The ethical difficulties that arose when I decided to write about the First Person Accounts from Schizophrenia Bulletin took on a new urgency when I considered including in this book a discussion of my mother’s story of schizophrenia and institutionalization. How could I responsibly comment on and interpret my mother’s words from the perspective of both literary scholar and daughter? Would I be able to listen to her story without interference from my own memories of and feelings about her experiences of mental illness? Could I do justice to the trust she had in me as her daughter that allowed her to tell me things she would never have told a psychiatrist, journalist, or anthropologist collecting her story? How would I account for the things she chose not to tell me, either because I was her daughter or because I had become a university professor, a position she felt was way above her in class and intellectual ability, or because she had decided to keep some things secret from everyone out of shame or pride or practicality?

Numerous barriers seemed to stand in the way of my undertaking this particular project. The most obvious was the fact that my mother had never written her story down. She often told me as I was growing up, ‘Never put anything in writing that you don’t want the whole world to see.’ She was afraid that her words would be taken from her, misused, distorted. While we had numerous conversations about her experience of schizophrenia during the last twenty years of her life, conversations that
sometimes lasted hours at a time, I had never written anything down, unwilling to betray her trust by committing her words to paper. Even if I had transcribed her story, I was not a folklorist or anthropologist or oral historian and had not been trained in the skills researchers in those disciplines use in the field in order to collect stories. I was a literary scholar, accustomed to reading words on the page and trying my best to interpret them. To add to these difficulties, after my mother died in 1998, while I was no longer afraid of her being hurt by the telling of her story, I worried that, without her active involvement in the narrative, I would somehow get it wrong and fail to do justice to her memory.

Yet I kept feeling drawn towards including my mother’s story in this project. For one thing, despite her fear of putting things down on paper, when I was in my first years of graduate school she asked me if I would write about what had happened to her. She didn’t exactly put it as a question, but as an imagined possibility.

‘I was thinking’, she said one day as we were sitting on the front porch of the house in Hollywood, California, where I had grown up and where she still lived with my father. She was perched on the porch railing, crunching on the ice from her glass of iced tea and swinging one leg back and forth. Because of her anti-psychotic medications, she moved constantly. The drugs created a paradoxical combination of sluggishness and jitters. ‘Maybe I could tell you all about my schizophrenia and you could write it all down. Maybe people would be interested in reading about it.’

This was a startling proposal coming from my mother. She was one of the least self-centered people I have ever known. She never wanted attention on herself and rarely thought anyone would be interested in what she had to say.

‘Sure’, I said. ‘I would love to do that.’

But I knew then that the time wasn’t right. It was the mid–1980s and I was swept up in studying for my qualifying exams and only got back to L.A. a couple of times a year. On some level, too, I think I just didn't want to hear about it, not just then, even though in my academic work I was already focusing on narratives of mental illness, reading all the memoirs I could find on the subject, and signing up for every possible graduate seminar in psychoanalytic theory and feminist criticism. I was busy read-