

Working with paediatric patients with Syndrome of the Trephined

The Benefits of Interprofessional Collaboration

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Introduction

Syndrome of the Trephined (SoT) or sunken skin flap syndrome, is a rare complication resulting from craniectomy due to a prolonged absence of the skull bone. This syndrome causes severe neurological symptoms and requires prompt diagnosis and intervention to prevent permanent neurological sequelae.

Typically, patients with SoT will experience neurological symptoms and dysautonomia's which can severely impact their ability to engage purposefully and meaningfully with their environment. These physiological issues are caused by the imbalance of the intracranial/extracranial pressure gradient, and the treatment is to nurse the patient in the Trendelenburg position i.e. supine with the head tilted down approximately 20 degrees.

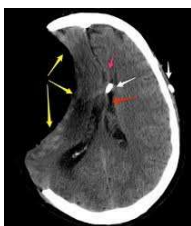


Figure 1: CT image of a patient with SOT

Aims

The typical recommended approach to working with people with SoT is to halt all rehabilitation until cranioplasty can occur. We detail how music therapy, occupational therapy, physiotherapy, speech therapy and nursing within the context of the broader allied health and medical team, and in conjunction with the family, can and should work collaboratively with an interdisciplinary focus during this period, see Figure 2. We demonstrate the benefits to the patient, family and interprofessional team.



Figure 2: Examples of joint approaches

During the period of SoT traditional goal setting can be challenging. Due to short windows of wakefulness and opportunities per day, individual disciplinary skill achievement may not be possible. Maintenance of physical skills & function and an emphasis on family centred care is usually more appropriate.

Furthermore, active engagement with the environment is essential to enhance receptive skills and to facilitate opportunities for advocacy and self-expression.

Methods

When traditional rehabilitation is not possible, we find the following strategies useful when working with complex patients:

- Up to 1 hr therapy sessions, twice daily maximum
- Quality of life important
- Cohesive and personalised interventions
- Relationship based approach
- Age-appropriate interventions
- Joint therapy sessions
- Family-centred practice (see Figure 3)

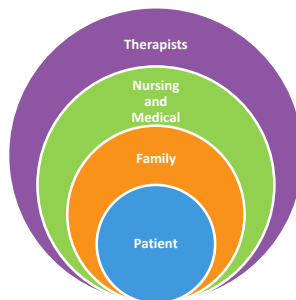


Figure 3: Family-Centred Approach

While each profession in the interprofessional team has discipline specific interventions we find that as a team we can work responsively and creatively to combine these interventions utilising an interprofessional approach. This enables consistent access and crucial support, which maximises a patient's functional capacity. We carefully plan and coordinate our disciplines to work collaboratively with patients. The following graphics provide examples of joint approaches to achieve therapeutic goals in SoT. At the centre of all interventions the family's priorities of health, mood and wellbeing are always central.

Speech and Occupational Therapy will combine to target cognition, language and mealtime/dysphagia goals, and support participation in normal social experiences. Careful planning prior to these activities requires consultation with the CNS, who plays a key role in ensuring the patient is safe to leave the ward and well enough to participate in an off-ward session. See Figure 4.

Goal: Normal Social Experiences



Figure 4: Examples of joint approaches

Goal: Engagement in Previously Enjoyed Activities



Figure 5: Examples of joint approaches

Physiotherapy and Music Therapy sessions are often combined. The inherent cues found in music provide cues for movement and support physical rehabilitation. The CNS works collaboratively with the interprofessional team ensuring everyone is updated on the patient's condition and this allows allied health professionals to adapt their therapy sessions accordingly and facilitate engagement in previously enjoyed activities. See Figure 5.

Outcomes

Utilising a collaborative interprofessional approach which focuses on interdisciplinary goals ensures:

- a positive therapeutic relationship is maintained
- engagement in appropriate clinical interventions
- communication, cognitive, and physical abilities during the acute stage of an admission are maintained
- sensory stimulation and opportunities for advocacy and emotional support are provided.
- important personal milestones and events can be supported

Conclusions

Carefully implemented trauma-informed teamwork which focuses on holding a family when traditional rehabilitation isn't appropriate is essential for long term patient outcomes. A coordinated interprofessional allied health approach maximising rehabilitation opportunities following neurosurgery supports both patient and family adjustment through extended and traumatic hospital admissions.

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