

Challenges for Allied Health Professionals working with disorders of consciousness patients and their families

Prof Jenny Kitzing
Julie Latchem
Cardiff University
Coma & Disorders of Consciousness Research Centre



The research centre: social, ethical, legal aspects...



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Original foundational data: Interviews with family members

- * 75+ family members with relative in PDoC
- * Wide range of individuals and families
- * Follow some over time (re-interviewed years apart)
- * Also started with some interviews with consultants (in ICU, neuro-rehab, neurosurgery etc)... Spot the gap!

- * Multiple gaps – including nurses, AHPs, ... care assistants,... And care home gardeners, chef, cleaner (see Julie Latchem's work on hotel staff)
- * Case managers, social workers, Continuing Health Care funding assessors...and more

Diverse themes and publications

- * Quality of care centre provision
- * Need for case managers
- * Decision-making re interventions - DNACPR to CANH
- * Case study of one family's journey
- * Advance Decisions

All publications open-access at: www.cdoc.org.uk

Focus today: Allied health care professionals

1. Background...
2. Online resources
3. Interviewing AHPs
4. ... and developing CPD training and an e-learning resource for AHPs

- * Jenny Kitzinger: Not a health care professional: (social anthropologist/sociologist/Prof of Communications research.... Also a sister)
- * Julie Latchem (formerly matron of neuro-specialist rehab center, physio... and now completing her PhD)

RESEARCH PAPER

Physiotherapy for vegetative and minimally conscious state patients: family perceptions and experiences

Julie Latchem¹, Jenny Kitzinger², and Celia Kitzinger²

¹School of Social Sciences, Cardiff University, Cardiff, UK; ²School of Journalism, Media and Cultural Studies, Cardiff University, Cardiff, UK and ³Department of Sociology, University of York, York, UK

Abstract

Purpose: To examine family perceptions of physiotherapy provided to relatives in vegetative or minimally conscious states. **Method:** Secondary thematic analysis of 65 in-depth narrative interviews with family members of people in vegetative or minimally conscious states. **Results:** Families place great significance on physiotherapy in relation to six dimensions: "Caring for the person", "Maximising comfort", "Helping maintain health/life", "Facilitating progress", "Identifying or stimulating consciousness" and "Indicating potential for meaningful recovery". They can have high expectations of what physiotherapy may deliver but also, at times, express concerns about physiotherapy's potential to cause pain or distress, or even constitute a form of torture if they believe there is no hope for "meaningful" recovery. **Conclusion:** Physiotherapists can make an important contribution to supporting the patient group and their families but it is vital to recognise that family understandings of physiotherapy may differ significantly from those of physiotherapists. Both the delivery and the withdrawal of physiotherapy is highly symbolic and can convey (mis)advertent messages to people about their relative's current and future state. A genuine two-way dialogue between practitioners and families about the aims of physiotherapeutic interventions, potential outcomes and patients' best interests is critical to providing a good service and establishing positive relationships and appropriate treatment.

Keywords

Disorders of consciousness, family, physiotherapy, vegetative

History

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Key findings

Families associate AHPs with:

1. Caring for the person (and the family)

'[we had] all these pictures [...] of [my brother] on nights out and doing things, so people could remember that he wasn't just this horribly smelly vegetable thing [...] And she [the physio] was the only one that started looking at these pictures and she was interested in them, you know, and asking about them and talked to [my brother]. But no one else did. They came in and they went out. And it was so lonely.' (Lily)

2. Maximising comfort and maintaining health/sustaining life (e.g. contracture, chest health)

3. Facilitating progress & identifying or stimulating awareness

AHPs attentive to the person, hearing the family, and doing interventions that prompt signs:

'when Sid was put on the tilt table he woke up (does thumbs up gesture).'

4. AHPs - 'giving' or 'taking away' hope

– fear of premature loss of access, 'revolving door' or one-way exit?

'she said she was really excited about working with him, and gave the impression anything was possible'. (Jane)

'He was just shockingly horrible... the things he was saying about Nin. 'Well, I can see it's quite evident Nin hasn't got any reactions, and I don't think there's much hope for an outcome'. In front of Nin, that Nin's not going to get better!' (Felicity)

The withdrawal of therapy - withdrawal of hope, 'relegation', betrayal, abandonment

'from that point onwards [time of therapy withdrawn] it's fairly clear that [...] there's going to be no improvement, ..., you suddenly realise that they clearly think that this is pointless. ... it feels like a kind of relegation. [...], to "this patient is no longer one for whom we can do anything, other than simply support life... It [withdrawal of therapy] certainly felt like that implied a downgrading of care for the remainder of the person.' (Martine)

Continuation of some interventions:

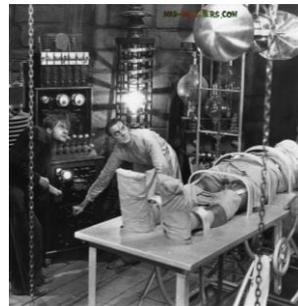
... when 'care' becomes 'torture'

Suctioning

- * I'm sure I don't need to tell you how distressing it is to watch a relative having their lungs suctioned, [...], and there's not a damn thing you can do to protect them or even explain to them or reassure them. You know, if it was a dog, you could stroke its ears and make soft noises at it. If it's child you can cuddle it and say it's all going to be better very soon, be brave. But for someone in a PVS state, there's absolutely nothing you can do. (Josie)

Splints

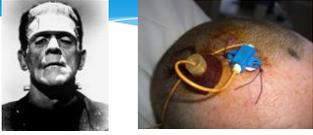
- * Splinting: 'forced' to wear splints 'mummified' appearance of the splinted limbs, and the marks left on arms and legs.



Tilt table

- * 'terrifying' (Rhiannon)
- * Causing 'agony' – 'panic', 'cruel' and 'wrong' (Rosie)





So...

- * Families can consider AHP care to be of critical importance (person-centred, maintaining physical comfort in now, and future potential)
- * Withdrawal of AHP support can be hugely symbolic (taking away hope)
- * Continuation of some interventions (once benefits no longer believed in) can become seen as torture
- * Can be mismatch between practitioner and family views, expectations, interpretations

Mind the gap...
towards dialogue and bridges

Developing on-line resources

Talks and training not sufficient reach (and lots of professionals without 'critical mass')

- * Healthtalk.org – see module on vegetative and minimally conscious states
- * CPD Training and e-learning



- * Oxford University Dept of Primary Care
- * healthtalk.org provides free, reliable information based on sociological research
- * shares people's real-life experiences e.g. You can watch people sharing their stories about cancer, stroke, autism, MND, death, drugs+++
- * 3+ million users each year
- * 80% of medical schools use healthtalk

Module on long term coma, VS + MCS [search 'vegetative' in healthtalk.org or go to section on nerves/brain]

- * Diagnosis and prognosis
- * Impact on family – hope, determination, pride, anger, despair...
- * Decisions Making
- * etc

CPD training and e-learning Interviews with AHPs

Wonderful resource of reflection, skills and experience...

- * Daily practice and skills
- * First encounters with DoC patients
- * Communication with families
- * Role in MDT

How many of you can remember the first DoC patient you encountered?

- * Thoughts
- * Feelings
- * Skill needs?

Examples: AHPs – on first seeing aPDoC patient

- * “Scarey”
- * “seeing his wife – desperate”
- * “trying to get any type of response”
- * “I can still see him standing on the tilt table”
 - * “overwhelmed for that person”
 - * “Are they able to understand what I’m saying?”
 - * “bang – life is significantly changed’
- * “What am I meant to do?”
- * “I’m right back at the starting blocks – where do I start?”
- * The patient is not able to tell me what their goals are”
- * “daunting”
- * “Intimidating”

What is our role?

- * An MDT team...

Working with families

- * Try to empathise (even if can never truly understand)
- * Listen
- * Good family involvement
- * Dialogue
- * Realism & shaping expectations
- * Careful observations/interpretations/explanation of ‘responses’/reactions
- * Having tried Everything – by specialist assessment/care
- * Keep treating them as the person that they are
- * Approach the person as still being there
- * Work with the family

Developing the resource

Materials –

- * Filmed interview with families
- * Filmed teaching sessions and/or presentations (Jenny Kitzinger and Julie Latchem)
- * Transcripts of interviews with families (not filmed)
- * Initial ideas for interactive components
- * Specially designed guided reflective practice inserts

Teaching materials

Undergraduate material – a series of 4-6 workshops to both compliment and mirror some content within the online resource.

- 1) Understanding VS and MCS
- 2) Core AHP care practices
- 3) Caring relations - Families and therapists relations – perceptions, experience and communication
- 4) Ethics and the law (MCA, life sustaining treatment and best interest decision making)
- 5) ANH withdrawal and Palliative care

- * **Section A: what is VS & MCS.** Definitions, Diagnosis, Prognosis - What is PVS. Different injuries and outcomes
- * **Section B: Core AHP care practices:** Range of services SLTs, OTs and Physios might offer e.g. communication support, splints, swallow tests, tests for awareness, tilt tables, chest physio, positioning in chair/ bed, basic comfort. The focus here is not on training in technical skills but discussing the evidence-base for each intervention, consent/best interest issues, service provision and challenges.
- * **Section C: communicating with families** (specifics: e.g. what if think family is not acting in "best interests?")
- * **Section D: Law and ethics:** Mental Capacity Act 2005, Best Interests/LPAs/Advance Decisions. Providing and withholding life-prolonging interventions

- * What's missing?
- * Where next
- * Anyone want to contribute their experience e.g. of 'their first' DoC patient...?.

THANK YOU



Twitter
@cdocuk



Jenny Kitzingler
Co-Director of Coma &
Disorders of Consciousness
Research CentreJ
OMEC Bute Building
King Edward VII Av
Cardiff
CF10 3NB
Kitzingerej@cardiff.ac.uk

Julie Latchem
Doctoral Student
School of Social Sciences
Cardiff University
1-3 Museum Place
Cardiff
CF10 3BD
LatchemJM@cardiff.ac.uk