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The lived experience of people with brain injury living in long term care facilities: specific implications for social isolation

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ABSTRACT

Introduction. The provision of appropriate long term care facilities for people with acquired brain injury is a portentous issue internationally. There is a global lack of long term care facilities for people with acquired brain injury and they are often placed in facilities for the physically disabled or the elderly. It is unclear whether these facilities are suitable and what effect they may have on well-being and social isolation.

Aim. This interpretive phenomenological study explored how adults with acquired brain injury experience living in such long term care facilities. Additionally, it described how such living arrangements impact on social isolation, a particularly devastating psychosocial consequence of acquired brain injury.

Method. One-on-one, semi-structured interviews were conducted with seven adults who had acquired a brain injury. Each participant had been living in a long term care facility for at least one year. They were asked questions related to their general lived experience as well as specific questions to explore their experience of social isolation.

Findings. Thematic content analysis of the interview data led to the following five categories of themes: overall evaluations (guarded approval, and disapproval); general lived experience (autonomy, choice, freedom, burden, boredom, and basic needs); social isolation (loneliness, companionship, and belonging); sources of isolation (living with the disabled, different disability, age differences, pets, and facility setup); and sources of well-being (positivity, and meaning). The main findings were that the general lived experience of people with ABI was mainly negative. The facilities generally met only basic needs and seldom met higher level psychological needs. Social isolation was

commonly reported among residents with ABI in long term care facilities and was linked to age differences and having a brain injury in a facility geared for people with other disabilities. The findings were understood in relation to Bronfenbrenner's ecological systems theory and Maslow's hierarchy of needs.

Conclusions. The findings of this study contribute towards filling a theoretical gap in understanding the lived experience of people with ABI in long term care facilities and how this contributes to social isolation. The findings have potential value to family members of people with acquired brain injury considering various living arrangement options. They can also be useful for long term care facilities housing people with brain injury to make changes that may result in greater well-being of their residents.

Keywords. Acquired Brain Injury, Adults, Long Term Care Facility, Social Isolation, Well-Being