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**Between a rock and a hard place: navigating the ethical demands of narrative inquiry and creative nonfiction**

Abstract:

Narrative inquiry, which has been simply defined as ‘stories lived and told’, is a field of qualitative research with a well-established philosophical, ethical and methodological base. As such, it has much to offer creative arts researchers who are seeking an appropriate theoretical framework for investigating lived experience and presenting research outputs in storied form. However, when the genre of the resulting story is creative nonfiction, certain tensions arise between narrative inquiry practice and the writing of vivid, insightful creative nonfiction animated by the author’s personal voice. Narrative inquiry is rooted within the academy, so its principles are aligned with those upheld by Human Research Ethics Committees: assuring free consent, guarding confidentiality, and protecting participants from harm. In contrast, creative nonfiction practitioners, along with journalists and biographers, are less likely to be concerned about subject’s rights, and more likely to valorise author’s rights, reader’s rights, truthfulness and the ‘necessities of the text’ when ethics are discussed.

For the creative component of my doctoral thesis, I investigated people’s experiences of caring for terminally-ill family members at home. I developed a conception of my project as a biographical type of life writing within the field of narrative inquiry, with a creative nonfiction book manuscript and accompanying exegesis as the research outcomes. Consideration of how conflicting loyalties and competing values can create moral quandaries in which author’s rights are pitted against subject’s rights led me to the research problem at the heart of my thesis. Expressed in terms of the elements juggled, what I endeavoured to do was to take a non-exploitative, non-maleficent approach to the task of producing non-superficial, non-rose-tinted, nuanced accounts of home-based palliative caregiving.

This paper presents narrative inquiry as a useful, credible and appropriate theoretical framework for creative arts researchers, particularly when undertaking the ethically-challenging task of writing other people’s lives. I argue that consulting and negotiating with my research participants throughout the draft writing stages enhanced their trust in me, and greatly increased the richness of what I was able to include. I also present an example of how fraught the process of soliciting feedback and negotiating the final version of a story can become, when divergence occurs between the viewpoints of subject and author.

Biographical Note:

Janene Carey's PhD was conferred in August, 2011. She has published several scholarly papers based on her research and sections of her book manuscript have been published in *Re-Placement*, a national anthology of creative writing, *TEXT Journal of Writing and Writing Courses*, and *Australian Book Review*, after she was shortlisted for the 2010 Calibre Prize.

Keywords:

Narrative inquiry — creative nonfiction — ethics of life writing — palliative care

As a field of qualitative research with a well-established philosophical, methodological and ethical base, narrative inquiry has much to offer creative arts researchers, particularly those who are investigating lived experience to produce a literary work. My PhD project, 'A Hospital Bed at Home', involved iteratively interviewing people about their experiences of caring for a terminally-ill family member, and writing a linked collection of biographical creative nonfiction stories, one of them a memoir about my own experience of looking after my mother when she was dying of breast cancer. I found narrative inquiry, an interpretivist qualitative methodology that studies people in a way that 'takes into account the social actor's reasons and the social context of action' (Neuman 2000, p. 76), supplied me with important literature on process and ethics, and also provided justification for presenting my research in storied form. In effect, the writers I quote below constitute my family tree as a researcher, as the issues raised in their work significantly shaped the methods I chose to employ.

Research employing narratives of lived experience has become increasingly common in anthropology, psychology, history, sociology, linguistics, education and health studies (Riessman & Speedy 2007). The "narrative turn" began in the 1970s, arising from dissatisfaction with the prevailing normative ideal of presenting social reality from a detached, neutral, authoritative, pseudo-objective standpoint (Barone 2008); although, of course, narratives of lived experience, with their rich and engaging details of characters, intentions, beliefs, circumstances and consequences, have long been an appealing way for people, as 'storytelling animals', to make sense of human behaviour (Barnard et al. 2000; Polkinghorne 1988). Jerome Bruner's (1986) contention that storytelling is a mode of cognitive functioning, not just a vehicle for emotional expression, bolstered the acceptance of narrative in social science research. Bruner's analysis in *Actual Minds, Possible Worlds* (1986) focuses on literary fiction, but contains the seed of an idea that has since become commonplace: that people account for their experiences in terms of narrative structures; that we lead storied lives. Instead of looking for general causes and universal truths, the narrative mode is context-sensitive and particular, it 'deals in human or human-like intention and action and the vicissitudes and consequences that mark their course' (Bruner 1986, p. 13).

Narrative inquiry is 'the interdisciplinary study of the activities involved in generating and analysing stories of life experiences (e.g. life histories, narrative interviews, journals, diaries, memoirs, autobiographies, and biographies) and reporting that kind of research' (Schwandt 2007, p. 203). Jean Clandinin and Michael Connelly define it more simply: 'Narrative inquiry is stories lived and told' (2000, p. 20). Catherine Kohler Riessman notes that the term "narrative", often used synonymously with "story", lacks a clear-cut definition. It can refer to 'an entire life story, woven from threads of interviews, observations and documents' as well as 'a discrete unit of discourse: an answer to a single question, topically centered and temporally organised' (2007, p. 429). She identifies the essential ingredients distinguishing narrative from other forms of discourse (for example, chronicles, reports, arguments) as sequence and consequence. 'Events are selected, organised, connected, and evaluated as meaningful for a particular audience' (Riessman & Speedy 2007, p. 430). Donald Polkinghorne divides narrative inquiry into two camps: one that collects

people's storied accounts of their experiences and uses this as data to be analysed for the purpose of exploring themes, developing categorisations, or interpreting constructs like self-identity, social roles or cultural norms; another that gathers descriptions of events and actions, and configures them into an emplotted story unfolding over a certain period of time (1995). The latter type of narrative inquiry is the one I employed in my project.

Narrative inquiry and research-based creative arts practice that seeks to represent lived experience have a natural affinity. Like literary texts, a well-done narrative study offers its readers an expanded sense of the topic and its complexities, as well as the opportunity for living vicariously (Clandinin & Connelly 2000). In 'Creative nonfiction and social research', Tom Barone discusses how creativity in the presentation of social research can entice readers into the internal world of the text and allow them to connect and empathise with the situation and the characters as they would in reading fiction. The subtlety and complexity that a literary presentation can introduce promotes ambiguity rather than certainty, and provides space for a reader to derive meaning that is personally relevant, 'to take the text home into the world of her daily experiences to see what it might say about familiar conditions, conventional practices, and the values and ideologies that support them' (Barone 2008, p. 112).

Although narratives of lived experience may serve to convey significant truths about the human condition, ever since postcolonialism turned its critical gaze on anthropology, and the subjects of ethnographies began to "speak back" about misrepresentation and misappropriation of their lives and cultures, there has been much concern about the ethical aspects of life writing among academic practitioners, theorists and critics. As Clifford Geertz notes, 'What had once seemed only technically difficult, getting "their" lives into "our" works, has turned, morally, politically, even epistemologically delicate' (1988, p. 130). In the final chapter of *How Our Lives Become Stories: Making Selves*, Paul John Eakin points out that life writing depends on a "fiction", namely that individuals and their lives can be commodified in the form of a textual representation; this fiction then creates the possibility of disrespecting a person by treating them as a "thing" to be pinned down and evaluated, thereby assaulting their very personhood (1999, p. 172).

A long-running debate on the intricacies of ethical practice can be found in the narrative inquiry literature, most notably in the edited collections *Ethics and process in the narrative study of lives* (Josselson 1996b) and *Handbook of narrative inquiry: mapping a methodology* (Clandinin 2007). Narrative inquiry is rooted within the academy, so its principles are aligned with those upheld by Human Research Ethics Committees: assuring free consent, guarding confidentiality, and protecting participants from harm (Josselson 2007). Even so, narrative researchers Ruthellen Josselson (1996a), Katherine Borland (2006) and Susan Chase (1996) all acknowledge occasions where they have caused distress to participants, by interpreting life stories in ways that were alien to the participants' conceptions about their identity and the meaning they attached to their experiences. Whilst defending their scholarly mandate to create more textured meanings via theory and analysis, the researchers recognise the divergence between their own communicative agenda and that of their informants. Josselson describes feeling ambivalence – even guilt – about

switching her allegiance from participant to reader: ‘Where in the interview I had been responsive to them, now I am using their lives in the service of something else, for my own purposes, to show something to others. I am guilty about being an intruder and then, to some extent, a betrayer’ (1996a, pp. 69-70).

In contrast to the angst about appropriating lives voiced by social scientists, biographers and creative nonfiction writers tend to wear their interpretive independence as a badge of honour (Carey 2008). Biographies marked as ‘authorised’ are frequently regarded as tainted goods: a full and frank account from an independent narrator is the gold standard. In her article ‘Dogs in the Graveyard’, which discusses the ethical dilemmas involved in telling all about a life, biographer Cassandra Pybus mounts an argument for writerly integrity. She says her integrity as a writer is bound up in ‘the veracity of the tale I am able to construct out of the vagaries of memory and the treacherous detritus left behind’ and also in her desire to ensure that the story she writes ‘does say something meaningful about the human condition’ (Pybus 2000). Similar issues arise in creative nonfiction. Although, like conventional journalism, it works with factual information, creative nonfiction is allowed to be subjective, to be animated by the personal voice of the writer. Explicitly or implicitly there is always an ‘I’, a lively intelligence behind the words, making sense of the subject (Bloom 2003; Perl & Schwartz 2006).

As G. Thomas Couser notes, conflicting loyalties and competing values create moral quandaries for all life writers (2004). On the one hand, examples abound of life writing causing harm by deliberately or inadvertently impinging upon the subject’s privacy, reputation, or sense of self (Couser 2004; Donaldson, Read & Walter 1992; Eakin 1999). On the other hand, biographers, scholars and journalists rightly position interpretive independence as life writers’ principal bulwark against hagiography, superficiality and dishonesty (Bloom 2003; Chase 1996; Pybus 2000). According to Janet Malcolm, the result is a moral impasse: betrayal is the inevitable canker at the heart of the writer-subject relationship, because after trust is won and confidences are imparted, the ‘text’s necessities’ must take precedence over the subject’s feelings (Malcolm 2004, p. 163).

The ethical quandaries of life story research have no easy solutions; however, some narrative researchers (for example Clandinin & Connelly 2000; Ellis 2007; Josselson 2007) advocate a form of ethical thinking which takes account of specific situations and the responsibilities embedded in particular relationships. Relational ethics promotes the values of care, trust, empathy and dialogue in human relationships, and is linked to feminist philosophies that have developed in opposition to Kantian conceptions of universal moral principles and rational, autonomous individuals (Christians 2000; Koehn 1998). Relational ethics emphasises connectedness and ‘requires researchers to act from our hearts and minds, to acknowledge our interpersonal bonds to others, and to initiate and maintain conversations’ (Ellis 2007, p. 4).

As I discussed in an article for *TEXT* written midway through my PhD candidature (Carey 2008), determining how to deal with the ethical tensions involved in telling a story about someone else’s life in a way that would not hurt, exploit or misrepresent

them, while still telling it in a way that would preserve my integrity as the writer of that story, became a central aspect of my research project, one that could not be simply addressed via the standard Human Research Ethics Committee guidelines regarding informed consent, confidentiality and anonymity. Firstly, in situations where the research focus is emergent rather than predetermined, locating informed consent before data collection begins, and requesting upfront agreement to publications based on that data, is an ethically problematical practice (Richards & Schwartz 2002). Therefore, in my study I decided to defer the consent-to-publish permission until the participant and I had negotiated a full working draft of the story. Secondly, the privacy and confidentiality of personal information is almost impossible to guarantee when the material being gathered is richly descriptive and the aim is to present it in its proper context rather than stripping it of all identifying features. With this in mind, I decided to warn participants that I could not promise anonymity; the best I could offer was the thin disguise of pseudonyms. When they signed the Release of Information form, my participants also chose between false names and real names in publications; like other researchers working with narratives of illness and death, I found real names were the most common preference (Grinyer 2002). Finally, my working processes ended up being intensely collaborative. I did not just take a finished story back to the respective participant and negotiate changes at that point. Instead, we were involved in an iterative cycle of interviews, each one incorporating the participant's feedback about how my current draft was shaping up as well as introducing new material that revised, extended, and deepened what I had written so far (Carey 2008).

Soliciting feedback from subjects prior to publication is regarded by many nonfiction writers as a risky practice because, when faced with their words on the page, the person may want to retract the interesting admissions and sensitive details that had surfaced during the course of the interview (Gutkind 1997). But it can be hard to predict what aspect of the text will touch a nerve with your informant – often it can be something that the writer regards as trivial (Gutkind 1997). I found that when one of my participants asked me to amend or delete some detail (not because it was inaccurate, but because on reflection they regretted having mentioned it) I generally had no difficulty in complying. On the few occasions where I felt sure that acceding to their request would weaken the story, I explained why the statement needed to stay as it was, and managed to convince them. On the whole, my negotiations with participants proved amicable and fruitful, and each case had a happy ending in that everybody did eventually sign the release form agreeing the story I had written about them could be published.

Rather than corroding my writerly integrity, I found that the iterative cycle of gathering information, drafting the narrative, seeking feedback, and negotiating disagreements led to revisions and extensions of the stories that made them infinitely richer. Given early drafts to review, participants corrected my errors and misapprehensions and gave me extra information to fill in sections that were sketchy. They also came to trust me with a more complex, nuanced version of events and motivations. For example, during our third interview session, a caregiver eloquently described how her sleep had been disrupted by her husband's night-time

hallucinations, and I was able to add a thousand extra words to a story that I had thought almost finished.

None of the foregoing is meant to imply that all of the negotiations were sunny and free of tension. For example, by the end of our second interview, I could tell it was going to be difficult to produce a story that Ben would not find confronting.<sup>1</sup> We agreed on the angle – how an already fraught relationship with his wife had been tested by the demands of her terminal illness – but Ben seemed to believe that idiosyncratic deficiencies on Lynne’s part could explain much of what had gone wrong between them. Based on what he told me about their shared history, I could see plausible alternative interpretations. I felt that some of his explanations had a self-aggrandizing bias, and that I would have to find a way of incorporating a countervailing point of view. I could not write the story in a way that would take sides or be overtly critical of my main informant, because ethically (treating participants with respect), pragmatically (being committed to negotiation) and stylistically (show, don’t tell), making judgemental statements was out of the question. But neither did I want to simply take Ben at his own valuation and present only his version of what had happened, completely effacing Lynne in the process. As a mother and a feminist, I felt great empathy and compassion for Lynne, a woman with three small children who, it seemed to me, died before she could work out how to satisfy the part of her unfulfilled by childrearing and domestic duties. So, at the point in the story where Ben was explaining Lynne’s shortcomings, I step forward as the narrator and say:

As I listen to this, I notice that I am feeling increasingly sad about how things transpired for Lynne. During the years that Ben was enthusiastically bounding ahead with his professional career, achieving business success, winning medals for excellence and flying off to be on government committees, it sounds like Lynne was sinking into the scenario described by Betty Friedan in *The Feminine Mystique*, losing her sense of self in the role of wife, housekeeper and mother, and becoming increasingly discontented with her lot in life (Carey 2011, pp. 59-60).

All up, negotiations over ‘Three steps behind’ took three months. There were many delays in responding to my phone calls, emails and letters, and I waited a long time for feedback that would clarify the exact nature of the problem. I wanted to address Ben’s concerns, but found myself having to guess what they might be. It was a fraught, frustrating time, and I have to admit that I didn’t always manage to live up to my own lofty ethical standards. In my exegesis, I included the following critical analysis of one of my letters to Ben, looking closely at what it says, and what it fails to say:

Firstly, although the tone is friendly, there is a certain formality in the wording and the presentation (doubtless I printed it on university letterhead) that would have served to remind Ben he was involved in a research project on a topic we both regarded as important. I reinforced the significance of his participation by mentioning my desire to present the story at an upcoming conference as an example of a male caregiver’s perspective. Ben is a person who often discusses opportunities to “contribute” to the welfare of friends and the goal of “making a contribution” to

society in general. So, I was appealing to his altruism and his generosity. Secondly, I accepted and even validated his excuse of being ‘too busy’ to respond, and made no mention of the possibility that the draft of the story had distressed him, even though I suspected this was the case. Therefore, I made it harder for him to discuss other reasons for his non-responsiveness. Finally, I presented him with two options: we could work on revising the story, now or later, or he could just sign the release form. I did not remind him of his right to ‘withdraw from the project at any time without giving a reason’, nor did I point him to the sentence in the information sheet that mentions the option of ‘withdrawing the written and spoken information you have provided’. Why not? Because that was the outcome I most wished to avoid, having invested months of effort to get the story to this point. Also, I did not want to imply that severing our connection, without any attempt to talk things through, was acceptable to me. We had a relationship that predated our researcher-researched one, and I think neither of us would have wanted it to end on a sour note (Carey 2011, pp. 205-6).

With hindsight, I believe I failed to recognise how ‘the dynamics of persuasiveness, personality and power’ might have been working in my favour and casting a shadow over what, ideally, would have been an authentic conversation (Josselson 2007, p. 552). The letter should have at least canvassed the possibility that Ben might have experienced the story as hurtful, and explicitly assured him of my goodwill. It should have reminded him of his inviolable right to withdraw himself and/or his material from the project, while making it clear that my strong preference was for us to keep working together. I think I could have communicated with Ben more honestly and more ethically in this letter, and still achieved the same outcome. After a protracted discussion process and fairly minor modifications to the story, he did eventually send me a signed release form, opting to have his real name published. I believe he came to accept the story as my honest interpretation of the information he had shared with me, but still felt confused and ambivalent about the nature of his relationship with Lynne, and did not entirely agree with my portrayal of it.

As Janet Malcolm reminds all who write about other people’s lives, in juggling the competing ethical imperatives of the subject’s feelings and the text’s necessities, often ‘the best [we] can do... is still not good enough’ (2004, p. 163). At least being aware that the predicaments exist is a step up from blithely assuming that there are none. In my thesis, I sought to take a non-exploitative, non-maleficent approach to the task of producing non-superficial, non-rose-tinted, nuanced accounts of home-based palliative caregiving. I hope I came close to achieving my goal of presenting stories about real people dealing with an extraordinarily challenging situation, and bringing to it the full range of characteristically human strengths and weaknesses, without hurting, embarrassing or misrepresenting those who so generously agreed to speak with me.

## Endnotes:

1. To read a section of this story, see Carey, J 2010, 'Excerpt and research statement: A Hospital Bed at Home', *TEXT: Journal of writing and writing courses*, Special Issue Number 7, October, The ERA era: creative writing as research, <http://www.textjournal.com.au/speciss/issue7/Carey.pdf>

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