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I live my life according to the pain

The Lived Experience of Chronic Pain in Adults
Living in Rural Queensland

Thesis submitted by

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For the Doctor of Philosophy

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I declare that this thesis is my own work and has not been submitted in any form for another degree or diploma at any university or other institution of tertiary education. Information derived from the published or unpublished work of others has been acknowledged in the text and a list of references is provided.

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Statement of the contribution of others

This thesis has been made possible through the support of many people, as follows:

Supervisors:

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Professor Kim Usher, School of Nursing, Midwifery and Nutrition, James Cook University

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Conventions used within the thesis

In the presentation and discussion of the analysis of the participant's transcripts (Chapters 6 through 9), excerpts from the transcripts were presented. The following conventions were used to acknowledge these:

Pseudonyms were assigned to each participant to preserve their anonymity.

All quotes were presented in italics

Identifying information such as the name of the town, or of an individual was removed and replaced with a generic description within a bracket in normal font.

Pauses within a quote are denoted by a dash (-).

Comments about the demeanor of the participant at that time (or other relevant information such as hesitation, tears) were also placed in brackets and presented in normal font within the italicized quote.

Each quote was ascribed to the participant, and the page and line numbers are indicated in brackets following each quote.

Three dots (...) indicate that words were left out of a quote, usually for brevity's sake.

An example of these conventions:

Gary is proud of his past accomplishments: *When we first moved here we had a beautiful veggie garden. - We sat down one night there and we had nine different veggies on our plate that we'd grown off the land and we used to breed our own dairy goats, have, their own dairy fed milk and breed our own pigs and we used to feed the dairy goat milk to the*

piglets and have them on grain ration ... And the man over at (Name) Pig Factory here in (Town) said they were the best piglets he'd ever seen. (p19, L642-648).

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Abstract

Chronic pain is ubiquitous in people all over the world. Australia is no exception, with up to a fifth of the population claiming that they have experienced chronic pain over the past year. Chronic pain has been explored in a multitude of studies over the past century, with the majority being quantitative studies aimed at understanding the patho-physiological aspects of pain, or the psychological/behavioural management issues. More recently, qualitative studies have been undertaken to begin to understand the individual person's perspective on chronic pain in an attempt to inform health care professionals so they can better assist those they care for to live with their pain. In this study, living in rural areas provided a contextual background to living with chronic pain. Geographical distance often imposes restrictions on the health care services that are available, and these restrictions increase the impact of living with chronic pain in a rural area. The aim of this study was to answer the question: What is it like to live with chronic pain in a rural area of Queensland? An interpretive study using van Manen's (1997) approach to hermeneutic phenomenology explored the experiences of seven adults living with chronic pain in rural areas of Queensland. Hermeneutic phenomenology was chosen as the underlying philosophy for this study. Conversational interviews were conducted with adults between the ages of 23 and 55 years in small towns in several parts of Queensland. The interviews were transcribed verbatim, and the resulting transcripts analysed using van Manen's (1997) analytic approach. Several sub-themes emerged and fell into the four existential concepts or essences described by van Manen: spatiality, temporality, corporeality and relationality.

Spatiality - 'The country style of life' included four sub-themes. 'Distance is the biggest problem' spoke of geographical distance to sophisticated health care that was found to be a problem, both in additional physical discomfort during travel, and in personal and financial costs. As well, a diminution or lack of health care services in country areas was apparent. 'Living in a small town' assists the person to deal with their chronic pain quietly and privately. The 'Safety and comfort of living in a small town' revolved around the trust and the relationships participants developed with community members over the

years. ‘Retreating to private spaces’ permitted disengagement from others, both mentally and physically, fostering relaxation and reducing pain.

Temporality - ‘This is my life now’, was constituted by four sub-themes. The temporal discontinuity between ‘what was’ and ‘what is now’ was explored in ‘I am different to what I was’. Grief was endured because of these changes and lives and identities were fragmented. As part of this experience, participants also attempted to retrieve a sense of self. ‘This is my life now’ told of the endurance and acceptance of the pain, and the recognition that the pain would be a constant companion. ‘Things will not improve’ extended this theme with reference to uncertainty, maintaining independence and the value of distraction. ‘Pace of life in the country’ demonstrated some of the positive factors that assisted with living with chronic pain in a rural area – quiet, fewer interactions and the slower rhythm of the country lifestyle.

Corporeality - ‘Some days are better than others’ included four sub-themes. ‘Pain is invisible – but it really does hurt’, related the psychological burden of not being able to actually demonstrate the hurt, and feeling like a fraud. ‘Difficult to name – all there is is the pain’ emphasised participants’ inability to articulate pain and the increased necessity for health care professionals to be astute in their assessment of the person living with chronic pain. ‘What’s wrong? What’s wrong? – the meaning of pain’ tells of making sense of the pain for peace of mind and giving it a name so as to legitimize it. ‘Balancing the pain’ brought forth the experience of persisting versus pacing of activities to reduce the effects of the pain, being aware of personal limitations, use of analgesia, and distraction to cope with the pain. ‘Mind over matter – the scary mental side of things’ tells of believing in their own body rather than worrying that they were losing their mind, the effects of mind over the somatic body and of depression, of memory loss and of cognitive dysfunction.

Relationality - ‘Relationships in Pain’ included four sub-themes. ‘Silence on pain’ relates stoicism, reticence about the pain, independence and perseverance. ‘Privacy – you don’t have to look and act happy’ protects as it keeps the pain from others. ‘Support and

comfort' from family, friends, community, animal companions and God helps cope with the pain. Good, solid family relationships empower, but as the circle widens, support and comfort became less apparent. 'He just doesn't understand' paints a telling story of participants' relationships with health care professionals. Inadequate care and difficult interactions were often experienced. As a consequence, traveling great distances to consult compassionate doctors occurred, although nurses were seldom mentioned.

Several key recommendations arose from the findings of this study. In respect to education, suggestions for future curricula development to help health care professionals to learn to provide more empathetic assistance to people living with chronic pain were made. In respect to clinical practice, the development more effective strategies to assist people living with chronic pain is suggested. Advanced practice nurses with an interest in, and further studies in assessing and managing chronic pain are needed in rural areas, both as practitioners and as mentors to other nurses. Adoption of standardised pain management strategies by professional organisations, and especially dissemination of these through their rural networks would assist health care professionals to practice in a consistent and contemporary way. The importance of aggressive and thorough pain assessment of people seeking health care advice in rural areas is an important finding in this study and should be utilized by all first-contact health care professionals.

In reference to research, specific recommendations were made. Since pain assessment and pain management are currently taught in the health care disciplines and have been for at least a couple of decades (personal experience), research projects are urgently needed to determine why this knowledge has not translated into practice in order to address the indifference, lack of knowledge and the stigma that people living with chronic pain face from the professionals who are supposed to assist them. Further qualitative studies are recommended to increase the scope of knowledge of the experiences of people living with chronic pain in rural areas.

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