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Developing a multimedia learning resource for allied health professionals: exploring the challenges of prolonged disorders of consciousness

(To be published in Physiotherapy Journal Vol 102) (Published abstract)

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Relevance:
Recognising the increasing number of people being sustained with prolonged disorders of consciousness (PDoC), this study introduces new research with allied health professionals that is being used to create a range of digital resources to support allied health professionals undergraduate education and practitioner CPD.

Purpose:
Previous research (Latchem et al., 2015) identified a mismatch between understandings that families of people with a PDoC hold of allied health professionals interventions and the aims and understandings of allied health care professionals delivering those interventions. This study explores a) how allied health professionals [AHPs] understand and navigate practical, ethical and legal issues surrounding the care of these patients, b) the learning needs of both qualified and pre-registration AHPs and c) uses the data to create e-learning resources for AHPs and their students.

Methods/analysis:
This qualitative study uses video- taped interviews with 15 physiotherapists, occupational therapists and speech and language therapists purposively sampled from NHS and independent care providers, and workshops conducted with mixed AHP pre-registration students. The interviews/workshops were transcribed and analysed thematically, adopting a grounded-theory approach to examine experience and learning needs surrounding PDoC care. Emergent themes informed the focus and structure of the e-learning resource.

Results:
AHPs described how the needs of PDoC patients shifted the focus of, and extended, their clinical skills. They reported struggling adjusting to, and finding satisfaction in, their work with this client group who don’t ‘improve’, have a clear rehabilitative nor declining trajectory. Satisfaction however was derived through close multidisciplinary team working. The intertwining of their therapeutic work occurred to such an extent that AHPs resisted defining a distinct disciplinary role and instead discussed their work as entirely interdisciplinary. AHPs repeatedly identified the dilemmas faced by families and discussed the tensions in their own thinking as their clinical objectivity clashed with their own sense of and feelings about the patients’ level of consciousness. They highlighted concerns about the ethics of medical ‘advancements’ and life-sustaining treatments and expressed uneasiness and uncertainty regarding their role in treatment withdrawal situations. Pilot workshops are being developed around these key issues and e-learning resources to support needs for training will be ready for dissemination at conference.
Discussion and conclusions:
Families and allied healthcare professionals can question patients' level of awareness and the rationale of treatments. However, when families expect ongoing therapeutic input for their relative, or conversely see them as ‘irretrievably gone’, this sits in tension with AHP’s clinical reasoning or at times, their relentless striving to capture signs of awareness and for ‘rehabilitation’. Ethical, legal, social and clinical dilemmas collide in the care of PDOC patients, challenging much contemporary clinical practice and pre-registration education. This study and the developing multimedia learning resource demonstrate the interplay between these elements and the scope for CPD support.

Impact and implications:
The research is developing a new multi-media resource to improve understandings of caring for PDOC patients/their families and related ethical/social/clinical issues. The resource builds on Kitzinger and Kitzinger’s successful healthtalk.org module for families and has buy-in from the core AHP Professional Bodies. Our aim is that this AHP-facing resource will have high accessibility, MDT value and impact on personal, practice and curricula development.

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