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Review

Book Review

A Story of a Marriage Through Dementia and Beyond: Love in a Whirlwind

By Laurel Richardson
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Laurel Richardson, Distinguished Emeritus Professor of Sociology at Ohio State University, has been an inspiration to me since I came across her work in the first edition of the *Handbook of Qualitative Research* whilst undertaking my PhD back in the early 1990s. In her chapter 'Writing: A Method of Inquiry' (available in later editions of that handbook), she wrote:

> I have a confession to make. For 30 years, I had yawned my way through numerous supposedly exemplary qualitative studies... "Coming out" to colleagues and students about my secret displeasure with much of qualitative writing, I found a community of like-minded discontents … [who also] … found much of qualitative writing yes – boring. (2000, p. 924)

Since then, recognising myself as one of those discontents, I have become part of that community and continue to be inspired by Laurel's work, alongside others who share the belief that writing research from our selves is an enjoyable way of knowing, and learning, and passing knowledge on to others. As we explore our own processes, creating possibilities for new understandings, we also find opportunities for creative analysis, maybe through poetics, performance, song, or illustration. Through using different forms of re-presentation and writing, we can discover new aspects of our topic and strengthen the community of individual voices within it: writing from our selves we can take risks, be open, honest and engaging, and fully present in our work.

Laurel's latest book, *A Story of a Marriage Through Dementia and Beyond: Love in a Whirlwind* (2023), was written in her late 80s, after forty years of marriage to Ernest, a fellow academic. Her story feels particularly poignant for me, resonating as it does with several areas of my own experience at this stage of my life and marriage of over 60 years.

I read this book quickly from cover to cover and, recognising its importance and value, I wanted to share my responses and encourage others to read it. Again, quickly, I began to write a version of this review and sent a draft to a critical friend, Carolyn Ellis, who has known Laurel very well over a long period of time. Her feedback brought me up sharply to the realisation that in reading Laurel's book and in my first attempt to write a review, I had stepped back too far, protecting myself from getting close to my own feeling responses, telling myself I needed to focus on Laurel's experience rather than my own. Yet in the very first paragraph, Laurel thanks Ernest for his willingness to allow her to write this book as *honestly* as she could—I needed to be honest too.

I reread the book, slowly, allowing myself to *notice* the parts that touched the sore spots in me, my own experiences of being a carer for my physically disabled husband, who was diagnosed with vascular dementia eight years ago and is now unable to stand or walk unaided. Like Laurel, I am also in my 80s, and like her, I am an academic and married to a man who has been successful and creative in his life and in his scientific work. Although we live on different continents and among different cultures, Laurel's journey and my own are paralleled and, in some ways, different, too. There are several types of dementia—all of them difficult to manage—but Lewy body dementia, which Ernest had, could be seen as the most difficult of all. As well as the usual symptoms of dementia, Lewy body often bring with it aggressive verbal, physical, and sexual behaviours.

Through this book, Laurel hopes she can show and tell others what Ernest has endured whilst also focussing on her own experiences, in the hope that other caregivers will find in this book someone who has walked in her shoes: 'A kindred spirit who gets your pain' (p. 4). That is indeed what I have found.

Arthur Frank in *The Wounded Storyteller* tells us that,

> Storytelling is **for** another just as much as it is for oneself. In the reciprocity that is storytelling, the teller offers herself as guide to the other's self-formation…The moral genius of storytelling is that each, teller and listener, enters the space of the story **for** the other. (1995, pp. 17–18)

As the reader, I have been the listener who has entered the space Laurel creates as teller in this book. In that space, I have connected with her and myself in ways that have changed and strengthened me, and I am grateful for that.

Laurel does not shy away, as I did, from sharing her thoughts and feelings, and the complex nuanced lives of a couple living with the worst effects of distressing disease who can still sometimes find hope, laughter, and loving connection. Her unflinching autoethnographic story shows how their personal struggles are shaped by the culture and context of the changing circumstances in which they found themselves year after year as the disease progresses, living in a hitherto unknown world of dementia that Laurel says is like living through 'a whirlwind' (p. 1).

Each chapter covers a dated period, tracking Ernest's descent into Lewy body dementia. She tells us that she writes as a way of relieving her stress: she writes about events as they occur; she writes to keep faith with herself to handle whatever she might be given, consciously challenging herself to use different formats. She tells us,

> I did not write to tell a "story," a step-by-step narrative. Rather, I wrote to join my previous life with the one I was now living. I wrote in pieces: my life was in pieces. (p. 3)

In the introduction, Laurel seamlessly addresses the ethical issues that arise when writing personal stories, which inevitably involve writing about others. She shows how, in the early stages of her writing when Ernest was still alive, she performs her 'relational ethics of care' (Ellis, 2017) through their conversations, informing him about her intentions to write about him and his dementia journey, seeking his consent and asking for his help to check if the way she represents his truths and meanings feels true to him. In the beginning, Ernest, a novelist and Emeritus Professor of English, was able to suggest some changes, point out repetitions and potential distractions, just as he had done with her previous writings. As Laurel put it, '[him] the novelist helping me, the novice creative non-fiction writer' (p. 3).

She read to him the first three pieces of her collection:

> "You're writing about me," he said. He looked pleased. "About my dementia?"
>
> "Yes," I said. "Maybe a book. Is that alright?"
>
> "As long as you tell the truth," he said." …
>
> "And let the readers know how brave I am." (p. 3)

Since returning to the rewriting of this review, I too have had conversations with my husband, telling him about the book, asking if he'd like to read it (which he declined) and telling him I would be including some of our shared stories in my review. He replied, 'That's okay with me'. Although he often reads my writing before submission, he declined to read this review. He is at the stage where he has lost interest in many things, even in his beautiful garden, which has been his creation and passion throughout our married life.

Laurel's book follows Ernest's progression from the earliest signs of cognitive deterioration and transient global amnesia (TGA) in November 2008, right through to just beyond his death from Lewy body dementia in November 2020. Laurel believes that the TGA marked the start of Ernest's 'descent into dementia… [when] his life and our lives changed' (p. 9). She shows, often through tender dialogue, the nuanced and complex changes in Ernest's thinking and behaviours after he had spent those three days in 'an altered state of confusion, memory loss and wordlessness' after which he became sleepy, 'cognitively present, but fearful…and easily emotionally bruised, unexpectedly fragile'. (p. 9). There was a similar point in my own relationship when I noticed a major shift in my husband Dave, but only with hindsight can we know this as the beginning of a major life transition, as if the pathways we have been travelling along together for many years have divided into two paths that each of us needs to travel, sometimes alone.

By 2010, Ernest, author of three novels and many academic papers, had lost interest in writing, international travel, and playing his saxophone. As his life changed, their shared lives changed too. Two years later they rescued two 'small and smart' Papillon dogs: brother and sister. The couple bonded deeply with these beautiful creatures, named Bashi and Lily, whose needs shaped the couple's new lives. The dogs provided a new purpose as they moved forward, and sometimes led to unexpected conversations. 'Ernest and I talk often about the dogs and death… we talk more about death and the dogs than we do about each other's deaths' (p. 11). For the next six years the dogs, who by then have been trained as *certified* therapy dogs, accompany them wherever they go, even by plane.

This book is like a beautiful cabinet full of large and small drawers filled with large and small stories, like the Bashi and Lily story, which evoked a small story of my own: during COVID I decided that I needed an animal. Dave has always vetoed the idea, and I have always accepted his veto. This time, I refused to do that, and with the support of our son Peter, who lives locally, I now have little Rosie, my cat. Peter drove me four hours each way—during lockdown when we were not allowed to do that—to pick up this tiny kitten that has changed my life (and Dave's—he's also in love with her). So of course the Bashi and Lily stories caught my attention. There were other stories that caught me, but in less welcome ways ...

The nine long years of gradual deterioration pass by in one chapter until the story picks up in 2019 when Ernest is unable to read his watch. Laurel realizes this is a serious new stage, and after extensive testing Ernest is diagnosed with "mild cognitive impairment, probably Alzheimer's – always fatal" (p. 18). I notice the difference between the way I am given this news in the UK and the way it was told in the US, even before a brain scan. The 'always fatal' was not added to Dave's diagnosis after a brain scan. This is when the couple reached out to support groups, which they embraced with some relief, like us.

In January 2020, the first case of COVID-19 was confirmed in the USA, leading to the closure of the support groups. Laurel feels 'bat-shit crazy' as she's left to cope alone, and things get worse. She writes 'I go to sleep wishing Ernest were dead ...I imagine him dead, me released from being care-partner, me free to be me, uninterrupted. Me free to travel, sleep, write, talk to friends, sons…I can't stop myself'. (p. 41) My own thoughts and feelings are hard for me to see on the page, but the compassion I feel for Laurel helps ease my shame. The Lewy body aggression begins to show itself, and Laurel feels unsafe; Ernest is admitted to hospital where his medication is adjusted, and he returns home, unable to remember his hospital stay. Embedded in this story is concern about the costs of medical help in the US and the realisation for me that although the NHS is free to all citizens, it does not finance care for all dementia sufferers, which is viewed as 'social' care.

When Ernest's aggressive behaviour returns, Laurel finds a memory care facility near their home. In September 2020, two months before he dies, he is admitted: they are COVID free. 'He is locked in; I am locked out.

OMG! I am going to be alone forever. I have never lived alone' (p. 60). (As a response, I am thankful for the six months I chose to live alone in my 50s.) After a month, Laurel is allowed to visit, outside or on the porch. The separation creates a despondent place inside her: 'Wrung out. Shivery. Sweaty. ... I feel it's happening in a much deeper place inside me. …a place of despondency? Desolation? Fear? Knowing?' (p. 70)

A few weeks later, Ernest is admitted to an intensive care unit, followed by discharges and admission to several other facilities. After not being allowed to touch him for eight weeks, Laurel massages his arms while having a loving conversation. She explains that 'just because Ernest is not living at home it does not mean I am not care-taking, decision-making, loving, grieving, worrying' (p. 82). When Dave is in intermittent respite care, when I can no longer cope without a break, I know this too.

Finally, Laurel fights to have Ernest admitted to hospice care. She describes eloquently the vast difference between the medical model of care and hospice care, 'I know he will be treated with comfort, care and dignity' (p. 89). Laurel marvels that there is, 'a doctor talking to me about spiritual matters!' (p. 9). I am saddened that the scarcity of hospice care in the UK is mirrored in the US. Hospice care in the UK must rely upon charitable donations; in the US Medicare covers the cost or Medicaid for those without insurance.

Laurel tells us that dementia is the third leading cause of death among older populations in the US and that ten million cases of dementia are diagnosed in the US each year. The burden of care falls on unpaid family members and friends, and three-quarters of those fear for their own health. The picture is similar here in the UK.

Weaving in autoethnographic and sociological methods and scholarship, as well as a list of reading and resources for caregivers, scholars, and others, this book will appeal to students and academics across a wide range of disciplines: health, communication, nursing, and allied health courses covering death and dying, end-of-life care, dementia care, and, of course, those pursuing writing as a method of inquiry, autoethnography, and creative non-fiction.

I believe the knowledge within this book will also be of value to caring professionals, whether medical or charitable, and for those of us involved in writing for wellbeing who support carers of any kind. It is equally important that this book is read by policymakers.

This beautifully written book offers emotional support to those in service as caregivers, like me. Connecting with Laurel's experience, even though painful at times, has allowed me to view my own unfinished journey through fresh eyes and recognise the need for self-compassion, especially for those of us who accompany partners while growing old ourselves, doing a job that would be excluded from on grounds of age if we were to apply!

Laurel has created a beautiful autoethnographic story that lives up to all that she has taught us over many years. Her story ends with her family celebrating Ernest's eighty-second birthday, thirteen days after his death, when they scatter his ashes in their chosen place, in peace at last.

She writes,

> This is where Ernest will be and this is where I will be when my time comes. I feel here we will be fully present to each other in ways beyond my understanding, but, for now, perfectly comforting. "C'mon Bashi and Lily…That's settled…We can go home, now." (p. 97)

References

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