

Creating a 'Healthtalk' web-based resource on family experiences of disorders of consciousness

Grant holders: Prof Jenny Kitinger (Cardiff University), Prof Celia Kitinger (University of York) and Prof Sue Zeibland (Oxford University)

Project overview

This project involved collecting and analysing video-recorded in-depth interviews with 22 family members of severely brain-injured patient, exploring people's experiences of having a son, daughter, sibling, partner, parent or other relative in a vegetative or minimally conscious state. The new video-recorded interviews were added to an already-existing data set of audio-recorded interviews (partially funded by a Wellcome grant) making 65 family interviewees in total.

Our findings showed: (a) the isolation and lack of information and support experienced by some families; (b) lack of clarity from some family members about their own role in decision-making and (c) a lack of awareness about the role of the patient's prior expressed wishes, values and beliefs. The research suggested a need for improvements in communication, decision-making processes and compliance with the Mental Capacity Act 2005. Our findings also highlighted some of the complex emotional and social challenges confronted by families, and the lack of accurate cultural representation of prolonged coma-like states.

We translated this research into a multi-media, on-line, support and training resource developed to address the needs identified and to help families to contribute to decision-making about their relative, backed up by reliable medical and legal information. It was also designed to be of use to practitioners in the field.

The resource is in the form of a section for the award-winning charity website healthtalk.org.uk – a site which 'provides free, reliable information about health issues, by sharing people's real-life experiences' and covers over 80 different health conditions. Our new section focuses on family experiences of vegetative and minimally conscious states. Information is presented under 39 topic headings, grouped under key themes (e.g. 'Impact on family', 'Decision-making about medical treatments' etc). Each topic page includes a summary of key issues illustrated with film clips from the interviews (250 clips in total), alongside clinical and legal information. This resource provides support for families, a tool to facilitate good clinician-family communication, and information for professional training, clinical guidelines and legal/policy discussion. The researchers launched the new resource at a conference for practitioners, ran training events and are developing ongoing publications (see www.cdac.org.uk).