivers. Research into the transition from hospital to home or from inpatient to outpatient rehabilitation services suggests that this process often does not occur smoothly. For example, in an Australian study, a quarter of carers of people with TBI reported that they received inadequate information about services available after discharge. Few carers were accessing formal financial, travel or accommodation supports and only one third of clients were reportedly accessing ongoing therapy [5]. In a further study of individuals returning home after an ABI, participants reported that organising post-discharge services was a difficult process, mired in bureaucracy and inflexible or complex eligibility criteria [15]. In the latter study, case management services were not in place before or immediately after discharge, and clients experienced delays in commencing community-based services after returning home. As a result of this lack of coordination and planning, levels of caregiver satisfaction tend to drop substantially between inpatient and outpatient services [5,23]. It has been suggested that reduced satisfaction at this point in time might also be due to a slowing of the spontaneous recovery experienced by the person with brain injury [5]. However, the anxiety that this phase creates is only likely to be exacerbated by a simultaneous reduction in services that could play

Messages for the Clinician

- Assume that clients are likely to have ongoing service needs at various points in their lifetime and that even after neurological rehabilitation is complete, consideration should be given to issues of quality of life.
- Collaborate with clients and their caregivers about future service needs and assist them to source possible services options and form links with these services.
- Monitor the long-term needs of clients and provide targeted rehabilitation when possible to address defined needs.
- Initiate working closely with other professionals (such as social workers and psychologists) to ensure that social and emotional needs are addressed at all ages and life stages.
- Ensure that, during rehabilitation and beyond, therapy promotes participation in daily life activities and valued life roles to assist adaptation to changes in ability over time.
- Seek out specialist training to develop relevant skills for ongoing management of chronic rehabilitation needs.

a role in assisting clients to come to terms with their current status and future potential.

For young people with CP transitioning into adulthood, lack of allied health services and orthopaedic care are identified as challenges [19]. A review of transition services in Victoria, Australia, found that families were often inadequately prepared for the transition to adult health services. Variation occurred in terms of the age at which transition was first raised and the information provided about new services. Young people and their families reported feeling apprehensive about moving from the safe, nurturing environment of paediatric services with which they had had a long-term relationship, to adult services which were perceived to be less friendly and helpful. There was little lead up to the transition, few formal processes in place and no consistent staff member to manage and coordinate the move. Families reported feeling lost in this new system and, in addition, sometimes encountered long waiting lists for services and a shortage of health professionals with relevant expertise [22].

1.3.2 What is required to smooth the way?

Recommendations from research and service evaluation across different diagnostic groups carry similar themes. Caregivers of people with TBI reported that the anxiety they felt on discharge from hospital could have been relieved through the provision of improved transition planning and monitoring of post-discharge service access [5]. Similarly, people with ABI and their caregivers felt that case management needs to be instigated well before discharge to organise formal support services [15]. The process of transition of young people with CP from paediatric to adult services can be facilitated by an identified coordinator leading the development of specific processes, such as a documented transition plan that indicates the target age for transfer, the skills that may be required by the young person and family to effectively engage with adult services, and an agreed programme to target these skills [22]. Clear information about what to expect from the new service is recommended across all client groups [5,24].

Addressing the client's and caregivers' emotional support needs is another area of focus for transition. Close collaboration with clients with an acquired injury and their families is encouraged to uphold inclusiveness and dignity, and to promote a sense of control over the situation rather than exacerbating anxiety and despair at this time of change [15,21]. For young people with CP, it has been advised that greater emphasis be placed on understanding and addressing the client's and family's emotional needs as they leave paediatric services and enter the adult sector [22]. A Canadian transition programme aims to acknowledge the difficulties parents face as their child with a disability enters adulthood and advocates a shared management approach to transition, using skill building programmes to gradually shift responsibility from the parent to the child/adult [24].

The relationship and interaction between services at transition points is a further consideration, with research indicating that planned dialogue and collaboration between services is critical for a positive client experience [3,15,19]. A review of the transition experience of young people with CP in Australia recommended that the paediatric service initiate contact with the adult service to assist in establishing an early relationship with a key coordinating person. It was further advised that the adult service make contact with the client prior to the first appointment, if necessary arranging a one-to-one meeting with the designated cooordinator to provide information and allay anxieties prior to meeting the new interdisciplinary health service team. To support ongoing quality of service provision after transition, it was proposed that a professional development programme be developed that included formal and regular knowledge-sharing opportunities between previous and current service providers [22]. These specific recommendations for the process of interaction and mutual support between the pre- and post-transition services are equally relevant to hospital and community organisations servicing adults with acquired injuries.

1.4 Listening carefully and providing relevant information

Client and caregiver needs for clear information from professionals at all stages of service delivery is a recurring theme across a range of studies [5,15,22]. A US-based study found that outcomes for people with TBI and their carers were adversely affected by a lack of education throughout their healthcare experience [25]. Lack of information across the continuum of care has been identified as a prime reason for dissatisfaction with services [5]. A critical appraisal of the literature investigating the information needs of carers of relatives with an ABI described several requirements. In addition to general information about the injury, carers reported the need for health professionals to answer questions honestly while retaining hope for improvement [26]. Health professionals in a Canadian study defended the provision of vague information on the basis that long-term outcomes were often uncertain and that their aim was to avoid either upsetting the family or giving them "false hopes" [23,p.589]. However, feedback from clients and caregivers indicates that insufficient or conflicting information may be more detrimental to their understanding and acceptance of the consequences of brain injury [21].

Research further suggests that the importance of the interaction between the client and clinician extends beyond information giving. When transitioning from hospital to community-based services, development of a good relationship with therapists improved clients' and caregivers' perceptions of their community rehabilitation [15]. Young people with CP have often developed close relationships with their paediatric service providers and their confidence when moving to adult services was reportedly dependent upon the strength of their relationship with their new service coordinator [22].

The need to develop trusting relationships with health professionals is not surprising when one considers the emotional journey that accompanies the experience of brain injury. As previously discussed, anxiety, depression and loneliness are frequently described issues among people with CP and stroke [7,9]. It is expected that grief will occur after a brain injury and that the grief process is experienced in a highly individualised way [6]. An understanding of how clients are progressing through this process is central to building a therapeutic connection.

When interviewed one year after their injuries, people with TBI reported feeling regret and mourning for their loss of potential and previous life roles. They identified feeling alone and dehumanised during the recovery process, and commented that insensitive communication and lack of empathy from health professionals had the effect of diminishing their sense of hope. In particular, they felt rejected by professionals who did not seem to believe their subjective reports of the difficulties that they were experiencing, and they needed their issues to be confirmed or given legitimacy by these professionals [6]. This need appears to be long-term in nature, with another study finding that even eight years after injury, lack of acknowledgement of their suffering was a major determinant of reduced life satisfaction among people with TBI [27].

Chamberlain [6] asserts that, to promote recovery, health professionals need to engage the whole person rather than focusing on symptoms and deficits. Clients use personal narratives of their experience to assist their recovery and restore their self-hood. People with more severe disabilities may have greater difficulty conveying their narratives and may tend to rely on caregivers to fulfill this role. Given their evident importance in the recovery process, actively listening to clients' stories deserves considerable attention from clinicians.

Messages for the Clinician

- Provide honest, easy to interpret information, in both verbal and written formats at all stages of the health care continuum. If outcomes are uncertain, convey this by providing broader information on the range of likely outcomes. Ensure that this information is provided in a sensitive way and offer ongoing support and the opportunity for clarification.
- Make an effort to actively listen to clients' narratives of their experience. When relevant, listen to caregivers' translations of these experiences.
- Fully acknowledge clients' and caregivers' concerns and take them seriously. If it is unclear why they may be experiencing certain difficulties or symptoms, assume the role of collaborator and assist them to investigate the stated concerns.

1.5 Collaborating on achievable goals

Goal setting has long been considered a routine part of the neurorehabilitation process, involving the therapist and client formulating a statement about the desired outcome of intervention [28]. In settings with a team of service providers, such as stroke units, interdisciplinary goal setting is seen as important [2]. Clients with brain injury and their caregivers have reported that the process of setting goals increases their interest in rehabilitation and influences their perceptions of intervention success [15].

However, identifying goals is not always straightforward. In a study examining the transition from hospital to community rehabilitation services for people with ABI, many participants reported general goals such as "getting my life back to the way it used to be" (p.826) and appeared to be unaware of the more specific rehabilitation goals that they were working towards. These participants were confused about the process of goal setting, with many stating that their therapists had set the goals and that they believed this to be the therapist's role [15].

The experience of clients and families having difficulty specifying goals is not a new one to most clinicians, given that clients are often unsure what to expect of intervention and therefore what aims may be realistic. In addition, clients with acquired injuries may continue to be wedded to the idea of 'how things used to be' for some time after their injuries. A study of people who were more than five years post-injury found that their quality of life had improved over time and that they were better adjusted to their new lives than were more recently injured people [8]. It is possible that, at this later stage, clients may find it easier to contemplate more specific, realistic goals. In any case, it is likely that the clinician will need to provide information about the possible outcomes of intervention and the limits on what might be achieved to assist clients to set well-targeted goals at any stage of the rehabilitation process.

Messages for the Clinician

- Collaborate with clients to formulate and document specific, achievable goals in language that is understandable to both client and caregivers.
- Assess the client before setting goals and use assessment information to inform realistic goal setting. Explain to the client and caregivers what might be possible given the current situation and client abilities, which outcomes are probable and which outcomes are unlikely (see Chapter 4).
- Refer back to the documented goals frequently throughout the intervention process. Review goal achievement after each stage of intervention and either set new goals or adjust current goals to target a more realistic outcome.

1.6 Actively supporting and involving caregivers

A growing body of research is being directed towards the caregivers of people with brain injuries [5,29 – 31]. This has occurred in recognition of the critical role played by caregivers in the client's recovery and long-term outcomes. Research suggests that people with acquired brain injuries consider their informal networks to be their most valued source of support and that this support is typically concentrated with one or two important people in their lives [15]. The health, stress and level of burden on primary carers are directly associated with the recovery of adults with TBI [32]. This is not surprising given that the person's social and community integration or re-integration is often dependent on caregiver support [2]. This support is also influential for adults with CP. For example, although general exercise has been shown to improve functional status, frequency of exercise participation was found to be dependent on caregivers' attitudes [33].

Carers also report a range of unmet needs that result in feelings of isolation and of being misunderstood [5,30]. In addition to difficulties accessing ongoing services, the need for support during the transition between services, and wanting to receive clear information (discussed in Sections 1.2, 1.3 and 1.4), caregivers report a lack of adequate training from health professionals. For example, a third of carers of people with TBI reported that they had not received relevant training from hospital staff before taking on their caring responsibilities [5]. A lack of social supports for carers over time has also been found to have significant consequences; carers without social support whose relatives lived with cognitive deficits and lack of insight reported experiencing increasing stress as time progressed post injury. However, these factors did not cause stress among carers who had social supports in place [29].

Caring for caregivers would therefore seem to be a worthwhile focus for health professionals in order to

Messages for the Clinician

- Pay attention to caregivers. Notice their apparent levels of stress and anxiety. Ask them about how they are managing and the types of formal and informal supports they have in place for themselves. Where possible, provide information about support services they can access.
- Regularly take time to explain what you are doing with the client and why. Seek the caregiver's feedback. Routinely invite them to ask questions. Teach them techniques they can use in the client's daily lives. Allow them to practise these techniques in front of you and, if required, provide encouragement, extra support and information to promote mastery.
- Promote a culture of teamwork between the health professionals in your service and the clients and caregivers who access it. Initiate regular evaluation of service outcomes that includes seeking caregiver perceptions regarding satisfaction with the service. Let caregivers know how you have used this information to adapt service provision.

promote positive long-term outcomes for their clients. The most direct solution to unmet caregiver needs is for services to provide or assist caregivers to source ongoing emotional, psychological and financial support [5]. However, even if organisational resources make it difficult to provide this type of assistance, there are simpler steps that individual clinicians can take to reduce carer burden. Satisfaction of carers with service provision has been found to depend partly on their knowledge of, and involvement in, the rehabilitation process [5]. In addition, research indicates that caregivers' perceptions of support may be as beneficial to their wellbeing as the actual support provided [29]. This suggests that making efforts to fully involve caregivers in intervention, paying attention to their current and changing demands, and simply conveying a genuine caring attitude will go some way towards lightening the caregiver load.

1.7 This book: Promoting collaborative, client-centred intervention

So how does a book focused on the upper limb contribute to the wider experience of clients and caregivers after brain injury? It is hoped that the information provided in subsequent chapters will:

- Clarify causes of observed characteristics and movement patterns and their consequences for current and future function (Chapter 2), which will in turn assist the clinician to collaborate with the client on setting achievable goals (Chapter 4).
- Promote confidence in translating research into practice in a way that fully appreciates the realities of the client's whole situation and day to day life (Chapters 3, 6–10).
- Build clinicians' confidence regarding clinical reasoning and decision-making that considers the client's context and the aspects of life that have meaning for him or her (Chapters 3, 4, 5 and 11).
- Provide a framework for client- and family-centred assessment, goal setting and intervention in an area of practice where clients and families often need support to become empowered members of the team (Chapter 3).
- Provide a common language among health professionals for understanding and communicating with each other and the client about upper limb function and how it might impact on the person's wider experiences of life after brain injury.

Above all, it is our hope that clinicians will be inspired to join with clients and their family/caregivers in problem-solving the best way to optimise upper limb use and comfort in a way that positively contributes to their lives.

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