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Evidence-based Reflective Commentary: When is a goal not a goal?

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Introduction and Context

The impact of childhood traumatic brain injury (TBI) is sudden and overwhelming - in an instant, the life trajectory of the injured child and their family is abruptly changed (Chevignard et al., 2020). Rehabilitation professionals, including paediatric physiotherapists, work alongside children and families in supporting recovery following TBI. Effective rehabilitation considers the background, needs and values of each individual and family when looking to integrate rehabilitation into everyday life (Baldwin et al., 2013; Ziegler and Hadders-Algra, 2020).

The value of collaborative working between healthcare professionals and key stakeholders - including experts by experience such as parents of children affected by TBI - is important in all aspects of health and care, and particularly relevant during the co-design process (Robert et al., 2022). Such collaboration can provide unique and important insights into the lived experience of those affected by TBI (Skivington et al., 2021).

This commentary is a reflection on the experiences of a paediatric physiotherapist (David) and worked alongside the mother of a child who suffered a TBI at the age of 11 (Kate) who worked together to co-design an intervention to support parents to deliver physiotherapy to their injured child following a TBI. This co-design work took place within the context of David's National Institute for Health and Care Research funded PhD (NIHR301583), resulting in a digital intervention called 'Physio Together'. It was during co-design discussions that the topic of rehabilitation goals was raised.

Talking about goals

Within the context of rehabilitation following TBI, parents reflected that talk of 'goals', 'strategies' or 'targets' could become code words for 'failure', 'not good enough' and 'not who you were'. It is not disputed that goals are an integral part of the rehabilitation process, and achieving the best outcome is a shared aspiration of the family and healthcare professionals alike (Young et al., 2024). However, where language around goals is deemed to be negative, this can exacerbate underlying anxieties, expectations, and low self-esteem of children who are at increased risk of developing poor mental health (Anderson et al., 2009; Roberts et al., 2022).

Furthermore, it was reflected that as the pre-TBI family trajectory gets further away, terms like 'goals', 'strategies' or 'targets' may feel increasingly extraneous. Such terms may not capture what is most important to a child or family, especially if they are not truly patient-centred (Prescott et al., 2019). This can leave parents feeling bewildered and scrutinised, living between appointments with endless to-do lists of tasks that may feel only vaguely relevant. Therefore, collaboratively, it was felt that a goal is not a goal when it lacks meaning, causes heightened anxiety and where the metaphorical goalposts seemingly keep shifting.

It follows that by bringing together clinical expertise and lived experience during the co-design processes, the issue of rehabilitation goals was explored, and unique insights discovered. In light of parental reflections and feedback, it was agreed that the wording around rehabilitation goals could be reviewed. This reflected a shared

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conviction that rehabilitation should move away from prescribed lists of exercises to taking part in interesting and meaningful activities (Novak, 2011). This included the idea of 'rehab in disguise', described by Kate as being a way of sustaining positive engagement in personalised and meaningful rehabilitation integrated into family life.

Shifting the language towards participation

The language of the World Health Organization's International Classification of Function, Disability and Health (ICF), can be helpful in moving rehabilitation towards a more participation-based focus (WHO, 2001). Additionally, the F-words of childhood development is a child and family-friendly framework that embeds the words Functioning, Family, Fitness, Fun, Friends, and Future into the ICF and enables a holistic understanding of the child and family context prior to the onset of TBI whilst also guiding rehabilitation and shared decision making (Rosenbaum and Gorter, 2011).

Collaboratively, we propose that the final F-word 'Future' could be expanded to include 'Future hopes'. This provides a shared focus for 'what we are collectively working towards' and offers an alternative way of framing the concept of goals beginning in the acute hospital setting and continuing throughout rehabilitation. Our collaboration revealed that the timing of discussions about 'Future hopes' with families should be a fluid and dynamic process. If done sensitively, considering 'Future hopes' in this way could meaningfully connect rehabilitation with existing interests and passions of the child and family. It could also provide flexibility in capturing and incorporating new interests and endeavours as they change over time.

'Future hopes' – an example

An example of this was shared by Kate, who described how her child participated in a set of beginner Kung Fu classes with other children with TBI, plus siblings if they wished (CBIT, 2016). The classes were part of a collaboration between the Child Brain Injury Trust (CBIT) and Cambridge Centre for Paediatric Neuropsychological Rehabilitation (CCPNR), Notable motor benefits accrued by her child were evident to Kate in the areas of gross motor function, coordination, proprioceptive and vestibular function, and balance. Additionally, other skills critical to cognitive processing, interpersonal communication and social functioning were also fostered. Kung Fu was originally presented as an opportunity to 'learn something new' by doing a familiar activity that peers took part in, however quickly evolved into a 'Future hope' as it became a new-found passion for Kate's child who over time built on the initial skills to become a part-time Kung Fu teacher.

In this example, learning Kung Fu has provided a platform for self-expression whilst fostering new connections with siblings and friends following the TBI (Lyon et al., 2021). Kate reflected that gaining new interests, skills and confidence has been a reciprocal process for both her child and the wider family enabling them to review and reframe meaningful 'Future hopes'.

Conclusion

As each family is unique in its composition and experiences, it is vital in our opinion, to include a trauma-informed and individualised approach to rehabilitation according to the ecology of each family (Hobfoll et al 2007; Baldwin et al., 2013). Outcomes for children and families are reciprocal and bi-directional (Wade et al., 2019; Jenkin et al., 2022), therefore specialists working in this field are fundamental in guiding them from the outset to continue a successful and evolving neurorehabilitation programme. Having a clear means of establishing and relating rehabilitation to what is meaningful to children and families may play an important part in this process.

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