Connections between choice, control and occupational identity for people with spinal cord or brain injury

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Introduction: In Western societies people assume that they will have choice and control about how they spend their life and the occupations they engage in. The implications of a spinal cord injury or a brain injury on exerting agency through choice and control have received little academic attention.

Objective: The aim of this qualitative study was to explore concepts of choice and control from the perspective of the person with brain injury or spinal cord injury and their family members.

Method: A qualitative descriptive research design was used with data collected through semi-structured in-depth interviews typically lasting 2 hours or more. Participants were recruited through services that provide supports to people at home. Data were analysed thematically.

Results: Three adults with spinal cord injury, five with brain injury and two with both plus four carers participated in the study. Having a sense of control in their own lives was important as a lack of control led to experiences of frustration and anger. Feeling out of control was characterised by a disconnect between who they were and the opportunities and capabilities available to them now. They had to work at reclaiming identity or reshaping the old identity through occupational engagement. Adjusting to the new set of capacities was an ongoing process and involved making choices about the occupations that sustained them and connected them to others.

Conclusion: The strong nexus between occupational identity, choice and control and occupational engagement provides direction for a focus on reclaiming and reshaping identity during recovery.