Brain Injury Case Managers' Experience of Mental Capacity and the UK's Mental Capacity Act: Supporting Decision Making

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Introduction and Aims

The UK’s Mental Capacity Act (MCA) provides a legal framework, designed to empower and protect individuals who are adjudged as lacking the mental capacity to take specific decisions. Limited research exists on potential limitations of the application of the MCA for individuals with an acquired brain injury (ABI). Hidden effects of ABI can have a detrimental impact on individuals’ ability to engage in decision-making. An assessment of an individual’s abilities needs to be informed by their cognitive, executive and behavioural issues challenges that impact upon decision-making. Brain Injury Case Managers (BICMs) work closely with individuals with ABI, assessing needs, structuring rehabilitation interventions and providing support, and have significant experience of clients with impairments to decision making. The aim of this research was to gain understanding of BICMs’ experiences and knowledge of the impact of ABI upon decision making and mental capacity. It is hoped this aim will support improvements in the services offered to individuals with ABI.

Methods

93 BICM’s responded to an online questionnaire containing multiple choice questions, 4 and 5-point Likert Scales and free text comment boxes. 12 BICM’s were interviewed by telephone. Data were analysed using a mixed thematic approach using deductive and inductive methods, as described by Braun & Clarke (2006). An initial deductive framework was applied to the data in order to identify pre-constructed themes based on the conventional content analysis conducted from the questionnaires.

Results

Theme 1: Disagreements with other professionals
The quantitative data identified that 92% of BICMs reported having disagreements with other professionals over capacity of their clients to make decisions. BICMs identified five main reasons for disagreements with professionals:
1. a lack of knowledge of ABI by non-specialist professionals
2. “false” appearances of capacity by individuals who sound more competent in discussion than in practice
3. lack of collaboration by assessors with family members or involved professionals
4. Flawed “question and answer” method of assessment
5. professionals having their own agenda

Theme 2: Hidden disabilities
Participants explained that many non-specialist assessors do not understand the hidden disabilities associated with ABI, leading to clients being deemed, wrongly, to have capacity. Specifically, case managers identified that a lack of knowledge of executive dysfunction, lack of insight, initiation problems, difficulties with idea generation and communication difficulties, the impact of mood and environment on decision-making and, fluctuations in capacity can lead to inappropriate assumptions of capacity.

Theme 3: Vulnerability in the community
Participants noted concerns that non-ABI-specialists often failed to appreciate the level of vulnerability of ABI survivors in the community. In particular with regards:
1. Financial abuse by family members and others

Results continued

Theme 3 contd:
1. Increased vulnerability to substance misuse and criminal activity
2. Increased risk of homelessness or of living in insanitary conditions, of sexual vulnerability and engagement in prostitution
3. Slowed/delayed maturation when the ABI took place in childhood

Theme 4: Issues with the MCA
Participants noted difficulties that participants raised about the use of the MCA with clients with ABI. In particular:
1. What constitutes an unwise but capacitous decision?
2. Flawed assessment processes which are office based, depend upon verbal output and are not functional in nature
3. Lack of underpinning knowledge of executive impairment and insight issues
4. A lack of clarity in the MCA guidance

Conclusion

Failure to train staff about common (if hidden and complex) ABI sequela leads to flawed processes of assessment, conflict with regards the outcomes of assessment and unnecessarily increased risks to individuals.

Improved training of generalist staff will reduce theses risks, promote interdisciplinary working and enable more accurate assessments to be undertaken.