'Making a Difference': A New Care Paradigm for Pregnant and Parenting Aboriginal People

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ABSTRACT

Objective: To describe community-based stakeholders' views of how safe and responsive care "makes a difference" to health and well-being for pregnant and parenting Aboriginal people. Community-based stakeholders included community members, providers of health and social care, and health care and community leaders.

Methods: A postcolonial standpoint, participatory research principles and a case-study design were used to investigate two Aboriginal organizations' experiences improving care for pregnant and parenting Aboriginal people. Data were collected through researcher field notes, exploratory interviews and small group discussions with purposively selected community-based leaders, members and providers. Data were analyzed using an interpretive descriptive method.

Results: Community participants' views of "making a difference" emphasized: recognizing relevant outcomes of care; acknowledging progress over time; and using a strengths-based approach in which providers appreciate individuals' efforts and the challenges of their contextual circumstances.

Discussion: "Making a difference" to pregnant and parenting Aboriginal people would facilitate Aboriginal peoples' efforts to tackle the deeply embedded socio-historical determinants of well-being and capacity, and thus shift priorities for care upstream to focus on such determinants. Such a paradigm for care would integrate multiple perspectives on desirable outcomes within local frameworks based on values and priorities of Aboriginal parents, while also incorporating the benefits and wisdom of existing yet further downstream approaches to care.

Conclusion: Design and evaluation of care based on community values and priorities and using a strengths-based approach can improve early access to and relevance of care during pregnancy and parenting for Aboriginal people.

MeSH terms: Indigenous health services; prenatal care; postpartum programs; health care quality, access, evaluation

La traduction du résumé se trouve à la fin de l'article.

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Aboriginal* women, in Canada and elsewhere, are often late or low participants in prenatal care and experience poor outcomes of care relative to the general population. Several studies have examined factors influencing both late and low participation in care among Aboriginal and other populations.¹⁻⁵ Two programs of research^{6,7} and several evaluation studies^{8,9} with Aboriginal communities found that community involvement in program design, implementation and evaluation improved participant satisfaction, early access and participation in care, and that this enhanced women's health behaviours such as improved nutrition, decreased tobacco and alcohol consumption, and feelings of mastery related to infant care. These studies contribute to understanding the benefits of involving Aboriginal communities in program design and implementation, but measured benefits as identified by researchers and health care stakeholders, rather than by Aboriginal people themselves. Researchers in the area of cultural safety assert that to improve care for Aboriginal people, we must recognize the effects of inequalities in power between groups in society on the health care system, and involve Aboriginal people in evaluating their experiences of safety within health encounters.^{10,11} However, research has yet to identify outcomes for care that are derived from pregnant and parenting Aboriginal peoples' views.¹²

In our previous analyses of successful approaches to care developed by Aboriginal organizations,^{13,14} we found that organizations situated the purpose of care within Aboriginal parents' view of pregnancy and childrearing as a window of opportunity for Aboriginal people to turn around the intergenerational impact of residential schools.† Results highlighted the

* The term Aboriginal "refers to organic political and cultural entities that stem historically from the original Peoples in North America, rather than collections of individuals united by so-called 'racial' characteristics" (Royal Commission on Aboriginal Peoples, 1996). These include the First Nations, Inuit, and Métis Peoples of Canada.

† From the mid 1800s until as late as 1996, an estimated 100,000 Aboriginal children, ages four to eighteen years old, were removed from their families and placed in residential schools as part of the federal government's assimilation plan. Residential schools involved deliberate suppression of language and culture, substandard living conditions, second-rate education, and widespread physical, sexual, emotional and spiritual abuse, and is an internationally recognized form of genocide (Convention on the Prevention and Punishment of the Crime of Genocide, 1951, cited in Krug, Dahlberg, Mercy, Zwi & Lozano, 2002, p. 216).

critical importance of building successful programs on an understanding of the impacts of colonization on Aboriginal people's relationships and experiences in health care. Positioning providers and organizations to work in partnership with Aboriginal people toward their vision to transform the impact of this history will shift the goals and expected outcomes of care.

In this paper, we describe community-level participants' views on how safe and responsive care can make a difference to Aboriginal women and families. Results capture how care oriented to respond to Aboriginal peoples' priorities facilitates relevant outcomes, acknowledges the time required for change on deeply embedded determinants of health, and ultimately improves early access and participation in care. A beginning framework is presented, which shifts emphasis toward outcomes and indicators for care that are based on values and priorities of Aboriginal parents, while also incorporating the benefits and wisdom of existing approaches to care.

METHODS

A critical postcolonial stance and participatory research principles^{15,16} shaped the focus and methods of the study. Critical postcolonial perspectives provide insight into participants' experiences within the struggle to understand, deconstruct, resist and transform the impact and institutions of colonialism.¹⁷⁻¹⁹ Both postcolonial and participatory research perspectives are inclusive of different value systems, sensitive to differences, view all forms of knowledge as valuable, and seek to generate knowledge that is relevant to stakeholders and useful for solving practical problems. A case study design²⁰ enabled collection of in-depth contextual data to understand the determinants and processes of individual and organizational participants' experiences improving care for pregnant and parenting Aboriginal people.^{21,22} One urban and one rural Aboriginal health care delivery organization reputed to have developed a successful approach to care participated. Ethical approval for phase two was obtained from the University of Ottawa Health and Social Sciences ethics review board, the ethical review committee of the participating Tribal Council, the Board of

TABLE I
Phase Two Sample Composition by Subgroup

Sample Subgroup	N	Aboriginal Identity # (%)	Female # (%)
Leaders	17	11 (64.7%)	15 (88.2%)
Providers	25	9 (36%)	23 (92%)
Community Members	15	15 (100%)	12 (80%)
Total	57	35 (61.4%)	50 (87.7%)

* Though many participants fit into more than one category, they are only counted once in this profile.

Directors of the Health Organization, and the Chiefs and Councils of the participating communities. Field work was conducted from June to September of 2004. Participants in each setting were purposively selected using network sampling techniques to obtain a variety of perspectives from community members, providers and leaders. Participants often had multiple roles, such that a leader could also be a provider, as well as a community member. The first author used one-to-one exploratory interviews and small group discussions to collect data, according to the preference of each participant. Interviews lasted from 45 to 120 minutes, were taped with participants' consent* and transcribed. Data were analyzed by the first author using interpretive descriptive methods²³ supported by NVIVO© software. Phase two participants were then invited to discuss preliminary results in workshops held in the study communities in April of 2005.

RESULTS

Table I shows the community-level participants. The participants identified the following themes as important for evaluation: acknowledging progress over the long term; using a strengths-based approach; and recognizing relevant outcomes.

Acknowledging progress over the long term. Many participants emphasized that care must be oriented to facilitating clients' and communities' long-term efforts to turn around the intergenerational impact of residential schools.

This healing will take seven generations. It won't take four generations... It will take seven. It's the generations, and that's what's hard for us as nurses too, to really... when you feel disappointed, then it's... it's like remembering that. It's not about me or my disappointment, it's about the seven generations down the road. And that's where their

* Three participants preferred to have notes taken during the interview.

healers and their visionaries... that's the way they view it, that's the patience that they have (Provider).

Crucial to appreciating how this approach to care during pregnancy makes a difference, is understanding where each person is starting from, what their goals and priorities may be, and how the current challenges and tasks of pregnancy may fit into the longer-term challenges in their lives. Such understanding means that pregnancy can become a window of opportunity toward healing.

During pregnancy is the time that I see women most likely to make a change. Sort of as an observation... if someone is having a lot of alcohol or drugs involved with their life or is not really very healthy, I find that when they find out they're pregnant, it tends to turn them around and they tend to work very hard to do the best they can for that pregnancy. And often I'll see that it lingers on. You know, that change of the nine months will have been so great, that after the baby's born they are able to continue on a healthier way. So, I think it's a really great opportunity (Provider).

Participants were unanimous in the view that their expectations of positive changes are over consecutive pregnancies, and even over generations.

Participant: *They can come to me, and I can teach them about... you know, the early stages of pregnancy and conception and what it means, about development,... and [about] how important it is to be sober, and that's I think the knowledge that the women are gaining. In the next pregnancy, it makes it difficult for them [to know] whether to keep the baby or not, or go through the pregnancy, because they already now know... they have prior knowledge, but actually this is the development stage. And if this baby... if I'm drinking heavily at this stage then my baby could be born with FAS.*

Interviewer: *So it might not have a big influence on their (current) pregnancy but it would maybe change their behaviour with subsequent pregnancies.*

Participant: And that's the point (Provider).

Rather than comparisons to externally-imposed measures of short-term success, evaluation needs to be tailored to individual and community realities and expectations, and focused upon appreciating the magnitude of positive changes over time. For example, infant attachment outcomes can be used as an indicator of both individual and community progress, rather than just against objective standards:

You're sort of hoping, wishing for these parents to really get what it's all about. Now it is happening... they are bonding at a completely different level than they were probably bonded with ... and they are aware of what's available for their babies... like the hopes and dreams... they're just aware of that... And so even if the time spent with their babies isn't always 100% positive... it is 100% more positive than it was, say, 20 years ago. I think there is a shift happening (Provider).

A strengths-based approach. A strengths-based approach contributed to an upward spiraling change process that recognized strengths as they accumulated in the context of peoples' history and circumstances. Most significant to this building-on-strengths approach, the majority of participants (e.g., providers, community members, leaders) described "speaking up", "speaking out", and "finding a voice" as one of the most important strengths that people developed through involvement in care activities and relationships. All stakeholders saw finding their voice as increasing strength and improving individual and collective capacity to name and take action on issues.

Things are changing: more women are speaking up, more people are coming out and speaking about their experiences [with interpersonal violence]; trust is growing, but there is still lots of work to do (Community Member).

Many participants attributed these evolving strengths to people developing self-esteem and pride as an Aboriginal person. For example, they would say, "It's been really something, watching the breakthroughs. You can see the shoulders come up, and the head come up". Many providers described watching these changes in body language and eye contact as "the best part about my work".

Recognizing relevant outcomes. When asked how safe and responsive approaches to care make a difference, many community members described positive outcomes such as, "the number of people who are on a healing path", "the degree to which abuse is talked about", "leaders carrying the hurt-[an important indicator would be] that the leaders are able to be on a healing/forgiving path", "a lot of [mothers] are back to breastfeeding", "they are really aware of the dangers of drug and alcohol during pregnancy", "there are less addictions, the rate is down", "the rate of teenage pregnancies would go down" and "if a baby was conceived in a happy way - not a rape - the family and grandparents relate to the baby as a human-this is getting better - before it wasn't so good. Now people are more able to let the hurt go and not take it out on the baby".

These outcomes reflect not only the long-term challenge of turning around the intergenerational impact of residential schools, but also biomedical, behavioural and population health approaches to care.

Positive outcomes were also recognized at the collective level. Participants talked about the community believing that the health care organization and providers were safe, and respectfully responding to their concerns.

And when the word gets out, I mean you can talk about advertising in newspapers and what have you, but the best promotion of (our program) has been word-of-mouth. So until the word gets out that you can trust this program, they aren't going to come. And it's one by one by one that that happens. And we miss [measuring] that. A paramount indicator is that they came (Leader).

Participants talked about collective-level outcomes such as improved access and participation in educational programs, drug and alcohol services, domestic violence and child apprehension support services as important program outcomes. For example:

Even in the junior high, graduation has increased. I believe health has increased... I think there are probably fewer FAS children because of the pregnancy outreach program... and the healthier lifestyles. I believe that there are fewer women caught into domestic violence than there were before because they didn't feel like they had any alternative... again it was education... I think there is less alcohol. I think another battle that we have

to deal with is drugs. ... but if we didn't have the workers there I think it would be far worse than it is (Leader).

Patterns of *who* receives care reflect how safe programs improve access. Care accessed by those who are very vulnerable, exploited and marginalized is an indicator of the safety and responsiveness of the organization and providers. This leader went on to say:

And there are sexually exploited youth/children... [and] we are getting the street workers coming in for their AIDS testing and various testing and some of them actually ended up going to other programs... a few actually started coming into Adult Basic Education (Leader).

Another important indicator at both individual and collective levels is *when* care is accessed. Many participants described a pattern of increasingly *early* access to care and education as a choice, rather than as a reaction to problems or crisis. For example:

I actually had a lady two weeks ago who came into me and she has actually decided to plan a pregnancy... She's been in a new relationship for a while and they are actually talking about having a family together. She already has, actually, two older children, so she really wants to plan this one. This is pretty awesome. This is awesome stuff (Provider).

DISCUSSION

These results underline the importance of empowering approaches to evaluation, as well as expected goals and outcomes of care for Aboriginal people during pregnancy and parenting. Empowerment evaluation is "the use of evaluation concepts, techniques, and findings to foster improvement and self-determination".^{24p.5} Empowering methods integrate strength-based approaches, prevention, and community priorities and conditions within intervention design and evaluation.²⁵ Empowering approaches to care requires recognition of individual and collective strengths,²⁶ safe environments,²⁷ as well as the influence of social and relational contexts. Empowerment evaluation of intervention outcomes can include, and therefore facilitate positive factors such as neighbourhood networks, community organizations, a sense of ownership over community well-being,²⁸ as well as spiritual and cultural beliefs and values.^{29,30} The flexibility of

participatory and empowerment methodologies^{31,32} can incorporate perspectives of community and client stakeholders to evaluate client experiences of safety and responsiveness of care, putting citizens or clients in the role of partners in evaluation. Such approaches may serve to facilitate 'partnership' relationships between communities, clients and health care organizations and providers. The longer-term time-frame of expected outcomes suggests the need for longitudinal evaluation across the experience of pregnancies rather than the more usual cross-sectional approach to measuring indicators.

Evaluation would ideally acknowledge and facilitate the significant efforts of Aboriginal individuals and communities to "turn things around". In contrast, colonizing approaches to evaluation attribute positive changes solely to health service organizations, and position Aboriginal communities and individuals as passive objects in care. Thus, outcomes reflecting both the values and priorities of Aboriginal participants as well as the more conventional outcomes for maternal and child health programs (such as the degree of infant attachment, or breastfeeding initiation and duration rates) must be included in order for care to be seen to make a difference. Table II illustrates how an integrated framework based on Aboriginal peoples' values and priorities for pregnancy and parenting could incorporate the benefits, but not impose, the value orientation and priorities of more conventional approaches to care (e.g., biomedicine, lifestyle and behaviour, and population health). Such an approach could shift the care paradigm and support pregnant and parenting Aboriginal people in a way that addresses and supports their capacity to fully realize their dreams for their children and their own parenting experiences. Shifting the care paradigm to emphasize action further upstream toward the root causes of health inequities may improve relevance and safety of care for Aboriginal people and communities, thus encouraging early access to preventive benefits and meaningful engagement in care during pregnancy and parenting.

Further research is needed across a greater number and diversity of settings to confirm or add to our understanding of salient aspects of approaches to and evaluation of care during pregnancy and parent-

TABLE II
Integrated Framework

	Goal of Care During Pregnancy and Parenting	Examples of Important Outcomes
Upstream	Safe and Responsive Care <ul style="list-style-type: none"> • facilitate Aboriginal People (AP) to turn around IGIRS* • change relationship between AP and health care system • acknowledge and support self-determined efforts r/t: <ul style="list-style-type: none"> – accept self and others – recognize strengths – be and become a parent – understand and heal childhood experience – understand and heal relationships (with self, others, culture) 	<ul style="list-style-type: none"> • progress along a healing path • building strength and capacity • develop trusting relationship with caregiver: <ul style="list-style-type: none"> – express satisfaction with care – describe relationship as safe over consecutive pregnancies, come earlier for care and/or more regularly for care – continue to develop care relationship over course of pregnancy and parenting
	Population Health <ul style="list-style-type: none"> • Identifying and intervening to improve access to the determinants of health: <ul style="list-style-type: none"> – e.g., access to health services – e.g., personal capacity and coping skills – e.g., poverty – food and housing insecurity 	<ul style="list-style-type: none"> • feels safe to access care early and related to personal priorities and values • change in planned pregnancies over consecutive pregnancies • improved access to secure food and adequate housing
	Lifestyle and Behaviour <ul style="list-style-type: none"> • provide information and support to enhance positive health behaviours and reduce known risk factors or behaviours: <ul style="list-style-type: none"> – e.g., Addictions – decrease tobacco, alcohol and drug use – e.g., Breastfeeding – improve knowledge, support, initiation and duration of breastfeeding 	<ul style="list-style-type: none"> • aware of dangers of tobacco, drugs and alcohol during pregnancy • decrease or abstain from tobacco, drugs and alcohol use during pregnancy • improvement over consecutive pregnancies • improvement over consecutive generations
Downstream	Biomedicine <ul style="list-style-type: none"> • limit occurrence and impact of pathologies • provide access to specialized treatment <ul style="list-style-type: none"> – e.g., manage Fetal Alcohol Spectrum Disorder – e.g., manage gestational diabetes – e.g., manage intrauterine growth retardation 	<ul style="list-style-type: none"> • low birthweight • prematurity • IUGR†

* IGIRS = Intergenerational impact of residential schools

† IUGR = Intrauterine growth retardation

ing for Aboriginal people. Adequate time and resources are required to enable community-based participants with long-standing trusting relationships to take a more active role in research design and implementation, thus enabling more Aboriginal voices to be heard.

CONCLUSION

This study described Aboriginal providers', leaders' and community members' views of important outcomes of care during pregnancy and parenting. Results show that evaluation of outcomes of care for pregnant and parenting Aboriginal people must recognize and appreciate the unique experiences of individuals, families and communities within a broader historical con-

text of Aboriginal people's lives. Positioning care to acknowledge progress and appreciate strengths may improve early access to and relevance of care during pregnancy and parenting for Aboriginal people.

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RÉSUMÉ

Objectif : Décrire la façon dont les intervenants communautaires perçoivent l'importance de soins sûrs et adaptés pour « faire une différence » sur les plans de la santé et du bien être des femmes enceintes et des parents autochtones. Parmi les intervenants communautaires, on compte des membres des communautés, des fournisseurs de soins de santé et de services sociaux, ainsi que des responsables communautaires et sanitaires.

Méthodologie : Une perspective postcoloniale, des principes de recherche participative et une étude de cas ont été employés pour examiner deux expériences d'organismes autochtones pour améliorer les soins prodigués aux femmes enceintes et aux parents autochtones. Les données ont été recueillies à partir des notes des chercheurs travaillant sur le terrain, d'entrevues exploratoires et de discussions en petits groupes avec des fournisseurs ainsi que des responsables et des membres de la communauté, tous choisis à dessein. Les données ont été analysées à l'aide d'une méthode descriptive d'interprétation de données.

Résultats : Les perceptions des intervenants communautaires sur l'importance de soins sûrs et adaptés pour « faire une différence » qui ressortent sont : la reconnaissance de résultats pertinents en matière de soins, la reconnaissance de progrès graduels et l'utilisation d'une démarche axée sur les forces, laquelle permet aux fournisseurs d'apprécier les efforts déployés par les personnes et les défis posés par leur situation contextuelle particulière.

Discussion : « Faire une différence » sur les plans de la santé et du bien-être des femmes enceintes et des parents autochtones pourrait faciliter le travail entrepris par les peuples autochtones pour s'attaquer aux déterminants sociohistoriques, profondément ancrés, du bien-être et de la capacité et, par conséquent, entraîner un changement de priorités en matière de soins en amont afin de se concentrer sur ces déterminants. Un tel paradigme de soins intégrerait plusieurs perspectives quant aux résultats souhaitables à l'intérieur de cadres locaux, en fonction des valeurs et des priorités des parents autochtones, tout en intégrant les avantages et la sagesse d'approches existantes en aval en matière de soins.

Conclusion : La conception et l'évaluation de soins fondées sur les valeurs et les priorités communautaires et faisant appel à une démarche axée sur les forces peuvent favoriser l'accès rapide aux soins et la pertinence de ceux-ci pour les femmes enceintes et les parents autochtones.