A Place to Call My Own – Understanding the Experience of Home for Young People with Disabilities Living in Long-Term Residential Care

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**Abstract**

This exploratory study was based on a new model of residential care that was designed specifically to provide a home-like environment to young people with severe disabilities and complex chronic healthcare needs (i.e., Multiple Sclerosis (MS) and Acquired Brain Injury (ABI)) to allow them a more appropriate and dignified lifestyle. In 2006, there was an estimated 6,500 people with disabilities under 65 years of age living in residential aged care in Australia (Australian Bureau of Statistics; ABS, 2008). These living environments have been found to be inappropriate and inadequate for young people with disabilities (Cameron et al., 2001; Winkler et al., 2006), particularly given that they may not require 24-hour nursing care.

It is important to consider the nature of home in more detail when thinking about living environments for marginalised groups of people (e.g. people with disabilities), especially as it has been found that the nature of home can impact on the quality of life (Annison, 2000). In order to understand the meaning of “home” for a group of people who live within a particular environment, it is essential that we seek to understand the perceptions of those individuals. In order to provide optimal services, the subjective experience needs to be heard and understood.

The current research was conducted in accordance with Interpretative Phenomenological Analysis (IPA). This method allowed the research to retain the voice of the service users at the forefront and ensured that their views remained paramount. Multiple domains of home, as they were experienced over time, were examined through a series of semi-structured personal interviews conducted with seven residents with either MS or ABI at their residential care setting. The study aimed to understand the residents’ ‘lived experience’ within the residential apartments, and specifically to answer the following questions:
1) How do residents experience home within a residential care setting? and;
2) What influences their sense of home?

Two core themes emerged from the data, namely *Perceived Qualities of Place* and *Identity*. These themes seemed to be inextricably interlinked with each other, and to the extent that they overlapped, a sense of *Home* was created. These two core themes were influenced by a core process that took place for this group of residents, namely, *Deconstruction and Reconstruction* of their sense of home. The core process was influenced by the theme of *Connections*. *Connections* was constructed from three sub-themes: *Interactions with the physical environment*, *Relationships with family and friends*, and *Relationships with staff*. These themes influenced the way in which deconstruction and reconstruction occurred as well as the nature of identity and the perception of place.

The current study produced four major findings. First, connections appeared to be paramount to the development of a sense of home having an influence in multiple ways. Although previous research has linked the importance of social relationships to general well-being and quality of life, the current study has found that these perceptions of relationships also impacted on the participants’ sense of home. Positive relationships, particularly with staff, created a sense of belonging and comfort that assisted in the reconstruction of their sense of home. Interactions between participants and family were especially critical to the participants’ sense of home.

Second, the sense of home emerged as an important concept that is comparative, temporal, tenuous and vulnerable to deconstruction, and needs to be considered by service providers. Deconstruction appeared to take place more rapidly than reconstruction, highlighting the importance of prevention. Home was a vulnerable
construct that could be easily destroyed through negative interactions with the physical environment and/or interactions with others. Third, the construct of home was intimately linked to the sense of identity. It is important for service providers to appreciate these linkages and respond accordingly. This type of information is rarely used in relation to the design and provision of services in environments that provide long-term care for young people with chronic and complex health needs. Finally, this study has built a theory that shows the link between the existing models of home proposed by Despres (1991). Although these models have been proposed as four distinct conceptual approaches to home, this study has highlighted that they do not operate in isolation. Instead, home is a multi-dimensional construct that is influenced by many factors. It can be influenced by connections, perceived qualities of place and identity. However, identity needs to be congruent with a sense of belonging. Identity needs to be a construct that becomes more focal in service delivery.
Originality of Thesis

I hereby certify that this work has not previously been submitted for a degree or diploma in any university. To the best of my knowledge and belief, the thesis contains no material previously published or written by another person except where due reference is made in the thesis itself.

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Hayley Danielle Quinn
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