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**End-of-life care for elderly within aged residential care
facilities:
Views and perceptions from their next-of-kin**

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requirements for the degree of

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with an
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Dedication

To my family, best friends and Beau, with love.

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To my parents, thank you for everything. I could not have got through this year, let alone the last four years, without the phone calls, the words of encouragement, money (and more money), all the hugs, food parcels and the countless other things that you both did, which were never taken for granted or will ever be forgotten. I couldn't have done it without either of you. Thank you.

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Abstract

By 2051, the number of people aged 65 and over will account for 1.33 million of New Zealand's population (Statistics New Zealand, 2006). This has created attention as to what current practices and facilities are available to this cohort of New Zealand's population, and what more we can do to make sure we provide adequate services. Limited literature provides insight into what takes place within aged-residential care (ARC) facilities during end-of-life (EoL), especially within New Zealand, even though approximately 40% of those aged 85 and above in New Zealand do already die in ARC facilities (Gibb, 2014). This project investigates the experiences and perceptions of EoL care for elderly within ARC facilities, from the perspective of their next-of-kin (NoK)/family member. Eleven NoK/family members who experienced the passing of their elderly relative within an ARC facility, were recruited as participants. The study used a qualitative method with semi-structured interviews. The interviews were then transcribed, and analysed using thematic analysis on Dedoose, a web-based application, to draw themes from the data. Questions were kept broad and open, so that participants would be able to relay their story as openly as possible without interruptions. The findings are presented under ten major themes which includes; the occurrence of a 'crisis' for their elderly relative, the responsibility and adjustment to the role of NoK, changes in the elderly relative's personality, the effort and kindness experienced within the ARC facility, reflection of the conversations participants had with their elderly relative, the multi-dimensional effect of pain, the process of letting go and

anticipatory grief, expectations of the 'good death', the influence family has on the experience of being the responsible NoK/family member, and the participants experience of grief while managing the funeral. The interpretation of the results highlighted the extended period that is considered to be EoL and its care within an ARC facility, as opposed to only the last few days before death. This research enables an insight of what entails EoL care within the environment of the ARC facility, as well as allowing the NoK/family member to share the story of their experience.

Preface

I am at work, standing by the nurse's station in the hospital wing of the ARC facility in Gisborne, New Zealand, where I was working as a physiotherapy aide. I've been told that *Jean* is now under palliative care and no longer requires her daily physiotherapy sessions. I have spent the last six months nearly every day for at least 20 minutes with *Jean* helping her move and stretch her limbs which were now no longer under her control, she had motor neuron disease. During those sessions, we would talk. She would tell me about how she was feeling and her frustrations with her disease. She had told me personal details of her life, all about her adopted children; I would get regular updates on them. She told me all about her husband, how they first met, their life together, what he did and how he had died. She told me all about her life, her first job, her jobs following that. How she was originally from Scotland, still having a bit of the accent to prove it. I'll never forget *Jean's* face when she said to me one day, "I don't feel like myself today, I don't feel like myself anymore at all". I realised then how much she was suffering both mentally, physically and emotionally. And now this woman who I had built this relationship with, who had shared so much with me was dying and her palliative care meant that no visitors were allowed. In the end I didn't get to say goodbye to *Jean*, she died a few days later, and to this day I still think of her often.

This was the moment that grabbed me. I knew I wanted to find out more; what had gone on behind that closed door for *Jean*? Had her being in that room catered to her wishes? Had she been given all that she needed in order to pass

peacefully? Who made these rules? Nobody told me, nobody asked questions. What if that meant that nobody had asked *Jean* what she had wanted?

A friend of mine said to me earlier this year; we all die someday, it's just a matter of when and how. It is the 'how' that I am interested in, and it is the 'how' that has lead me to conduct the following research.

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