

Understanding experiences of goal setting and planning for patients with severe acquired brain injury & their carers

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Executive Summary

Key messages

Engagement of people with acquired brain injuries and their family members in the goal setting process is complex and variable, particularly when cognitive and communication impairments are present. This study showed that patients and family members are reliant on healthcare workers for education about the nature and complexity of an acquired brain injury, and that this may also influence their level of engagement in routine goal setting interviews. Findings suggest that healthcare workers who are collaborating with people with acquired brain injuries and their family members should take time to build a relationship of trust, respond to patient and family members' needs, actively seek to understand patient and family members' goals, and be given opportunity to develop finely-honed reflective listening skills.

Purpose

This study examined the extent to which healthcare workers involved patients with moderate to severe brain injuries and their family members in goal-setting processes and the strategies they employ to support involvement in both acute and rehabilitation settings.

Rationale

Patient-centred goal setting is a central part of contemporary rehabilitation practice but to date, there exists little guidance for clinicians working with patients with acquired brain injuries as to the approach and strategies that facilitate engagement in the goal setting process. There is a need to maximise engagement in the goal setting process to ensure that intervention is targeted towards recovery and contextually appropriate for the individual.

Methods

This mixed methods study included thematic analysis of the routine goal setting interviews conducted between healthcare workers, inpatients with acquired brain injuries and their family members / carers (as relevant), along with analysis of

completed surveys measuring level of engagement in goal setting (*Lynne Turner-Stokes, available from contacting author*). Participants were recruited from both acute and rehabilitation hospitals within one healthcare network enabling exploration of goal setting across varied inpatient settings.

Research findings & implications

Healthcare workers endeavour to engage patients with acquired brain injuries and their families in the goal setting process across both inpatient acute and rehabilitation settings. Strategies that enhanced engagement during routine goal setting included:

- taking time to understand the individual's life context,
- responding to questions and concerns,
- seeking clarification about an individual's understanding of brain injury and their likely progress, and
- allowing all parties involved an opportunity to share their perspective on their future to maximise collaborative goal setting.

The ability to balance service system demands with individual patient concerns requires a level of experience and sensitivity. The importance of providing opportunities for healthcare workers to develop finely-honed communication skills and a solid understanding of goal setting processes when working with people with acquired brain injuries and their family members should not be underestimated.

Use of the research

The outcomes of this project are an essential step towards developing robust and collaborative processes for goal setting with patients and their families after moderate-severe brain injury both within the hospital system and more broadly. Specifically, the outcomes of this project can inform work instructions for health care workers, as well as highlighting that the professional development of health care workers should include opportunities for development of skills in collaborative goal setting informed by best available evidence. Further investigation of the strategies employed by healthcare workers in the community, and by healthcare workers who

may be working with the person with a brain injury within a compensation framework is warranted. The opening of the new state wide ABI service at Caulfield provides an important opportunity to develop specific training modules for healthcare workers in collaborative goal setting and reflective listening, which build on the findings of this research.

Potential impact of the research

Setting goals that are meaningful for the person with brain injury and their family both during acute care and rehabilitation is considered an essential component of care, helping to shape the person's future, their participation in meaningful activities and ultimately their discharge destination. The data from this project identifies clear opportunities to improve patient and family engagement in goal setting, and provides strategies for healthcare workers to use in their daily practice. This potential impact of the research is that it will assist healthcare workers to change their practice and in turn, increase patient satisfaction with their level of engagement in setting their goals and care pathways after brain injury.

Background

Patient centred goal setting is well established as a central part of contemporary rehabilitation practice and care planning for severely injured persons with acquired brain injury. In brain injury rehabilitation, involving patients in their own healthcare decision-making is purported to lead to meaningful rehabilitation goals, increased patient participation in rehabilitation and ultimately a shared understanding of the reasons for rehabilitation (Doig et al., 2009; Payton, Nelson & Ozer, 1990). It is acknowledged that patients are more likely to actively engage in their rehabilitation program if they perceive the established treatment goals to be relevant and the therapies to be targeted towards meeting these goals (Armstrong, 2008). Effective goals are those that are established early during the patient's admission to hospital (not necessarily just in the rehabilitation setting) and are collaboratively set through involvement of the patient, their family (where relevant), and healthcare workers. Collaboration between patient, family and healthcare workers is fundamental to this process, however it is widely acknowledged that it is difficult to engage severely injured patients in goal setting (Sugavanam et al, 2013; Conneeley, 2004), and as a result patient engagement may not be routinely seen in clinical practice.

Despite the general consensus that wherever possible patients should be involved in goal setting, little agreement exists in the literature regarding the most effective methods to elicit patient involvement (Sugavanam et al., 2013). A recent systematic review (Levack, et al, 2006) demonstrated not only that there are real difficulties engaging people in goal setting, but despite 13 publications studying the effect of approaches to goal planning on outcomes, approaches as well as clinical benefits were inconsistent. Therefore, while positive therapeutic effects of patient engagement in goal planning have been observed in some individual studies (Levack, et al, 2006), there remains little guidance for clinicians as to which generalizable, therapeutic approach should be used in practice.

Research Questions

The research questions addressed through this study were:

- (a) To what extent do healthcare workers involve patients with moderate to severe acquired brain injuries and their families in goal-setting processes in both acute and rehabilitation settings?
- (b) What strategies do therapists use to facilitate patient and family involvement in goal setting?

Method

A mixed methods study which included (i) thematic analysis of goal-setting interviews between healthcare workers and patients (and their families/carers as relevant), and (ii) surveys of healthcare workers and patients (and their families/carers as relevant).

Participant recruitment

Three groups of individuals participated in this study designed to understand how to engage patients and their families in collaborative goal setting after brain injury and stroke. These three groups were:

A. *Patients with a brain injury or stroke*: Individuals were eligible to take part in the study if they had experienced a brain injury or stroke which resulted in moderate to severe restrictions in daily activities, were aged 18-64 years (working age) and were either TAC compensable or non-compensable patients.

B. *Family members*: The family members (carers, or persons responsible) of the patients were invited to take part in the study if they had participated in goal setting with the patient and their healthcare worker. For patients who were unconscious/unable to communicate, only the family members (carers, or person responsible) was approached to take part in the study, since it would be routine clinical practice to undertake the initial interview and goal setting process with only the family in the absence of being able to conduct the initial interview with the patient.

C. *Healthcare Workers* involved in brain injury and stroke patient care were invited to participate in this study, these were Occupational Therapists, Social Workers and Early Support Coordinators (TAC). These workers were invited to participate because they had responsibility for conducting initial interviews or goal planning interviews with patients or family members regarding referral for rehabilitation assessment, initial goal setting or planning for future needs.

Patients who met the eligibility criteria were identified by the healthcare workers (occupational therapists and social workers) as potential participants on their admission to either the acute or rehabilitation setting. Potential patient participants were approached by an independent research assistant and invited to participate in the study prior to the initial, usual goal setting session. Potential family member participants were also approached by the independent research assistant, in person or by phone, to participate in the study prior to the session. Healthcare workers were provided with verbal and written information about the study by senior members of the research team and invited to participate. All participants (patients, family members and healthcare workers) were required to complete written consent.

Method

This project was conducted in 2 phases.

Phase 1: Routine clinical initial interviews between healthcare workers, patients with acquired brain injuries and family members, and where goal setting was a focus, were audiotaped. The audiotaped interviews were transcribed verbatim and analysed using NVivo Version 10. NVivo 10 is a software program specifically designed to support the analysis of qualitative data. Two investigators were involved in coding the interview transcripts and undertook thematic analysis to identify important thematic groupings and the relationships between these groupings [Pope & Mays, 2006].

Phase 2: Following completion of the routine clinical interview, healthcare workers, patients with acquired brain injuries and their family members were asked to complete a survey: a Level of Engagement in Goal Setting survey. In this way, there may have been up to three Level of Engagement in Goal Setting surveys completed per interview. This survey is self-administered and is designed to record the level of

engagement that patients or their family members perceive they have in their own goal setting. The results from these surveys were quantitatively analysed and aggregated results for each group of participants are contained within this report.

Results

Participants

This study consisted of fifteen initial goal setting interviews conducted between September 2013 and January 2014 with individuals who had been admitted as inpatients with acquired brain injuries which had resulted in moderate to severe restrictions in daily activities. At the time of reporting, five interviews were conducted in the acute setting and 10 interviews were conducted in a rehabilitation setting. One participant and their family member were involved in two interviews; once in the acute setting and then again in the rehabilitation setting, therefore the participants consisted of a total of 14 patients and 15 interviews. Eight healthcare workers were involved in conducting the goal setting interviews, all of them were occupational therapists. Some of these workers had significant experience of acquired brain injury management, where others had lesser experience.

Of the 14 patient participants, five individuals had a diagnosis of stroke, and the remaining 9 individuals had been admitted with a traumatic brain injury. Reasons for traumatic brain injury include incidental fall (n=3), road traffic accident (n=2), occupational accident (n=1), and other (n=3). Individuals ranged in age from 32 – 64 years of age. Nine individuals had non-compensable injuries.

Table 1: Patient characteristics

Characteristics	n=14
Males, <i>n</i> (%)	7 (50)
Age, years. <i>mean (SD) median</i>	51.3 (11.4) 56.8
Compensation status, <i>n</i> (%)	
TAC	2 (14)
WorkSafe	1 (7)
Non-compensable	11 (79)
Individual participated in interview, <i>n</i> (%)	12 (86)
Family member participated in interview, <i>n</i> (%)	
Partner	5 (36)
Parent	3 (21)
Other	2 (14)

Extent of engagement in goal-setting processes

Thirteen patients with brain injuries and 10 family members participated in the 15 goal setting interviews. On five occasions, patients with brain injuries were interviewed alone; family members were interviewed alone on two occasions, and eight interviews involved both patient and family members.

When asked to rate their perceived level of participation in the interviews, the majority of patients (n=8) rated their engagement as good or very good (see Figure 1). Family members were also asked to rate engagement in the goal setting process. Two family members elected to rate their own engagement in the interview process and perceived that they had moderate involvement (n=1) or good involvement (n=1). Other family members (n=5) elected to rate the engagement of the person with a brain injury and there was greater variance in these scores.

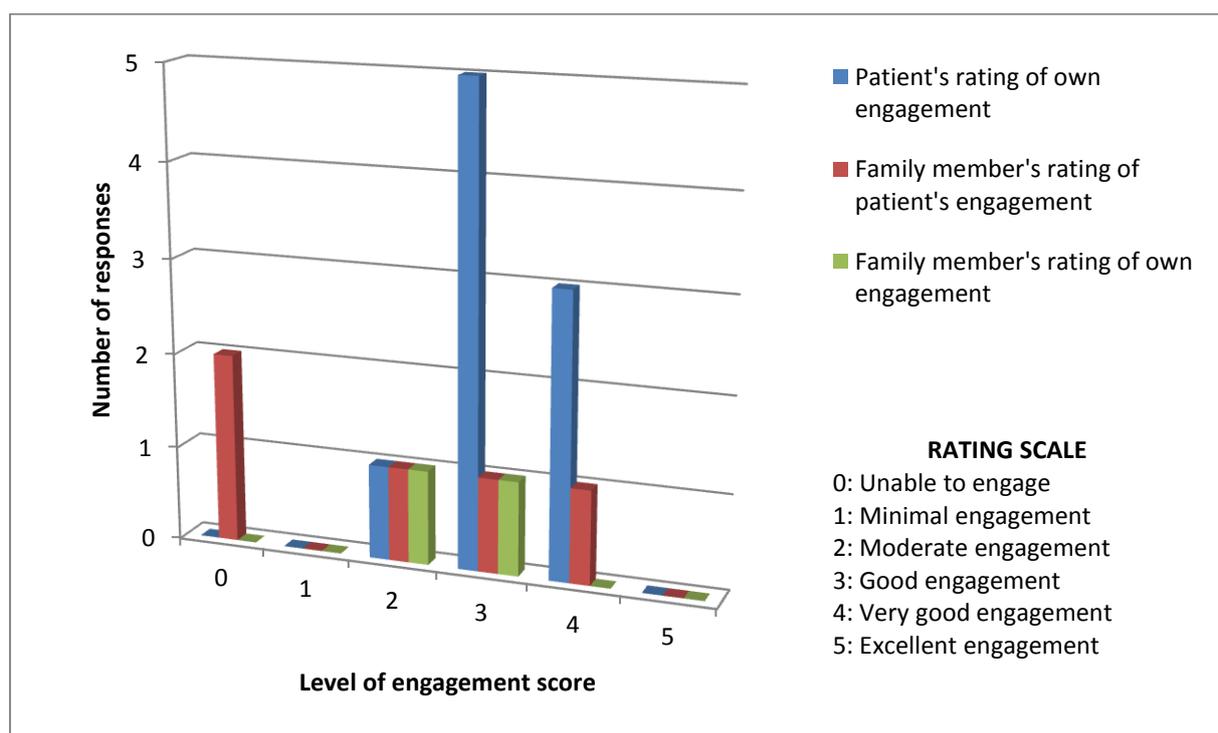


Figure 1: Level of Engagement in Goal Setting scale responses

This study also examined the congruence between the healthcare worker’s perception of level of engagement in the goal setting process with the perception of the person with the acquired brain injury specifically (see Table 2). There were nine occasions where both the person with the brain injury and the occupational therapist completed rating forms, and four occasions where a rating wasn’t completed by the patient. In six of the instances (67%) where the patient rated the interview, the healthcare worker and the patient had consistent perspectives about the patient’s level of engagement in the process. However in a small number of instances (n=3) the patient thought that their level of engagement was greater than that perceived by the healthcare worker.

Table 2: Relationship between the paired ratings by the healthcare worker’s perception and patient’s self-perception of the level of patient engagement in goal setting session

		Person with a brain injury self-perception of level of engagement rating			
		Unable to engage	Minimal – moderate engagement	Good, very good or excellent engagement	Patient did not participate
Healthcare worker’s level of engagement rating	Unable to engage	-	-	-	-
	Minimal – moderate engagement	-	n=1	n=3	-
	Good, very good or excellent engagement	-	-	n=5	-
	Patient did not participate	-	-	-	n=4

Major themes arising from interviews

Audio recordings of the routine interviews conducted as part of clinical care revealed that all healthcare workers endeavoured to involve patients with acquired brain injuries and their families in the goal setting processes to some extent. Data demonstrated that a variety of strategies were used by healthcare workers to facilitate engagement in care planning. The main themes describing strategies that support engagement are presented here.

The experience of injury and hospitalisation: Supporting people through the 'unknown'

Interviews revealed that the process of understanding the nature and complexity of an acquired brain injury, and in fact navigating the hospital system, was a new experience for participants (both patients and family) and one that they had not been prepared for.

Mother: I don't think when he was in ICU that there was a reaction to the torch going across but apparently now there is on one eye so that's good. Before he opened up his right eye a little bit and there was a flutter. Look I don't know whether or not that's a reaction, I don't know.
(participant 3)

Healthcare Worker: You do have a say in where you go, yeah.

Husband: How would I know where to suggest? (participant 1)

In the acute hospital system particularly, this lack of knowledge may result in participants expressing vulnerability and reliance on healthcare workers to advise them about goals for recovery and to make decisions about the most appropriate discharge pathway. There was evidence in the interviews of healthcare workers providing information to patients and family members that aimed to increase awareness of processes and support realistic expectations during hospitalisation. They created space for patients and family members to ask questions and express their uncertainty. Recognition and acknowledgment that the experience of injury and hospitalisation was new and unfamiliar underpinned some of the other strategies observed during the interviews.

Investing time in building a trusting relationship

Healthcare workers were observed to take time to build a respectful and trusting relationship with both patient and family members as able, and in many cases, this occurred early in the goal setting interviews. They achieved this through taking time to explain their role and understand the patient and family member's journey to date, recognising that the event surrounding a brain injury was significant and unexpected. The therapeutic relationship was enhanced when healthcare workers used reflective listening strategies and when they were able to demonstrate that they had been collaboratively engaged with the person and/or their family.

The therapeutic relationship was also enhanced when healthcare workers sought to understand the life roles and activities of the person *prior* to their acquired brain injury. This demonstrated a commitment to understanding the person within the context of their broader life experience and also suggested a degree of commitment to working towards recovery.

Mother: *Prior to the accident he's a very, very - was very fit, very fit. He used to run and he'd walk his dogs [...]*

Healthcare worker: *So a very fit and active guy then.*

Mother: *So you've got a lot to work with.*

Healthcare worker: *We do.* (participant 3)

There was evidence of this relationship development in interviews conducted within both the acute and the rehabilitation context, and when this occurred, there appeared to be greater engagement in the interview and enhanced opportunities for focussed goal setting.

One challenge in goal setting and relationship building with this client group is that they may have limited capacity to retain information due to their brain injury. Healthcare workers were observed to repeat information and assist the participants to recall previous conversations in an effort to elicit or maintain their involvement.

Healthcare Worker: *Has anyone explained what my role is now that you're here at rehab?*

Person with brain injury: *Yeah, but I've forgotten.* (participant 12)

The repetition and reinforcement of information from previous encounters provided evidence of the healthcare workers' commitment to supporting a collaborative process of goal setting and maintaining a focus on goal directed therapy.

Being responsive to patient and family members' questions and concerns

The process of adjusting to the reality of a brain injury is both complex and confronting for the person with a brain injury and their family members. There were many instances where healthcare workers were observed to engage with patients and family members in a way that met, or at least endeavoured to understand, their

needs. This was often as an extension of the time spent building a therapeutic relationship. Healthcare workers sought clarification about what the patients or family members understood about acquired brain injury, the progress that patients had made to date and how they perceived their discharge needs. They frequently provided education aimed at furthering the patient or family member's understanding and enabling them to gain clarity about the next phase of recovery which in turn supported goal identification.

Person with brain injury: Look, like, of course I'm worried. I'm going to be alone again. It would be great if I can have somebody come a couple of times a week just to help me have a good shower. I know my friend she's a nurse but she's got her own family. I don't want to...

Healthcare worker: So it sounds like you, no matter what, you definitely want to be at home and you'd be open to receiving some assistance?

Person with brain injury: Yep.

(participant 13)

Given that these interviews were frequently conducted early in the patient's admission, and were often the first occasion that the healthcare worker had met the patient, there was frequently an emphasis on gathering data that would subsequently underpin goal setting. The interviews contained many instances of healthcare workers skilfully weaving together data gathering, responding to patient or family concerns and education provision within a natural conversation. There were also some instances where healthcare workers relied more upon the structured data collection forms used within the inpatient stay and at times this restricted their ability to attend to patient or family member needs.

Asking patient and family members about their goals

The focus of goal setting varied depending upon the setting where the interviews were conducted. In the acute context, the focus was on planning for transfer to appropriate rehabilitation, whereas in the rehabilitation context the goals related to recovery and discharge. Regardless of the setting, healthcare workers consistently were explicit in asking the patients or family members, 'what are your goals?'

Healthcare Worker: What goals do you have? What things would you like to work on while you're here at hospital?

Person with brain injury: [Pause] What goals?

Healthcare Worker: Yeah, is there anything you want to work on?

Person with brain injury: No, just get a bit stronger, that's all. (participant 2)

Responses were most meaningful when healthcare workers had created a positive and open environment by investing time in building a therapeutic relationship and responding to patient or family concerns.

There was some evidence of healthcare workers ensuring that goals were relevant to the patient's broader life context. They did this through exploring the meaningful occupations and interests of the patient and this enabled the identification of goals that were suitably contextualised. People with acquired brain injuries frequently had difficulty articulating goals and often only identified broad goals such as "I want to go home" or "I want to get stronger". In some instances healthcare workers tried to break goals down through asking for further detail, making suggestions or engaging family members further in the process.

Healthcare Worker: All right. Now I just want you to try and have a think about and tell me what you want to be able to do yourself here?

Person with brain injury: I want to get back to how I was.

Healthcare Worker: Yep. Tell me how that was.

Person with brain injury: More independent...

Healthcare Worker: More independent.

Person with brain injury: ...than what I am now.

Healthcare Worker: With what things? Can you tell me what things?

Person with brain injury: Walking, going to the bathroom, showering, driving.

(participant 9)

Communicating therapist-led goals to patient and family members

In all of the interviews, the healthcare workers provided information to the patients and/or families about the goals and plans from the healthcare worker's perspective. This was particularly important when the patients with brain injuries or their family were unclear about the degree of recovery that was possible and how they might achieve the greatest outcome. Frequently, healthcare workers provided significant direction and support to clarify the treatment focus for the person with a brain injury.

Healthcare Worker: To be honest though, the main goals that we need to work on - obviously we've got arm goals and we want to keep you improving in your therapy. You've got to have ongoing therapy. The main goals are making sure that you've got all the equipment that you need and that you both are comfortable with Lisa taking on that carer role, and that you're going to be safe. We'll still be referring you through for therapy once you get home. (participant 5)

All goals were identified in the healthcare setting. People with a brain injury identified goals that facilitated transfer to rehabilitation or discharge into the community, or that optimised outcomes within an inpatient service. Ideally this communication about therapist-led goals took place within a broader discussion about the 'fit' between these therapist-led goals and the goals of the patient and/or family. This enabled the patient and family members to make sense of the goals and to collaboratively decide on the priorities and plans.

Therapists' confidence and skill in engaging patients and family members

As a by-product of this study, there was opportunity to observe a number of healthcare workers conduct goal setting interviews. While it must be acknowledged that the process of being audiotaped may impact on the performance of healthcare workers during interviews, there was variability in the observed confidence levels, reflective listening skills and skills in elicitation of goals by the clinicians who were conducting goal setting interviews. Healthcare workers demonstrated differing levels of knowledge about brain injury and the process of recovery, and provided a varying depth of information to patients and their family members. Some healthcare workers appeared more flexible in their approach to information gathering to support goal

setting, while others adhered more closely to the structure of the organisational documentation. Healthcare workers may need to vary their style to ensure effective engagement by patients and family members in goal setting processes.

Discussion / Implications

People with acquired brain injuries often have a range of impairments and activity limitations which require management within both acute and rehabilitation settings. The complex nature of the injuries as well as the unfamiliarity of the hospital setting can be unsettling and overwhelming for the individuals themselves and for their family members. The process of goal setting may include multiple parties and necessitates a balanced approach involving provision of education, supported decision making and understanding of the broader life context of the individual with the injury.

This study supports the idea that goal setting is most effective when healthcare workers, people with acquired brain injuries and/or their family members have had opportunity to develop a therapeutic relationship and can create an environment where individual perspectives and priorities can be shared. The therapeutic relationship is best established when efforts are made to understand the broader life context of the person with the brain injury and recognise the person as an individual, leading to the development of personally-relevant goals. Even with the establishment of a sound therapeutic relationship, the presence of post-traumatic amnesia or higher level executive deficits, along with the unexpected nature of the injury can impact upon how goals are established and whether knowledge of them is retained. Given that some participants with brain injury in this study were observed to have decreased capacity to retain information, services should explore the most effective ways to record and review goals. Strategies that enable all parties to maintain a focus on goal attainment and engagement in the recovery process could be further explored.

A range of strategies to support engagement in goal setting have been noted during this study (see Appendix 1 for a summary of strategies). It is hypothesised that adoption of these strategies may maximise opportunities for patients with brain injuries and their families to participate fully in the goal setting process. While outside the scope of the present study, understanding *how* to support healthcare workers to develop proficiency in using these strategies is a clear next step to build on the findings of the present study.

Within an inpatient setting, service system priorities are often focussed on identifying the most appropriate transfer or discharge options and minimising length of stay. Healthcare workers are often challenged to facilitate these processes while still responding to individuals concerns and maximising the functional outcomes associated with therapy. This tension has the potential to restrict the development of patient/family-directed goals and may also reduce the overall engagement in the goal setting process. Goals do not always transfer through from the acute setting to the rehabilitation setting, and changes in healthcare workers between settings can create further challenges in establishing and reviewing goals. One strategy that might be considered to support continuity and carry over of goals between changing healthcare workers and settings is engagement of an independent patient-advocate. Although not currently utilised within the health services where this study took place, this model has been shown to work effectively in overseas contexts. Use of patient-advocates to support goal setting was described by Holliday and colleagues (2007). They described a process whereby the patient-advocate supports the patient and family members to identify their goal priorities and then supports the process of discussing the goals with the healthcare team. Adoption of a process such as this may provide opportunities for the patient and family member's goals to be clearly documented in their own words and acknowledged by the team as central to the recovery and planning experience.

Collaborative goal setting requires specialist skills and highly developed communication particularly when working with individuals with a brain injury who have communication deficits or problems with higher level functioning (Sugavanam et al, 2013). As observed through the interviews, there were varying degrees of confidence demonstrated by the healthcare workers who were conducting the goal setting interviews, and variable levels of success in engaging patients and their family members in the goal setting process. This observation is supported by the work of Sugavanam and colleagues (2013) who highlighted that, when working with people with acquired brain injuries, healthcare workers may benefit from opportunities to hone their communication skills and understand more about goal setting methodology. This could be achieved through provision of opportunities to review a video- or audio-taped interview that they have conducted with a patient,

seek feedback directly from the patient or family member if appropriate, and participate in a focussed mentoring or training process.

Conclusions

This study highlights that the process of collaborative goal setting involving healthcare workers, individuals who have acquired brain injuries and their family members is complex and requires specialist skills. Patients and family members are frequently reliant on healthcare workers to provide education and determine the steps required for recovery. Opportunities to improve collaborative goal setting are identified and the need for healthcare workers to have well-developed reflective listening skills is advocated. Strategies to support the engagement of people with acquired brain injuries and their family members in goal setting have been outlined, these include building a therapeutic relationship, responding to patient and family members' needs and actively engaging patients and family members in the goal setting process.

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Appendix 1

ENGAGING PEOPLE WITH ABI AND THEIR FAMILY MEMBERS IN THE GOAL SETTING PROCESS: SUGGESTED STRATEGIES

The following strategies should be adopted when engaging individuals with acquired brain injuries and their family members in the process of goal setting.

Take time to build a trusting relationship

- Listen actively to the priorities and concerns of the patient and/or family members, acknowledging the significance and impact of the injury
- Communicate in a respectful manner, recognising the patient & family members as equal partners in the goal setting process
- Make efforts to understand the life history and pre-injury priorities of the individual who has sustained the brain injury
- Clearly explain the role of healthcare worker
- Share knowledge of clinical expertise in a collaborative manner

Be responsive to patient & family members' needs

- Value the perspective of the patient and/or family member in every encounter
- Ask questions to determine patient and family members understanding of progress
- Support individuals to maximise comfort within an unfamiliar hospital context where necessary
- Provide education, positive feedback and encouragement to the patient and/or family to support active engagement in goal setting

Ask patients and family members about their goals

- Create an environment in which patients and families feel comfortable to share their own goals
- Assist patients and families to understand the therapeutic techniques and the steps that may be required to progress towards identified goals
- Provide information to patient and/or family about the discharge process and discuss the goals required to facilitate engagement in setting goals
- Facilitate a focussed discussion with patient and/or family members about their interests, meaningful occupations, hopes and concerns - these provide the context within which to establish goals

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