### **Beginning with Our Voices:**

# How the Experiential Stories of First Nations Women Contribute to a National Research Project

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#### **ABSTRACT**

The purpose of this paper is to review how the experiential stories of First Nations women contribute to a national research project. The project focuses on how women's healing is impacted by their views about themselves as - and the stigma associated with being - a drug user, involved in crime and an Aboriginal woman.

Our project began with three First Nations women on our research team documenting the role of stigma and self-identity in their personal healing journeys from problematically using drugs and being in conflict with the law. In this paper we discuss how key components of feminist research practices, Aboriginal methodology and community-based research helped us position the women's experiential stories in authoritative, recognized and celebrated ways in our study. We illustrate how the women's stories uniquely contributed to the creation of our interview questions and the research project in general. We also discuss how the women personally benefited from writing about and sharing their experiences. Key benefits include the women discovering the impact of the written word, promotion of their healing, personal recognition of their ability to offer hope to women in need, increased self-esteem, and increased appreciation of the importance of sharing their lived experiences with others. Our method of research differs from a conventional western scientific approach to understanding, and as such made important contributions to both the project itself and the women who shared their experiential stories.

#### **KEYWORDS**

Stigma, healing, identity, drug use, criminalization, community-based research, Aboriginal methodology, feminist research practices

"With every stroke on the keyboard there are years of pain being washed away and there is a joy that is overwhelming. Lost and desolate no more. Elated and heavenly are the feelings that pump through my veins straight from my heart into yours. My heart feels so good from having shared with you my life. Freedom is my friend."

(Acoose, unpublished manuscript)

#### INTRODUCTION

he idea for this project came out of a phone conversation between representatives from the National Native Addictions Partnership Foundation (NNAPF), the Canadian Centre on Substance Abuse (CCSA) and Colleen Anne Dell, the eventual Principal Investigator on the project—who was at the time from Carleton University. All participants agreed during our conversation that stigma has a destructive impact on the recovery of women in treatment for problematic drug use, in particular on their self-identities, and that little is known about how to effectively address this. We also acknowledged that many women in drug treatment share the experience of having been in conflict with the law.

We drafted a research grant application in response to our discussion. We sought additional partners to contribute their expertise, including an Aboriginal Elder, Aboriginal treatment providers, First Nations women who have been in drug treatment, treatment centre directors, academic researchers, and community agencies working with criminalized Aboriginal women. We also engaged three expert mentors to provide advice to our team in specialized areas, including traditional Aboriginal healing, drug treatment and rehabilitation. In June 2005, our team was awarded a three-year research grant from the Canadian Institutes of Health Research, Institute of Aboriginal Peoples' Health, to examine the role of stigma, identity and criminalization in First Nations women's healing from problematic drug use.

The problematic use of drugs among First Nations women is a serious health concern in Canada. According to the 2002-2003 First Nations Regional Longitudinal Health Survey, although the documented rate of illicit drug use in the past year is low (7.3 per cent) among First Nations (9.3 per cent for men, 5.3 per cent for women), it is still more than double the rate of the general Canadian population (3.0%) (First Nations Centre, 2005, p. 116). Aboriginal women also make up a disproportionate percentage of Canada's injection drug use (IDU) population, and IDU is a key mode of transmission for the human

immunodeficiency virus (HIV) (Barlow, 2003; Craib et al., 2003). Between 1998 and 2003, 66.9 per cent of all HIVpositive tests among Aboriginal women were attributable to IDU (Public Health Agency of Canada, 2004). Aboriginal women, including First Nations, are also over-represented in Canada's criminal justice system, including incarceration at the federal and provincial levels (Balfour & Comack, 2006; Canadian Human Rights Commission, 2003; Dell, 2001). In 2006, Aboriginal women made up 31 per cent of the federal prison population (Correctional Service Canada, 2006, p. 12), while Aboriginal Peoples represented approximately 3.3 per cent of Canada's total population (Statistics Canada, 2003). To further illustrate, between April 1, 1999 and March 31, 2004, over 2,700 Aboriginal females and about 900 non-Aboriginal females (a ratio of 3:1) were involved in Saskatchewan's correctional services (Johnson, 2005, p. 8), yet Aboriginal women made up only about 11 per cent of the province's population (Saskatchewan Women's Secretariat, 1999, p. 12).

Little is understood either about how women's healing from drug use is impacted by their views about themselves as drug users, involved in crime and Aboriginal women, or about the stigma associated with these identities. Our research team is currently conducting interviews with First Nations women in treatment at a sample of nine National Native Alcohol and Drug Abuse (NNADAP) programs in Canada. NNADAP centres are the main source of substance abuse treatment for Aboriginal Peoples in Canada. The goal of our study is to contribute to the drug treatment field original knowledge that will help improve the burden of ill health faced by First Nations women.

The purpose of this paper is to review how the experiential stories of First Nations women contribute to our research project. The project began with three First Nations women on our research team documenting the role of stigma and self-identity in their personal healing journeys from problematically using drugs and being in conflict with the law. In the first part of this paper, we discuss how key components of feminist research practices, Aboriginal methodology and community-based research helped us position the women's experiential stories in authoritative, recognized and celebrated ways in our study. We illustrate



how their stories uniquely contributed to the creation of our interview questions and research project in general. We then discuss how the women personally benefited from writing about and sharing their experiences. Our method of research differs from a conventional western scientific approach to understanding, and as such made important contributions to both the project itself and the women who shared their experiential stories.

#### Incorporating Our Voices Through Feminist, Aboriginal and Community-Based Research Approaches

Our research grant application centred on our team's commitment to doing research "by, for and with" women in drug treatment rather than "on" them (Fitzgerald, 2004; Kirby & McKenna, 1989). For us, this translated into designing our research to respect the rights, beliefs and values of everyone involved, including community members and academics participating on our research team and the research participants. Our team came to its understanding of respect over time and with the guidance of two Aboriginal Elders. We put our team's understanding of respect into practice in the project primarily by integrating it into the experiential stories of three First Nations women who had previous drug use problems and who had been in conflict with the law. It is important to acknowledge that we did not directly involve women currently in drug treatment because of their potentially vulnerable positions. Our inclusion of First Nations women's experiential voices challenges the claim that western scientific method is the only way to produce knowledge (Gatenby & Humphries, 2000). Contrary to our own methodology, that of western science does not typically accept people's everyday experiences as valid "knowledge" (Tickner, 2005). Neither does it generally promote working in collaboration with the holders of such knowledge (Smith, 1999). Our inclusion of women's voices also disrupts the long-standing power inequalities between the researcher and the "researched" that are characteristic of western science (Shope, 2006; Deutsch, 2004; Hunter, 2002).

To put our understanding of doing research "by, for and with" into action, that is, in incorporating the lived experiences of First Nations women into our project, we drew on principles of feminist research practices (Pederson, 2002; Kirby & McKenna, 1999), Aboriginal methodology (Schnarch, 2004; Gilchrist, 1997) and community-based research (Stoecker, 2003; Institute of Medicine, 1998). We chose these three methodologies because they coincide with our team's commitment to respecting the rights, beliefs and

values of everyone involved in the research process. The three approaches are also in accordance with one of the goals of our research, which is to provide a successful model of collaborative research.

Drawing on key components of feminist research practices (i.e., to privilege women's experiences), Aboriginal methodology (i.e., to serve Aboriginal interests) and community-based research (i.e., to produce knowledge with marginalized community members), it was decided that three First Nations women on our research team would document their experiences with stigma and self-identity in their personal healing journeys from problematically using drugs and being in conflict with the law. Sharon Leslie Acoose, Valerie Desjarlais and Jane Smith (pseudonym) each have a unique and elaborate history; two have been in and out of treatment and jail for many years and have both been sober for more than 17 years, and one has a primary concern of mental health and a secondary one of problematic substance use. A biography for two of the women is included at the end of this article. The objective was for Sharon, Valerie and Jane to reflect on their personal healing journeys in areas we identified as central in our research grant, including problematic drug use, mothering, stigma, treatment, identity as an Aboriginal woman, being in conflict with the law, as well as any additional areas they identified.

At the start of our project, Sharon, Valerie and Jane each shared her story in approximately 5,000 words. Anticipating multiple uses for the stories, it was decided that writing would be the most appropriate means to record them. Members of our team reviewed the women's written account of their experiences for descriptions, themes and patterns among them (Greaves et al., 2006; Carney et al., 1997). The women's stories, in conjunction with the academic literature, assisted our team in creating our interview questions and generally strengthened our project. The three methodologies that supported the documentation of the women's experiences and their incorporation into our project are briefly introduced below. We discuss how each helped us position the experiential voices of First Nations women in our study in authoritative, recognized and celebrated ways.

#### Feminist research

Central to feminist approaches to research is the improvement of women's lives (Fonow & Cook, 2005; Harding & Norberg, 2005). Such approaches accept as "truth" that women occupy a marginalized position in society, and that social structures seek to maintain a power

imbalance through patriarchy, misogyny and gendered and racialized practices (de Laine, 2000). Foundational to feminist research is that understanding women's oppression requires privileging their experiences. This is contrary to traditional approaches to social science (Cook & Fonow, 1986). Focusing on women as a general category, however, does not address existing power imbalances or recognize women's varied experiential knowledge (Shope, 2006). Privileging the experiences of First Nations women is particularly important in this project given the oppressive history of colonization of Aboriginal Peoples in Canada. That said, it is also important to acknowledge that First Nations women who are criminalized and who problematically use drugs are not a homogeneous group; they differ in countless ways, ranging from drug of choice to ethnic background and cultural experiences.

Our project's commitment to privileging First Nations women's experiences is illustrated in our approach to the development of our interview questions. As discussed, our project began with three First Nations women on our research team documenting their personal healing journeys from problematic drug use and criminalization. Each reflected on the important role of self-identity and the impact of stigma on her own healing. The women's experiential stories were reviewed alongside the empirical and theoretical academic literature. The experiential stories advanced our team's understanding of First Nations women's healing in several key areas, including the significance and meaning of community, the central role of hope in an individual's healing from problematic drug use, and the importance of physical and mental health in the healing journey.

#### Aboriginal methodology

Aboriginal research has been described as more a method than an area of study (McNaughton & Rock, 2003). Central to the method is directing research to serve Aboriginal interests, which is referred to by some as Aboriginal self-determination in research (Schnarch, 2004). This is important because the history of research with Aboriginal Peoples is fraught with disrespect and the appropriation of power, which is reflective of the history of colonization of Aboriginal Peoples in Canada (Smylie, 2004; Dua, 1999).

Aboriginal methodology maintains that Aboriginal interests should be central to the research study. Some Aboriginal communities follow ethical and moral protocols to ensure research is helpful and not in any way harmful. (Fisher & Ball, 2003; Castellano, 2004). A well-known Aboriginal research protocol in Canada is the OCAP

(ownership, control, access, possession) principles, which are rooted in the work of the 1997 National Steering Committee of the First Nations and Inuit Regional Longitudinal Health Survey. The OCAP principles suggest that avoiding the abuse and mistreatment of First Nations communities under study requires the administration of an inclusive protocol that indicates the collective ownership of group information, First Nations control over research and information, First Nations management of access to their data, and physical possession of data by First Nations (Schnarch, 2004).

In our team's attempt to serve Aboriginal interests with our project, we used the OCAP principles as a beginning point to discuss varied and often contentious aspects of our research. In addition to the OCAP principles, we relied on ethical protocols from treatment centres involved in the study, guidelines from the National Native Addictions Partnership Foundation and an Elder's teaching on Aboriginal philosophy and clanship. The women's experiential stories and discussions about their documentation have also provided ethical and moral guidance to our study.

Sharon, Valerie and Jane raised fundamental issues about recording their lived experiences, including how the stories will be used in the future, how they will be compensated for sharing the stories and how to support the emotional well-being of the writers in the documentation of their lived experiences. They also suggested that the stories be shared with the research participants to offer them hope and guidance in their healing. Consequently, we put two of the women's stories in a booklet that we distributed upon completion of interviews at treatment centres. Again, adhering to a purely western approach to understanding, which relies on secondary sources in the form of published academic literature, would neither have provided our team with depth of understanding nor instilled compassion as did the women's stories. It is simply not possible to serve Aboriginal interests with our research without the experiential voices of First Nations women.

#### Community-based research

Community-based research is generally defined as "a collaborative approach to research that equitably involves, for example, community members, organizational representatives and researchers in all aspects of the research process" (Israel, 1998, p. 177). The focus on community participation is rooted in constructionist and critical theorist evaluations of "the socially created nature of scientific knowledge" (Israel, 1998, p. 177). It can be argued that



those in marginalized social positions have traditionally been excluded from the production of knowledge. Community-based research focuses on shared participation throughout the research process and works with the strengths and resources of community members to increase the quality of the research (Fletcher, 2003).

The contributions of Sharon, Valerie and Jane's experiential stories to the construction of our interview questions illustrate our team's commitment to producing knowledge with marginalized community members. A second and possibly more insightful illustration is the knowledge gained by our team from the women's experiential stories about the importance of hope in an individual's healing from problematic drug use. Not only was this critical in the construction of our interview guide, it was also perceived as providing our research participants with a tangible "message of hope", the applicability of which we verified with all members of our research team. Messages of hope are not found in academic literature.

Turning the idea of a "message of hope" into action, we decided to offer the interviewees a tangible gesture of hope in the form of a gift of an oyster/pearl. The inspirational story of the oyster is described by Nabigon (2006): The strongest example I can find in Nature comes from Sister Water, the cradle of Mother Earth's womb. In her depth can be found the teachings of the oyster totem. Here the oyster's precious jewel, a pearl that starts out as a grain of sand, is nothing more than an irritant that has entered the barnacle or oyster at some point and cannot be removed. That oyster has lodged in its folds something that is very painful to its habitat-being. The sand cannot be removed and now the oyster must contend with it, using its natural abilities to deal with the situation. Unlike humans who pretend "it" will go away, the clam pulls from its inner qualities a working solution. The clam totem's teaching resembles our own feeble attempts to make peace with our emotions. It didn't ask for the lesson, but it was forced to take a negative aspect of life and work with its principles. In this instance Nature teaches the oyster to tap into its intrinsic abilities to protect itself from corrosion. The oyster now heaves up its own mucus in multiple layers until it polishes smooth the intrusive entity—the grain of sand. Time then becomes the key. The outcome is a jewel that is admired by all. (pp. 52-53)

Upon completion of an interview, we provide the interviewee with a natural oyster that has a pearl in it. While the oyster is being opened, the researcher shares the story of the pearl as Nabigon describes it.

The experiential stories of three First Nations women on our research team meaningfully informed our research in multiple ways. The majority of these important contributions could not be gained through a strictly western scientific approach to research that relies primarily on academic sources and generally neglects the everyday lived experiences of individuals, in particular those who are marginalized and typically not a part of the production of knowledge. We share the perception that drawing on key components of feminist research practices, Aboriginal methodology and community-based research has helped us position the experiential knowledge of First Nations women in our study. In conjunction with a western scientific approach, the women's voices led our team to an enhanced understanding in key areas of our study and a strengthened research project.

#### The Benefits of Sharing Our Stories

For this paper, Sharon, Valerie and Jane each reflected in writing on what it has meant to them to share their healing journeys with the project. In approximately 1,000 words, each woman wrote freely about her experiences and thoughts. The women wrote separately because of the personal nature of their reflections and because they could potentially influence each other's assessments. They answered two questions, one about what it has meant to be asked to share their story, and another about any benefits or drawbacks to them personally from sharing their story. Their reflections were reviewed for descriptions, themes and patterns among them. Five dominant themes were identified, discussed and verified among the authors.

None of the women wrote about negative consequences from sharing their stories, with the exception of describing the difficulty of doing so, as discussed below. The five main themes identified in their reflections are: discovering the impact of the written word, promotion of their healing, recognition of their ability to offer hope to women in need, an increase in their self-esteem, and increased appreciation of the importance of sharing their lived experiences with others. Each benefit is presented in the women's own powerful and candid words.

#### The impact of writing about our experiences

Sharon, Valerie and Jane each relayed how writing about their personal experiences affected them differently than speaking about them. The tangibility of their words was equated with confirmation of their healing. They also thought that writing their stories gave them a sense of permanency. The women relayed that it was in some ways more difficult to write about their experiences, although the words they used were identical. The written word was identified as having potential to leave a powerful and lasting impression on the reader as well as the writer.

Sharon: Sharing my story always gives me a new faith in myself, as I am able to look at what I wrote. Sometimes I never cease to amaze myself because I feel so silly for what I put me through. Trust me, there are days when I can jump on the pity train and my ass rides for a long time. But when I read what I wrote... then I become revived once again.

Valerie: I verbally shared my story so many times in the past 20 years, but never actually sat down to write it. I asked myself 'How do I write this?"... As I wrote my story, I realized it was similar yet different than verbally telling my story. Well, words are words that come out of your mouth and people can misinterpret what you're saying, and some even forget the message you're leaving. Whereas, with writing, you can leave a message of hope and can provide courage to someone who is really searching to understand one's life. Someone may be reading my story 50 years from now, when I have passed this physical life and moved to the spiritual realm.

# Sharing our experiences is a part of our healing journeys

Each of the women communicated how sharing her story with the project was an important part of her own healing journey. Once again, they acknowledged that while it is difficult to reflect on their pasts, it is important for them to do so to progress in their healing.

Jane: Putting my experiences on paper was extremely difficult yet exhilarating... I must continue to vocalize the challenges I have faced and those that are ongoing. That is how I survive; by sharing and loving, contributing to my community and thereby growing.

Sharon: Sharing my story is what I do. It is where my continued healing journey brings me new appreciation for other women who are in need... The ghosts of the past surface at different times when I am sharing and the memories are painful. But at the end of the day I know that I will be okay because it is all part of my continuous healing journey... Writing this is self-discovery of my inner Medicine Wheel that I carry in my heart, mind, body, and soul.

#### Our stories offer hope to women in need

The idea of offering hope to the participants in our study through the gift of an oyster/pearl was discussed as an illustration of First Nations women's experiential voices contributing to the project. Hope was relayed in Sharon, Valerie and Jane's motivation for sharing their life experiences. Their collective desire is to provide hope to women in need, with whom they have experiences in common.

Sharon: It meant that sharing my life without alcohol/drugs might benefit the lives of others that are new in recovery and need to hear the possibilities. When I was out on the street or in prison or in treatment there was never anyone there for me. When I am asked to do something today that may save a soul, I have no hesitation. It is important to be able to reach out and touch the heart of a woman that has no idea how to love and to show her the way. It is important to give her hope for a renewal of life that she thought would never be and to give her peace of mind... Through sharing my life, perhaps one day another woman will benefit... I hope it will give one woman one small chance at full recovery.

Valerie: I realize people will make use of the only resources that they have within reach and if its alcohol and drugs, then that's the only resource they have. This is one of the main reasons I agreed to write my story. I hope this written document can become a resource for inspiration and hope rather than turning to addictions.

### Documenting our lived experiences increases our self-esteem

The women spoke of an increased sense of self-esteem and a general feeling of well-being as a result of sharing their experiential stories with the project and with the women who will participate in interviews. It has been documented in the literature that this benefit occurs when individuals tell their stories in their own voices and perspectives. (Ristock & Pennell, 1996; Stanley & Wise, 1991). Once again, the women noted that the necessity of reflecting on their experiences didn't make it easy.

Jane: Although frightening at times, I am committed to breaking the stigma... An improved self-identity has emerged and I am learning more about myself as I continue on my lifelong healing journey. With the love and support of my family, friends and community I am stronger... Through my experiences in this project with my story I now feel more worthy of holding my Spirit name.



Sharon: Whenever I am asked to write or speak to my recovery as an addict it is an honour that I bestow to be very high and it makes me feel good about being alive. It always means so many good things when you are asked to share, it makes you feel worthy and important to another human being... Being asked to write this important piece of work is just another stepping-stone in my path. It has brought me great joy to be able to do it... I am very fortunate to be able to break the silence so that other First Nations women will know it is okay to reach out. So yeah, being asked to write this has been a revelation and a means to an end. It is self-discovery... [For] me being asked to do something like this is a tiny miracle that makes me feel like a million bucks.

## Appreciation of the importance of sharing what we have learned

Sharon, Valerie and Jane each wrote at length about the importance of sharing with others what they have learned in life. Writing their stories for the project provided them with this opportunity. They saw sharing what they have learned as markedly different from sharing hope. The latter is about encouraging and inspiring individuals to take up the challenge to heal, whereas the former is more about the mechanics of "how to" heal.

Sharon: So you ask what it has meant to me to share? Well, it is amazing. And, if there is more that I can do to put a smile on some First Nations woman's face by her benefiting from my story then all this would have been worth it. This is fierce...I want so much to make a difference in another First Nations woman's life. I mean, I know that I cannot save the world, but maybe I can help save one small piece.

Valerie: The first initial thought I had for writing this story was, "They are going to use our stories just like a 'guinea pig,' don't they ever quit trying to study Indian people and see what makes them tick." But then I realized writing my story also provided me with the opportunity to continue to carry the message to those whom are still struggling with substance abuse and provides them with an opportunity to really look at what keeps them a prisoner in their own world.

#### **CONCLUSION**

This paper has focused on how including First Nations women's experiential voices in an otherwise standard western scientific approach to research has benefited both the research project and the women who shared their stories. We drew upon components of feminist research practices, Aboriginal methodology and community-based research to design our study to be "by, for and with" our research participants rather than "on" them. For us, this means that our research respects the rights, beliefs and values of everyone involved in it. This paper has discussed and provided examples of how we have honoured our commitment to this form of research by incorporating into our project First Nations women's experiential stories about stigma and self-identity in their personal healing journeys from problematically using drugs and being in conflict with the law.

#### Biographies of Sharon and Valerie

Sharon Leslie Acoose is from Sakimay First Nation in Eastern Saskatchewan and is of Saulteaux decent. A recovering addict with 17 years of sobriety, she has spent many years in and out of both prison and treatment. She is presently an Assistant Professor with the School of Indian Social Work at the First Nations University of Canada, Saskatoon Campus. She is also enrolled in the PhD program in the College of Medicine, Department of Community Health and Epidemiology at the University of Saskatchewan. Her passion, her love and her life is to work with other Indian women who have mirrored her life.

Valerie Desjarlais is a Saulteaux woman who resides at the Kawacatoose First Nation in Saskatchewan. She is a graduate of the University of Regina with a Bachelor of Human Justice degree. She has specialized training in therapy, domestic violence and chemical dependency. Along with her formal education credentials, Valerie has personal life experiences of violence, addictions, incarceration and loss. She shares these experiences in blunt and humourous ways. She enjoys challenges in her life, and as frustrating it sometimes gets, she continues to pray and to rely on the Creator to help her with her everyday tasks.

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