

British Sociological Association: Phil Strong Memorial Prize

What is the Relationship between Acquired Brain Injury (ABI), Identity and Rehabilitation?

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Background

Whilst managing an Acquired Brain Injury (ABI) rehabilitation centre I began to question why the very resources set up to assist individuals seem to be organised in such a way that those that appear most in need can be the very people at risk of exclusion, both in terms of accessing services or gaining successful rehabilitation outcomes. Specifically, it appears that the “objective” biomedical framework used to assess and provide for ABI survivors may be incomplete as a method for ensuring the system helps those most in need. In order to access the position of “patient,” the individual is required to perform as patient in a manner which is consistent to one that is expected. Brain injury often hinders the capacity to participate in social interactions fully due to losing important behaviours and social skills such as interpreting social cues or a lack of understanding subtleties such as tone of voice or body language. Accessing and participation in rehabilitation after acquired brain injury often requires a great deal of identity work through interaction; an inability to participate fully may have a significant impact on accessing as well as the success of the rehabilitation process.

Research Questions

The aim of this ongoing research is to explore ABI survivor experiences of rehabilitation in terms of access, participation, inclusion and identity-work. The objective is to hold these against analysis of biomedical and other discourses of ABI and the structure and delivery of ABI rehabilitation provision. The longer term objective is to use the study’s findings to inform ABI services to enable better provision. Specifically, I wish to understand:

- How does acquired brain injury and processes and practices of rehabilitation interact with identity work and development of an individual’s sense of self?
- What role do external agencies and other actors (e.g. family members, health care professionals etc) play in developing this relationship between ABI and identity?
- How does this inform us with regard to a) the ways in which brain damage and its effects are usually understood in mainstream biomedical discourse b) how ABI rehabilitation is organised and c) the implications for the ABI survivor?

Methods

Data generation for this research has involved analysis of discourses on ABI, including in neurophysiology and health and social policy. These are considered alongside the following methods:

- Questionnaires to establish services used in ABI rehabilitation and attitudes towards them. These are being completed by survivors at different stages of their rehabilitation. This can range from those who have been in the rehabilitation hospital for only a couple of days to those who have been post injury over 20 years.
- Non-participant observations of rehabilitation practices, goal planning meetings and clinics to observe interactions within the rehabilitation setting. This includes observations in the acute setting of the hospital, on the wards at a specialist rehabilitation hospital, attending multi disciplinary team meetings, staff meetings, occupational therapy sessions, physiotherapy sessions and community brain injury team groups and classes.
- Semi – structured Interviews with brain injury survivors, family members and health care professionals to explore attitudes and assumptions from the observations further.

This design will enable multiple perspectives on the issues under study together with cross-checks and balances in analysis as data generated by each method informs the others.

Implications

This research draws together an Interactionist perspective on identity and institutional processes with critique of biomedical discourse and health care organisation and practice. It hopes to make a theoretical contribution to the sociology of biomedicine and health care organisation, as well as work which investigates the body, identity and disability, particularly hidden disabilities such as those connected with brain injuries. The practical implications of this research would inform decision makers as to what extent identity work and participation underpins the success of the overall rehabilitation process.

Progress to date

After gaining NHS ethical approval and having completed an extended literature review I am currently half way through data collection. Data collection began in February after an initial pilot study. Questionnaires were distributed through a community brain injury team and through a charity that provides services for acquired brain injury survivors and their families. However, these have continued to be distributed through different avenues as field work has continued.

Initially I focussed my observations on the rehabilitation wards of the hospital. From there, I was able to follow interesting leads and expand my research to include other departments and meetings. I hope to begin interviews very soon where I will be speaking to acquired brain injury survivors, family members and carers and health care professionals.

Activities supported by the prize

I am incredibly grateful to the British Sociological Association (Medical Sociology Group) for awarding me the Phil Strong Memorial Prize in 2012. It has been exceptionally valuable as it has provided me with a vast range of opportunities to attend national conferences, training and to take advantage of networking opportunities.

This has included attending the training course “Doing research inclusively, doing research well,” where my eyes were opened to new insights and ideas of working with and alongside disabled groups as part of your research; elements of which I will be directly applying to my research.

I also attended the excellent conference “Identity after Brain Injury,” organised by the Oliver Langwell Centre. It was particularly beneficial to attend this conference as three of the key speakers had travelled from Australia and many of their ideas and research has provided central themes of my literature review and analysis.

I was also able to attend the BSA annual conference this year which provided me not only with superb networking opportunities with like minded colleagues, but also the opportunity to attend some extremely fascinating presentations, many of which were useful and directly applicable for consideration in my own work.

Later this year I look forward to attending a conference entitled “Narrative approaches to neurological conditions,” and I am lucky enough to be presenting at the BSA Med Soc Conference, both of which will undoubtedly be both enjoyable and highly informative for my research.

Finally, my research was assisted greatly by the Phil Strong Memorial Prize as it could cover the extensive cost of conducting fieldwork including the creation and printing of a large variety of participant information sheets and consent forms, required when hoping to recruit people with a wide array of different needs, carers and health care professionals. This has meant that it was much easier for a greater diversity of people to access and take part in the research; something which I feel is core to the success of the project.