NORTHERN COMMUNITY MEMBERS’ PERCEPTIONS OF FAS/FAE: A QUALITATIVE STUDY

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Abstract / Résumé

A qualitative research project addressing concerns and beliefs regarding fetal alcohol syndrome (FAS) and fetal alcohol effects (FAE) was conducted in a northern community in Canada. Concerns and beliefs identified by service providers, community resource agencies, community members and individuals personally affected by FAS/FAE comprise different levels of understanding of these issues. The community also identified barriers to dealing with FAS/FAE.

Cette étude, effectuée dans une communauté du nord du Canada, traite d'un projet de recherche qualitative sur les idées et les questions que les gens ont sur le syndrome d'alcoolisme foetal (SAF) et les effets de l'alcool sur le foetus (EAF). Les dispensateurs de soins, les agences de ressources communautaires et les membres de cette communauté concernés par les problèmes de SAF et de EAF ont permis de dégager divers niveaux de compréhension du sujet. La communauté a également identifié des obstacles qui entravent le processus de prévention et de traitement des SAF et EAF.

Introduction

Fetal Alcohol Syndrome (FAS) and Fetal Alcohol Effect (FAE) have been the subject of a variety of studies. These conditions occur as a result of a woman drinking during pregnancy so that the fetus is detrimentally affected both cognitively and physically. The effect of alcohol on the fetus varies greatly from no effect at all, to minor birth defects, to severe brain damage, as well as miscarriage and stillbirth. The effects are dependent on how much the woman drinks and when during her pregnancy she drinks.

Prevalence rates of FAS/FAE among Aboriginal people are highly variable (Bray and Anderson, 1989). In Canim Lake, British Columbia, 65% of children born prior to 1976 were diagnosed with FAS, while only 17% of those born in the 1980s were found to have the syndrome (Robinson, Conry and Conry, 1985). In the Yukon, alcohol detrimentally affected 46 per 1000 Aboriginal children, while in northwest British Columbia, 25 per 1000 children were affected (Asante and Nelms-Matzke, 1985). Robinson, Conry and Conry (1987) found the prevalence rate to be at the unexpected high of 190 per 1000 in an Aboriginal community in northern British Columbia. However, although prevalence rates provide an understanding of the magnitude of the problem, they do not reflect the human or emotional impact of FAS/FAE.

The study was conducted in response to an invitation from the Dene Cultural Institute to the Arctic Institute of Canada to conduct a community assessment on the issue of FAS/FAE. The name of the community and the specifics related to the community will not be identified so that the anonymity of community members is maintained. In response to the invitation, the researchers designed a study to examine the concerns and beliefs of people about FAS and FAE. The Dene Cultural Institute requested this qualitative approach because an earlier epidemiological study, conducted in another northern community, had concluded there was a very high incidence of FAS/FAE. Knowledge of the study results had a detrimental effect on community members as teachers believed that there was little or no hope of making a positive impact if the children were already “predetermined” to have limited abilities of understanding. Such a study has the potential to serve as a self-fulfilling prophecy and “cause” an epidemic (The Lancet, 1993) because it does not take into consideration the impact of awareness of the results on the person and families in the physical, emotional, or spiritual domains. Thus, personnel from the Dene Cultural Institute requested an exploration of the level of knowledge about, and the perceptions of FAS/FAE, and of the support (potentially) available within the community. Support would be vital if and when people started facing the tragedy of cognitive and/or physical disabilities that are inflicted on infants in utero.
because of drinking. In response, we designed a qualitative study exploring beliefs and concerns around FAS/FAE rather than establishing prevalence in a quantitative manner. In addition, we explored what the psychological and social implications of FAS/FAE were on individuals and on the community, as a review of the literature provided little evidence in this field. The lack of data in this area was another reason to conduct a qualitative rather than a quantitative study.

The fact that personnel from the Dene Cultural Institute requested this study, did not automatically mean unlimited access to the community and its members. Elsewhere (Kowalsky et al., 1996) we have described the process of gaining entry into this community. This process was guided by our contact person and proved to be of major importance in enhancing our understanding of conducting research in a culturally sensitive manner. Based on these experiences, we have identified culturally sensitive guidelines for entry into an Aboriginal community.

**Methods**

Qualitative research allows an understanding of issues and concerns of people in their natural environment that gives due emphasis to the meanings, experiences and views of all participants being studied. Data collected in qualitative research are usually in narrative rather than in numerical form and data analysis consists of organizing, summarizing and interpreting these non-numerical observations.

The current study can be described as a field study in which data are collected from individuals in their natural environment, with the aim of understanding the practices, behaviours and beliefs of individuals or groups as they normally function in real life (Polit and Hungler, 1991). Data were collected by means of participant observation, which is a naturalistic data collection strategy in which the researcher takes part in the community under study. In our study, the principal investigator (LK) lived in the community and took part in its activities (Kowalsky et al., 1996). Our approach was flexible and guided by a member of the Dene community who served as the contact person. When we contacted people, we explained the purpose of the study and that the study was under the direction of the Dene Cultural Institute and the University of Calgary. We stressed that participation was optional. The interview guide contained open-ended questions, including “Do you consider FAS/FAE as an issue in the community and to what extent? What do you think are barriers in dealing with FAS/FAE? What strategies would you recommend in dealing with this issue?” The interview focused on these general areas but also followed the direction the interviewee wished to go and varied from formal and informal
to spontaneous. In addition to these more formal interviews, there were informal discussions and observations of behaviours, activities and conversations.

Initially, the researcher planned to tape record the interviews but immediately discovered that this hampered the spontaneity of the interviews. Therefore, the investigator made notes regarding the interviews and unstructured observations (field notes) as soon as possible. At the end of the day more detail was documented, as well as preliminary interpretations. No identifying information was recorded.

Selecting study participants depended partly on the contact person who provided guidance. After the researcher satisfactorily demonstrated her cultural sensitivity through both word and action, she was directed to explore the issue of FAS/FAE with members of the Dene community but not with the Elders (Kowalsky et al., 1996). Data collection was also dependent on opportunities arising during our participation in the community. Last, we used snowball sampling and asked the interviewees whether there was anyone else they would recommend to contact for further understanding of the issues. Approximately fifty individuals who represented service providers, community resource agencies, and individual community members were interviewed. The interview process was considered complete when no new people were recommended for interviews.

Collected data (interviews and observations) were broadly grouped into themes and concepts. To achieve the goal of the emergence of a larger, consolidated picture, data were continuously reviewed to refine the themes and to "test" findings in the research setting. Independent reviews and interpretations between the investigators enhanced data quality.

Study Results

As the study progressed, it became clear that within the community there was a wide range of understanding and perceptions about FAS/FAE. Those less impacted by the FAS/FAE problem tended to have more general beliefs and opinions, while those who worked with or had children with FAS/FAE had very definite beliefs and opinions. People in the community often held more than one role (e.g., a teacher and a parent) and, thus, could provide two different perspectives. The following sections more fully describe the concerns and beliefs of community members about FAS/FAE. This is preceded by a section on estimated prevalence of FAS/FAE in the community.
Community Members' Perceptions of FAS/FAE

Estimated Prevalence

Estimates of prevalence mainly came from teachers as they saw groups of children together and they believed FAS/FAE had an impact on their work. Teachers estimated 40% of the kindergarten class and 25 - 30% of the students of the general student population have FAE, while only 2/300 elementary school students had received a FAS diagnosis. Some teachers observed a trend that, in some years, a higher percentage of students were affected with FAS/FAE than in others. For example, a higher percentage (40%) were estimated in the kindergarten group, grade two was a “difficult group”, children in grade six were “displaying angry behaviors”, and an estimated 50% in grade nine were affected. Estimates can be biased for several reasons: some teachers may be more aware of FAS/FAE and, thus, detect it faster than others; disruptive students may affect others and behavioral problems may be more prominent; teachers may use it to explain away ineffective schooling; or dysfunctional families may have children with behavioral problems similar to FAE. Another hypothesis is that siblings from a cohort of women who are still drinking throughout consecutive pregnancies were now in the school system. However, this apparent pattern may also be a result of chance alone. Some informants in the Aboriginal community indicated whole families were affected and most members of the Dene community could recall a FAS child they knew, but no one had attempted to estimate the percentage affected in their own Aboriginal community. Therefore, the fact that only non-Aboriginal professionals appeared to estimate rates might contribute to the perception of high prevalence rates.

Prevalence rates estimated by non-Aboriginal community members appeared to be generally consistent with what has been reported in the literature. Whereas the general literature indicates FAS/FAE is more prevalent in the Aboriginal than in the non-Aboriginal population in the Yukon and northern British Columbia, as reported by Robertson (1987), community members in this study estimated that the proportion of FAS/FAE in the two populations is about the same. The common thread of concern professionals have about the prevalence of FAS/FAE is that diagnosed FAS is only the tip of the iceberg and that FAE is much more prevalent than FAS.

Service Providers

Those who work in services established by some level of government, such as personnel at hospitals, the correctional and young offenders centres, the alcohol and drug counselling and information services, social services, churches, and schools can give a more complete picture of the issue of FAS/FAE than can sheer numbers. Several representatives of
these groups were interviewed. Throughout the study period, individuals (both Aboriginal and non-Aboriginal), expressed the belief that members of the medical profession (doctors and nurses) and those in Social Services were knowledgeable, and would educate people about FAS/FAE. However, this did not seem to be the reality. When a respected member of the medical profession was asked to give a presentation on FAS/FAE to the community, the physician asked what FAS/FAE was. This same physician indicated that FAS/FAE was seldom observed during his/her years of experience in the North. Rather, the doctor said that what appeared to be more serious were multiple physical defects and complications resulting from dehydration of newborns because of parental neglect during binging. One case cited was of an infant who was undergoing renal dialysis as a result of dehydration and neglect related to alcohol abuse. A second case was of a severely retarded child who required total care in a facility because of a similar situation. In contrast, a member of the community indicated that it was generally acknowledged that this particular child had FAS.

According to nurses interviewed, discussion about FAS/FAE seldom arose in work related conversations, even though one nurse estimated one out of five women had a pregnancy or delivery associated with alcohol and that spontaneous abortions were common. The nurses indicated that when pregnant women were treated for ailments or injuries related to alcohol abuse, teaching concentrated on the specifics of how alcohol is detrimental to the individual, but regarding FAS/FAE, teaching was only done in broad terms, namely, that drinking can harm the fetus. The nursing profession had minimal resources for FAS/FAE teaching, and from an administrative perspective, the issue of FAS/FAE was not of primary importance.

The social service staff were very interested in the discussion of FAS/FAE. However, their knowledge and awareness of the issue ranged from absolutely no knowledge about FAS to a strong awareness and desire to address problems regarding FAS/FAE in the community. Social Service personnel expressed their eagerness to become involved in assisting the work of others in regards to this problem.

The RCMP demonstrated their lack of knowledge about FAS/FAE by asking for an explanation about what it was and then indicating that it was not a topic discussed within RCMP ranks. Nor was any interest expressed in having an educational session once their lack of knowledge was apparent. The RCMP identified that their particular focus of work was only to respond to the immediate situation. When questioned about how often RCMP see pregnant women drinking, only a few incidents could be recalled, even though the RCMP noted that roughly 90% of all calls involve alcohol. In a later interview, frustration was voiced by one person that the RCMP
assumed women who are pregnant do not drink. She indicated that when the RCMP stop a vehicle to determine whether a person is driving under the influence and see a pregnant woman driving, they assume she is not drinking and discontinue the investigation, when in fact the woman has been drinking.

Personnel of the correctional centre were very concerned with the effect FAS/FAE has on their work and caseload. Correctional centre workers stated that at least two or three of the fifty inmates were assumed to be afflicted with FAS, although they did not have the formal diagnosis. They indicated that these inmates always did well in the kitchen, where there is structure and consistent supervision.

The alcohol and drug counselling representative noted that several clients were considered to have FAS only as a result of a query on some charts, but admitted that neither formal diagnosis nor specific resources were sought for these clients.

Community Resource Agencies

Services provided in response to the needs perceived by the community indirectly reflect the attitudes of a community because the resources are where the community's energy of helping others is placed. In this particular community, resources included such agencies as the women's shelter, day care centres, foster parents, the Native Friendship Centre, and the Métis office. Many of the concerns and barriers to dealing with the problems of FAS/FAE, voiced by individuals in these agencies, are similar to those of the service providers and will be summarized under the section of barriers to dealing with FAS/FAE as defined by the community.

The discussion of FAS/FAE was not an issue in the Native Friendship Centre or the Métis office. However, when a description of FAS/FAE was given, one Aboriginal person said that about 40% of the children in the community would fit the description of FAS/FAE. This estimate is about the same as what the teachers gave. Although an interest was expressed in FAS/FAE, there was little awareness of the issue.

FAS/FAE was not brought up at the women's shelter, as it was believed that such a topic would frighten and upset women who were already experiencing much distress in their lives. Violence related to drinking was often associated with women coming to the shelter. Those in day care centres said it has not been until more recent years that they have had children in their care who were thought to be FAS/FAE.

The biggest impact of FAS/FAE on the community resources was seen in the foster parent group. These parents wept openly in a meeting, expressing their frustration that the severe cognitive and physical abilities
of their foster children were entirely preventable. Foster parents also expressed anger, as they perceived no effective way to prevent women from inflicting what they believed was an unnecessary life sentence on innocent children. The stress of these foster parents was compounded by the fact that they had sensed neither recognition nor any support for temporary respite care from the community. They found they had to rely on other foster parents who were already tired and over worked for that reprieve.

During discussions with community members, there was a sense of both emotional and spiritual pain that no one in professional organizations identified. This absence of awareness and sensitivity to the issue of inner pain became apparent only after community members expressed it so profoundly.

Community Members

Members of the Dene community, but also some non-Aboriginal people within the community, shared on an individual basis the perceptions and concerns they had about this issue. Talking with those representing or working for an agency reflects a broader and perhaps more distant perspective whereas communication at this level reflects what is at the core of dealing with this tragic disability. The following are comments expressed by the people we identified as being more involved in, and having a better understanding of, the issues related to FAS/FAE.

Belief Systems

A member of the Dene community said his people believe that the unborn are more valuable than children already born and, therefore, protection of the environment is vital for future generations. There was concern that the present generation is unaware of how its actions will impact future generations. The researchers believe that this concept about environmental care could also be applied to teaching how care of the mother's body affects the unborn and future generations. This connection could emphasize that not only does the process of environmental misuse threaten the culture but also the destruction of one's body is threatened by alcohol.

Another cultural belief is that those born with limitations are closer to the Creator, are blessed and have a special place in the community. This was identified by one Aboriginal leader as being a wonderful concept except when dealing with something as preventable as FAS/FAE. In those situations, the belief could be a possible barrier. Specifically, the Dene people differentiate between cognitively and physically disabled individuals in that cognitively disabled children are considered to be gifts from God while the physically disabled are products of evil. Therefore, by diagnosing the
problem and thus giving it a label, people could use the diagnosis as an excuse to shun someone. This is especially so with FAS children as the physical defects are obvious and may be deemed a source of shame.

An individual recalled how in the past, children were carefully planned for and each had a special place in the community. Conception was planned for and done at the time of the full moon or when the northern lights danced. Each child had special powers because of the stars and their alignment. Each child had a special gift and a specific purpose in life. The people carefully planned for and controlled their population. Thus, the historical sacredness of conception is a marked contrast to the unplanned conceptions during a drunken state and the devastating results of continued drinking throughout the pregnancy. The people believed that a pregnant woman should be respected or she would have an early death both emotionally and physically. They expressed a belief that a mother was to be held sacred in pregnancy or else would have an unhealthy and undisciplined child who would die early.

Knowledge About FAS/FAE

While talking with different community members, we gained a much broader perspective of the problem of FAS/FAE. Many people in the community indicated that knowledge is fundamental to dealing with the issue of FAS/FAE. People working in the treatment centre acknowledged their lack of understanding about this issue. This lack of knowledge and understanding was also communicated in an indirect way. When the issue was discussed on an individual basis, what was not said became as important as what was talked about. For example, an individual described how he adopted a child because the mother drank. He said that the child was missing a kidney because of antenatal drinking but was otherwise normal and very active. What was not said was that the baby’s activity level could also be a sign of the effects of prenatal drinking.

The following are anecdotal stories of how individuals became aware of FAS/FAE. One person indicated that when she became pregnant she read all she could about pregnancy and, in her search for knowledge, happened to come across some information about what effect alcohol has on the fetus. Another individual said that at a party she noticed that one woman was not drinking or taking any drugs. When asked why, the woman indicated that she was pregnant and drinking was not good for the baby. The interviewee remembered this situation, and when she became pregnant, she too refused to smoke or drink, but only because she thought it was not good for the fetus. Only at a much later date did she realize the specific effect alcohol has on the fetus. Others indicated they stopped
drinking and smoking when they were pregnant because they instinctively knew it was harmful to the baby. One member of the Dene community indicated that it was just common sense not to drink during pregnancy but that young women today have no “common sense”. We question whether some of this lack of “common sense” is a subtle sign of FAE.

Teaching and Education

A recent graduate from the school system indicated that only birth control and sexually transmitted diseases, not FAS/FAE, were topics taught in grade nine or ten. Currently, AIDS, a new subject in the previous year, but not FAS/FAE, is discussed among peers. This individual was aware that FAS children were small and perhaps retarded but was uncertain about the latter. In another situation, a child brought home a grade six health curriculum on the reproduction system for parental approval, but it contained no mention of FAS/FAE.

A teacher in the school system acknowledged that FAS/FAE is not taught specifically. When adolescent girls informally asked her about pregnancy and because FAS/FAE is an interest of hers, she took the opportunity to stress the devastating possibilities if one drinks during pregnancy. When an Aboriginal alcohol and drug counsellor had a discussion with high school students about substance abuse, questions related to FAS/FAE were clearly absent. This lack of interest could be a result of a lack of awareness of FAS/FAE as, clearly, the school system has the potential to teach this subject.

Awareness of the Problem

One member of the Dene community said an Elder had lamented that “children have no brains” and cannot sit quietly and listen to the stories and wisdom of the Elders as has been a cultural tradition. Several arguments were raised to explain that this hyperactivity could be due to family breakdown and abuse or due to a growing restlessness in adolescents as a problem of the whole society and not attributed to FAS/FAE alone. Also, those that are seeing children as hyperactive may perceive it from the sedate, adult perspective on life.

The sadness that people feel about losing their culture and losing their traditional ways has been compounded with the sadness and realization that there is a generation who have difficulty learning the traditional language and ways. These deficits may have been imposed on them prenatally by alcohol. We found that most people in the community could recall seeing a pregnant woman drunk or knew of at least one or two children whom they believed were affected by the mother’s drinking. Some were aware of the terms FAE/FAS and some were not.
The investigator met with the Chief and Council briefly to explain the direction of the project and to request permission to talk with some more Elders in the Dene community about FAS/FAE. However, they denied permission, stating that Elders would say they knew nothing about the issue anyway. After further discussion with others in the community, we concluded that the Chief and Council were not fully aware of what FAS/FAE is. A member of the Dene community with whom the investigator consulted on a regular basis concurred with this. If individuals on the Band Council do not fully understand the issue, how can others in the community be expected to have an understanding? Because FAS/FAE is a sensitive issue and has the potential of creating emotional turmoil, those in positions of support must have a solid knowledge base.

Individuals Most Affected

Those closest to the issue of FAS/FAE, such as parents or individuals who thought they themselves might have FAS/FAE, are really at the core of this disability concern. Parents of children with FAS/FAE argued about whether or not it was beneficial to obtain the diagnosis of FAS/FAE. Proponents of obtaining a diagnosis said that it helps understanding the reason for the many emotional and behavioral problems of a child and that the child may be harmed if there is no diagnosis, as the child would not be understood. They also argued that it helps to get funding and resources in place. Others indicated that a diagnosis might limit the children as it labels them and that FAS/FAE is not the real problem anyway. The real problem is really cultural discord and alcoholism. They also argued that there is a real danger of inflicting more guilt on mothers of FAS/FAE children when they are already dealing with many emotional and spiritual issues. They also said there are no supports in place to help women and families work through these powerful and intense issues. One parent said that even though their child was FAS/FAE, the child would not be singled out as different but would be treated in the same loving way that all their other children were treated.

As the topic of FAS/FAE was discussed, some individuals would come to the researcher afterward and inquire whether some of the physical and/or psychological symptoms they experienced could be due to the effect of maternal drinking. One person said that learning about FAS/FAE helped him understand and accept his repetitive problems with the law, as he believed that he was a FAS child. The possibility of being FAS/FAE helped some people accept that perhaps it “was not all their fault”. Thus, some respondents who were possibly FAS/FAE perceived a diagnosis as poten-
tially liberating and providing hope for them as it put their own struggles and behavioral problems in perspective.

One member of the Dene community summed up the issue of spiritual and emotional pain and confusion in the following way:

There is spiritual murder going on. This is when you don’t know who you are and you are called a bastard. All outward things tell you who you are so you look to outward things such as alcohol, drugs, sex and abuse. Spiritual murder is when you don’t know who you are and do not know the past. There is need for healing to come to life.

**Barriers to Dealing with FAS/FAE as Defined by the Community**

Throughout the interviews, respondents indicated what they perceived as barriers in the community in dealing with the sensitive and complex FAS/FAE issue. The following is a list of these barriers (in no particular order). Where needed, we have provided our own assessment and critique of these barriers.

**Sensitive Subject of FAS/FAE**

Historically, the people of the community have been reluctant to deal with issues such as AIDS or sex education. When condoms were to be distributed in the school system, sex education became a controversial topic in the community. Many articles were written in the local newspaper debating the condom issue. In contrast, when a presentation on the sensitive subject of FAS/FAE was offered to the community, only one person came to the first presentation. Only after much phoning and encouragement did several individuals attend the second presentation. Organizers of the presentation said that of those who attended, the Aboriginal people indicated they came as “parents” while the non-Aboriginal people indicated they came only as “care givers” and not as parents. The belief of the organizers was that the non-Aboriginal people who attended did not want to have the stigma of being in need.

**Religious and Philosophical Discord**

Some members of the Dene community shared their beliefs about the friction between organized religion and traditional Aboriginal spirituality that hampered working together on issues such as FAS/FAE. Religion has an impact on this issue because medical and other health care professionals predominantly adhere to a very traditional and religious perspective.
In traditional Christian belief, Man (denoting the human race) is considered to be the most complex and sophisticated creature on earth and is recognized as ruler over creation based on the Genesis story. As a result, all living things are perceived as objects for the advancement of the human race. In a pyramid, Man is placed at the top. In Aboriginal belief, all creatures and plants must follow the laws given by the Creator. However, because Man constantly tries to break them, he is the lowliest of all creatures, at the bottom of an inverted pyramid.

We believe that these underlying differences have repercussions throughout the cultures. Actions that follow the philosophy that earth is Man's to use for whatever purpose he may want, regardless of the effect on other living things, have resulted in environmental devastation. The difference in philosophies has been evident in some of the land claim issues, for example, those supporting the interest of the larger, non-Aboriginal society, have scoffed at the Aboriginal interest to preserve sheep in an area of the Northwest Territories. A member of the Dene community compared their interest in preserving sheep and their habitat to non-Aboriginal persons wanting to preserve piles of metal they call antique cars.

As the Aboriginal society has been pulled into the different philosophy and materialistic lifestyle of the larger non-Aboriginal society, many people have lost some respect for their own culture and environment and for the individuals in it. Alcohol abuse has been an attempt to fill the void of lost spirit and culture. Long-term alcoholism has had a negative effect, as is evidenced by the high prevalence of sexual abuse, physical abuse, family discord, and, ultimately, FAS/FAE.

Some in the non-Aboriginal community identified the "holier than thou" attitude of church members as being a barrier to understanding and caring when dealing with issues of alcohol abuse and its consequences. Community members believed some church members to be very biased, and yet they fill many of the key positions in the health organization. Some expressed concern that certain physicians would not prescribe birth-control pills to single women because of their religious belief, which could result in pregnancy in teens who are likely to be experimenting with sex and alcohol. It was believed that this situation just perpetuates the feelings and emotions about the health care system that occurred after the mismanagement of the tuberculosis problem that had occurred previously in the Aboriginal population. Another example of this attitude was a comment made by a health professional of this religious persuasion that pregnant women did not care enough to stop drinking while pregnant. This issue of religious persuasion is a very complex one, and the strong, dogmatic stand of the church about such issues greatly affects community unity. Members of the Dene com-
Community also mentioned the religious influence several times. They attributed some of the friction and jealousy between Dene families to differences between religious dogmatism and Dene spirituality. Although this difference was not discussed directly in relationship to FAS/FAE, these underlying feelings would hamper discussion of such a sensitive emotional topic. Individualism, the goal of a materialistic society, has also permeated the Dene community culture and some of the community grieves the loss of community spirit and the ability to support one another in times of struggle such as when dealing with FAS/FAE.

Lack of Anonymity

The community where we undertook this qualitative research has a relatively small population, so people recognize others quickly according to the car they drive. Community members said that where one’s car is parked is seen as a public announcement of where one is or what meeting one is attending. If there were support groups about FAS/FAE, people attending the meetings would lose their anonymity and therefore dealing with this sensitive issue would no longer remain a private matter. Even the investigator experienced this small community phenomenon as cars were easily recognized as those of acquaintances driving toward her.

Lack of Knowledge

As alluded to before, knowledge about the FAS/FAE issue was greatly lacking. Many individuals identified this as a barrier. It was not uncommon when the investigator was phoning to arrange interviews to be asked what FAE was. People generally had some understanding of FAS, although this varied greatly. To illustrate this problem, one physician questioned what the syndrome was prior to his role in the seminar on FAS. Other examples include, a lack of awareness of the long-term cognitive effects of FAS/FAE children, questions about whether a male’s drinking had any effect on the pregnancy, and a lack of awareness that any drinking during pregnancy is considered unacceptable. One individual in the school system indicated that some young girls expressed the belief that if no one saw them drink, no one would know they had drunk, not even their fetus, and so the unborn child would not be affected. Some people thought that the community either “did not care to know about the problem” or “considered it to be someone else’s problem and therefore lacked an interest in knowing.”

Denial

The use of defense mechanisms, especially denial, was a common barrier that was mentioned throughout the interviews. This defense mechanism was articulated as more of a barrier within the non-Aboriginal commu-
Community Members' Perceptions of FAS/FAE

Denial took the form of ignoring that the FAS/FAE issue affects the community as a whole and identifying it as someone else's problem. Perhaps the lack of interest and attendance at the presentation of FAS/FAE was a sign of denial and lack of concern about the issue. However, organizers did admit that more effective advertisement about the presentations might have brought better results. Many Aboriginal people are already dealing with many stressful issues and not acknowledging FAS/FAE intellectually or emotionally is a protective strategy against more pain. One person indicated that counsellors have encouraged them to raise painful issues in healing circles, but having talked about these issues they have found no safety supports and assistance to complete the healing process. This concern is fundamental. Perhaps denial does serve a purpose, although one cannot condone ongoing use of this coping mechanism.

Attitudes Toward Alcohol

Professionals perceived that the belief of many youth in the community is that alcohol is fun and not a drug. This perception is encouraged because no other options for entertainment are available. Some parents have attempted to deal with this problem by offering their homes as meeting places for groups of adolescents to watch movies together and to socialize. A need for an adolescent centre to provide for other alternatives of entertainment has been expressed.

The Uniqueness of the Community

This barrier is difficult to clearly define but several members of the Dene community indicated that the community had a predominant "red neck", or "old boys network" or a "holier than thou" attitude. Because of the unique mix of non-Aboriginal and Aboriginal population, many used terms that denoted a separation of the two cultures—a "we/them" attitude. Although the study took place in a northern community, southern activities, attitudes and values clearly influence it; it is becoming a materialistic and individualistic-oriented southern society coupled with the alcohol problems of the north. When the investigator asked a general question about what individuals believed to be most needed in their community (irregardless of the FAS/FAE issue) many expressed a need for a bridge to be built over the river that separated the non-Aboriginal and Aboriginal communities. Through physical barriers, emotional barriers are created. Some people in the non-Aboriginal community had asked, "What do they do over there anyway?" This question may be a sign that there was recognition of the need for more interaction and communication between the two cultures.
FAS/FAE: Part of a Bigger Problem

During interviews and conversations, individuals indicated that people need a lifestyle change if the long term effects of FAS/FAE are ultimately to resolve. Such a change means decisions that may be difficult and complex. Some professionals said they are eager to work with the children and with the issue of FAS/FAE but are at a loss as to how to motivate people to work towards change. A community member suggested that this could be accomplished by “planting seeds” or talking about and teaching FAS/FAE.

Even if the school system or other professionals guided the person with FAS/FAE, the concern is that care in the home may be inconsistent or inadequate. Some professionals were frustrated with family breakdown, dysfunctional families, violence in the home, lack of positive role modelling, and perceptions of resistance by parents to follow through with the guidance. In the school system, anger management is taught and used throughout the day, but teachers saw these eight hours of guidance and role modelling as being insignificant when compared to sixteen hours of living in a poor home environment.

Discussion

In this study we discussed the different perspectives, beliefs and awareness of people and groups in a northern community which is struggling with the issues of FAS/FAE. We also identified several barriers to dealing with drinking during pregnancy and towards FAS/FAE.

Our study broadened the limited perspective of epidemiological studies that determined the existence of a high incidence of FAS/FAE in northern communities to include an understanding of the problem from the perspective of a community and its members. The intensity of the feelings, the pain and the suffering cannot very well be addressed by a quantitative study. The FAS/FAE issue demonstrates that it cannot be separated from the dynamics of the context in which it occurs and, therefore, it is ineffective and undesirable to study the causes and prevalence of disease in isolation (Oppenheimer, 1995).

Epidemiology is just one of the approaches in addressing the major determinants of health in a population, and should be complemented by other quantitative approaches, as well as qualitative and historical studies (Pearce, 1996). Each study that falls along a continuum from epidemiological studies to qualitative research and finally to participatory action research can complement and augment further understanding of the FAS/FAE health concern. The story of the ten blind men, each of whom touched a different
part of the elephant, illustrates this point. Each described the “truth” of what an elephant looked like—a wall, a tree trunk, a snake, or a hose. So too, each discipline provides a bit of the truth about FAS/FAE. Sharing these views can only provide a deeper understanding of the truth of FAS/FAE and enable communities and individuals to deal with the painful and unnecessary long-term effects of alcohol on individuals.

At a personal level, when I (LK) was asked to become involved in this qualitative project, I too had little appreciation of the underlying emotional and spiritual issues. My first response was, “yes, mom drinks and the babe is detrimentally affected with physical and cognitive problems...” I was little prepared for the confrontation of spiritual agony that the community was experiencing as they found they were losing so much that is precious to them in their language, their traditions and their way of life. As community members try to regain some of the culture that has been forgotten, they are being hampered because so many of the younger people have learning difficulties. At one point, I became so physically overwhelmed with the sadness and the pain that I went to my room and wept. As mothers come to the realization of FAS/FAE, there must be spiritual and emotional supports for them as they face this tragic disability brought about by their own drinking during pregnancy. If these support systems are not in place, there is a risk that these women will deal with this crisis in much the same way that they have dealt with other crises in their lives: by turning to alcohol. If this occurs, then the vicious cycle will continue.

Although we hope that this study and its process has the capacity to generate more involvement from the community and its members regarding the FAS/FAE issue, this study was not participatory action research (PAR). We focused on exploring concerns and beliefs. Even though this type of research is more likely to uncover the “real story” than epidemiological research, there are limitations as well. Some members of the Dene community indicated that many researchers come to the north and study, but the research is done “to” rather than “with” the community. We were sensitive to this issue and met people from the Dene Cultural Institute on a regular basis during the study period and also provided an extensive written report following the study. Our community advisors indicated that they found the results of the study helpful in getting a sense of what community members were thinking about in regards to this issue. Participatory action research would facilitate the process of people understanding and then deciding what must be done to facilitate their own health care. Indirectly, the investigator did “plant seeds” by encouraging the people to question and understand the relationship between alcohol and pregnancy.
Another limitation of this study is that the time spent in the community was approximately two months, which is not long enough to understand the intricate and deeply rooted beliefs and perceptions that prevail in the community. Also, we cannot be convinced that in this short time period as broad a range of informants as possible was contacted. It is possible that only those with similar attitudes and beliefs about FAS/FAE were contacted, as people tend to suggest only those with similar perspectives. However, we did encounter differing views during the interviews.

A third limitation was that although the investigator talked with many community members, she did not obtain the thoughts of the Elders who did not visit the community centre because the Chief and Counsel decided that going out to visit them individually was inappropriate.

We recommend that the community consider a participatory action research (PAR) project (Cassara, 1987; Bamsley and Ells, 1992; Rahnema, 1990; Smith, 1993) to facilitate and encourage political, economic, and social change through exploration and management of their own affairs in regards to FAS/FAE (Seeley, 1992). In the past, colonialism has hampered empowerment through community decision-making (Lange, 1988). An example of PAR is the story of the people of Alkali Lake who regained control of their community and effectively dealt with the high level of alcoholism in the community (Hodgson, 1987). At the request of the community, we were only able to facilitate the first step in PAR (Robinson, 1996). This step was to present to the community in an organized way what was understood about FAS/FAE and what the community people identified as barriers to their own community to start dealing with this health issue.

It would seem helpful for the community to appoint a respected community facilitator to encourage discussion within organizations and then between different organizations in the community. Community members did indicate that an ad hoc committee was once in place, but because of so many power struggle issues, it quickly dissolved.

Members of the Dene community still have much to do to help those individuals already affected by FAS/FAE and to prevent future generations from being affected by this preventable disability. Only as disciplines of research work together can individuals and communities address these concerns and issues.

Note

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References

Asante, Kwadwo O. and Joyce Nelms-Matzke  

Bray, Debrah I. and Perry D. Anderson  

Barnsley, Jan and Diana Ellis  

Cassara, Beverly B.  

Hodgson, Maggie  
1987 Indian Communities Develop Futuristic Addictions Treatment and Health Approach. Nechi Institute on Alcohol and Drug Education, Nechi Institute.

Kowalsky, Laura, Marja Verhoef, Wilfreda Thurston, and Gayle Rutherford  

The Lancet  

Lange, Lynda  

Oppenheimer, Gerald M.  
Pearce, Neil

Rahmena, Majid

Robinson, Geoffrey C., Julianne L. Conry and Robert F. Conry


Robinson, Michael

Smith, Susan E., Timothy Pyrch and Artmo Ornela Lizrdi

Seely, Janet A., Jane F. Kengeya-Kayondo and Daan W. Mulder

Weed, Douglas