

PERSPECTIVES IN REHABILITATION

Whose decision is it anyway? How clinicians support decision-making participation after acquired brain injury

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Abstract

Purpose: To raise professional awareness of factors that may influence the support offered by clinicians to people with acquired brain injury (ABI), and to consider the potential implications of these factors in terms of post-injury rehabilitation and living. **Method:** A review of the literature was conducted to identify factors that determine how clinicians provide support and influence opportunities for individuals with ABI to participate in decision making across the rehabilitation continuum. Clinical case studies are used to highlight two specific issues: (1) hidden assumptions on the part of the practitioner, and (2) perceptions of risk operating in clinical practice. **Results:** There are a range of factors which may influence the decision-making support provided by clinicians and, ultimately, shape lifetime outcomes for individuals with ABI. A multidimensional framework may assist clinicians to identify relevant factors and consider their potential implications including those that influence how clinicians involved in supporting decision making approach this task. **Conclusions:** Participation in decision making is an undisputed human right and central to the provision of person-centred care. Further research is required to understand how clinical practice can maximise both opportunities and support for increased decision-making participation by individuals with ABI.

Keywords

Acquired brain injury, clinical practice, decision making, risk

History

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► Implications for Rehabilitation

- There is an increasing focus on the rights of all individuals to be supported to participate in decision making about their life.
- A number of changes associated with ABI mean that individuals with ABI will require support with decision making. Clinicians have a critical role in providing this support over the course of the rehabilitation continuum.
- Clinicians need to be aware of the range of factors that may influence the decision-making support they provide.
- A multidimensional framework may be used by clinicians to identify influences on the decision-making support they provide.

Introduction

The principles of autonomy, empowerment and citizenship increasingly guide the provision of support to people with a disability, including individuals with acquired brain injury (ABI). This reflects a growing recognition of the inherent human rights of all individuals to participate in making decisions in all aspects of their lives.

These developments have been driven by new conceptualisations of disability that increasingly acknowledge the impact of social and cultural factors in the experience of people with a disability and emphasise the individuals as expert in their own life. This broad change has resulted in legal and policy

frameworks that seek to acknowledge and counteract the ways in which society contributes to the experience of people with a disability. For example, the United Nations Convention on the Rights of Persons with Disabilities [1] has translated the traditional concepts of human rights into a specific disability context, by obliging governments that have ratified the Convention to ensure that people with a disability have access to the support they require to exercise their rights and freedoms.

Despite these changes in understanding and policy, questions remain about whether they have led to the practical and attitudinal changes that were imagined, particularly in the lives of individuals with ABI [2]. Achieving change at the practical level may be particularly difficult because services for individuals with ABI incorporate aspects of both specialist rehabilitation and generalist disability services. Historically, brain injury policy and practice has been focused on rehabilitation and the restoration of function after injury [3]. However, it is well established that severe brain injuries are commonly associated with some form of permanent impairment [4], and engagement with long-term disability

supports is highly likely. It is therefore important for clinicians at all stages across the rehabilitation continuum to develop a common understanding of their role, to ensure that individuals are given the support and accommodations that they require in order to maximise their participation in decision making about their lives.

Decision making after ABI

The World Health Organisation, in the International Classification of Functioning, Disability and Health (ICF), defines decision making as “making a choice among options, implementing the choice, and evaluating the effects of the choice...” [5]. This definition highlights the complex nature of decision making, which is characterised by a number of discrete steps involving cognitive, emotional and personal appraisal processes. It not only identifies the need to consider the impact of an individual’s impairment on decision making but also the influence of personal and contextual factors [6].

There is a growing understanding of the difficulties associated with decision making for individuals with ABI. The existing literature has focussed on changes that may occur after injury, and explains why adults with ABI may make decisions that are not in their best interests [7]. A substantial part of the literature on decision making has focused on cognitive aspects [8], for example by describing the nature of deficits in decision making and identifying the specific neural regions and neurological processes involved. More recent research highlights the critical role of emotion in decision making. This focus is particularly relevant to people with ABI, since emotional changes are a common consequence of injury and can appear almost paradoxical, including increased emotional lability and reduced ability to experience different emotional states [9–11]. Psychological research has found that both high emotional activation, such as anxiety, and low emotional activation, such as depression, may interfere with an individual’s reasoning [12]. In addition to identifying specific deficits frequently associated with ABI (particularly traumatic brain injury), these studies have increased understanding about the complexity of decision making. In particular, research has highlighted that an individual’s values and prior life experience need to be taken into account when considering cognitive and emotional processes [13].

Efforts to overcome these difficulties and support individuals to make decisions for themselves are important because the individual is in the singular position of being able to align decisions with personal goals and values [14]. For individuals with a disability, the opportunity to make decisions about oneself is associated with increased self-determination [15], improved quality of life [16], psychological wellbeing [17], and the positive development of one’s own identity [18]. Where mental health care is concerned, increased involvement in decision making is associated with greater adherence to practitioner recommendations and shorter inpatient stays [19].

In accordance with these benefits, national and international policies aim to maximise the opportunities for individuals with a disability to make decisions about their own lives [20,21]. Self-directed funding initiatives that provide opportunities for individuals to exercise control over the type and nature of services that they access are one example of measures that provide increased opportunities for individual choice [22]. However, such initiatives alone are insufficient to provide opportunities to make decisions unless they are implemented with adequate consideration of the factors that influence decision making for individuals with a disability and are accompanied by changes at the practice level.

The research literature identifies a number of factors that influence decision making for individuals after ABI. These include:

- individual factors, such as communication difficulties, impairments in cognitive functioning [23], and beliefs about the potential of rehabilitation and the future [24];
- relational factors, including the presence or absence of close tie support [25] and how those in the individual’s support network, including rehabilitation clinicians, contribute to the construction of decision-making capacity [26]; and
- environmental factors, spanning structural and cultural dimensions, including features in the individual’s immediate environment, as well as systems in their wider environment, including access to funding and support services and laws and regulations [27].

Clinicians play a critical role in the social environment of individuals with ABI, and their actions may influence decision-making opportunities for people with ABI. These include assumptions held by clinicians, such as how they understand and assess decision-making capacity [28], and their attitudes towards individual autonomy [29]. Further, interactions between the individual and the clinician, including sharing of relevant information [29] and approaches to manage difficulty reaching agreement when making decisions [23] must be considered.

Given the broad range of factors described above, clinicians must be cognisant of a variety of influences on decision-making support and opportunities when working with individuals with ABI. As a comprehensive review of all of these influences is outside the scope of this paper, the aim is to raise professional awareness of two specific factors that influence the support offered by clinicians to people with ABI to make decisions across the range of different contexts that an individual will experience following injury, and how these may shape lifetime outcomes, in terms of post-injury rehabilitation and living. Two clinical case scenarios from the literature are used to illustrate the following factors: (1) hidden assumptions on the part of the practitioner, and (2) perceptions of risk operating in clinical practice. These factors were chosen to emphasise the need to consider both implicit and explicit assumptions in clinical practice. Analysis of these cases highlights the utility of a multidimensional approach in identifying influences on decision making.

The impact of hidden assumptions

Clinicians may be guided by a range of implicit assumptions when supporting decision making for individuals with ABI. These assumptions concern the individual and their relationships, implicit structural constraints and cultural norms, and may provide clinicians with a justification to proceed where little information is known, or has been sought, about the preferences of the individual with ABI. The following clinical scenario highlights how hidden assumptions about the individual during rehabilitation can shape decisions made by the treating team and influence long-term outcomes.

Case scenario one: JB

Case scenario one is taken from a case study described in detail by Matthews [30] in the psychiatric literature. This case was selected to exemplify how clinicians’ hidden assumptions may influence the support they provide to the individual to enable participation in decision making after a severe brain injury.

JB is a 24 year old man who sustained a severe traumatic brain injury (TBI) eight months previously as a passenger in a motor vehicle accident. Initially, JB’s orthopaedic injuries were treated while he waited for a vacancy in a

rehabilitation facility. The rehabilitation referral detailed the nature and treatment of his injuries, but included no detailed personal history (as this had not been taken from JB or his mother).

The orthopaedic team presumed that JB would live with his family following his treatment. JB's mother refused this plan, and reported that she stopped visiting JB in hospital when this was raised, as she did not wish for him to return home due to his previous criminal behaviour. JB did not live at home prior to his accident, but lived with friends. In hospital, JB had few visitors and was isolated from his family and social networks, which JB reported consisted of "a small group of criminal colleagues". His girlfriend did not visit, and JB reported that this made him feel "very down".

JB had a self-reported history of difficulties at school, and drug and alcohol use. He reported involvement in organised criminal behaviour from his late teens, and had spent 18 months in prison for theft. JB reported that he saw few options but to return to this lifestyle after leaving hospital. Staff questioned the aims of rehabilitation for JB, but also reported sadness at his isolation.

This case highlights the range of decisions to be made after ABI and the evolving role of clinicians in making and supporting these decisions. In the early phases of JB's acute care, where the focus of the medical team is the maintenance of life and mitigation of further injury and JB's ability to participate in the decision-making process is limited, decisions about his future have been made with limited input from him. At this stage, the dominant influences on the decisions made on JB's behalf are the approaches taken by his clinicians. Notions of legal capacity are central and the significant consequences associated with these decisions mean that clinicians are required to make them within a risk management framework. Because of this, clinicians are likely to apply a number of assumptions to the situation, based on their accumulated values, experience and knowledge. Although these assumptions provide one way to overcome a lack of knowledge about the individual's preferences, taking time to seek detailed information from the individual with ABI and those in their support network provides an additional and improved means of doing so. However, resource constraints and the urgency associated with decisions may impede the clinician's ability to achieve this. Further, clinicians may be faced with a complex fractured social situation in which it can be difficult to determine who is best positioned to represent the individual's views.

Inpatient rehabilitation may be the first setting in which JB is faced with the changes to his personal circumstances that have resulted from his ABI. A significant aspect of the role of the clinicians who work with JB will therefore be to support him to make these decisions, often within short timeframes. In this case, some decisions may have been made by clinicians, such as whether JB was a suitable candidate for rehabilitation, the key focus of JB's therapy program, and how approved visitors were involved in the rehabilitation program, with varying levels of input from JB himself. Later in his rehabilitation, decisions will include the timing of discharge, where JB is to live after leaving the inpatient setting, and what services or supports may be necessary. Although JB's immediate needs and the availability of resources at that time will be prominent considerations in these decisions, the outcome of these decisions will have lifetime consequences for JB.

Supporting decision making is a key responsibility of the team around the person with ABI, and requires clinicians not only to be aware of the impact of ABI on decision making, but also to consider what supports can be put in place during inpatient and

community-based rehabilitation to maximise the individual's current level of ability. For example, meaningful decision making requires the presence of alternatives, which are able to be conceived in the mind of the person exercising that choice. In this scenario, the alternatives available to JB in relation to many of the decisions to be made were limited prior to his injury due to his personal circumstances. For example, opportunities for employment were limited by his lack of formal education and criminal history. During rehabilitation, clinicians may develop and offer further options. However, the level of support that clinicians are able to provide and the availability of resources to support these alternatives into the future may limit these options.

The provision of decision-making support also requires clinicians to pay careful attention to ensure that the information they provide is accessible. Further, clinicians should ensure that individuals are able to experience a range of different outcomes, which may require clinicians to provide individuals with support to plan or implement a decision. Providing support can prove particularly challenging for the clinician, who may hold the view that the decision preferred by the individual is not a good one. Further, the experiences and values of the individual need to be taken into consideration when evaluating the outcomes of a decision, as these are strongly connected to how a successful outcome will be defined in the context of their life.

Further, clinicians need to consider the individuals and their decision-making experience in the context of their life story, and update their assumptions accordingly. Given his age and life story, JB's independent decision-making skills are still in a phase of development, and he is now faced with the prospect of having to make decisions in many situations that he has not previously encountered.

Clinicians need to be aware of pre-existing constraints on JB's decision making. For example, his pre-morbid functioning, particularly his limited formal education and coping style, may have a significant impact on his capacity to identify and evaluate various options. Similarly, clinicians supporting JB to make decisions in rehabilitation need to be mindful of the impact of his brain injury on his pattern of cognitive strengths and weaknesses, his own response to his injury (including a high level of distress, feelings of hopelessness, and limited belief in his ability to positively influence future outcomes), and his increased level of risk for developing anxiety and depression.

Clinicians also need to consider how JB's opportunities to make these decisions and the alternatives available to him are constrained by his environment and relationships with those around him. His relationship with his mother provides one example of the influence of relationships on available options such as his choice of living arrangements. His broader social network is also an influence on his decision making and, while already limited, has contracted further during his stay in acute hospital care and rehabilitation.

Similarly, JB's unstable housing history prior to his injury provided few options for discharge. In this situation, the alternatives assumed to be both available and appropriate by the initial treating team caused greater harm than good. Expecting that JB would return to live with his mother upon discharge presumed that JB's mother (who reported having a strained relationship with JB prior to his injury) would be willing to adopt a primary caring role and that JB, a 24-year-old man who had not lived at home for a number of years, would want to return to such an arrangement. Although the team appeared to make this decision, based on the need for a decision to be made and the presence of few alternatives, consideration also needs to be given to the long-term consequences of such a decision. Based on the information provided in the case study, it could be expected that

JB returning to live with his mother may lead to a breakdown of their relationship. Given that JB's injury appears to have led to a breakdown of many of his friendships, maintenance and support of this important relationship should be seen as a key priority for the team. However, the nature and maintenance of this relationship should be negotiated on JB and his mother's terms.

Aside from clinical approaches and assumptions, the influence of clinicians on decisions made following ABI also depends on the availability of resources to provide alternatives. JB's lack of access to social and economic resources prior to his injury may have played a role in team decision making. Where there are few dedicated options, which is often the case in relation to housing, searching out alternatives can be time consuming and fruitless, and may be considered by clinicians to be a relatively unproductive task given their own resource limitations. Further, there are disadvantages when individuals remain in hospital awaiting discharge accommodation. However, where service constraints exist, these should be discussed with the person with ABI and their support network, so that decisions can be made with this information in mind. Other members of the rehabilitation team, such as social workers, who have specialist skills in raising resources, should also play a role.

The negative consequences of brain injury for social participation, particularly increased rates of psychosocial difficulties such as decreased social contact, loneliness and depression, have received considerable attention in the literature over the last two decades [31–33]. Clinicians may unwittingly contribute to this diminished social participation by implementing decision-making processes which lead to individuals being moved to unfamiliar environments, or by selecting therapy tasks which do not impact positively on their ability to build or maintain their social network. In the case of JB, the apparent views of the rehabilitation team not to actively support JB to maintain his social networks throughout his inpatient stay may have a significant impact on his ability to re-engage with and maintain relationships over the long term.

It is important to acknowledge that clinicians face competing objectives. The intent to support individual autonomy and the maintenance of social networks is necessarily balanced against the need to minimise the risk of harm to the individual. In JB's case, the rehabilitation team may have taken the approach of limiting contact with his peers in order to manage adverse risks such as him being taken advantage of or lured into illegal activity.

Perceptions of risk

Judgments based upon the perceived presence and level of risk involved with particular decisions reflect another example of an assumption frequently applied in clinical practice. For clinicians, the consideration of risk associated with alternatives may be given particular emphasis where there is uncertainty about the unknown preferences of the individual with ABI. Risk management influences many aspects of clinicians' engagement with and service provision to individuals with ABI. There are sound reasons for clinicians to take such an approach, such as the evidence that individuals with an ABI are increasingly likely to incur a subsequent ABI [34]. The risks of financial and sexual abuse, and of making poor decisions due to lack of support, are particularly heightened following brain injury [35]. These risks apply both to the individual and to others in their social context. However, an over emphasis on risk may also have negative consequences, leading to unnecessary restrictions on participation with subsequent consequences on the individual's wellbeing. Case study two highlights the presence of risk and its perception by those around Ms Watson.

Case scenario two: Ms Watson

Case scenario two is taken from a case study described in the annual report of the Office of the Public Advocate, Victoria, Australia [36].

Ms Watson is a young woman who sustained a severe brain injury as a result of a motor vehicle accident. As a result of her ABI, she is unable to communicate via speech, has limited independent mobility, and a significant cognitive impairment.

After four years in hospital following her injury, Ms Watson was discharged to her mother and father's home, with the local authority providing significant funding for attendant care and services (including case management and specialist therapy). However, in the 18 months following discharge, Ms Watson's mother had a number of disagreements with service providers, which resulted in service providers advising that they would withdraw their service. Due to the mounting pressure on the family and subsequent risk to Ms Watson, an independent temporary guardian was appointed.

After extensive consultation, the guardian made the decision to remove Ms Watson from the family home to alternative accommodation, initially respite care. She has since been admitted to a rehabilitation facility, where she is participating in a 12-week rehabilitation program to maximise her independence. Her mother visits her regularly and is involved in her rehabilitation and social activities. Following the completion of the program, the guardian aims to move Ms Watson to accommodation closer to her family and is considering her long-term options.

The consideration of a number of risks has influenced decisions made by Ms Watson's clinicians and guardian. Her prolonged hospital stay of four years was likely a result of her need for a prolonged period of rehabilitation, but also due to difficulties finding a suitable place for her to live. Risk is often a critical factor in the assessment of accommodation as clinicians may be forced to weigh up a number of imperfect alternatives in relation to issues such as whether sufficient supervision can be provided to manage possible risk of injury, and whether geographical location enables continued access to rehabilitation. Since the move to her parents' home, clinicians have perceived risk to Ms Watson's progress in rehabilitation due to the influence of her mother. Risks to their own safety may also have been a consideration, if they continued to provide services in an environment in which they were unable to build working relationships with family members.

Risk management is an important motive in decision making by clinicians and is a key factor considered by those involved in this case. Risk cannot be removed from the process of decision making, but rather is intrinsic to appraisal of the likely outcomes of a number of options, which must include the possibility of adverse outcomes. However, clinicians must also maintain a keen awareness of the risks involved in not undertaking a certain action. This approach may be seen in the therapy team's decision to withdraw their services based on an assessment of increasing risk to them and their organisation, while attempting to undertake actions that they hoped would mitigate the resulting risk to Ms Watson and her family. The appointment of a guardian was made after a tribunal considered the risks of appointment of a decision maker (and the impact on Ms Watson's autonomy), balanced against the risks of not taking action and leaving her in the care of her parents without the provision of rehabilitation therapies.

The clinicians' assessment of risk has led to a range of actions, in which there appears to have been limited opportunity to canvass and consider Ms Watson's views. The urgency with which

the actions were deemed necessary appears to have created a situation where Ms Watson's communication impairment has meant that she has not been provided with sufficient support to present her perspective. This example highlights the additional challenges faced by a person with communication impairment, and therefore the need for clinicians to understand the persons and how best they communicate. Reliance on the views of a decision-making proxy, whether a family member or an independent guardian, introduces a further risk that the decisions made will reflect the values, hopes and fears of that individual, rather than those of the individual for whom the decision is being made.

Reconsidering conceptions of risk

Risk is generally conceived as negative and something that should be avoided. It has been argued that our society has developed a preoccupation with risk and has become a 'risk society' [37], in which the existence of an increasing array of risks is accompanied by an expanding regulatory framework to manage these risks [38]. Predominant understandings of risk management therefore focus on negative conceptions of risk and refer to an approach where measures are taken to identify and eliminate these risks.

Approaches to risk in health and rehabilitation settings include the development of clinical and practice guidelines. Although practice guidelines play a role in encouraging a more consistent approach to supporting or managing risk, the very nature of risk is variable and dependent upon the context in which it occurs and how it is approached by individuals with ABI and those around them.

Negative conceptions of risk are associated with preference for the protection of individuals over the provision of services which enable individual autonomy and choice [39]. Being able to take risks may hold a number of positive meanings on an individual level. In a qualitative study exploring individual notions of risk, Lupton & Tulloch [40] identified a key theme showing that taking risks was associated with feelings of self-improvement and control. As one participant reported, "life would be pretty dull without risk" (p.117).

It remains important for clinicians to understand the distinction, made by Browne [41], between recognising an individual's right to take risks and helping that individual to live at risk. Despite the level of perceived risk, the views of the individual about the nature and acceptability of that risk must also be taken into account.

Discussion

The cases of JB and Ms Watson provide examples of issues that arise in supporting decision making in individuals with ABI, including how the perceptions of clinicians who are providing this support can influence the individual's participation in the decision-making process. However, an over-arching issue relevant to each of these scenarios is the long-term consequences of decisions that are made with a focus on the "here and now".

One of the key themes to emerge from the literature about participation in decision making, and highlighted in these two cases, is the need to consider the long-term implications of decisions. Clinicians are frequently called upon to make decisions regarding, for example, aspects of an individual's treatment program. For example, a clinician may decide who is able to visit an individual while he/she is in rehabilitation, with the clinician's decision being based on what is in the best interests of the individual in achieving his/her immediate rehabilitation goals. However, such decisions may also have long-term consequences for an individual's self-concept and social participation. Often, decisions may be more complex than determining, for example,

whether or not particular visitors should be able to visit a client during rehabilitation, but may involve more subtle decisions that should form part of overt discussions between the individuals and their team. Such decisions may include deciding whether or how to facilitate or support these relationships after ABI.

Putting the voice of the individual at the centre of decision making

A striking similarity between the two cases presented was the lack of consultation and involvement of JB and Ms Watson in the decision-making process. From major decisions, such as where an individual will live, to more minor decisions such as how an individual would like his/her rehabilitation program to be structured, the individual who is most affected may be vulnerable to being excluded from the decision-making process and his/her voice may go unheard.

The case of Ms Watson demonstrates a paradox where autonomy may be lost in order to achieve "independence". This outcome can arise when clinicians automatically prioritise independence in self-care tasks (e.g. showering and meal preparation) over the individual's control of life choices. It is important for clinicians to consider which aspects of independence and autonomy matter to the individual, who may define independence as having control over their own lives (being 'in control' and able to make decisions) [41]. The significant value placed on acquisition of independent skills may well lead to a further risk to the individual's social participation, by removing him/her from his/her existing social networks in order to participate in rehabilitation.

Supporting individuals to make decisions about their own lives is not only a key principle in person-centred practice but also an imperative of the United Nations Convention on the Rights of Persons with Disability. Policy changes have also demanded that organisations and individuals working with people with a disability place significant weight on the individual's expressed wishes, and how these may be achieved whilst managing possible sources of significant risk to the individual.

Practice implications

These cases have highlighted the complexity of supporting individuals with ABI to make decisions about their own lives. While only two specific factors have been highlighted, clinicians must be mindful of a wide range of factors, including the impact of their personal values and beliefs on the nature of decision making support they provide.

Using a multidimensional approach to identify influences on decision making

The benefits of using a multidimensional approach to identify the various factors that influence social processes have previously been highlighted [42], and such approaches may also be useful when applied to decision making. Considering decision making from this perspective provides clinicians with a framework to recognise the contributions of the experience and skills of the individuals with ABI, their environment and the relationship between them. It allows clinicians to make explicit a range of factors that may be at play when supporting individuals with ABI to make decisions, including those that influence how clinicians involved in supporting decision making approach this task. This paper proposes a model across three dimensions covering individual, relational, and environmental influences that clinicians could apply in order to assist them in identifying the assumptions that drive decision making. This model is exemplified in Table 1. The table identifies components within each

Table 1. Using a multidimensional approach to consider the impact of assumptions on decision-making support and their potential consequences.

Dimension	Components	Assumptions that may be made by clinicians	Potential consequences
Individual	Pre-morbid health and functioning, cognitive strengths and deficits, level of distress	‘‘It doesn’t matter how many different ways I try to explain it, these are complex issues and I don’t think he’ll understand’’	Reluctance to provide information in a range of formats designed to meet the individual’s needs may exclude them from considering the full range of alternatives
Relational	Inter-Relational, relationships between the individual and their family members, significant other, friends or rehabilitation staff	‘‘The family argues a lot and it upsets her. There would be less disruption to service provision if she was living in a different environment’’	Limited involvement of family may influence long-term support and accommodation options
	Extra-Relational, relationships between members of the intra-relational group (e.g. between rehabilitation staff and individuals’ family)	‘‘He will only be in rehabilitation for a limited time and we have to make the most of it. His friends will interfere with his progress’’	Reluctance for clinicians to involve the individual’s friends in rehabilitation may lead to reduction of social network
Environmental	Structural, policy and funding in relation to health and rehabilitation, disability support and housing.	‘‘We know that there is a long waiting list’’	Knowledge that there is a lack of funding for appropriate housing options may result in consideration of less than ideal accommodation
	Cultural, cultural norms and attitudes towards disability	‘‘Even though we know that’s what he wants, we can’t possibly consider it - the risks are too great’’	Paternalistic attitudes towards the individual may influence what is considered to be in their ‘‘best interests’’

dimension and provides examples of assumptions made by clinicians and illustrates their potential consequences.

Applying a multidimensional approach to the case of JB may encourage his treating clinicians to consider a number of assumptions, both implicit and explicit, that may exist. For example, clinicians may identify how assumptions they have made about JB’s cognitive functioning limit their willingness to enable JB to participate in decision making. Clinicians may also recognise assumptions reflecting their own beliefs, for example, a belief that risk minimization is a decision-making priority that will influence substantially the range of options considered. These values and beliefs are likely to stem from a combination of factors and previous life experiences, including their cultural, socioeconomic and spiritual background. The role of these values and beliefs in determining the decision-making support they provide should not be understated. For example, in a study exploring how patients, families, and clinicians balance risk-taking and safety during transitions in brain injury rehabilitation, Andreoli [43] identified a relationship between the risk inclination or aversion of therapists and their willingness to support individuals with ABI to make decisions involving risk.

In considering the impact of decision making on social participation, it is important that clinicians also examine their beliefs about social participation, and understand the meaning of social participation from the perspective of the individual with whom they are working. This understanding can only be achieved through active and meaningful engagement with the individual and careful consideration of the different shapes of social participation. For example, the clinician could observe whether the individual has a large or small social network, identify the factors that have influenced this, and consider how these relationships formed.

In recent years, reflection has been increasingly recognised as a critical aspect of clinical practice. Although the role of reflection is central to identifying one’s own values and beliefs and their impact on clinical practice, further action is required if a significant change is to occur. Rehabilitation teams need to facilitate an environment where discussions about the values and beliefs of individual clinicians are recognised and the implications for practice considered openly.

The aim of this exchange should not be to criticise or attempt to change the values of individuals, but rather to consider the complex nature of supporting decision making for individuals with decision-making impairment and provide a method of collegial support in relation to these complex matters. Discussion about systemic constraints on decision making also needs to form a part of this team discussion. These constraints may exist at a number of levels. For example, government policy in relation to social services may mean that a lack of access to resources will influence the alternatives available regarding the individual’s health, housing or social integration. Similarly, lack of availability of specialised housing services may result in an extended inpatient admission, or discharge to an unsuitable location. Cultural attitudes and norms towards disability also influence what is considered to be in the individual’s best interests, and the range of potential options that may therefore be considered. In the time dimension, the expectations of others about how an individual should behave given his age and life stage may not match the perceptions of that individual.

It is important to note that there are likely to be a range of barriers to professional reflection in action, resource limitations being the most significant. Funders and insurers value outcomes in rehabilitation programs, and therefore place limited importance on the work that is required to go on behind the scenes to ensure that decision making is an inclusive process. This approach, which tends to favour formally assessed outcomes, means that clinicians value ‘‘doing’’ (defined as actively working with individuals towards rehabilitation goals) over reflecting. Additionally, this approach may result in clinicians favouring decisions that fit neatly into structures imposed by funding bodies.

A range of constraints exist beyond the level of the individual clinician. These may include the cultural environment of the organisation or service, a hierarchical approach towards team discussion and decision making, or the attitudes of others within the team towards participating in discussions which require practice and may cause a level of discomfort. In order to provide a service which best facilitates the participation of individuals, clinicians have a responsibility to discuss these barriers and ensure that these are part of an open dialogue among those who

are affected by them. Clinicians also need to be prepared to challenge these constraints, challenge the status quo.

Future directions

Further research is required for clinicians working with individuals with ABI to gain a fuller understanding of their experience of decision making. In particular, future research could explore how people with ABI experience the process of decision making, the factors that support their participation in decision making, and how clinicians can best provide support in order to maximise decision-making participation.

Declaration of interest

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