

# A NARRATIVE OF RESEARCH WITH, BY, AND FOR ABORIGINAL PEOPLES

ANGELINA BAYDALA, PHD  
UNIVERSITY OF REGINA

CHERYL PLACSKO, MA CANDIDATE  
UNIVERSITY OF REGINA

MARY HAMPTON, EdD  
LUTHER COLLEGE  
UNIVERSITY OF REGINA

CARRIE BOURASSA, PHD CANDIDATE  
FIRST NATIONS UNIVERSITY OF CANADA

KIM MCKAY-McNABB, PHD CANDIDATE  
UNIVERSITY OF REGINA

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## ABSTRACT

In an effort to contribute to the currently developing understanding of ethical protocol for Aboriginal research, this paper offers a reflection on how the First Nations principles of ownership, control, access, and possession (OCAP) are understood and enacted by one research team committed to community-based research and participatory action with Aboriginal peoples in southern Saskatchewan. This account focuses, not on the methodology, but on the interpersonal process of community-based action research designed to increase health care providers' awareness of the end-of-life health care needs of Aboriginal individuals and their families. It is our intention to bridge local and traditional knowledges, promoting respectful research with, by, and for Aboriginal peoples. To this end, we offer this narration of the personal meanings of our research process.

## A NARRATIVE OF RESEARCH WITH, BY, AND FOR ABORIGINAL PEOPLES

In order to contribute to the understanding currently developing of ethical research protocol for conducting research with Aboriginal communities,<sup>1</sup> we recount our experience of a community-based research initiative bridging traditional and current practices of end-of-life health care for Aboriginal individuals and families in southern Saskatchewan. We do not focus on the qualitative research methods used in this project but, rather, on the personal context in which the methods unfold. In recounting the process that we have followed, our intention is not to advance the rigidity of qualitative research methods, nor to proceduralize the notion of ethical research, but to offer an immersion into the lifeworld that we experience in conducting what we understand to be respectful research with Aboriginal peoples.

At present, there is a great deal of scholarly investigation into the question of respectful Aboriginal research. The 2005 focus issue of *Canadian Journal of Nursing Research* calls for identifying ways Aboriginal health and health inequities are successfully researched and understood. The 2005 Aboriginal Education Research Forum calls for conference presentations from researchers with respectful, caring, and passionate ways of conducting Aboriginal research. In the hope of exploring the inclusion of Aboriginal values and perspectives in Aboriginal research, these conference organizers ask, "What is Aboriginal research and what does it mean to Aboriginal commu-

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1 In this paper, we use the terms "Aboriginal" and "Indigenous" to refer to the first peoples of Canada who may or may not have "status" under the Indian Act as "First Nations" peoples.

ities?” In the spring of 2004, the Interagency Advisory Panel on Research Ethics organized a call for input to devise Canadian national guidelines for ethical conduct of research involving Aboriginal peoples. The Canadian Institutes of Health Research (CIHR), Natural Sciences, and Engineering Research Council of Canada (NSERC) and Social Sciences and Humanities Research Council of Canada (SSHRC) are consulting with Aboriginal research organizations across the country to begin the revision of research guidelines and policies to reflect greater sensitivity to Aboriginal knowledge and rights of communities and to develop an ethics of research involving Indigenous peoples (Ermine, Sinclair, and Jeffery 2004).

Although there seems to be general agreement that successful Aboriginal research needs to be respectful, it is not clear what exactly is *meant* by “respectful research.” Schnarch (2004) elaborates on the themes of ownership, control, access, and possession (OCAP), first generated by the Steering Committee of the First Nations Regional Longitudinal Health Survey, and notes how these themes reflect general notions long advocated by First Nations and other Aboriginal peoples in Canada, including Métis and Inuit peoples. He observes, “although there may be a good degree of consensus, the meaning and implications of OCAP continue to take shape and to be debated” (p. 81). Furthermore, he emphasizes that “the real challenge now is how to do research in ways that respect OCAP” (p. 89). Because there are numerous ways of putting principles into action, the purpose of this paper is to provide an experiential account of our time respecting these principles in order to illustrate a possible meaning of successful respectful research.

## OUR METHODS OF RESEARCHING END OF LIFE HEALTH CARE DELIVERY

Our research team is committed to participatory action research with Aboriginal peoples in southern Saskatchewan. Participatory action research (PAR) establishes liberating dialogue and emphasizes community-based production of knowledge (Mertens 1998). PAR makes space for voices that have been oppressed by formal knowledge systems. This research method implies cooperative exchange of academic and cultural knowledge to set the agenda for research and inquiry. Community meetings, the sharing of food, traveling to participants’ communities, observing cultural protocols, and providing honoraria develops relationships in which people can reflect on their communities and their experience and openly share ideas.

Our research team consists of Elders from several First Nations of southern Saskatchewan; Aboriginal and non-Aboriginal graduate and undergraduate students; faculty from the First Nations University of Canada, Luther College, and the University of Regina; as well as Aboriginal and non-Aboriginal health care providers. Our work focuses on promoting the inclusion of self-defined end-of-life health care for Aboriginal families within hospital settings as well as within community agencies in Regina. Different phases of this research have been supported by different grants.

The first phase of the research involved community building and was supported by the Saskatchewan Health Research Foundation (SHRF) and the Indigenous Peoples' Health Research Centre (IPHRC). This support allowed us to develop relationships with members of the community, to build our research team, and come to understand the direction that the research needed to take. We then developed research products (videos, presentations, information sheets) that were an appropriate response to the expressed needs of the community. The second phase of our research, supported by the Canadian Institutes of Health Research (CIHR), involved piloting the use of these research products in ways that respected the community's intention to promote culturally appropriate end-of-life care for Aboriginal families and gave recipients a chance to provide systematic feedback. We are currently in the third phase of our research, also supported by the Canadian Institutes of Health Research (CIHR), which is focused on developing space and further resources for Aboriginal families in a newly established bereavement centre.

Health care of the aging and dying is an emerging health issue significantly affecting Aboriginal communities. We came to understand that it was vital that research into differing interpretations of end-of-life care be done to eliminate existing disparities in quality of health care. It seemed that the most appropriate method for investigating culturally appropriate health care was qualitative analysis. The complex determinates of a healing relationship and a healing situation could not be investigated exclusively by observational methods. Where quantitative research must begin with definitions of health and care prior to investigation, qualitative research was able to inquire into the meaning of health care instead of inadvertently assuming what was being investigated. We sought to understand the meaning of care in contexts of actual practice. We spoke with health care providers who regularly provide end-of-life care; Aboriginal families who had experienced a significant death loss in hospital; and Elders, using traditional protocols, about their experiences of meaningful practices of care at end of life and how care can go wrong.

Such dialogues provided the basis for documenting differing interpretations and social concerns that health care providers and recipients and Elders identified when reflecting on health care practices. Systematic qualitative analysis and in-depth consideration of individual narratives formed the basis for generating greater understanding of the differences and similarities of end-of-life health care practices in traditional Aboriginal and conventional Western medicines.

Developing and maintaining trustful and respectful relationships was of utmost importance in the success of this research. Audio and video taping interviews and group discussions, transcribing, drafting edited materials without losing the intended meaning of the speakers, circulating editions to participants for verification of meaning, agreeing upon final renditions for release to the public — each of these steps required the on-going trust and respect of every contributor to the research project. Otherwise the research would not have moved forward and, thus, would not have been successful.

Unlike validation and process research, at the forefront of this interpretive approach to research is the hermeneutic principle that understanding is generated by the exchange of interpretations. The documents produced by the above outlined hermeneutic or interpretive approach are circulated as contributions to an on-going inquiry into the significance of care. The conclusions do not lay claim to reliability and validity across time and place, but instead offer in-depth understanding of lived instances internally validated by the iterative dialogical process of stating interpretations, verifying meaning, and generating understanding (Rennie 1999). This progressive analysis of meaning culminated in the generation of self-correcting understanding for the purpose of significant action, if not static truth.

## A NARRATIVE ACCOUNT OF OUR RESEARCH PROCESS

The contributors to this paper are those participants in the research project who are academic researchers working with Elders and community members. Focused reflection on our experiences conducting research into culturally appropriate end-of-life care were shared in dialogue, recorded, and transcribed. The transcription was analyzed within the context of our present concerns. The text from our focused dialogue was plotted into an historical narrative of the research process from its inception to its present state. The account was circulated and re-circulated to all members of the team for re-

iterative feedback to ensure accuracy of meaning. In light of the First Nations principles of OCAP, an account was constructed to consider possibilities for rebuilding trust, decreasing bias, improving research quality and relevance, preserving and developing culture, developing meaningful community capacity, and empowering change (Schnarch 2004). We used the form of narrative in our analysis because it communicates the lived time of our experience (Ricoeur 1983). Polkinghorne (1988: 11) explains, "Narrative is a scheme by means of which human beings give meaning to their experience of temporality and personal actions."

In many research and academic contexts, one story is expected to represent all peoples. On our team, we are careful not to put words in the mouths of others. The Aboriginal people of southern Saskatchewan do not speak on behalf of the Dakota Sioux, Métis, or any other Indigenous peoples, just as the non-Aboriginal people on the team do not speak on behalf of Aboriginal peoples. Carrie Bourassa, a Métis woman academic on our team, relates her experiences of tokenism:

I've just dropped off some research teams because they expect that you're going to be able to speak for other people and you can't. You're sort of that token person sometimes. It goes against our teachings. You can't speak for everybody, you can share what you've been taught, the gifts that you've been given to share but you can't speak on behalf of everybody.

In what follows, we allow the voices of our research team to speak for themselves. The following account of what has happened for us, how players came on board, and what pieces were done sequentially through time, is a less abstract, more personal representation of what we experienced as the process of fair, trustworthy, relevant, egalitarian research. First of all, we have found that this means literally creating space, geographical space, for research but also relationally creating space and protecting that space.

## THE INCEPTION OF A RESEARCH SPACE WITH, BY AND FOR ABORIGINAL PEOPLES

Our story began at the *Centre on Aging and Health* at the University of Regina. The Centre considered it important to have a committee for the study

of aging amongst First Nations and Aboriginal peoples. The first member of what would later be our research team, Mary Hampton, a faculty member with extensive research experience working with Aboriginal communities, was invited to develop this committee. She suggested, however, that it would be more appropriate for the Centre to ask an Aboriginal person to spearhead the committee. In the end, Mary, a non-Aboriginal researcher, was given a position she felt was a bit outside of her scope but for which she was eligible because of her university qualifications. Mary agreed to the position but requested that the committee be large and include Elders and as many people as possible from a diversity of Aboriginal communities. The Centre worked together with the Committee to find a way to make this possible.

University expectations, such as hierarchical structures of organization, presented inconsistencies with traditional ways. Instead of having a single person in charge of a hierarchical organization, the community, especially Elders, were involved at all levels. It was important not to conform to university expectations that research be led by a few experts. To begin building community-based research relationships, Mary approached a respected Elder to request guidance for the *Committee for Aboriginal Health and Aging Research*. Mary began by talking with Elders asking for guidance for the *Committee for Aboriginal Health and Aging Research*. Our guiding Elders requested that more of the Aboriginal community be represented on the Committee in various capacities. Although a non-Aboriginal centre, the *Centre on Aging and Health* was intent on opening a space for voices in the Aboriginal community. An understanding of what would be necessary for this to occur began to develop.

In order for our guiding Elder to become part of the Centre, he had to apply for membership in the Centre and this required completing university paperwork stating his qualifications. From our Elder's perspective, letting others speak for one's reputation was more appropriate than stating one's own accomplishments. Self-report of one's qualifications and accomplishments was contrary to his traditional ways. His response was, "I don't need to do this," which was correct; however, he saw the need for research into bridging conventional and traditional health care at end of life and agreed to apply for membership.

Principles of OCAP suggest that Aboriginal communities should lead or control the research. In our experience, some conventional university assumptions about how research should be conducted, namely that a select few academics direct a literature-driven research agenda, had to be challenged.

Difference of assumptions became apparent when questions were asked such as, “Why are Elders needed on the research team? What will be their role?” Members of the *Centre on Aging and Health* came to understand that research participants are not only in relationship with the researchers, and participants are not only collaborators on the research but, also, the community being researched sets the agenda and direction for research. Customs for conducting university research were altered so that Elders could be accepted as full research collaborators and the research could proceed as truly community-based. It is important to note that Elders are never self-appointed — they become Elders by being recognized by a community or communities they serve and, therefore, often have a very good understanding of community needs and priorities. Our guiding Elder said, “Based on my experience, and what I know from my own life, this is what needs to happen. This is a need in the community.” In this way, the idea for our project came from one Elder and yet from a community. Instead of the academic community saying, “This is what’s best for you,” the community being researched was given space to say, “This is what we need. This is what we think is missing and this is where we think you should direct the research.”

In our experience of research with Aboriginal communities, the academic researchers form mutual relations and a sense of equality develops within the community. This follows the teachings of the Medicine Wheel or Circle of Life where all on the wheel are equal. Through open communication regarding the needs of each party, a research relationship between community and academia founded in trust and mutual understanding allowed the team to move forward. The *Committee for Aboriginal Health and Aging Research* now has the freedom to conduct culturally appropriate research while receiving acknowledgment of culturally unique protocol and support from the university’s *Centre on Aging and Health*.

## ESTABLISHMENT OF MEANINGFUL RELATIONSHIPS AND RECIPROCITY

Schnarch (2004: 90) suggests negotiating “written agreements or memoranda of understanding that spell out the research relationship between your community or organization and your research partner(s).” In the first meetings of our Committee, we drafted the following statement of our research intentions:



1. to facilitate dialogue and understanding between Aboriginal and non-Aboriginal peoples about cultural issues of aging;
2. to encourage culturally competent research that will benefit Aboriginal communities;
3. to create a space where research topics that are priority areas for Aboriginal communities can be voiced;
4. to develop grant proposals based on information and service needs of Aboriginal communities;
5. to ensure that all research will observe ethical guidelines that protect ownership of traditional Aboriginal knowledge (e.g., First Nations' control).

### GATHERING A TEAM FOR STEERING AND ORGANIZING RESEARCH

With an understanding of the limits and possibilities of conducting community-based research, Mary began to build a community that could respect Aboriginal ways of knowing, meet academic requirements, and have all collaborators strong in saying, "This is for the Aboriginal community." Step by step, a community of researchers emerged and expanded by inviting faculty, graduate students, Elders, health care providers, and community agencies that provide end-of-life care services to enter into dialogue about their understanding of the research needs. In lieu of first going to the community as a researcher to collect something, we invited people in, offered lunch, and ate together. Only then did we ask the agencies to participate in a survey to assess community resources and research needs.

We were sensitive to the fact that people receive grants for Aboriginal research and intend to go into a community, take what they can, and leave without returning. As researchers with, by, and for Aboriginal peoples, we were intent on finding ways to give to the communities. We began by investigating whether education for health care providers on end-of-life care for Aboriginal families was an important topic in the community. The community survey confirmed that access to the provision of traditional Aboriginal care at end of life was very important. At that time, the people and agencies interviewed in the survey became community partners in the research. It was through the survey that it became apparent that our Elder's suggestion *was* a topic of research important for the community. Following through academically, our literature review indicated a paucity of research in this area.

Direction for refining the research questions and further validation for conducting the research was gained through focus groups with Aboriginal families who had experienced the passing of a loved one in hospital and with nurses and social workers who had provided end-of-life care for Aboriginal families. Qualitative analysis was used to develop a theory of Aboriginal families' needs for end-of-life care and of health care providers' needs for providing culturally sensitive end-of-life care, grounded in the expressed concerns of these groups in focused discussions. Representatives from Native Health Services and Palliative Care joined the team in this way. As representatives of the health care community, the research agenda was further validated by their contributions.

The research team expanded again when Kim McKay-McNabb began to interview Elders from her community about traditional end-of-life care. It was important to respectfully approach every Elder that was interviewed and to be committed to sharing the progress of the project with them. Commitment to this type of ongoing communication resulted in the development of what we call our "Elders' forum." The forum provides a means by which Elders can support on-going research and voice directions on important issues for Aboriginal communities. Now, we have Elders from various communities who have confirmed that end-of-life care for Aboriginal families in southern Saskatchewan is an important health care need. In this way, circles of collaboration have emerged from the original research direction proposed by our guiding Elder.

Forming the research community, identifying the needs of health care recipients and health care providers, and envisioning a useful research direction in response to these needs was the first stage of our research. Developing research partnerships was financially supported, both locally and provincially by IPHRC and SHRF. We were then in a position to request national-level support from CIHR.

## CREATING AND PROTECTING ETHICAL SPACE

Ermine, Sinclair, and Jeffery (2004) write of the need to create an "ethical space" for conducting research involving Indigenous peoples. We communicated our understanding of "ethical space" by telling the story of our research experience to one another and found that an ethical space is something that is generated continually as a project moves forward and develops. We identified how the protection of space for community-based research requires education and advocacy within research institutions. As such, we found it helpful

to translate the requirements needed for conducting ethical research with Aboriginal communities into terms that could be understood in a Western value system. Highlighting the similarities between qualitative research traditions and Indigenous peoples' understanding of ethical research methods has helped to keep a space of understanding open between institutions and communities.

### THE SPIRIT OF COMMUNITY

To create an ethical space requires the generation of a place that is protected from academic expectations of ideologically driven research, standing firm in a resolution to conduct oneself and the research in a community. Keeping an ethical space means creating an environment that demonstrates a passion, deep spirit, and commitment that moves people to share their stories; yet, a passion that is tempered with care and patience so that stories can be heard. Kim, an Aboriginal woman and academic, relates how in traditional teachings,

Elders do not tell you this and this, and that is the way you do it. You can sit with an Elder all day, and the next day, and not even talk to one another, but just go through the movements of the day together. There are things that you may be learning without knowing it. Then, at a point later, you may be able to recognize how all of those teachings were taught for a reason. Elders can tell you things, even though they don't tell you this, this, and this.

Ethical research with Aboriginal peoples is, in our experience, a spiritual relationship that allows for ambiguity. This means sustaining tension between knowing what to do while being receptive to other possibilities. In order to keep that space of possibility open, we accept uncertainty in terms of recognizing the project as greater than any one individual view. Kim speaks of there being something sacred about the project and it being about something more than we can know at this time. She relates how the grandmothers and the grandfathers are present in our research process; when there are problems, little bumps in the road, for each of us there is acceptance and a realization that this project is more than any one person. Kim recounts,

It is out of *my* control, I do not have the control. I am just a person moving along with the waters. I might have egg on

my face but this is way bigger than me, it is not about me. As a team we have come to respect each other, we might not agree on everything but we challenge each other and are protective of this space, even when we do not know why. At times one might say things out loud and think, "I don't know if I should have said it, but I just feel like I'm supposed to say this for something that's way more than me." We would not take as many risks if it were all self-interest. So far, it has worked out.

With a research team constituted from such diverse communities and walks of life, there seem to be certain qualities of character that members need to share. Schnarch (2004: 84) writes of how "some individuals may simply not have the necessary sensitivity or interpersonal or research skills to work in a First Nations, Inuit or Métis setting." In order for a community to be a part of every step of the process, trust, commitment, and tolerance for ambiguity are required in all members of the research team. These qualities also facilitate completing goals because there is the ability to say, "I don't know how but I trust that if I keep working that something will happen." The right person finds the right job and the work is not forced. We trust the process because we experience every single person committed to the work; each acts and together something is produced. Kim recounts the ethics of trust, respect, and generosity when working with the Elders on this project:

Things just happen on this project. I can remember coming upstairs and all of a sudden thinking to myself, "Well we need to give our Elders a gift and it can't just be anything. If it was up to me we'd be giving them the big star quilts but those are \$500 a piece." This would be so respectful because in our culture it is like giving a horse. It is one of the most respectful things we can give our Elders. Then I found a friend of mine, her mother was making star quilted pillows! So I asked the team "Do we have enough money?" and Mary said, "Yeah, we're doing it, we'll find a way!" Then, when we gave them to the Elders, I remember the look in their eyes. We always started out giving sweet grass first and then there is always a prayer, and we have discussions. It is

not just “Let’s get into the video,” a lot of preparation goes into getting into where we’re at and being able to talk with the Elders the way we do. There are so many different things that we do to get to that point. But if you could just see their faces when they were given that pillow, it is just so respectful, and I feel so honoured to be a part of that.

## CARRYING OUT RESPECTFUL RESEARCH VIDEO INTERVIEWS

Within our extended research community it was agreed that along with edifying presentations and information sheets it would be helpful to produce a video of messages from Aboriginal Elders to provide cultural education to health care providers. Considering how the research of Aboriginal peoples has been conducted in the past, at first our guiding Elder was resistant to the idea of a video. There is a danger of appropriating community knowledge, of communities losing control of the distribution of their knowledge, as well as many other risks. Perhaps because of the relationships we established and because Mary had a history of using video material in research with Aboriginal communities in acceptable ways, we were trusted to go ahead with a video production. Testament to this trust, our Elder contributed a song and narrated an introduction. At every step of the way, deciding what to include in the video involved consultation with Elders and showing the video to the participants before any public release. Otherwise, we agreed that the video format could become exploitative and disrespectful.

Kim describes a sense of putting her arms around all the Elders and their voices as a protection that “the project will be just the way that it should be.” We opted to keep production within our control as much as possible, instead of employing the services of medical media or a private production company. As suggested by OCAP, opportunities were provided to build research skills among people in Aboriginal communities and organizations. Students on our research team, strong in their Aboriginal traditions, conducted filming and interviewing. A video production group at First Nations University Indian Communications Arts Program (INCA) provided editing services.

### THE SPIRIT OF COMMUNICATION

The message is not just in the material, it is also in the delivery. An Aboriginal member of our team or an Elder is present when showing the

video and PowerPoint presentation. In this way, those of us that are immersed in the culture can speak to questions from our hearts without giving specific directives. There is no right or wrong way in the Aboriginal worldview. This is the Western way vs. the Aboriginal way. That is why Aboriginal parents are seen as permissive parents because every person has to be an individual to just find their own spirit. It is so open but also very freeing. Teachings are not prescribed. Learning is about becoming open-minded. This is all we can ask of our participants – to come with an open mind. If you hear any Elder open up a session, this is what they will say, “Just keep an open mind; there is no right or wrong.”

Our goal throughout this project was to offer health care providers an opportunity to understand the Aboriginal community and their need to receive end of life care in ways that respect traditional cultural values and beliefs. The challenge was to deliver the Aboriginal community’s message to health care providers without ignoring existing efforts of health care providers. Presenting results from our focus groups with Aboriginal families who experienced the loss of loved ones in hospital to an audience of health care providers at a regional conference, the messages were received with defensive indignation. Preserving the community’s messages and relaying them, whether health care providers want to hear these messages or not, we were taking a risk. As Mary relates:

We might get slammed again. There’s a very strong chance of that. We just need to articulate that we’re taking a stand here with this project and in this way. I’d say we are taking risks with the topic, with the way we’re doing it, and with what we’re building.

We came to the conclusion that the Elders, through their honest and articulate messages, are able to deliver community messages of the need for understanding and respect with the greatest chance of creating an open dialogue. Carrie expresses our desire to deliver the video and corresponding presentation in a manner that corresponds with the Aboriginal community’s values:

There’s always going to be a handful of people that don’t want to hear what you have to say no matter how you put it. But, instead of Aboriginal people always adapting to the

non-Aboriginal way of seeing things, I think it's time that we start to share, because we think that it's a gift that we're sharing, that we see these things this way. People can choose to be closed-minded no matter how we say it but I think we're going to break ground and they'll come around. It will be successful but there has to be a little bit of space and time for that to happen. Health care providers are going to go away and think about the presentation and then hopefully we're going to come back and we're going to have something else to build on. You've got to let it percolate a little bit. Then a situation might be encountered and suddenly the presentation twigs something and there is more reflection.

In the video presentation, it was relatively easy to preserve the atmosphere of the original messages from Elders meant for health care providers. However, we also agreed to provide an education curriculum more in tune with Western methods of learning, to develop lecture material in the form of a PowerPoint presentation, as well as information pamphlets to accompany the video. It was more challenging to maintain the spirit of the message in the PowerPoint format. Expectations of medical education drove the production of the PowerPoint talk and information pamphlets. Cheryl Placsko, non-Aboriginal academic, describes the feeling of

... standing in the middle and being pushed as a team to deliver something to nurses that is acceptable to them. And they're forgetting that what we're trying to do is to deliver a message from the Aboriginal communities. I don't know if it's going to be acceptable to you or not, but you have to hear it. You have to give it a chance. But if you make us change it so that it's acceptable to you, then the message is not delivered. We'd be destroying one thing in order for something else to be received, instead of a meeting of the minds or some sort of honest communication.

Research with, by, and for Aboriginal peoples has meant, for us, resisting the pressure to package the messages of Elders and Aboriginal family members in a way that non-Aboriginal people might expect. By maintaining the

integrity of the message and saying, “This is what Aboriginal people have to say and this is how we have to say it,” we risk not being heard. However, we risk not respecting the needs of health care providers by not meeting medical curriculum expectations.

Aboriginal families were sending the message that they feel they have to fight to spend time with the people that they love who are dying. By taking a strictly didactic approach to addressing this problem, by providing bulleted information, facts, and correct and incorrect procedures for providing end of life care for Aboriginal families, we risked communicating the message that following a correct procedure will provide the correct outcome — that is, cultural sensitivity. But we agreed that our research was about promoting greater understanding and being open to immersing oneself in another cultural way of doing things and not about getting answers. Carrie put it this way:

You don’t need to know all the ins and outs of some of these things. You don’t need to know why sweet grass is really sacred. You might want to learn about that someday, but you don’t need to know it. What you need to know is what we’re trying to provide you through the Elders’ words.

The research is not meant to prescribe a way of meeting death with Aboriginal people but rather to open us to the fact that it is an individual experience. The intent is for health care providers to know how end of life is such an important time and how community is important at that time. The difficulty with developing information pamphlets was that the experience of leaving this world for the spirit world is unique for each; each person may grieve differently, need different things. The message that “everybody is an individual” is very important to Aboriginal ways of knowing. Kim states it this way:

I don’t want to give instructions such as, “This is what you do,” because I know my family, and myself we all do different things. I’m an urban Indian. I’ve been raised by many different cultures. I have many different things trickled through my spirituality. People presenting have to say, “We don’t have definitive answers here. We don’t have a book that’s going to tell you everything.”



Most importantly, respecting the unique ways of people requires asking, “What would you like? How can I help you do this?” This is really what families want. They want for us to say, “How can I help?” “What do you need me to do?” Although this is what palliative care usually offers, it seems to be forgotten in other end of life health care contexts.

## LISTENING

A final aspect of our research experience involved carefully listening, validating intentions, and taking messages to the appropriate audience. We agreed that all participants need to take ownership of their messages, to agree with what was said, how it was understood, and who it was meant for. To this end, we spent meticulous amounts of time listening to the *communicata* going back to participants and saying, “Is this what you said to us? Is this ok?” giving people an opportunity to change their minds and to clarify.

Our task was then to organize the interview material in a way that would allow the story to unfold in a coherent way while preserving the integrity of the participants’ messages. One story line followed the process of death — from realization that a loved one was dying, to the gathering of community, through to the funeral and mourning. We then needed to organize the interview material in a way that would deliver the message to the intended audience. Members of the research team each indicated which portions of the interviews they felt were important to include. Yet, we soon developed a sense from reading the transcripts and watching videotapes of the interviews over and over that there were stories being told to two different audiences. In working with the transcripts, we realized that in some instances the interviews contained powerful materials that interviewees did not intend to be delivered to the health care community. Cheryl recalls how we came to understand that the Elders were speaking to two different audiences:

It became obvious to both Kim and I, separately, that the Elders seemed to be speaking with two audiences in mind. One audience was health care providers. The Elders seemed to have some very specific messages for health care providers. The other audience was Aboriginal families. The Elders often mentioned that this was the time they felt was right to pass on messages about ceremonies and traditions. It seemed to us that these were pieces not intended for everyone to see or hear.

We came to understand that the Elders were using this opportunity to reach their people in ways that they had not previously been able to. They seemed to be saying, "I didn't have the opportunity until now to pass this on and I want you to make sure that this gift is respected and used to benefit my community." Once we realized that the Elders were speaking to two different audiences, we shifted our purpose to follow their lead and became committed to developing resources for health care providers *and* for Aboriginal families. Again the community led the direction of the research and the team could be flexible and open to this turn of events.

## THE BEGINNING OF A FUTURE – DIRECTION FOR FUTURE RESEARCH

We continue to show our research productions to Elders and other community members, asking for guidance for the next steps of what needs to be done. This research becomes stronger as we proceed with the community and with the guidance of the most spiritually powerful people in the community, the Elders. This is the beginning of future research that will continue to be committed to honouring all of the people who have participated and will continue to allow the process to have a life of its own. We understand that if the research process becomes disrespectful then the research will not be able to continue.

Schnarch (2004: 84) suggests that respectful research may take more time, money, and moral fibre than traditional research methodologies. It is for you, the reader, to judge whether you think our research is respectful, but we have found that working with deadlines and institutional structures can make it difficult to base research in a community. A shift towards community relevance is a slow process that requires a significant investment of time. In our minds, what research in many cases is missing is a community that communicates with the researchers saying, for example, "Yes, we need research in this area but you're going about it the wrong way and this is really what's going to be applicable for us." Our university Centre continues to support the nature of our Aboriginal Health Research but how health care providers and fellow researchers will receive it is yet to be determined.

## CLOSING

This paper offers our account of principled research practice with, by, and for Aboriginal peoples that involves community-based research meth-

ods, community involvement, bridging of local and traditional knowledge, and relevant action in response to identified needs. Throughout our research process, Elders have opened and closed team meetings with prayers to the Creator. We end here with the hope for future respectful research that establishes communication, trust, and care with Aboriginal individuals, families, and communities.

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