

Article

Stories Rather Than Surveys: A Journey of Discovery and Emancipation

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Abstract

Empirical research, which has traditionally been privileged in Western health disciplines, has left notable gaps in the implementation of health interventions for Indigenous people and in the knowledge of and respect for Indigenous ways of knowing, both locally and globally. This article emphasizes the notion of pluralism in health research, and the responsibility of non-Indigenous researchers to collaborate respectfully and at a personal level with Indigenous people. It explores the value of unexpected forms of knowledge, and the need to recognize the stories and narratives of research participants as valuable in themselves, rather than as something to be dissected or reinterpreted out of context. Through the exploration of one data collection experience, we show how research collaboration, negotiation, and respect can transcend the boundaries between Indigenous and non-Indigenous people, researchers and non-researchers, those with and without disabilities, and between countries.

Keywords: Indigenous health, participatory research, narrative, social research methods

Author Note: Lauraine is a descendant of the Mandingalpa Clan, Yidiny tribe and Kulla Kulla Clan, Lama Lama tribe in North Queensland, Australia. She is one of the Australian Aboriginal women who shared her story, of illness and her struggle with the Health System, with researchers in the exploration of ways to redress health disparities and strengthen the voices of Indigenous women with disabilities. Her Aboriginal name is Jana-n Jigiddirri Jigiddirri, which means “standout willy wagtail.” Recently, she was honoured with a third name, Buligud, which means Grandmother.

Photographs of Lauraine, her paintings, and some of the other women who participated in the forum can be found at <http://www.wili.org/home/wili-projects.php?gallery=6>

Everybody is a story. When I was a child, people sat around kitchen tables and told their stories. We don't do that so much anymore. Sitting around the table telling stories is not just a way of passing time. It is the way the wisdom gets passed along.

—from *Kitchen Table Wisdom: Stories That Heal* (Remen, 1996, p. xxvii).

We each have separate stories, but this article focuses on the story of our coming together through a research project. In the early days of our union, Lauraine, after allowing us to interview her, showed us her painted story. It was our interactions and growth around this painting that formed the introductory framework for our story. Lauraine painted a second canvas after our first meeting, which she entitled, *Unfinished Journey*. This painting represented our current story—what we hoped to achieve together through the action phase of our research. *Unfinished Journey* was a testament to her belief that our relationship would endure over time, but also perhaps a reminder to us that researchers come and go from people's lives, sometimes in non-authentic ways.

Indeed, our story together is an unfinished journey—mainly about process. The reader may find herself saying, “But I want to know what happened. What were the outcomes of this research? Who benefited? Who benefited the most?” The answers to these questions might arrive in time; some of our answers are documented elsewhere (Barlow, 2009; Cochran et al., 2008; Kendall & Marshall, 2009) and will not be a part of the story told in this article. Through Lauraine's teachings, we have learned to resist the impulse to think from our Western empirical research systems as dictated by our training and background disciplines. Of course, we remain influenced by our backgrounds—for instance our dependence on writing, which is the preferred and dominant mode of communication in Western research, and to deny this would be unrealistic. Lauraine, on the other hand, uses creative options of communication open to her as a result of her background—“our elders were our libraries, our paintings are our history and our future.” Thanks to Lauraine's abilities, we now understand, as Ittelson (2007) observed, that

The constant obeisance that academics pay at the altar of language may represent an occupational blindness. Written language, in all of its many forms ... rests firmly on the foundation of the visual arts, and the visual arts, historically and contemporaneously, play an equally large and important role in communicating, recording and analyzing information. (p. 281)

To tell us her personal story, Lauraine used narrative, poetry, letters, paintings, touch, the voice of friends, and the inclusion of “us” into her family interactions. Lauraine's story and the connections we made with each other inspired an international gathering of Indigenous and non-Indigenous women (Kendall & Marshall, 2009). Unfortunately, at the time of the gathering, Lauraine was pronounced by her doctor as too sick to travel. Nevertheless, her story was still heard through video, paintings, poems, and the transcript of our interview. Lauraine's story has now been presented in multiple forms for nearly a decade, and her story continues to influence many women—it challenges non-Indigenous people to rethink the way they work and motivates Indigenous women to trust in the value of their stories. It has become an “unfinished journey” as predicted by Lauraine through her painting.

Why an International Forum? Why Women's Stories?

The international forum, *Women as Researchers and Partners: Participatory Action Research and Indigenous Ways of Knowing*, was held in Honolulu, Hawai'i on July 25-27, 2004. It was based on three important premises: (1) the voices of Indigenous women with disabilities must be heard,

(2) women have a need to come together in a unified forum to address issues that affect women, and (3) women can take a lead role in designing community solutions.

Across the world, Indigenous women with disabilities continue to experience discrimination and inappropriate services resulting from (a) the failure and reluctance of the dominant culture to understand the vast differences between European and Indigenous cultures and (b) the prevalence of popularized stereotypes of Indigenous women and their communities. Attempts to address these stereotypes and improve the appropriateness of services for Indigenous people with disabilities are hindered by small populations and the lack of power or influence associated with such small numbers. An international gathering was one way of redressing the balance and amplifying the voices of Indigenous women with disabilities.

In gathering the research that underpinned this event, many Indigenous women from around the world shared their stories with us. As one of the Australian Aboriginal women who shared her story of illness, her struggle with systems, and her supportive family, Lauraine explicitly reserved the right to interact with us in her chosen method rather than our chosen method. She directed our discussions, thus giving voice to and keeping control of her knowledge. Lauraine's story was told to us at her chosen time and place, with her chosen style and method. When we first gathered in Lauraine's kitchen to listen to her story, to record her story, and to use her story in planning the forum, we sat on different sides of the table—as is often the case—with the researcher on one side and “the researched” on the other. However, another vision of Lauraine's kitchen table emerged during our first meeting—one with Lauraine at the head of the table, with researchers on either side. It was not lost on us that this configuration was symbolic of the true, but often hidden, locus of power in research interactions.

Lauraine began her story by reminding us that “it wasn't until 1967 that we [Australian Aboriginal people] were accepted as humans”—that for the first nine years of her life, she was considered “non-human.” With this reminder, Lauraine, at the head of her table and in control of her own story, began our journey. In this article, we focus on Lauraine's story—her unfinished journey—as an example of how research can affect both the researchers and the researched.

The Start of Our Unfinished Journey

I've never had much sickness in terms of illnesses growing up. My mum hasn't told me if I had anything major as a child or as a bub. ... Aboriginal babies were not really medically looked after or treated. The mother, the parents, the father, the grandparents would just use their know-how, bush medicine, to try and help the child. But somewhere along the line the doctors agreed that I would've come in contact with or had rheumatic fever because I had a heart attack in 1992 ... I was 33.

—from Lauraine's story in “Come Sit with Me; Let's Yarn Together for a Little While” (Barlow, 2009, p. 55).

Catherine: So Lauraine, why didn't anyone ask for help back then for your family [in reference to the known family history of cardiovascular disease in Lauraine's family]?

Lauraine: We were never encouraged to talk—we only spoke, only opened your mouth to speak when you were spoken to. If you opened your mouth without having permission, you were flogged, my parents were beaten severely. ... Remember, we were not humans, so it was hard for us to speak up.

Catherine: We are interested in the story of your illness, Lauraine, and also what it means to be Aboriginal and have an illness?

Lauraine: See our story, Catherine, started before Edward [husband] and Lauraine ever became a couple—before Edward and Lauraine ever existed. Edward's father and his brothers were fighting enemies of my father and his brothers. So my family and his family could never get on. Every time they saw each other, it would be bloodshed, because they couldn't stand to look at each other. So Edward and I were like Romeo and Juliet, that's our story. When Tara [first-born daughter] became ill, I said to Edward, that's my blood and your blood fighting inside that child. Isn't that interesting?

Elizabeth: Lauraine, we have been talking to you about getting together with other women from around the world to discuss how they think about disability and chronic illness. What do you think about doing that?

Lauraine: Well, in history, women have always been saying, look I have a voice, you know, listen to me or do you have to speak to my husband? I recently went to a gynecologist, the whole time he sat there talking to my husband, discussing my body and my problem with my husband—and I thought “this is not happening in this day and age?” The doctor I see now, the first thing when I went to see her, and I sat down, she said “tell me your story—tell me about yourself,” which I did and from there, we have learnt together what is the best way to treat me.

Elizabeth: Will our talking today and in future make any difference to those doctors who don't want to listen to your story?

Lauraine: Yes, it's important. Since I've had my heart attack, that was the beginning of my journey with the medical profession! I think they see a black face and they keep putting you under the microscope, criticizing you and looking for your mistakes. When [Caucasian health professional] first came here, she saw how many bodies were sleeping in this house and she freaked because it just wasn't done like that in her life. But they [the extended family members who lived with Lauraine] needed love and comfort. We had no choice. [lengthy pause] You know, we can growl all we like—me and Edward—it's not until we call her [Caucasian health professional], a white face, that things get done to help us, I don't know. [another lengthy pause] One thing is that she [Caucasian health professional] has learnt a lot from us—we taught her and now she is starting to see me as who I really am.

Catherine: ... so what makes Lauraine, Lauraine?

Lauraine: I would have to say it's my family, and when I say family, I don't just mean my husband and my children. I mean everyone—my sisters and my brothers and their children, my mum, my memories, the good times, my weaknesses, my strengths, my sickness, my illness, my sense of humor and my faith. So to really know each other, we need to share these things.

Elizabeth: So, Lauraine, would you be willing to let us share those things today so we can get to know each other?

Lauraine: Of course, my dear.

After describing some of her life events during that afternoon, Lauraine surprised us by saying, “I can do this [tell my story] so much better by showing you.” She left the room and returned with a painting of beautiful greens, blues, and browns, with a golden center. She held up her painting—the painting of her life—and proceeded to tell her story through symbols.

Lauraine: This is my story—it depicts the year that I have just been through—I saw myself as a river, but I also saw myself as the nurturer, everybody wants to be around me. When I think of bamboo, I think of home and security. The fire is the insults and persecution. Teardrops—my tears kept flowing and the creek became a rapid, we were really tossed about on that rapid, but then the creek was dammed up—they had stopped the river from flowing, stopping us from being who we are. The eel is the keeper of a natural spring so the water can keep flowing—the old people say if you come across an eel, leave him there because it keeps the water there—Edward’s my eel. The jelly-fish teaches me to cope. To swim, the jelly-fish takes water in and then pushes it out to propel it forward—so when I have problems, I can take it all in, but I am able to push it away again because I already have too much to worry about.

At a subsequent gathering, to which Lauraine had invited other Aboriginal women to discuss the forum, each woman told her own story by way of introduction. Lauraine again brought out her painting and began to tell her story. Without hesitation, one of the other Aboriginal women stood and, without having previously seen the painting, reliably interpreted the story as it emerged through Lauraine’s narration. Lauraine made no mention of the symbols within the painting, only her life events and the emotions those events generated for her and her family. The other woman continued to move through the painting, correctly identifying the link between its symbols and Lauraine’s experiences.

This is how we learned more about Lauraine’s story, through data points on a canvas. The method of communicating was unfamiliar to us as non-Indigenous women and unknown to most health researchers. The story was based on symbols, colors, forms, and non-verbal concepts that were extraordinarily meaningful to, and clearly understood by, all the women in the room except us. Lauraine’s art formed an impressive language, both marginalised by the fast-paced modern world and something to be envied by those of us trapped in the endless stream of emails and texts. But, without cultural interpreters, we were excluded from this both historic and contemporary form of communication.

As mentioned earlier, we are forced to think about how often the non-Indigenous research academy silences the voices of Indigenous people by discounting the visual arts as storytelling in social science (Ittelson, 2007). Our analysis reinforced our resolve that Lauraine’s story should be told by her rather than by us, even though we had never thought it might be told in paintings. Certainly, we never anticipated that our journey with Lauraine would be captured in the second beautiful painting she presented to us the following week. This painting, the *Unfinished Journey*, became the theme for the international forum and inspired the women who attended to openly share their stories with each other.

Lauraine: Inspired by our first afternoon of conversation in my home, I did a painting and I called it *Unfinished Journey*. My painting honors the process of storytelling and how it brings people together to find a way forward. The circles in my painting represent different campsites. The dots tell a story of places of significance in my journey, a road that has not been an easy one to travel—the waves and curves. But it is a story worthy of recognition, something I didn’t always believe. The symbols are of meeting places or resting places. The handprint says “stop and sit for a while—let me tell you

my story.” By sharing our stories, we regain ownership of the land and our culture. Our journey is not finished yet and will continue until the last dot touches the beginning again. When I told my story that afternoon, I never realized how important it would become to me, my future, my family, and to so many others all over the world. My story makes me important ... aaah [laughter] gamon, Jumby [Aboriginal words for teasing and woman]. But true, it makes me powerful in ways I never thought I could be.

The Never-Ending Story

It was an afternoon of beginnings. We quickly realized that we had entered a never-ending relationship with Lauraine, one that continues to this day and still changes as our spirits enrich each other. The data collection process was nothing like we had imagined it would be—obviously, we could have easily reverted to our traditional model, but we resisted this urge and allowed Lauraine to take us on a journey of learning that continues to surprise us.

Over 30 Indigenous and non-Indigenous women from the United States (including Alaska and Hawai'i) and the Asia-Pacific region participated in the international gathering that was inspired by Lauraine's story and represented by her painting. Attendees included women with and without disabilities, researchers, grassroots community members, and community activists. Each woman who attended the forum came with her own set of values, ethos, and personal tragedies or tales of heroism—the women shared these stories with each other during an emotional two and a half day gathering. The women shared their stories in whatever form they chose, including through art, symbols, rituals, food, and the collective creation of symbolic artifacts. For instance, the Hawaiian women brought the necessary materials to make Hawaiian leis and taught the women this skill. As they wove piles of fragrant flowers and foliage into beautiful strings, they worked together, interweaving their stories of colonization, illness, solutions, and community strength.

The forum brought together women whose cultures and peoples had experienced similar colonization processes. For these women, the forum was a culmination of the networks they had formed throughout previous years as they worked towards this gathering in different ways and different configurations. The idea of an international community focused on the same goal—that of networking to address health disparities affecting Indigenous women who have chronic illness and disability—excited the women.

For us as researchers, the forum constituted an important final step in the participatory action research process—it was our action, and it represented closure because we had brought together women who had asked to be brought together. However, the forum also constituted a beginning, the facilitation of multiple and international conversations that would hopefully result in both global and local interventions, as well as document and confirm global and local respect for Indigenous ways of knowing. Reflecting on our journey over the last decade, we now realize its full impact on our lives and who we are, including how it has changed us and how it has reaffirmed for us that we can continue to learn in different ways and choose to reject our indoctrination as positivist health professionals and researchers.

Even if we chose to describe ourselves from a constructivist perspective, our experience with Lauraine forced us to re-think participatory action research and recognize that it is not inherently emancipatory even though it was intended to be so (Boog, 2003). Hart and Bond (1995) described a useful continuum of action research, noting that this approach could vary from experimental to empowering depending on how the “problem” was conceptualized. In our case, the “problem” with which we had entered the research was re-conceptualized by Lauraine and her friends in

their own way using their own methods. It was through their process of storytelling, rather than anything we had engineered, that the research became empowering.

Storytelling as Emancipation

Hearing Lauraine's story that first afternoon has led to an amazing journey for all of us. The story and the process of sharing the story in so many ways have taken us into a state of liminality, of being neither-this-nor-that, not really belonging in the old camp, but not fully belonging in the new camp either. Anthropologist and sociologist Victor Turner described the state of liminality as "a movement between fixed points [that] is essentially ambiguous, unsettled, and unsettling" (1974, p. 274) and as being "betwixt and between the positions assigned and arrayed by law, custom, convention and ceremony" (1969, p. 95). Through this journey, we have all been freed from constraints of the past and are willing to accept the uncertainty and fluidity of the future.

There is no doubt that research can be a powerful catalyst for those who are "researched," but only if they remain in control of their stories and the consequences of the research to the greatest extent possible. Since participating in the development of the forum and telling her story, Lauraine has continued to share her story. She has authored articles for local media and health magazines. She trained as a peer-leader of an international chronic illness management course, completed her Indigenous Health Worker qualification, and has become a telephone counselor. She serves as a community health promotion consultant and uses her story to motivate people to engage in healthy lifestyles. She has also contributed to audio-visual resources focused on her story to inspire other women with chronic illness. At the launch of one video, *Murri Women Yarning* (Prince Charles Hospital Indigenous Health, 2005), Lauraine stated, "I never thought my story was worth anything until one day when two lovely white researchers asked me to tell my story. We talked many times and I told them my story—my story has helped people all over the world so now I tell my story all the time—my story is worth something and I've been telling it ever since."

But how should stories be told in research? Certainly, there is a need to consolidate knowledge and build bigger pictures by collapsing multiple stories. Nevertheless, stories that are told by the storyteller herself, possibly with a researcher as a co-constructor, need to be distinguished from stories that are themed and re-constructed by researchers (Barton, 2004). Researchers in Indigenous communities should be cautious about the need to retain the coherence and medium of a life story. This is particularly true in our experience. The way in which non-Indigenous researchers might choose to theme and interpret the life story of an Indigenous woman with a disability is likely to differ, purely as a result of cultural biases and insensitivities, from that of the person telling the story.

According to Smith (1999), a Maori researcher from New Zealand, the central goal of any Indigenous research agenda or project should be self-determination, simultaneously engaging the processes of "decolonization," transformation, healing, and mobilization. Indigenous research must have a focus on healing and survival rather than on describing problems. The forum was dominated by stories of healing and survival, and through this process, health and motivation were certainly generated. Notably, we became aware that by ensuring the role of storyteller remained with the "researched" rather than with us as researchers, the focus of the research changed dramatically. We entered the research with the intent of identifying the factors that prevented Indigenous women from accessing services (Kendall & Marshall, 2004), as is usually the focus of Western research (i.e., "problems" experienced by "vulnerable" groups). We wanted to explore ways to redress health disparities and strengthen the voices of Indigenous women with disabilities. Instead, we were presented with strength, resilience, a desire to be in control, and a

focus on solutions grounded in the lives of the participants rather than in the artificial health systems that dominated their lives. This approach to research placed our participants as experts and ourselves as naïve learners, who were simply being allowed to share in a collective form of knowledge that was previously unknown to us.

There is an assumption, however, that collaborative processes will automatically address the damage created by decades of insensitive and inappropriate research inflicted on Indigenous people. Without paying adequate attention to the process of emancipation for both Indigenous participants and non-Indigenous researchers, collaboration can remain tokenistic (Cochran et al., 2008). The forum focused on the use of storytelling, in all its possible forms, to show how participatory research can move beyond rhetoric to emancipation for those involved, including researchers. This approach embraces and legitimizes participatory “voices,” rather than merely enabling participatory “actions” (Clapton & Kendall, 2002). The power of participatory voices in research is that it also assumes competence of community participants to determine and oversee action after the research is concluded (Johnson et al., 2011).

Experiences such as ours are emblematic of the rich, complex level of analysis that can be entertained when one employs a participatory approach to research. This approach engenders trust through empathic understanding and consideration of the other, thus allowing participants to explore more completely the nature and meaning of their experience in their own context and in their own way. As outsiders, our respect for our research findings is enhanced by the depth of our understanding and our ongoing relationship with those who are traditionally regarded as anonymous participants and quickly forgotten. By researchers adopting this approach to the negotiation of the research relationship, many culturally offensive actions could be avoided.

The Big Picture

Influenced by Lauraine, we decided that it was our ethical responsibility to stop and listen to the stories of individual Indigenous women with disabilities and address the challenges raised by participatory research regarding the ownership and management of stories. We wanted the stories of the women to have a place and to be valued in their own right beyond the borders of culture, gender, disability, and class. At the same time, we wanted to tell a larger story about how cultures can come together through international storytelling—how this approach can transcend the isolation created by artificial boundaries between Indigenous and non-Indigenous people, researchers and non-researchers, those with and those without disabilities, and between countries. The importance of this bigger picture is highlighted in a conversation with Lauraine while preparing this manuscript.

Elizabeth: Lauraine, do you remember that day when you first let us into your home and shared all those things with us? What do you think about that day now?

Lauraine: Elizabeth, that day, so many seasons ago, I’d have to say I didn’t realize how much it would change my perception of myself and I didn’t think it would have any impact on anyone. My story is so very similar to so many others—it’s just an echo of so many others who have come before me and will come after me. But I hope those who come after me don’t have so much of a struggle as I did and my mother did and my grandmother did. I hope that they don’t have to work so hard to get recognition of their stories. Someone will eventually get the understanding that they need to listen—hopefully, they will say “hey, this is the way to go—this is the time for us to walk together—no-one in front, no-one behind—just all in one line.”

Elizabeth: I remember you once saying that you had never really told your story to anyone, but nowadays it's in the public domain in so many forms—what does it feel like to know that your story has had so much impact?

Lauraine: To be honest, it's a little bit scary you know, how much impact my story has had because my story seems no different to anyone else, no matter what race you are. It's not a special story, it just has my name to it. I'm proud that it's had so much impact and I can only hope that it always is a positive impact—I'd never want any part of my story to hurt anyone. My intent is for my story to be told to help someone else and I think it has helped many people now.

Catherine: And it is your ill-health that has made you famous, Lauraine. Is that something you expected?

Lauraine: Well, you call it my ill-health, I would call it a part of my strength. Not that I really want illnesses, but it makes me more determined—my body is deteriorating, but my mind is still very much alive. As long as I can talk. ... and I only see that my body is deteriorating when they [medical professionals] tell me it is—I don't feel it.

Catherine: This is our first joint publication that will make its way to an academic audience. Have we fulfilled our objectives or is it yet another beginning?

Lauraine: I'd say we've fulfilled our objectives, but it is also a new beginning—it's exciting because it is another beginning. You, Elizabeth, and I will be going on another adventure after this one and every turn and twist of the journey is important. When an exciting event happens, it's always another beginning because there is always something that you take with you but there's so much more waiting out there for us. So I don't feel that we have started to draw together enough yet—a part of the story is completed so we can put that into the bigger picture, but we have started the next section now, so we have to color that section in before we can talk about the big picture. The big picture! I just remembered something that happened in primary school. We had a composite class [pupils of mixed years and ages] and our teacher was very artistic and creative. She wanted to encourage everyone in the class to be aware of the use of colors and how we can all contribute to a big picture. To help us get the idea, she brought a page from a poster, or maybe it was a comic book. It was an ordinary page with a picture of Donald Duck [cartoon character]. She counted up how many pupils were in the class and she ruled a grid on the back of the page and she numbered each square so each child ended up with one small square—what we had to do was get that little square—it probably would have been only an inch wide—from that little square, we all had to transfer the picture on the front of that square to a bigger piece of paper—we had to copy it as closely as possible using anything we wanted—some used crayons or paints or pencils or anything. We didn't know what we were drawing on our paper, just copying as best we could. When everyone had copied their little squares on to a big page—and that took us a couple of weeks or so—once everyone had finished copying their little area, she asked each of us to put all the pieces together. We were all excited—we all went up one-by-one and put our pieces into place and we had a big poster of Donald Duck! We were all so amazed and so proud of what we had done—we had all cooperated and done our best—even though we ended up with different colors, different shades of blue and different textures, the fact is, it was Donald Duck—it was wonderful. All of us gave ourselves a big pat on the back and clapped our hands. It was a good experience I think on how

we could take a small picture that only each one of us could see—we could enlarge it and share it with the others to see a beautiful big picture. I thought that was excellent. She spoke about how much we could achieve together even though we each had a different piece of the puzzle. When it all came together, see how they all fit together. I've never forgotten that lesson—that cooperation and sharing. She wanted us all to remember that we are always part of a bigger picture no matter where we are—we may only be a small square, but when we all join up, we magnify our little square to a big square and we make up a big picture.

Elizabeth: So where do we go from here, Lauraine?

Lauraine: Well, I don't think this is the end—it's another beginning and I am so proud to be sharing another beginning with you lovely women—we are all sisters under the skin, maybe different colors, but our hearts and emotions are all one. Ladies, I'm ready for the next chapter!

We know that stories told by the people who own them are far more powerful than any other form of communication (Cochran et al., 2008); yet with Lauraine's story, we were forced to consider that women who paint their stories have an equally powerful form of communication—and one for which we may need a cultural interpreter. Our journey together has validated the notion of pluralism and the responsibility of non-Indigenous researchers to collaborate respectfully, often at a very personal and ongoing level, with the Indigenous participants of their research. If we are to find solutions to ingrained health disparities, we need to build research that can be truly emancipatory and decolonizing for all women, Indigenous and non-Indigenous, disabled and non-disabled, and educated and uneducated. However, we will need to work together in an honest and open manner that respects unexpected forms of knowledge. Stories must be recognized as precious belongings, not something to be dissected and reinterpreted out of context.

As we first listened to Lauraine's story, viewed her story on canvas, and were gradually drawn into her life, we knew that this experience was already becoming part of "our" story. Our story became intertwined with the stories of many more women who participated in the forum and continue to interact with us on several levels. For instance, our story is ultimately about developing an ability to identify and reject models or frameworks that limit our thinking and action. As one example, we are aware of the ethical concerns that have been voiced regarding protecting a research participant's identity versus openly encouraging their involvement in the research process—which includes authorship (Giordano, O'Reilly, Taylor, & Dogra, 2007). In this circumstance, we chose to reject the expected method of presenting data and, instead, followed the lead of researchers such as Nespor and Barber (1995). These researchers described their experience of writing collaboratively with parents of children with disabilities following their realization that they could not claim to be the authors of such meaningful narratives belonging to others. More recently, Bosworth, Campbell, Demby, Ferranti, and Santos (2005) have also chosen, in the spirit of participatory research, to identify the participants of research as authors of that work.

After reading this manuscript, Dr. Caroline Eick, an expert in oral histories and cross-group relationships, eloquently described how our partnership has permitted us to

bring to light the agency, dignity, creativity, and central role played by Indigenous women in research that is focused on their health. As they [the researchers] explored their own de-centered place in the research process, they became the peripheral personas, learning to live in "liminality." Within this liminality, they had to go beyond

observing the “other” (the women whose lives they sought to understand), and instead, were forced to experience themselves as the “other.” When they were brought into the center of the Indigenous women’s experiences, it was only by the women’s invitation and by joining with them in an on-going relationship. (Eick, personal communication, August 11, 2012)

This cogent observation articulates the important shift in power that can occur when researchers allow themselves to suspend their own models and frameworks and fully appreciate someone else’s perspective rather than simply supporting participation in research.

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