Caring vs Curing
Embodied Engagement: I am not Alone

By Susan Bardy



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Introduction

This is the sequel to *Choosing End of Life Nursing*, the volume which familiarised the reader with my life and the developments in my nursing career and the gradual passion of caring for people in end of life situations.

In this work I wanted to succeed in understanding vocational ideations of palliative care nursing. For many months I played with the thought that I needed to find out why it was that I was so strongly attracted to the philosophy: why was it was that this was the one caring model I never tied of?

In this volume the personal journey joins with the broader culture of palliative care nursing by interviewing those who chose palliative care nursing and examine the reasons for changes in careers from acute, curing based nursing to palliative caring for those in end of life nursing.

Chapter One—*Celebrating by Sharing*—is the longest section of the study where I travel the world of palliative nursing with participant observers. It is about the actively working nurse and includes extensive analytical discussion of how I understand the sense of professional change, and the significance of beliefs for the reasoning behind vocational transformation. Here is where experienced palliative care nurses in interview situations join me. This is where we compare notes about our nursing practice and it is where I first meet the research findings.

Chapter Two—*Inner Secrets of Being There at the End of Life*—is where I spend time with interview transcripts and begin to give answers to how and why participants chose the nursing of terminally ill people.

Chapter Three—*Almost the End*—is the concluding discussion that addresses the heart of the research question and gives an answer to transformation of nursing ideals from a curing model to a caring only approach when death of the patient is inevitable.

The *Epilogue,* is where I write another letter this time to both of my sons and ask them to be there when my time comes for the end of life through a life limiting illness. I ask them to see that the palliative care professionals observe my final wishes.

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Chapter 1
Celebrating by Sharing

In the previous volume I have mentioned how auto-ethnographic methodology does not necessarily specify contributions from 'others' as data, but does not discourage it either.[1] Chang maintains that in auto-ethnography the researchers' past and present is the primary source of data, but she acknowledges that interviewing others does play a role.[2] An example of this is Carolyn Ellis' interactive interview with Christine Kissinger and Lisa Tillman-Healy.[3] A dinner party conversation between the three introduced how the interviewer by contributing her story stimulated a spirited discussion about eating disorders. Laurel Richardson transcribed her interview with Louisa May in the form of a poem that described a painful life.[4] Chang again believes that collaborating in this manner could stir memories of personal experience that often becomes a valuable research finding. I could not help but agree with this as I muse over how I should introduce this section. Here I bring into focus stories of others, complementing my autobiographical account of nursing transformation.

A group of invited nurses joined me in describing how they came to work in the area of palliative care. These participants, in their independent way, added knowledge to complete the jigsaw

1.
2. H Chang, *Autoethnography As Method* (Walnut Creek, CA: Left Coast Press, Inc, 2008), 105-106.
3. C Ellis, C Kiesinger & L Tillman-Healy, 'Interactive interviewing: talking about emotional experience', in *Reflexivity and voice,* edited by R Hertz Sage Publications, Thousand Oaks, California, 1997).
4. Laurel Richardson, *Fields of Play: Constructing an Academic Life* (New Jersey: Rutgers University Press, New Brunswick, New Jersey, 2001).

of palliative caring. Since I was the one who invited them to share personal and professional stories I was responsible for their safety during the interviews. I envisaged the possibility of discussing intimate experiential stories that I would be trusted with, and as such I paid close attention to ethical aspects of interviewing. Participating nurses were each given written information about the project and asked to sign a document stating their agreement to be a part of the research. This they all did. I also committed to keeping their person anonymous by using pseudonyms throughout the writing of the interview transcript.

Encounters of a personal kind

During twenty years in palliative care nursing I not only observed patients' prognosis but also watched how other nurses undertook this work. On the whole my personal stories directed this study, but I also travelled the wider world of the palliative care culture in an auto-ethnographic style where I was the initial object and subject of the research.[5] To compliment this I invited peers in palliative care nursing to share their stories to be the source energy of my work in an attempt to unlock my understanding of what it is which is motivation for people to chose nursing those who are at the end of life.[6] With this let me I introduce the next research activity that for me was not only stimulating but added ethnographic relevance. I am referring to the interviews with invited nurses whose ten or more years of clinical experience in palliative care complemented the study. The knowledge gained from the interviews strengthened and supported the way I saw clinical practice in end of life nursing. Little did I realise at the time that sharing experiential stories with colleagues in a setting of unstructured interviewing contributed not only to my

5. Elligson, '"Then You Know How I Feel": Empathy, Identification, and Reflexivity in Fieldwork', *Qualitative Inquiry,* 4/4 (1988): 492–514; C Ellis, *The Ethnographic I'*, (Walnut Creek, Lanham, New York, Oxford: Alta Mira Press, 2004); A Kolker 'Thrown Overboard: The Human Cost of Health Care Rationing', in *Composing ethnography*, edited by C Ellis & A Bochner (Wlanut Creek, California: Alta Mira Press, 1996).
6. Chang, *Autoethnography As Method,* 106.