

Dying to Research: An Autoethnographic Exploration of Researching Māori and Whānau Experiences of End-of-Life Care

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Abstract

The authors critically reflect on the autoethnographic process involved in navigating a smooth pathway towards investigating dying, death and bereavement for Māori whānau (families) in a way that supports and gives voice to their experience. This study, based in the Māori & Psychology Research Unit at The University of Waikato, is supported by a Health Research Council Erihapeti Rehu-Murchie Career Development Award. It explores the “end-of-life” journeys of Māori and their whānau in South Auckland and Waikato, through the dying process and subsequent challenges of bereavement. The researcher’s journey from novice to someone fully enmeshed in the struggles and triumphs of conducting research with Māori is examined. There is reflection on the challenges and issues that have emerged since settling on this research topic. These include ethical concerns, and the processes and outcomes associated with negotiating tensions between a shifting academic objectivity and the development of a methodology requiring subjective reflexivity.

Keywords

indigenous, autoethnography, palliative care, Māori, whānau

Introduction

The Reluctant Autoethnographic “Self”

What is autoethnography?

Pieces of thoughts—words, ideas, meanderings, ghosts

Echoes of ghosts, plaited together, randomly

A sense of needing to weave thoughts into

A clean, artistically crafted whāriki—a story.

To tell a story perhaps?

Or to convey a meaningful moment on the way to

Becoming a conveyer of knowledge—a knower?

Am I a scribe—a servant—a facilitator of others’ stories?

Re-enacted through my disjointed, misbehaved words

Dis-membered accounts—non-linear passages

(recorded on different pages of different journals and written at different times in different places?).

This writing—non-trajectory focused, “in the moment” of my jumbled, disorderly world, where the words on the page should appear full bodied and full of promise—

Strong limbs and spine

Eloquently delivered through long slender fingers

Knowing palms, like all seeing eyes.

But instead, I feel as though I am in the “limbo space”

Caught between the empty space above the line and below

Not knowing, not seeing, not thinking, not feeling enough
of anything.
What is “enough” and when do I *know*, I know?
(Journal entry, February, 2010).

As a novice ethnographer utilising autoethnography, I explore in this paper the setting up of the Kia Ngawari: Investigating Palliative Care of Māori and Their Whānau Project. Investigating end-of-life experiences of Māori (New Zealand’s indigenous population) and their whānau, this qualitative study includes 30 face-to-face interviews and nine case studies, and relies on whānau to share their stories. Engaging with autoethnography revealed a tension. In this paper I explore the struggle between being positioned as an impartial observer and my natural inclination as a Māori researcher to be empathetically immersed in the research process. I knew I needed to be open and transparent with participants, but my academic and clinical training (I was an ACC-registered sexual abuse clinician from 1998–2007) taught me to be an impartial observer of other peoples’ lives. The opening quotation from my journal reveals I was challenged by the introspection autoethnographic reflexivity requires. I felt reluctant to use myself as a research “subject”. I asked myself, “Ethically, is it possible to be open, truthful *and* objective?”

Background

It is assumed that Māori prefer to die at home, with the support of whānau; however, research on their actual experiences of dying, death and bereavement has yet to be undertaken (Ngata, 2005). Although Māori have a wealth of information concerning dying, these experiences remain largely anecdotal. Qualitative research will most likely capture the experiences in a methodologically rigorous way, and will enable an in-depth analysis of dying, death and bereavement (Buckle, Corbin Dwyer & Jackson, 2009). A better understanding of Māori needs will inform whānau about what is required at this time. The information will also increase the capacity and capability of the health workforce to support quality end-of-life care for Māori (Ministry of Health, 2001; Schwass, 2005), as it is known that Māori—the largest minority group—underutilise available resources and do not access palliative-care services as frequently as Pākehā (New Zealand white majority population), (Muircroft, McKimm, William & MacLeod, 2010). Papaarangi Reid (2005, p. 45) states:

Māori whānau often want to provide care for their relations who are terminally ill or have high needs—either at home, or in a hospital or hospice. But there are many barriers still in the way of this, in the kind of state support provided, and in the services in hospitals or hospices. We have to improve the palliative care services themselves, and the flexibility of how and where the services are provided. And we have to ensure that whānau are supported in their care for family members. That’s not only providing real choice—it’s also meeting needs and rights.

Autoethnography

Auto (self), ethno (sociocultural), and graphy (study), can be defined as “highly personalised accounts that draw upon the experience of the author/researcher for the purposes of extending sociological understanding” (Sparkes, 2000, p. 21). By taking into account the phenomenological world of the researcher and the culture of dying, autoethnographical research provides me with an opportunity to gain a deeper understanding of those who are dying and their whānau. It provides an opportunity to explore my “lived experiences” and the abstract conversations I engage in, in relation to the research process (Ballard, 2009, p. 480). Autoethnography provides me with a way of getting to know myself as a researcher, highlighting areas of weakness or vulnerability, and revealing my strengths. These insights raise awareness of the level of honesty and truthfulness needed to strengthen the quality of my engagement, analysis and writing.

Ellis and Bochner (2006, p. 433) describe autoethnography as a genre of writing that “shows struggle, passion, embodied life, and the collaborative creation of sense-making in situations in which people have to cope with dire circumstances and loss of meaning. Autoethnography wants the reader to care, to feel, to empathize, and to do something, to act.” For Ballard (2009, p. 480), autoethnography is deeply linked to communication ethics:

Autoethnography is able to show how ethics exist in indecision, how struggles in the midst of phenomenological moments are outside of language, and how communication gives us life through acts of acknowledgement. If you resonate with the story and the calls of conscience, ethical dilemmas, aporias, and communicative moments that define who we are, then you have gone into the heart of communication ethics.

Ellis's (1993) autoethnographic account of her brother's sudden death by air accident provides insight into early autoethnographic "truth"-telling. "'True' stories such as this fit in the space between fiction and social science, joining ethnographic and literary writing, and auto-biographical and sociological understanding" (Ellis, 1993, p. 711). Ellis states the goal of her autoethnographic writing is to:

reposition the reader vis a vis authors of texts of social science by acknowledging potential for optional readings and encouraging readers to "experience an experience" that can reveal not only how it was for me, but how it could be or once was for them. This experimental form permits researchers and readers to acknowledge and give voice to their own emotional experiences and encourages ethnographic subjects (co-authors) to reclaim and write their own lives. (2003, p. 711)

Auto(no)graphy: Subject/Object Tensions

I encountered two barriers to employing autoethnography. The first concerned my vulnerability engaging my own subjectivity. The reflexive process challenged me to be transparent about my involvement and to share something of my Self within the research process. Going inside my Self was outside my comfort zone. Objectivity left me feeling disembodied. I had been trained to be "in my head"—not my heart. How do I do this research without feeling like a deathmonger—a person who waits for death, watches death unfolding, scrutinises death and its hostages? I felt confused by this academic, objective stance and my natural desire to be fully integrated (emotionally, physically and spiritually) in the research process. How could I be a *detached* observer when my cultural inclination was to feel and behave in a *connected* way?

The second issue involved my academic training, which had taught me how to be invisible within textual representations. As an independent mental health research contractor, I had previously designed and carried out research with a variety of people, including tangata whaiora (Māori mental health consumers), mainstream mental health service users, victim survivors of sexual violation and New Zealand health professionals. However, I did not reference my Self in the design, fieldwork, analysis or textual representations. What I personally experienced remained outside this process—I was essentially invisible. I had always struggled to balance my empathetic style of engagement with being an impartial researcher. Autoethnography brought this tension to the surface.

Making my Self visible within the fabric and text of the research process brought a risk of representation. This methodology called into account claims to "validity and trustworthiness", and required them to be de-centred (Lather, 1995). I felt a sense of uncertainty—writing my Self into the research was not going to be easy. My desire to be fully involved in the research process was juxtaposed with an academic imperative to be impartial and objective. I felt frustrated by these dichotomised standpoints, which behaved more like wrestling conjoined twins. I had spent so long removing traces of myself from my research projects that I was now struggling to write my Self in.

The whakataukī (proverb), "The kūmara doesn't talk about how sweet it is", pointed to the disjuncture between myself as an autoethnographic subject and as an objective researcher. In previous research, whether it used a mainstream methodology or a kaupapa Māori (Māori-centred) framework (Smith, 1999), the lens and focus were always on other participants; my role was to gather and analyse people's stories, and present the narrative data in an informative and unbiased manner. I did not have to appear anywhere, except perhaps on the title page or in the introduction—my "partial perspective" in the process (Haraway, 1991).

My struggle with maintaining objectivity kept me from freely expressing my Self (thoughts, feelings, actions and reactions). What was wrong with me? Why couldn't I move loquaciously from one space (subjective Self) to the other (objective researcher) and back again? Why was it difficult to transport my reflexive insights into the written genre? Yvonna Lincoln (2010, p. 5) asserts that Michelle Fine's idea of "Working the hyphen refers to studying the Self-Other conjunction, that fragile and sometimes fractious splice between ourselves as subject and object and those for whom we work, as subject and object."

Drawing from Richardson (2000, pp. 15–16), I asked myself: Will what I write make a "substantive contribution", have "aesthetic merit", effectively utilise and reflect "reflexivity"? Will it have "impact" and "express a reality"? As Richardson (2000, p. 925) points out:

we are homogenized through professional socialization, rewards and punishments. Homogenization occurs through the suppression of individual voices and the acceptance of the omniscient voice of science as if it were our own. How do we put ourselves in our own texts, and with what consequences? How do we nurture our own individuality and at the same time claim to "knowing" something? These are both philosophically and practically difficult problems.

Embracing Autoethnography

Two things prompted me to critique my objective positioning, and to work the tension embodied in the subject-object hyphen, reminding me of Ballard's (2009, p. 480) assertion that autoethnography "is able to show how ethics exist in indecision, how struggles in the midst of phenomenological moments are outside of language, and how communication gives us life through acts of acknowledgement". The first involved talking to a kuia (female elder) with a life-threatening illness about her views on the research project. After each meeting I reflected in my journal on what the kuia had said or had not said, and how I felt at this time.

The second concerned a personal event when a close friend was diagnosed with an aggressive brain tumour—she had 4 months to live. Suddenly I felt myself slide from outside the "dying space" to being inside it. No longer did I have the luxury of being an impartial onlooker. I entered a tapu (sacred, restricted) space where someone I loved was dying and was trying desperately to live. Ellis's (1993) story about her brother's death now made sense. Dying is part of everyday life and as a researcher I cannot separate myself cognitively, emotionally, physically or spiritually from this reality.

Further, my father's sudden death 2 weeks ago imprinted an emotion-filled watermark on my life. In this space, claims to objectivity appear inappropriate and disrespectful. The call for research excellence is not about being outside the dying space, but rather, being fully present in it.

Reflexivity: Noho Puku

I knew that karakia (invocation, prayer), whanaungatanga (establishing connections), waiata (chants, songs) and manaakitanga (hospitality, kindness) are important aspects of Māori research, but unless I started to use my emotional, intellectual, spiritual and physical faculties to really listen to people I would miss vital information. Journal entries of conversations with the kuia encouraged me to noho puku (sit with the feelings and tensions inside me). I began to read non-verbal tohu (signs) and they guided me. Her words resonated in my tinana (body), hinengaro (mind) and wairua (spirit). I wrote:

The kuia taught me that when it is our turn to face our own death we may choose to focus on "living" and not "dying", refusing to give up our hope ... No matter how old, wise or spiritually learned our kuia and koroua [elderly men] are, they too may be afraid of dying. They may not be able to talk about dying or what will happen to their whānau after they die ... She taught me not to think about dying in a linear, seamless kind of way ... but in an ad hoc, disjointed way, like life itself. She taught me that words like "dying" may be just small black and white words on the researcher's forms but these can be terrifying omens to the dying.

Ethical considerations are embedded in these reflexive insights. I need to ensure that I am fully present when I am walking alongside people who are dying. I need to resist the call to objectivity and become fully engaged. I will be interviewing the most vulnerable group of people—the dying and their whānau. I realise that genuine connections need to be established in the recruitment process, which requires strong rapport-building skills on my part. An emotionally distant researcher would be quickly detected and perhaps rejected. An “impartial” researcher would be unlikely to generate an environment where meaningful recruitment and engagement was possible, and which enabled examination of psychological, medical, environmental and spiritual dimensions. The research process, from first contact to final farewell, must be something people enjoy being involved with, and they need to feel safe. Sharing their stories with a researcher who is actively engaged as a listener will hopefully promote a rich and rewarding experience for everyone.

In working the reflexive subject-object space I am obliged not only to embrace my subjectivity but to share these experiences with my readers in order to promote a deeper understanding and awareness of the issues facing those who are dying and their whānau. This has led to a shift away from the academic obligation to represent myself as an empathetic neutral observer to being a Māori researcher, living research and researching living. Weiss and Fine (2000, p. 66) point out that as researchers:

We have an ethical responsibility to retreat from the stance of dispassion all too prevalent in the academy ... analysing, writing and publishing in multiple genres at one and the same time: in policy talk, the voices of empiricism, through the murky swamps of self-reflective “writing stories”, and in the more accessible languages of pamphlets, fliers and community booklets Reflections on our responsibilities as social researchers must punctuate all texts we produce. Without such reflection in the name of neutrality or researcher dispassion, we collude in a retreat from social responsibility and the academy remains yet another institution without a soul in a world increasingly bankrupt of moral authority.

Autoethnography has opened up a space to develop a methodology for researching the lives and stories of those who are dying and their whānau in a more meaningful and responsive way. As Lincoln (2010, p. 7) reminds us:

Paradigms and metaphysics do matter. They matter because they tell us something important about *researcher standpoint*. They tell us something about the researcher’s proposed *relationship to the Other(s)*. They tell us something about what the researcher thinks *counts as knowledge*, and *who can deliver the most valuable slice of this knowledge*. They tell us how the researcher intends to *take account of multiple conflicting and contradictory values* she will encounter.

Harakeke Talk Tool

One example of an ethical consideration I addressed concerns the vulnerability of the dying. The kuia made me aware that participants may not respond to a traditional interview process (complete with questionnaire sheet and digital recorder). To engage people enough to tell their story, an alternative method was required. I developed a visual tool that draws on the well known harakeke (native flax) whakataukī. The whakataukī reminds participants of their connections to whānau, the physical environment, spiritual realm and continuity of life.

The “Harakeke Talk Tool”—a term coined by Linda Waimarie Nikora, to whom I am grateful—takes the form of a watermark of a large flax bush printed on A3 paper. Each harakeke spike represents a different aspect of a person’s life, a timeline, iwi (tribe), person or event. New spikes can be included or artistically decorated as different information is added. Responses are recorded during the interview, or participants may record them between interviews. Encouraged by MacLeod’s (2008) words, “to get it right we must ask [Māori] what to do and how to help,” it is my hope the “Harakeke

Talk Tool” will give participants support to share safely their stories while articulating their future needs and hopes.

Conclusion

The autoethnographic process gave me an opportunity to critique the academic imperative to be objective. As a novice ethnographic researcher seeking stories from people who are dying, and their whānau, I experienced a much-needed shift from struggling to be an impartial researcher to being fully immersed in a qualitative research process that utilised a reflexive ethnographic methodology.

Autoethnography helped me to develop insight into my own stance as a researcher, which led to a shift from objectivity to working with the tensions produced by the subject-object dichotomy. It enabled me to make some important adjustments to ensure that the research project uses the best research methods to interview vulnerable people. It has contributed to an increased likelihood of engagement, allowing a more meaningful research experience to emerge for participants.

Perhaps most importantly, the autoethnographic journey has helped me to shift from being outside the discourse of dying, death and bereavement to inside it. As Ellis and Bochner (2006, p. 439) comment:

Instead of being obsessively focused on questions of how we know, which inevitably leads to a preference for analysis and generalization, autoethnography centres attention on how we should live and brings us into lived experiences in a feeling and embodied way. This is the moral of autoethnographic stories—its ethical domain.

I am left with a deep knowing that people who are dying and their whānau will drive this research. It is my job to listen to the dying and their whānau, carefully recording their thoughts, feelings, hopes, dreams and sorrows. At the same time, as a researcher engaging in such moving and tapu work, I need to care for myself while listening at all times to our Atua (Gods), tūpuna (ancestors), kaumātua (elders) and pou āwhina (Māori supervisors) to guide me.

Autoethnography opened up a subjective space, inviting me to be open, truthful and present as a researcher and writer. I happily inhabit this space, with all my confusions, frustrations and contradictions, knowing that I am better positioned to meet the fullness of those who are living with dying, and their whānau. My journal reflects this journey:

Shifting Autoethnographic Landscapes

I am listening to the spaces impregnated with silence
Witness to the whimpering calls from inside and outside my “self”
I try to “know” them
I read them like they are words on a full page
Sometimes they bleed, blur and fade easily.

I listen carefully
I hear the silent spaces joining, fusing
At first I sense a glimmer of something
It emerges, soft, unformed, amoeba like
I listen until the listening becomes a feeling.

The feeling turns into a word and the word becomes a sentence
I listen until the sentence speaks to me the names of its tūpuna
In their names is a knowing that fills the silent spaces
Noho puku—sitting with the filled silent spaces
The places speaking our tūpuna.

Holding their weeping words deep in my belly

Keeping them warm
Days, nights, weeks pass until they form images
My mind becomes filled with their voices
The bell birds sing from the top of the harakeke.

Their voices are tūpuna sounds
I watch as the words meld and fuse into visions—watery awa
Pathways that trail into the distance
My eyes follow them, scanning the river banks
Periphery landscapes fill with new meaning.

I take the visions and weave them until a whāriki takes shape
At first, the visions are lumpy and uneven but they soften
I roll the whāriki out in front of my supervisors—my pou āwhina
I have become the tabula rasa
The waiting blank slate.

I bear the vision
And listen to the silent spaces
I make the changes I need to make to
Make the
Change.

Glossary

atua	gods
awa	river
harakeke	native flax bush
hinengaro	mind
iwi	tribe
karakia	invocations, prayers
kaumātua	elders
kaupapa Māori	Māori-centred
koroua	elderly men
kuia	female elder
manaakitanga	hospitality, caring for others
noho puku	sitting quietly on an issue
pou āwhina	research supervisors
tangata whaiora	Māori mental health consumers
tapu	sacred, restricted, taboo, respected
tinana	body
tohu	sign (spiritual signifier)
tūpuna	ancestors
waiata	song
wairua	spirituality (personal and collective)
whakataukī	sayings, proverbs
whānau	family (includes extended family)
whanaungatanga	establishing connections
whāriki	traditional woven mat; story

References

- Ballard, R. (2009). Granpa's call: Conscience, ethics, and aporias. *Qualitative Inquiry* 15, 467.
- Buckle, J., Corbin Dwyer, S., & Jackson, M. (2009). Qualitative bereavement research: Incongruity between the perspectives of participants and research ethics boards. *Social Research Methodology. International Journal of Social Research*, 13(2), 111–125.

- Ellis, C. (1993). Telling a story of sudden death. *Sociological Quarterly*, 34, 711–730.
- Ellis, C., & Bochner, A. (2006). Analyzing analytic autoethnography: An autopsy. *Journal of Contemporary Ethnography*, 35, 429–449.
- Haraway, D. (1991). Situated knowledges: The science question in feminism and the privilege of partial perspective. In D. Haraway (Ed.), *Simians, cyborgs, and women: The reinvention of nature* (pp. 183–201). New York: Routledge.
- Lather, P. (1995). The validity of angels: Interpretative and textual strategies in researching the lives of women with HIV/AIDS. *Qualitative Inquiry*, 1(1), 41–68.
- Lincoln, Y. (2010). “What a long, strange trip it’s been”: Twenty-five years of qualitative and new paradigm research. *Qualitative Inquiry*, 16(3), 2–9.
- MacLeod, R. D. (2008). Respecting culture near the end of life. *European Journal of Palliative Care*, 15(2), 57.
- Ministry of Health. (2001). *The New Zealand palliative care strategy*. Wellington: Ministry of Health.
- Ngata, P. (2005). Death, dying and grief. In M. Schwass (Ed.), *Last words: Approaches to death in New Zealand’s cultures and faiths* (pp. 29–41). Wellington: Bridgett Williams Books with the Funeral Directors Association of NZ.
- Richardson, L. (2000). Writing: A method of inquiry. In N. Denzin and Y. Lincoln (Eds.), *Handbook of qualitative research* (pp. 923–948). Thousand Oaks, CA: Sage.
- Reid, P. (2005). Contemporary perspectives. In M. Schwass (Ed.), *Last words: Approaches to death in New Zealand’s cultures and faiths* (pp. 41–49). Wellington: Bridgett Williams Books with the Funeral Directors Association of New Zealand.
- Schwass, M. (Ed.). (2005). *Last words: Approaches to death in New Zealand’s cultures and faiths*. Wellington: Bridgett Williams Books with the Funeral Directors Association of New Zealand.
- Smith, L. S. (1999). *Decolonising methodologies: Research and indigenous peoples*. London: Zed Books.
- Sparkes, A. (2000). Autoethnography and narratives of self: Reflections on critical action. *Sociology of Sport Journal*, 17(1), 21.
- Weiss, L., & Fine, M. (2000). *Speed bumps: A student-friendly guide to qualitative research*. Columbia, NY: Teachers College Press.