Disorders of Consciousness and Complex Neuro-disability: What do Service Users Access?

T Clark, G Alba-Garcia, D Blacker & A Cassim
tclark@rhn.org.uk

Background

A Disorder of Consciousness (DoC) is a state of wakefulness without or with only minimal awareness. Those who remain in this state for more than four weeks after their brain injury are deemed to be in a Prolonged DoC (PDoC), They have highly complex and life long care needs, with constant risk of deterioration.

There is little evidence to guide their likely long term complexity or care needs. National guidance advocates the use of rigorous 24 hour postural management (the use of wheelchairs and bed positioning to prevent pressure areas and preserve joint health) and easy access to interventions to manage spasticity and pain, such as medications, injection therapy and splinting (RCP 2013).

The RHN is home to many adults with profound brain injuries. Amongst them, 66 adults who remain in a PDoC. They have access to specialist Physiotherapists, Occupational Therapists, Nurses, Wheelchair Engineers, Consultant Physicians and expert Splinting, Seating and Spasticity Clinics. We wanted to quantify which services people in PDoC use when they are available, to understand areas of complexity and improve understanding of their long term needs..
We hope this information will help inform the national perspective on the needs of people in PDoC and support the provision of appropriate clinical services in the wider community.

Method

The records of 66 adults in PDoC, ranging from 11 months to 41 years since injury (median = 6 years) were surveyed with a standardised data collection tool to evaluate markers of disability complexity and to quantify the clinical resources being used to maintain physical health.
Three common areas of complexity were identified:
- Postural Change
- Limb Contracture
- Spasticity

To further understand 'complexity', we explored the levels of expertise required to effectively manage each complexity and potential care burden. This included identifying the involvement of health care practitioners able to fabricate bespoke or customised equipment or splints, Nursing and Health Care Assistants able to support daily splint application or sleep system use and access to a range of expert clinicians for spasticity management.

Results

The main physical complexities were contracture, spasticity and poor posture. All required complex interventions.

24 hour/7 day postural management programme
- 100% of residents were able to be seated
- 35% required custom seating systems
- 13% required custom bed systems
- 26% had a craniectomy and required a specialist head rest

Splinting
- 97% had one or more splints
- 68% of splints were custom made by an expert clinician

Spasticity
- 63% received botulinum toxin treatment
  - received an average of 3 botulinum toxin treatments
  - required botulinum toxin treatment to an average of 2 limbs
  - 39% received treatment for cervical dystonia
- 9% received Intrathecal baclofen
- 9% received Intraneural phenol

Conclusion

People in PDOC experience a changing and complex physical presentation in the years and decades following their brain injury. Secondary impairments (such as spasticity and contracture) are very common and threaten physical health, comfort, participation in daily activities and ease of care. Failure to prevent or manage secondary impairments can increase the level of disability suffered - but effective management is difficult, even in the most expert of settings.

In the years since their brain injury, our residents required continual expert support from Therapists, Wheelchair Engineers, Nurses and specialist Doctors to maintain their physical health. Their complex care requirements fluctuated over the years, but never disappeared. They frequently required a level of clinical support not easily available in the community.

People in a PDOC require lifelong expert clinical services from a broad interdisciplinary team. Further work should focus on quantifying the impact of physical management strategies on quality of life, burden of care and health outcomes. Health care planning and provision for this group of service users should consider the duration and complexity of their future needs.

Royal Hospital for Neuro-disability

West Hill, Putney, London SW15 3SW
020 8780 4500 | www.rhn.org.uk | info@rhn.org.uk
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Common Physical Complexities & Clinical Needs

Postural Changes

66/66 had a 24 hour 7 day postural management programme

66/66 had a tilt in space wheelchair

66/66 received input from PT, OT, Nursing and W/C Engineers to support their postural needs

23/66 required a customised wheelchair made by a Wheelchair Engineer

9/66 required a customised sleeping system

Limb Contracture

64/66 had contractures affecting one limb or more

64/66 used splints and needed help to wear these daily

45/66 had customised splints which required expert fabrication by a therapist and regular review

On average, our patients had 3 limbs affected by contracture

Spasticity

52/66 were referred to Spasticity Clinic with spasticity impacting care and/or comfort.

42/66 received botulinum toxin treatment and needed follow up

Repeat treatments were common

An average of 1-2 systemic medications for spasticity which needed regular expert review

12/66 required further expert spasticity support.
- 6/66 - intrathecal baclofen pump
- 6/66 - intraneural phenol

Reference

Royal College of Physicians. Prolonged disorders of consciousness: National clinical guidelines. London, RCP, 2013