### Full-Length Article

# Exploring the effectiveness of music therapy intervention as part of interdisciplinary assessment and treatment for patients with prolonged disorders of consciousness

Rebecca Susan O'Connor<sup>1</sup>, Dee Mary Gray<sup>1</sup>

<sup>1</sup>The National Rehabilitation Hospital, Dublin, Ireland

### Abstract

Twenty-nine patient participants took part in a 4-year study at a rehabilitation hospital in Ireland where two music therapists worked as an integral part of a Prolonged Disorders of Consciousness (PDOC) interdisciplinary team (IDT). The research explored the impact of music therapy as part of IDT assessment and treatment for patients with PDOC and their families. PDOC is defined as diminished or absent responsiveness and awareness persisting for more than four weeks following a catastrophic brain injury. A mixed methods approach incorporating a case study series, the Music Therapy Assessment Tool for Awareness in Disorders of Consciousness (MATADOC), questionnaires from patient's families and IDT members, and video analysis was undertaken. Three case studies series are outlined to illustrate aspects of the clinical work and address the research questions. Findings suggest that music therapy can enhance an IDT and have a positive impact on PDOC patients and their family members. A permanent PDOC music therapy service was established at the hospital incorporating the music therapy assessment and treatment pathway that was developed in this study.

Keywords: Music therapy, interdisciplinary team working, prolonged disorders of consciousness, family working

multilingual abstract | mmd.iammonline.com

### Introduction

### Defining Prolonged Disorders of Consciousness (PDOC)

PDOC comprise a continuum of conditions with two primary diagnostic categories: Vegetative State (VS) and Minimally Conscious State (MCS) [1, 2]. Patients who are in VS are unaware of themselves or their environment; they have no discernible indications of consciousness despite evidence of wakefulness [3]. They display reflexive, primitive behaviours that are not occurring in response to particular stimuli. A person in continuing VS may cry, grimace, yawn, smile and move their eyes, head and limbs in an automatic way with no evidence of sustained, purposeful or voluntary behaviours [1]. Laureys et al. [4] propose a more neutral and descriptive term for VS, Unresponsive Wakefulness Syndrome (UWS), however, for the purpose of this paper the authors will refer to the term VS.

Patients in MCS may show signs of limited, inconsistent conscious awareness such as command following and visual pursuit, localisation to noxious stimulation and appropriate

## PRODUCTION NOTES: Address correspondence to:

responses to emotional stimuli without being able to communicate functionally. Although these responses are inconsistent, they are reproducible above the level of spontaneous or reflexive behaviours, indicating some degree of awareness of self or environment [1, 5].

Three research questions included in our study were: Does the inclusion of music therapy within an IDT enhance the service offered to PDOC patients? How does music therapy impact the experience of family members? Can a music therapy assessment and treatment pathway be developed for this patient population?

### The importance of assessment with PDOC patients

Patients with PDOC present as one of the most complex and challenging patient groups to assess and treat due to the cognitive profound physical, and communication impairments and high level of medical needs that they often present with. Accurate diagnosis and assessment of awareness is crucial as failure to correctly identify or measure levels of awareness can lead to misdiagnosis and at times withdrawal of treatment [5, 6]. Research suggests that a creative approach from skilled clinicians in combination with robust and sensitive measurement tools are vital [3] and patient's arousal levels need to be maximised through adequate stimulation within assessment procedures [7,8].

# *Music therapy assessment and treatment with PDOC patients*

The rationale for the clinical application of music with patients with PDOC can be found in a range of sources [2, 9,

Rebecca Susan O'Connor, E-mail: <u>beckysoconnor@gmail.com</u> | COI statement: The author declared that no financial support was given for the writing of this article. The author has no conflict of interest to declare.

10]. Music can convey emotion, stimulate memory irrespective of the need for verbal processing, and provide optimal stimuli for people whose cognition is severely compromised [11]. The auditory modality has been identified as the most sensitive modality in identifying responses with this population group [12].

Music therapy assists with IDT assessment and diagnostic procedures with the application of the Music Therapy Assessment Tool for Awareness in Disorders of Consciousness (MATADOC) [2]. The MATADOC has a defined treatment protocol that uses a range of musical stimuli, including single auditory stimuli, complex musical sounds, and musical activities to measure a broad range of functional non-musical behaviours. The primary aim of the protocol is to determine awareness in the patient whose consciousness is compromised, using musical stimuli. The assessment is undertaken in four sessions over a ten-day period, and focuses on five behavioural domains: auditory, visual, motor, arousal, and communication. The MATADOC also examines individual's responses in additional areas specifically related to auditory and musical stimuli including vocalisation, behavioural responses to music, awareness of musical stimuli and emotional response.

All tasks in the MATADOC primarily use live music although recorded music is occasionally utilized when this maintains musical authenticity. The musical stimuli employs both music that is known to be personally meaningful to the patient and unfamiliar music which is entrained to the patient's breathing rate by the music therapist.

The MATADOC can assess the lowest level responses typical of VS patients but can be expanded to provide assessment tasks for patients who are demonstrating responses typical of MCS and MCS emergent patients (MCSE) [2].

### Material and methods

Patients in a PDOC do not have the capacity to provide consent due to the profound cognitive, communicative, and physical impairments they present with. Consent was obtained by the patient's next of kin for them to receive music therapy intervention, in their best interest, as part of the study. Ethical clearance for the study was applied for and obtained from the rehabilitation hospital ethics committee. Data was collected and stored adhering to the rehabilitation hospital guidelines. A music therapy assessment and treatment pathway was trialled and developed through the course of the study.

Traditionally PDOC patients who attend the rehabilitation hospital undertake a battery of assessments of awareness. These include the Sensory Modality Assessment and Rehabilitation Technique (SMART) [13], the Wessex Head Injury Matrix (WHIM) [14], the Coma Recovery Scale – Revised (CRS-R) [15] and a speech and language therapy

(SLT) assessment protocol. All PDOC patients who attended the rehabilitation hospital for the duration of this study, twenty-nine patients in total, also received a MATADOC assessment. Of the twenty-nine participants who took part in this study, seven were diagnosed as VS, twenty MCS and two as emerging from MCS (EMCS).

MATADOC scores were integrated within the IDT assessment protocols to contribute to the overall assessment of awareness for each patient. Video graphic recordings of music therapy assessment sessions were obtained to provide objective, detailed analysis of patients' responses to musical stimuli by both the music therapists as well as members of the IDT with an aim to inform IDT treatment.

Following IDT assessment all patients received four, hour-long music therapy treatment sessions per week throughout the course of their rehabilitation. Members of the IDT were also present to work on specific identified conjoint goals. An individual auditory regulation programme was designed for each patient where the music therapists recorded audio files with music that stimulated optimum responses from patients as identified during the MATADOC. The resulting programme was given to the ongoing long-term care facility at discharge. Twelve months post discharge an audit of the impact of the auditory regulation programme was completed by all the long-term care homes.

Service feedback questionnaires were completed by the IDT and family members of all PDOC patients who took part in the study.

### Results

The value of music therapy as a core component of the services offered for all the PDOC patients who took part in this study, those with a diagnosis of VS, MCS and EMCS, was exemplified within the questionnaires completed by members of the IDT. The impact of music therapy input in enabling family members to reconnect with their loved one in a safe appropriate space was identified in the service evaluation questionnaires.

The study led to the formulation of a music therapy assessment and treatment pathway in collaboration with the IDT.

Music therapy input was divided into five phases as outlined in table 1.

- 1. Pre MATADOC assessment.
- 2. Discipline specific assessment including the MATADOC.
- 3. IDT family feedback.
- 4. Treatment phase including the creation of **auditory** stimulation programmes.
- 5. Preparation for discharge.

Table 1.Music therapy assessment and treatment pathway	
	Music therapy assessment and treatment pathway
Stage	Pre MATADOC assessment phase
1	Music therapists (MTs) liaise with IDT in relation to
	optimum positioning for assessments and medical
	stability
	MTs meet the family and collate a musical profile
	Pre-assessment music therapy sessions undertaken
	to informally identify responses to a variety of
	musical stimulation
	MTs attend formal IDT family meeting outlining
	music therapy assessment and treatment approach
Stage	Discipline specific assessment phase
2	Music therapists:
	4 MATADOC assessment sessions
	Occupational therapists:
	Sensory Modality Assessment and Rehabilitation
	Technique (SMART)
	Wessex Head Injury Matrix (WHIM)
	Coma Recovery Scale – Revised (CRS-R)
	SLT, nursing and physio:
_	Discipline specific formal assessments
Stage	IDT family feedback phase
3	MTs liaise with IDT regarding MATADOC and IDT
	assessment findings and diagnosis
	MTs plan collaborative treatment sessions with IDT
	and family
	MATADOC assessment findings diagnosis and
	diaguas treatment phase
Stage	Treatment phase
Juge	Collaborative sessions with IDT and family
4	MTs develop individualised auditory regulation and
	stimulation programme
	MTs and IDT liaise and feedback with family
	throughout
Stage	Preparation for discharge
5	MTs attend IDT family meeting discussing
c .	treatment findings and implementation of identified
	music- based strategies
	MTs develop auditory regulation guidelines and
	create prescriptive music CDs
	MTs and IDT meet with team members from the
	long-term care facility providing education and
	support to the team
	MTs contribute to IDT discharge report

# Audit of auditory regulation programme

The audit that was carried out involved contacting the on-going care settings of all twenty nine patients who took part in the study twelve months post discharge. All participant's had been discharged to long term care facilities and the audit identified the value and continued implementation of this programme.

# Summary of audit results from twenty-nine patient participants:

• **100%** of discharged patients received recommendations or auditory regulation and stimulation programmes including prescriptive CDs.

• 95 % of patient's family or carers completed the audit.

• 85% of patients who were audited were still using the programme and guidelines up to twelve months post discharge.

• 15% of patients who were audited had discontinued using the auditory regulation programme due to sickness or a deterioration.

### Case studies

The following three case studies are examples taken from the case study series. They illustrate aspects of the clinical work undertaken and highlight the impact of the MATADOC and the music therapy treatment pathway on this patient population, their families, and the IDT.

### Case study I: Tom

'Tom's\* case study illustrates how findings from the MATADOC were applied in the treatment phase of the study where specific music identified in the MATADOC was used to help manage distress, support regulation and address pain management.

Tom is a 30-year-old man who was diagnosed as being in MCS following a catastrophic hypoxic brain injury with diffuse axonal injury following a cardiac arrest secondary to an opiate over dose Tom is visually impaired, has no volitional movement with spastic tetra paresis increased tone and bilateral upper limb contractures, communication and cognitive impairment. Tom was admitted to the rehabilitation hospital five years post diagnosis as he was displaying extreme distress with long episodes of crying and shouting, becoming upset when approached or touched making it very difficult for staff to manage him in the long-term care facility.

Tom underwent a MATADOC assessment as part of his IDT assessment process to contribute towards his diagnosis but also to identify any significant responses to musical stimulation. The music therapists presented a variety of sounds, several different musical instruments including the guitar, piano, percussion, violin, and flute, and familiar songs identified as meaningful prior to his injury by his family. Music was presented in a sensitive, controlled manner as per the MATADOC protocol, aiming to identify an auditory profile. The assessment process detailed the specific sounds and music Tom was most responsive to by analysing video recordings and monitoring consistent, reproducible responses to the auditory stimuli. As a result of the detailed analysis of his specific responses to a wide range of musical stimulation utilising a variety of keys and instruments throughout the MATADOC assessment process, it was identified that Tom appeared to calm, and his crying gradually reduced during clinical improvisation when the music therapist played the flute, matching the music to the rate of his breathing patterns and body movements, in the key of D minor – which reflected the pitch, sounds and intensity of his vocalisations.

No consistent, repeatable responses to other keys or instruments were observed. It appeared that the minor nature of the key also reflected and attuned to the sad and painful nature of his emotions and presentation. The music therapist produced music aiming to reflect any observed changes in Tom's behaviour, the emotional quality of his sounds, and his movements. Initially up to twenty minutes of playing the flute in this specific way was required before Tom displayed any behavioural responses indicating conscious awareness of the sounds.

As music was played, he gradually became able to demonstrate a level of awareness of the music evidenced by consistent and reproducible breaks in his crying and slowly moving his head towards the source of sound, smiling as he began to regulate his breathing. These responses were significant as research has identified that the psychophysiological parameters, for example changes in breathing rhythm, muscle tone and heart rate, are meaningful due to the implicit intersubjective resonances, mimicries, comovements and interactional related behaviors that may occur [16]. The use of music in this sensitive and attuned way repeatedly helped Tom to calm.

Tom's ability to respond to music became an integral aspect of his overall care. As one of the nurses stated, "Music therapy promotes calmness and relaxation for Tom even for a few minutes which facilitates the implementation of our nursing care." When Tom became distressed, the nursing staff would contact the music therapist to come to his bedside, play the flute and support him to calm. The nurses fed back that this was specifically beneficial before they carried out Tom's Activities of Daily Living.

Tom's consistent responses led to the formulation of an auditory regulation programme including specific CD recordings of the identified flute music and guidelines for staff to use when required, as part of his twenty-four-hour care package to help alleviate his distress. The nurses recorded and monitored his responses to the music on a chart by his bedside, so the music therapist was able to update and adapt the music accordingly.

Upon discharge, the CD recordings and auditory regulation programme were sent to his ongoing care facility as part of his IDT discharge package. This input proved continuously beneficial; in the music therapy post discharge audit staff stated that they continued to use the CDs and requested regular updated CDs up to two years post discharge.

### Case study II: John

John's\* case study details music therapy and IDT intervention with a patient in MCS. John is a 39-year-old gentleman in a PDOC resulting from complications following treatment of a central neurocytoma in right thalamus (WHO grade 2). He underwent a burr-hole biopsy and EVD placement, complicated by an intraventricular bleed and cranial radiotherapy for radiological tumour progression. Pre morbidly Tom was academic, played the piano to a high standard and was an athlete. Following his brain injury, he had a visual impairment, tracheostomy, global weakness, was fully dependant for all activities of daily living, and was fed by a gastrostomy tube.

The MATADOC was undertaken as part of John's overall IDT assessment. The MATADOC identified consistent, purposeful responses to musical stimulation; John also displayed increased arousal levels, emotional responses to familiar music specifically when the music therapist played the piano and some potentially purposeful movements when music was played to reflect his movement patterns and emotions.

Following his IDT assessment, the team analysed videos of the MATADOC to identify his positive behavioural responses to music and inform the team's rehabilitation approach. Music therapy treatment sessions with members of the IDT took place four times a week in the music therapy room for the duration of his rehabilitation.

An improvisation approach was taken in the music therapy sessions with the music therapist playing the piano, incorporating a variety of keys, musical genres and singing, attuning to his movements and emotional responses. Familiar songs that were identified as significant by his family were also played as well as pieces of piano music that his family said he had himself played pre morbidly. When these were played there was a consistent change in his arousal levels with eye opening and an increase in movements indicating an increase in arousal and awareness as a result of the musical stimulation.

For patients in PDOC, maintaining arousal is a significant problem which interferes with engagement in rehabilitation. Research has identified that music can stimulate and prime attention and arousal levels for PDOC patients [11, 17, 18]. Because John's arousal levels consistently increased during musical stimulation, IDT and music therapy sessions became an intrinsic aspect of his rehabilitation program. Within the conjoint IDT music therapy treatment sessions up to six clinicians and family members could be present at any one time.

During these sessions, the music therapist played improvised music on the piano or flute to attune with and match John's body movements, breathing patterns, subjective mood, and behaviors. John's positioning and any body movements were enhanced and facilitated by the physiotherapist and occupational therapist whilst his emotional responses were observed and supported by the psychologist.

The social worker was able to sit with the family as they observed John's responses to support their changing perception of him and the SLT facilitated and guided the team in relation to his communication intent. The nurses played a key role throughout sessions in supporting the patient physically and his family emotionally. The physiotherapist acknowledged the benefit of the conjoint sessions stating, 'The IDT treatment sessions enable us to work with John on so many levels - physically, cognitively, perceptually and emotionally through the music'.

The specific music therapy techniques applied to attune to John provided a rich environment for his behavioural responses to be observed and responded to by the IDT. The sessions also provided an accessible space where his family members had opportunities to gain more understanding into his current needs and abilities.

### Case study III: Amy

Emerging research highlights the high burden and emotional difficulties identified for caregivers and relatives of patients with PDOC [19, 20, 21, 22]. Romaniello et al. [22] state the need for 'psychological interventions and supports, since caregivers represent an important part of an all-embracing support and care network for patients with PDOC'. The following case study illustrates how the flexible and nonverbal medium of music can be used in IDT music therapy sessions with families to support their emotional needs and to explore alternative ways for them to connect with their loved one.

Amy\* is a 45-year-old mother who was in a disorder of consciousness following a grade V subarachnoid haemorrhage from a solitary anterior communicating artery aneurysm rupture complicated by obstructive hydrocephalus and a seizure disorder. Baseline multi-disciplinary assessment, including the MATADOC, diagnosed her as MCS. In the MATADOC Amy had displayed increased arousal levels during musical stimulation, she was able to make reproducible vocal sounds as well as display inconsistent but appropriate emotional responses to familiar music.

Amy's husband had identified with the team that their seven-year-old daughter Molly\* was finding it very distressing visiting her mother. Amy's husband and daughter attended regular music therapy sessions with Amy over a period of four months in the music therapy room. In initial sessions, it was immediately clear that Molly found it extremely difficult and painful to be with her mother, avoiding eye contact, positioning herself as far away as possible from Amy. Amy had played the guitar socially at family gatherings and music had been an activity that Amy had shared with her daughter before her injury.

The music therapists supported Molly in exploring practical creative ways to 'be' with her mother, specifically

playing the guitar and teaching Molly how to play songs that they had both enjoyed listening to. Molly was also able to take part in writing simple songs with the music therapists, identifying, and expressing her feelings about her mother and her sense of loss. With the support and facilitation of the music therapists and her father, Molly developed a singing style she called 'Mummy talking' where she was able to take part in vocal interactions with her mother, learning how to match Amy's vocalizations within musical conversations. During treatment phase, Molly also attended sessions with the medical social worker in close liaison with the music therapists, to support her adjustment to the current situation and provide the emotional support she needed.

As sessions progressed, it became apparent that Amy was much more responsive, awake and displayed optimum arousal levels whilst interacting musically with her daughter. Her face would light up and she became animated engaging in eye contact, smiling and occasionally laughing during musical interactions with Molly present. The music therapists assisted Molly in compiling her songs into a songbook and created a personalised audio recording onto a CD for Molly to take to her on going care facility on discharge.

### Discussion

Data obtained from the research study can be analysed to address the three research questions.

1. Does the inclusion of music therapy within an IDT enhance the service offered to PDOC patients?

The value of the MATADOC tool in positively contributing to IDT assessment for this complex patient group was identified. A 98% inter-reliability with the SMART assessment on diagnosis with study participants was recorded. Within the study the music therapists carried out conjoint IDT sessions with all twenty-nine participants including those with a diagnosis of VS as well as MCS; 95% of music therapy treatment sessions involved several professionals from the IDT. The benefit of this approach is reflected in relevant literature as identified by Kennelly and Brien-Elliot [23] who state that interdisciplinary working is 'not simply a multi professional provision but a unified strategy that fuses therapy specific methods in attaining shared rehabilitation goals'.

Members of the IDT identified that the music therapy sessions were an optimal space for behaviours to be observed and conjoint goals to be addressed. An occupational therapist stated 'The MATADOC assessment assists in providing a comprehensive assessment of awareness complimenting the use of the other tools including the SMART and the WHIM. The MATADOC's strength is in the detailed assessment of auditory responsiveness which is one of the largest sensory processing routes'.

Furthermore, a psychologist on the team expanded on the strength of the medium of music with this population

identifying how the musical space creates opportunities for IDT members to work collaboratively and can offer patients a sensitive and flexible approach to address their holistic and multifaceted needs. She stated, 'Working as though through the music, in relation to the music, alongside the music; with all that conjures in mind, emotion, meaning, memory, identity and ways of being opens up all team members in that interaction, to rich, creative and shared clinical opportunities with an individual post acquired brain injury'.

The value of music therapy in supporting sensory regulation, relaxation and facilitating communication was also identified through the questionnaires. A nursing manager stated, 'We have found music therapy beneficial to our patients with PDOC and those with behavioural and emotional issues. It promotes calmness and relaxation which facilitates the implementation of our nursing care'. The medical consultation in agreement stated, 'In our ward music therapy has become a valuable therapy used to help calm and support PDOC patients who exhibit extreme agitation'. Regarding the potential of music therapy to facilitate nonverbal communication with this complex patient group, the medical consultant acknowledged how music therapy can at times elicit responses from patients when other therapies are not accessible to them. He states that 'In my experience music therapy has been a novel and very welcome 'last chance' rehabilitation approach used to try to open up an avenue of communication/interaction with our Prolonged Disorder of Consciousness patients particularly when no other approach has worked'.

The impact of music therapy in supporting auditory regulation for the patients also became apparent as the study progressed. According to RCP Guidelines [1] and Gill-Thwaites and Mundy [12], regulating sensory input is crucial for PDOC patients in order to control the environment and reduce the rate and complexity of stimuli that patients are exposed to.

The music therapists in the study found that by exploring and assessing patient's responses to specific auditory stimulation during the MATADOC, rich information was provided that contributed to the IDT's understanding of individual patient's threshold for auditory stimulation. This information guided the music therapists in the development of the individualised auditory regulation programmes.

2. How does music therapy impact the experience of family members?

Family members of all patients who took part in the study, and were able to visit the rehabilitation hospital, attended music therapy sessions. Working with patient's families has always been an important aspect of the music therapy service within the rehabilitation hospital. However, one the most exciting aspects of this study was having the opportunity to explore and develop intense close working with the family members of PDOC patients. This study enabled the music therapists to maximise family members' opportunities to interact with loved ones in a structured and protocolled way and to evaluate the impact of this way of working through family feedback questionnaires.

The Medical Social Worker stated, 'Music therapy plays a vital role within the IDT in supporting the families whose loved one is in a PDOC – facilitating siblings, parents and children to be together in a meaningful way that promotes human connection, allows for emotional expression and harnesses the strengths of individuals as well as the family unit within a safe supportive space'.

Feedback from family members strongly indicated that they found the music therapy sessions invaluable in finding a way to 'be' with their loved ones through music. As one family member stated, 'I am delighted that I could participate in music therapy sessions; I could see my husband respond emotionally to the music and the therapists. The music gave us an enjoyable way of spending time together and it helped me to see what he was able to do which was very important as you can get caught up in what your partner isn't able to do anymore'.

A parent whose daughter engaged in music therapy fed back, 'the music therapy sessions were vital in helping us look creatively at how we could reconnect as a family'. Another patient's young daughter reported, 'it was great to have the music therapy sessions to work on something together with my mum, I can see when she is listening and sometimes, she smiles and it's really nice for me to spend time with her when she can't talk anymore'.

3. Can a music therapy assessment and treatment pathway be developed in working with this patient population?

The study led to the formulation of a music therapy assessment and treatment pathway in collaboration with the IDT. Following the conclusion of the study this pathway became an integrated part of the IDT treatment offered to PDOC patients at the rehabilitation hospital.

## Strengths and limitations

An important strength of this study is the use of the MATADOC as a structured, validated assessment tool which enabled the music therapists to contribute towards overall IDT assessment utilising an evidence-based approach. The involvement and contributions of a highly qualified and experienced IDT added to the quality and depth of the music therapy intervention.

Whilst positive outcomes regarding the impact that music therapy can have on enhancing an IDT, contributing to diagnosis, and on supporting family members were identified, there are limitations of the study as it is an unblended, uncontrolled qualitative descriptive case series. Future studies are required to demonstrate that this intervention improves outcomes compared to other interventions, specifically in reducing the length of hospital stay. The non-randomization of participants was also a limitation as all twenty-nine patients who attended the rehabilitation hospital during the four-year period of the study took part. There was a limited number of patients as participants were dependent upon the number of admissions during the time. Also, due to the complex nature of the patient population and their physical limitations three of the participants became physically unwell and had to withdraw from the study.

### Conclusions

In summary this four-year study enabled the music therapists to obtain rich data clearly identifying positive answers to the research questions. The encouraging evidence gained has also enabled the music therapists to further explore the impact that music therapy can have in assessing and treating this complex patient population. New opportunities for research have been created resulting from the initial study. At the conclusion of the study and in response to the overwhelming positive outcomes, research funding was applied for and obtained for a further three years in order to take part in a multi-site international study titled 'Validating the Music therapy Assessment Tool for Awareness in Disorders of Consciousness (MATADOC) against the best practice external reference' [24].

Most significantly is that as a direct result of this study, music therapy assessment and treatment is included in the National PDOC care pathway and a permanent music therapy service has been established as part of the IDT in the PDOC unit at the rehabilitation hospital.

\*Names have been changed to ensure confidentiality

#### References

- Royal College of Physicians. Prolonged disorders of consciousness: National clinical guidelines. London, RCP, 2013.
- Magee, W.L., Siegert, R.J., Lenton-Smith, G; Daveson, B.A., Taylor, S.M. (2014). Music therapy Assessment Tool for Awareness in Disorders of Consciousness (MATADOC): Standardisation of the principal subscale to assess awareness in patients with disorders of consciousness. Neuropsychological Rehabilitation, 24 (1), 101-124.
- Magee, W.L., O'Kelly, J. (2015) Music therapy with Disorders of Consciousness: Current Evidence and Emergent Evidence-Based Practise. Annals of the New York Academy of Sciences, 1337, 256-262. Sciences, 1337, 256-262
- Laureys, S., Celesia, G.G., Cohadon, F. Unresponsive wakefulness syndrome: a new name for the vegetative state or apallic syndrome. BMC Med 8, 68 (2010). https://doi.org/10.1186/1741-7015-8-68

- Giacino, J.T., Kalmar, K., Whyte, J. (2004) The JFK Coma Recovery Scale-Revised: measurement characteristics and diagnostic utility. Arch Phys Med Rehabil. 85(12) 2020-9.
- Giacino, J.T., Ashwal, S., Childs, N., Cranford, R., Jennett, B., Katz, D.I., Zasler, N.D. (2002) The minimally conscious state: Definition and diagnosis criteria. Neurology, 58(3), 349-353.
- Hirschberg, R., Giacino, J.T. (2011) The vegetative and minimally conscious states: Diagnosis, prognosis and treatment. Neurologic Clinics, 29(4) 773-786
- 8. Schnakers, C. (2012) Clinical assessment of patients with disorders of consciousness. Archieves Italiennes de Biologie, 150: 36-43.
- 9. Vogl, J., Heine, A.M. Steinhoff, N., Weiss, K., Tucek, G. (2015) Neuroscientific and neuroanthropological perspectives in music therapy research and practice with patients with disorders of consciousness. Frontiers in NeuroScience, 9 (273) 1-6.
- Heine, L., Castro, M., Martial, C., Tillmann, B., Laureys, S., Perrin F. (2015) Exploration of functional connectivity during preferred music stimulation in patients with Disorders of Consciousness. Frontiers in Psychology, 6:1704. doi: 10.3389/fpsyg.2015.01704
- O'Kelly, J., James, L., Palaniappan, R., Taborin, J., Fachner, J., Magee, W. L.(2013) Neurophysiological and behavioral responses to music therapy in vegetative and minimally conscious states. Frontiers in Human Neuroscience, 7, 884. doi:10.3389/fnhum.2013.00884
- 12. Gill-Thwaites H., Mundy, R. (2004) The Sensory Modality Assessment and Rehabilitation technique (SMART): A valid and reliable assessment for vegetative state and minimally conscious state patients. Brain Injury 18, 1255-1269.
- Gill-Thwaites H., Mundy R., Elliott K. Sensory modality assessment and rehabilitation technique manual. version 2. London: Royal Hospital for Neuro-disability; 2008.
- Shiels A., Horn S.A., Wilson B (2000) The Wessex Head Injury Matrix (WHIM) main scale: A preliminary report on a scale to assess and monitor patient recovery after severe head injury. Clinical Rehabilitation 14: 408–16. doi:10.1191/0269215500cr3260a
- Giacino, J.T., Kalmar, K. Diagnostic and prognostic guidelines for the vegetative and minimally conscious states. Neuropsychol Rehabil. 2005;15(3-4):166-74. doi:10.1080/09602010443000498.
- 16. Boeseler, K. (2012) Needs orientated, emotional-communicative dialogue in music therapy with unresponsive wakefulness syndrome patients in neurological early rehabilitation. In Jox, R.J., Kuehlmeyer, K., Marckmann, G., Racine, E. (Eds.) Vegetative State - a paradigmate problem of modern societies: medical, ethical, legal and social perspectivies on chronic disorders of consciousness. Practical Ethics, Zurich: Literature. 80-94.
- 17. Magee, W.L. Why include music therapy in a neurorehabilitation team? ACNR 2020;19(2): 10-12
- Magee, W.L. Music in the diagnosis, treatment and prognosis of people with prolonged disorders of consciousness. Neuropsychological Rehabilitation, 2018;17;28(8):1331-9.
- Leonardi, M., Giovannetti, A.M., Pagani, M., Raggi, A., Sattin, D. (2012) Burden and needs of 487 caregivers of patients in vegetative state and in minimally conscious state: results from a national study. Brain Injury, 26(10) 1201-10.

- Tramonti, F., Bonfiglio, L., Di Bernardo, C., Ulivi, C., Virgillito, A., Rossi, B., Carboncini, M.C. (2015) Family functioning in severe brain injuries: correlations with caregivers' burden, perceived social support and quality of life, Psychology, Health & Medicine, 20(8)1-7
- Chiambretto, P., Rossi Ferrario, S., Zotti, A.M. (2001).Patients in a persistent vegetative state: Caregiver attitudes and reactions. Acta Neurologica Scandinavica, 104(6), 364–369.
- Romaniello, C., Simoni, C., Farinelli, M., Bertoletti, E., Pedone, V., Northoff, G. (2016). Emotional Burden, Quality of Life, and Coping Styles in Care Givers of Patients with Disorders of Consciousness Living in Italy: Preliminary Data. Brain Impairment, *17*(3), 254-264. doi:10.1017/BrImp.2016.26
- 23. Kennelly, J., Brien-Elliot, K. (2001) The role of music therapy in paediatric rehabilitation. Paediatric Rehabilitation, 4, 137-143.
- 24. Magee, W.L. (2016) Validating the MATADOC Against Best Practice Standard External ReferenceStandard. IdentificationNo. NCT02959736.Retrieved from https://clinicaltrials.gov/ct2/show/NCT02959736

### **Biographical Statements**

**Rebecca O'Connor** qualified as a nurse before training as a music therapist and has 32 years music therapy experience in

health and education. She established the music therapy service at the National Rehabilitation Hospital (NRH), Dublin working with children and adults who have had an acquired brain injury or spinal cord injury. She is currently Service Lead of the Creative Arts Therapies Service at the NRH. Rebecca is a Senior Lecturer on a number of Masters Therapy training courses with a special interest in research, has a Masters in research methodologies, is a qualified Neurologic Music Therapist and publishes and presents regularly on her work.

**Dee Gray** obtained a Masters in Music Therapy at University of Limerick in 2011. She has established music therapy positions in areas including mental health and paediatric palliative care. She currently works as a senior music therapist at the National Rehabilitation Hospital and LauraLynn Irelands Children's Hospice and has a special interest in area's including prolonged disorders of consciousness, Interdisciplinary working and family centred music therapy practise.