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Beyond the text: Voices of self in aphasia

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ABSTRACT

This thesis is about the stories people with aphasia tell about self and identity. It is also a story about the process of research with people with aphasia. It is about narrative and self-construction and it is in itself a narrative. While there has been much discussion about the need for interventions which take into account self and identity in aphasia and innovative pioneering work on therapies addressing identity, there is, however, still little specific reported research in aphasiology that addresses these issues. This applied project sought to further understand the impact of aphasia on the construction of self by exploring self and identity using a narrative approach and using a more participatory approach to research. It was grounded in narrative and relational theory and this led to exploring self and identity through life stories. Eight people with aphasia took part in a life story interview. These were analysed using the voice centred relational method which culminated in eight interpretive narratives. The main findings of this qualitative inquiry were support for the notion that biographical disruption is not the only response to aphasia, support for a relational approach to self and identity and support for inclusive research practices in aphasia research. The strengths and limitations of the project were examined and implications for research and practice were developed.

Dedicated to Marcus Bevin

02.06.1970 – 04.05.2000



With permission of the artist, Terry McKenna, Hawke's Bay

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A circular arrangement of names, likely representing a group of friends. The names are written in a circular path, following the curve of the circle. The names are: Mary Lui, Lauren Sleeman, Brigitte Larkins, Gwenda Kingsland, Judy Simpson, Robyn Richardson, Richard Volz, and Richard Fergusson.

My late mother whose love of learning and role as storyteller in our family has greatly influenced this work.

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EPIGRAPH

The outcome is a demonstration of knowledge as a subjective relational enterprise, always created and recreated between individuals rather than in isolation.

Ruthellen Josselson and Amia Lieblich, 2001, p.285.

READERS' GUIDE

I entered this process with a background in speech-language therapy and a particular interest in aphasia. I had already completed an Honours project in psychology with people with aphasia using a narrative approach and I felt that this project could be broadened to consider self and identity in aphasia. I assumed that this would be a very straightforward process. However, the time of doctoral exploration has exposed me to many approaches to self and identity and to research philosophies in the human sciences. What appears in print, here and now, will never represent the process as it occurred. It is laid out in a linear way, chapter by chapter, but it will not capture the circular and sometimes serendipitous nature of the research process and of the discoveries. I have formed this text to achieve a piece of work that is intelligible. In developing a methodology to support people with aphasia to tell about self and identity, I am greatly influenced by the subjective and relational nature of knowledge creation (Josselson & Lieblich, 2001). I consider the reading of this document to also be a relational activity. However the conversations are constrained by time, by the distance between text and meaning, and by the silence of the conversations that may be had with the participants as the stories of this research project are read.

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