Mothers talk about their children with schizophrenia: a performance autoethnography

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Introduction

In 2000, my older son David, who was 23 at the time, was diagnosed with schizophrenia. Schizophrenia is a severe mental illness, characterized by neurocognitive deficits and psychotic symptoms such as hallucinations and delusions. It is a leading cause of disability, taking a huge toll on individuals, families and society. As I went through the various stages of coming to terms with my son’s diagnosis, I found myself in two worlds: in one I was a grieving mother trying to cope with a devastating illness in my family, learning to talk to medical professionals, dealing with the loss of my dreams and hopes for my son, and understanding my new role as a life-long caregiver for him; in the other I was a communications scholar with a particular interest in narrative and identity listening to stories: my own stories as I told my friends my troubles, the stories of other parents I met at family support groups, and the stories of mothers who had written accounts of their experiences. My interest in these narratives led me to begin conducting research on social and cultural aspects of schizophrenia. My work in this area has resulted in both traditional academic journal articles and presentations (Schneider 2002, 2003, Schneider et al. 2004) and less traditional performance pieces. I present the script for one of these less traditional pieces below. It is based on interviews I conducted with mothers of people with schizophrenia and on my own experience as a mother of a person with schizophrenia. Autoethnography refers to an approach to social science research in which the experience of the researcher is recognized as a salient part of the research process. Autoethnography typically uses non-traditional genres, such as this script, for presenting research to address ethical and political problems in the representation of research. These genres allow researchers to both break with and continue the ethnographic tradition of representing the lives and experiences of others.

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These compelling and moving plays present a series of vignettes that dramatize various aspects of the lives and experiences of people with cancer. Mienczakowski (1995, 2001) also advocates the use of what he calls ethnodrama for the presentation of health research and has produced performances about the health consumer experiences of people with schizophrenia and about the experiences of people in a drug and alcohol detox centre. I have no background in theatre, but I was intrigued, as performance seemed to offer a way to address the vexing ethical and political problems of representation and voice that I was struggling with in my own research.

These problems of representation are, of course, not mine alone, but grow out of the so-called ‘crisis of representation’ (Clifford & Marcus 1986) that overtook the social sciences in the mid-80s. This crisis involved a growing awareness that the descriptions constructed by academic researchers in their academic journal articles were just that – descriptions, representations, versions of social worlds produced by and for academics. Some scholars began to reject the traditional realist agenda in the social sciences that purported to discover ‘truths’ about social worlds and report them to readers. As Denzin (1992) says, traditional realist approaches ‘privilege the researcher over the subject, method over subject matter, and maintain commitments to outmoded conceptions of validity, truth and generalizability’ (p. 20). It was no longer possible to maintain the primacy of what Sparkes (2000) calls the ‘author evacuated’ (p. 22) text, in which an invisible author is but a conduit for transmitting the ‘reality’ of the world under study to readers. A number of scholars in the last 15 years (e.g. Becker et al. 1989, Paget 1990, Conquergood 1991, Ellis & Bochner 2000, Bochner & Ellis 2001) have searched for ways to acknowledge and address the political implications of and the power relations inherent in traditional academic forms of representation. These scholars have advocated the incorporation of personal narratives and the use of genres not traditional in the academy as a way to address, if not resolve, some of these issues of representation. This has resulted in a wide variety of forms of representation for ethnographic research including poems, plays, ethnodramas, dramatizations of everyday conversations and interviews, dramatic, staged or improvised readings, short stories, memoirs, fiction, creative non-fiction, photographic essays, personal narratives and essays, and fragmented or layered texts (Richardson 2002, Denzin 2003). The attraction of all these forms is that they ‘declare a reality but simultaneously reveal it as make-believe’ (Gergen & Gergen 2001, p. 19). They allow researchers to both break with and continue the ethnographic tradition of representing the lives and experiences of others.

These forms are far outside the mainstream of traditional academic ways of representing research, but I believe that we need to take seriously Gergen & Gergen’s (2001) assertion that there is no one best way to represent research. They suggest that we ‘savor variety in our forms of representation’ (p. 31). As Coffey & Atkinson (1996) point out, researchers now have the opportunity and the necessity to make conscious choices in forms of representation. In particular, we must be aware that, as Gergen & Gergen (2001) point out: ‘representation does far more than communicate about a subject; it simultaneously creates forms of relationship’ (p. 12). Much has been written about the relationship between the researcher and the researched, both during the research process and in how the researched are to be represented, with particular attention to equalizing a relationship that is often seen as exploitative. However, I am particularly interested in the way forms of representation can impact the relationship between the researcher and the audience. While traditional forms of representation often produce alienating distance and a hierarchical relationship between the researcher and the audience, I am seduced by the performance of research as I believe it can reduce the distance and increase a sense of connection between researcher and audience.

I have chosen to call my work performance autoethnography, although this term is just one of many used to describe the experimental work referred to above. Ellis & Berger (2002) describe autoethnography as a form of social science research which consists of ‘stories written in an autobiographic genre about the relationship of self, other, and culture’ (p. 849). Ellis & Bochner (2000) credit Hayano (1979) with the introduction of the term autoethnography. Hayano used it to refer to anthropological research done by researchers who are true insiders in a community. In the years since, the meanings and uses of the term have evolved, making it difficult to provide either a precise definition of the term or a concise description of what autoethnographic research might involve. For example, in their article in the second edition of the Denzin & Lincoln’s (2000) Handbook of Qualitative Research, Ellis & Bochner (2000) spend an entire page of densely printed text simply listing terms and methodological strategies that have been used under the general rubric of autoethnography. In general, in these efforts, ‘the living body/subjective self of the researcher is recognized as a salient part of the research process’ (Spry 2001, p. 711). Researchers fold their own experiences into the experiences of others by studying ‘those biographical moments that connect us and our private troubles . . . to the larger public culture and its social institutions’ (Denzin 1997, p. xviii). Personal narratives, both of the researcher and of other participants in the research, are thus central to autoethnography.
I have also chosen to perform my autoethnographies rather than present them simply in textual form. As Gergen & Gergen (2001) point out, when we expand our modes of expression, we expand the number of people who can join in the ‘dance of understanding’ (p. 19). Mienczakowski (2001) says: ‘performed ethnography may... provide more accessible and clearer public explanations of research than is frequently the case with traditional, written report texts’ (p. 471). My performance pieces don’t use traditional academic genres and they contain no technical jargon, both of which are generally barriers to dissemination to a general audience (and sometimes even within the academy). Performance offers a more engaged relationship with audiences as it addresses the audience at an emotional level, not just a cognitive or intellectual level. Both performers and audience members participate in the performance in a more embodied way than is possible with writing, making the material more powerful and more memorable. Performance of stories provides a much richer sense of the people we study, and offers the audience ‘multiple places to stand in the story, multiple levels of emotionality and experience to which they can connect their own experiences in the world’ (Berger 2001, p. 508).

Performance also offers the potential for social change, something a number of writers associate with performance ethnography (e.g. Carlin 1986, Mienczakowski 1995, Denzin 2003). As Carlin (1986) points out, ‘to stage a point of view is a political action’ (p. 9), regardless of the form it takes. Bochner & Ellis (2001) say that through performance, research becomes more accessible for social action and cultural transformation. The script presented here offers mothers of people with schizophrenia a public voice, one that moves beyond the public advocacy role of promoting better legislation or more hospital beds that many mothers of people with severe mental illnesses find themselves in. It seeks social change through increased awareness of the experience of family members of people with schizophrenia, their grief at the plight of their children, and their role in their children’s lives. As one of the mothers (someone who has been involved in advocacy for 30 years) I interviewed said when she saw the finished performance, ‘No one ever hears about our experiences and feelings. Everyone should see this’. I do not yet have direct evidence that change is taking place, but mental health professionals hearing performances of this script have suggested that it could be used for teaching purposes, for example, having students read the script aloud in the classroom context. This offers the possibility that enhanced understanding and awareness of the experience of family members of people with schizophrenia will radiate outward as these students become professionals potentially in contact with many family members.

It is typical in articles of this kind for the author to include a section on implications for practice. While I believe that my work has implications for the practice of psychiatric and mental health nursing, it would be presumptuous of me to offer them, as I am a communications scholar, not a practitioner. I am delighted to find an audience outside my own discipline among readers of this journal, and I leave it to you, experienced professionals in the field, to tell me how you have found this work helpful in your practice.

Writing the script

My sources for the script consisted of open-ended interviews I conducted with eight mothers of people who have schizophrenia; my own experience as a mother of a person with schizophrenia; Louise Wilson’s (1968) book about her son Tony with schizophrenia, This Stranger, My Son: A Mother’s Story; and Margo Button’s (1996) book of poems, The Unhinging of Wings, about her son Randall with schizophrenia who committed suicide. I conducted most of the interviews in 2001. The transcripts then sat in my drawer for almost 3 years before I was able to read them, much less do anything with them. Even after all that time, I cried each time I worked on this script. Research cannot be just therapy, but I confess that it has been therapeutic for me. It has let me bring together my two worlds, the grieving mother and the communications scholar, and it has given me a way to tell a story that I think is worth telling.

As I constructed the script, I struggled with my role as the teller of others’ stories. I was interested in how mothers of people with schizophrenia construct their child’s identity before, during and after a diagnosis of schizophrenia, so I chose only segments of the interviews in which they talk about their children, rather than about themselves or their experiences. I used a chronological structure, although the mothers did not tell me their stories in chronological form. I worried that my interviewees might not be happy with the choices I made or that they would feel betrayed in some way, having trusted me and shared themselves with me, and that I might be ‘using’ their stories to tell a story that I wanted to tell.

My experience working on the script illustrates the tension that exists in the performance of research. The performance always takes place on at least two levels. The original storytellers perform their stories during the research interviews. The researcher/performer then reperforms, or reperforms when she selects material from the interviews, constructs a script and presents the stories. Through the performance, the researcher/performer makes private stories into a public story. On the one hand I believe that as the adapter of others’ stories, I have a responsibility...
to the people who have shared their stories to understand the meaning of their narratives to them and to present them in a way that honours them. On the other hand, I am not at all sure that this is possible. As the crisis of representation has taught us, we can never get to ‘reality’ or convey the ‘truth’ of others’ experience. Nor can we ‘give voice’ to others’ stories. We are left always and only with representations. The best we can do is to be aware that representation, whether through performance or any other means, is a political act that has real consequences for real people. Mothers are pretty much ignored in the rush to patients’ rights, so I have chosen to perform a story about what it means to a mother to have an adult child with schizophrenia and how that changes how she understands who her child is. I think this story will move listeners, and in a small way this is a political act, an act of advocacy that may lead to change in how parents of adults with schizophrenia are understood in the medical system. If we think of performance as being not so much about description of the experiences of the people under study as about connection with audiences (Ellis & Bochner 2000), then we can give up the search for accurate representation and instead focus on communicating something about those experiences to raise awareness, encourage compassion and promote dialogue.

A widely held misconception exists that schizophrenia involves split or multiple personalities. When people use the word ‘schizophrenic’ in casual conversation they generally refer to a tension between two competing roles or positions that must be managed simultaneously. Many such tensions exist in my story: between my two worlds; between me and my interview subjects; between my voice as the researcher/writer and my voice in the script; between me the researcher/writer/performer and the audience; between the introductory essay in this article and the script. Readers might be tempted to see these tensions as ‘schizophrenic’, but I ask that you never use this word casually in this way. Social realities are constructed through language use, and only through changing our use of language can we change societal understandings of schizophrenia, thereby changing the circumstances of the lives it touches.

Except for Louise Wilson, Margo Button and me (and our children), all names are pseudonyms. I thank all the incredible women who shared their stories with me and dedicate this script to them.

It’s like the person dies: mothers talk about their children with schizophrenia

My beautiful child

Louise Wilson (Tony): Tony was a handsome boy. Not one of our three subsequent children could compare with him. Even in infancy his bones had a sculpted beauty. You could see that his face would be long, and that he would have a long straight nose, a graceful mouth. Tony spoke in full sentences very clearly and very early. He had a keen awareness of beauty before he was even two years old. He could repeat a nursery rhyme after it had been said once. He had a photographic memory and tremendous intellectual curiosity. When Tony was six, he learned about Lincoln’s freeing the slaves. He was dreadfully upset by the whole concept of slavery. Tony was exceptionally sensitive, so easily hurt.

Barbara (David): David started playing the horn at the age of 5 and, by the time he was 6, he was playing in the junior orchestra, which had a minimum age 7. He had little solos, usually two or three notes, that he played with perfect intonation and musicality. I remember one where he had to hold a long note over a tempo change. A professional could not have done it more perfectly than he did.

Catherine (Ian): Ian had a very high IQ. When he first had it taken it was 130 and then it went up a little bit from there, so we knew he was a very smart little boy.

Donna (Sherri): She was our bright light. She took her first aid course before she could read, so she had to do an oral test. She wanted to join a hiking group, and she had to have first-aid to do it.

Sandy (Steve): I can remember being in the kitchen – we built this monstrous big house with too big a mortgage – and I could hear him down in the sandbox talking with a friend. He was six years old and he was explaining how mortgages work. His friend said to him ‘You must be rich, you live in this big house’. ‘Oh, no we’re not rich. Because the house is so big, we have a big mortgage, so we have to pay so much money. You’re probably better off in your smaller rental house’. I mean, this kid was six. Steve was like a six year old with a 60 year old outlook.

Looking back

Louise Wilson (Tony): Tony did not sleep well. Noise bothered him; the distant backfiring of an automobile, or the creaking of Dad’s steps on the stairs woke him into startled crying. Or sometimes for no reason at all he lay awake and wailed. Mother said that he had gas and she used to pick him up and walk with him, up and down the long front porch, patting him between the shoulder blades. As long as she walked he did not cry. As soon as he was laid down the crying resumed in a kind of breathless, weeping protest. He could not tolerate being alone or with anyone else except me. He did not want to be with other children. So slowly, so insidiously does one become accustomed to the most trying routine that only recently did I recall how Jack used to telephone from town to ask: ‘How is he today?’ Only now...
do I understand the enormous significance that such a question should be asked about a child, barely three years old.

Sandy (Steve): Steve was always different, always. He was always in his own world to some extent. He could interact, would interact, but it was almost always like he was working on two levels. And I wonder now, I've done some reading and they say they can see schizophrenia in some kids as young as five or six. I sometimes wonder. Especially with him getting so addicted so early.

Donna (Sherri): She would have asthma attacks as soon as she entered the school, or when she had to walk the dog alone. It would happen at stressful times for her. The asthma attacks got so severe that she would keel over and vomit. I now believe that was her schizophrenia, presenting in different ways. I think she's had this from a very young age, and it just took on different forms as she got older.

Barbara (David): He did well enough in school – we told him he needed to get 80% in all his courses to be able to go to any university he wanted, so he did. Not 79% or 81%, but 80%, we told friends laughingly, but puzzled, really, about why he would aim for 80% when he could have had 90% or 100%. He was quiet, silent even – one of his teachers described him as a strong silent learner. He made it an official policy in grade 11 to see if he could get through the whole day without speaking to anyone. In grade 12, he dropped the policy, but still did not say much. Now we know he already had schizophrenia.

Margaret (Rusty): Rusty was hit by a car when he was 13 years old, and after that he was terrified to ride in a car. He was terrified to ride on a bike; he wouldn't ride a bike for years. And as I look back, I think that is when the schizophrenia came out. Stress brings it out. I think that was his stress.

The beginning of schizophrenia

Catherine (Ian): There were so many pointers. He was telling us about how he saw this teacher on the street and she tried to run him down. Now we know it didn’t happen. But at the time we just thought perhaps it was his imagination. And he always had a problem washing his hands, he’d wash them over and over again. Then I had a call at the office; my neighbor told me she had found him out on the street streaking, running down the hill naked. Well first of all running down the hill, he couldn’t walk without a cane, and naked? So that was the beginning of our schizophrenia.

Donna (Sherri): I thought we were in for a rough ride through the teen years because between the ages of 13 and 15 her behavior became increasingly bizarre. She had pink hair and she wore black clothes and too much make-up, but so did all of her friends, and they didn't have schizophrenia. But then a darker side started to emerge. We discovered she was carving her body and then she disappeared for a number of days. When we found her she was afraid to come home. A whole series of things evolved which eventually led to hospitalization and the diagnosis of schizophrenia.

Barbara (David): David had been going gradually downhill for years. He had dropped out of his masters program and was working the night shift in an electronics factory. He came home one day and said he was going to have to quit because everyone there hated him. He could hear them all talking about him. There was a guy there who wore a Tommy Hilfiger tee shirt and he knew this was an anti-Semitic gesture toward him, because Hilfiger has almost all the same letters as Hitler. That’s when we knew something was really wrong.

Geri (Henry): Henry had always been a very social person, always had friends, on the phone all the time, making arrangements to go places and do things. He stopped doing that. He began staying in his room and he’d be in there for hours at a time. I thought, well, he’s studying; he wants to do well in his first semester. I checked on him, but he wasn’t studying. He was just lying on the bed staring at the ceiling and looking very depressed. He wouldn’t take calls from his friends. Then he began to neglect his personal hygiene. What we were seeing were the initial symptoms of schizophrenia, but we didn’t recognize them at that time.

Psychosis

Louise Wilson (Tony): I was in the basement taking the clothes out of the washing machine and I heard this screaming and yelling. I came up and found Tony fighting with the other children. He was hitting and almost killed them. Tony, I said, sternly, we have all had more than we can stand. A gob of spit struck me full in the face. For an instant I spat back, full in Tony’s face. For an instant he looked at me in astonishment. You’ll learn, he said. I do whatever I want to do and no one stops me. He gave me a ringing slap on the cheek and before I could recover from the shock and pain, he had opened the gate and was gone down the street.

Sandy (Steve): The night he was first sick, it was a very dramatic break with reality. We called him down to dinner, and he wasn’t coming. So my husband went up to get him and he found him writing on the walls in the hallway. That was just bizarre. He had already written all over in his room. Then he went outside and he was about to spray paint his own car.

Margaret (Rusty): He’d knock on our bedroom door and he’d say, Mom, they’re trying to kill me. Mom, they tried to stab me tonight. And, Mom, I didn’t think it was
very fair of you to send pictures all across Canada of me with no skin on my bones. I’d be up with him till maybe 2:30, 3 o’clock. And then I’d finally get him to go to bed and I’d make sure he was asleep so he didn’t leave the house again.

Donna (Sherri): I had a big party for Sherri when she turned 16, she was in the hospital, her first hospitalization, and I got all of her friends to come that day. It was a wonderful day. We were talking about that just the other day. She looked up and she said, ‘That was the last time I saw any of my friends’.

Geri (Henry): He tried to jump out the window when we lived downtown. We were 24 stories high and he tried to get out the window. The second time he walked into the river and fortunately someone was walking by and got him out. He said he was just going for a swim, but it was the middle of winter. And then he tried to OD on his medication.

Sandy (Steve): He came home from work one day and he had about 10 or 12 different packages of earplugs, all different kinds. And of course it didn’t dawn on me until later. ‘What are you doing with all of these earplugs?’ and he said ‘I have so much on my mind, I have so much on my mind, I can’t, I can’t think anymore’. He was trying to shut out the voices.

New Son
Margo Button

I search the blur for the son I knew, but you elude me like the smoke you huddle over. You are thin and bent, a husk from an ear of sweet corn, discard after the harvest, fodder during five dread years in the street. Your arms hang like folded wings as you ghost along the walk. Your feet shuffle, avoid the crunching leaves. Your embrace feels tremulous. It’s so good to be home, you say, as you go through the motion of smiling. Your eyes lower like blinds to shut out The light of others, or pierce like a laser,

Too bright. You look peaceful, Mom, you say, And I am glad you no longer know me, you who knew me so well. I forget the questions I came with, take your limp hand in mine, stroke the elegant fingers, get to know you. What are you thinking? Nothing, you say, unashamed.

The present

Louise Wilson (Tony): Always, wherever we are, we think of Tony, who has so much sensitivity, so much perception, and who could have given so much to life. It is three years since we have seen him. Often, when I am driving the car, I have the illusion his face is hovering before me, so clear, so well remembered. Then again, I am not even sure I would know him if I were to pass him on the street.

Donna (Sherri): She hasn’t done well. We’ve tried every medication going. We sit now and wait for one more to be released. She has all of the side-effects that they list. She still cuts herself. I still have to search her room for objects. She’ll take a pencil sharpener apart and cut herself. She was a size 6 when she was diagnosed and how she’s three hundred and some pounds. She had her life wiped out. She is afraid to leave the house a lot of days. She spends usually about 6 months a year in hospital, and we’re lucky – she takes her pills every day. She is afraid of the voices she hears, so she can’t wait to take her pills.

Sandy (Steve): On his own, he found a job. He works five nights a week. He shuttles cars back and forth for a car rental company. One time, he was so excited, he drove to Red Deer with two other guys to bring a vehicle back. Steve is not symptom free, but with this job it’s manageable. And when I look at Steve now I’m so proud of him. I know how much work it is for him to be normal for as long as he can be during the day.
Margaret (Rusty): Just before Christmas, Rusty and I were going someplace. He reached over, and Rusty is not demonstrative, but he reached over and touched my arm, and he said ‘Oh, Mom, I hope I don’t cry too hard when you go’. That really touched me. He has something to live for now, with his daughter. He has his daughter and he has his wife. That’s all Rusty ever wanted out of life, was to have a job and a house and a family. He’s never had a lot of high expectations. He loves this little girl but he doesn’t know how to be a dad to her. And he loves his wife.

Geri (Henry): Henry falls into that category of people. He’s very good about taking his medication but his body resists it. He gets very little relief so he has not worked a day in his life. He has a very, very low quality of life. Each day is a struggle for him. He is never without symptoms. He became very, very depressed starting probably about seven or eight weeks ago. We really became afraid. He has made three suicide attempts and we were afraid he was getting close to another one.

Barbara (David): He is doing really well now, although he still doesn’t speak much. We’re lucky, he takes his medication. He lives on his own. He goes to SAIT, taking a full time program in automotive technology. I help him register and fill out all his forms. He’ll probably always need that kind of support. He gets reasonable marks, great marks for a person with schizophrenia. I take his current level of functioning for granted, and sometimes forget, and wish for more.

Catherine (Ian): Everyday is a struggle to get him to do just the little things in life. It’s taken us years to have him as independent as he is now. I can even leave him alone now for maybe an hour, two hours. He knows where I am, I have a cell phone and he can call. But then we’re always afraid that, because of the short-term memory thing, he’ll forget what’s going on and fall down.

Geri (Henry): He is extremely difficult to live with a good deal of the time, but he’s worth it. As far as I’m concerned he’s worth every minute I’ve ever spent with him. He’s gentle, he’s free, he’s patient, undeserving of being stuck with such a devastating illness. There’s an expression about unconditional love. I get that from Henry and I don’t know anybody else who gives me that kind of love.

Donna (Sherri): I think Sherri’s life is hell. I don’t know if I would have the courage to live like she does. I think I would have done myself in if I suffered the hell she lives. But she still wakes up, and she smiles, and she hugs me every day. She helps make meals. She’s part of the family. She’s kind, she’s generous. It’s not the life she wanted, it’s not the life she was capable of, but she still makes the best of it, and I admire her for that. Schizophrenia is hell. It is.

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