

Fetal alcohol spectrum disorder in adults: diagnosis and assessment by a multidisciplinary team in a rural area

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Access to diagnostic and assessment services for fetal alcohol spectrum disorder in adults is relatively rare in the world. Since 2002, the Lakeland Centre for Fetal Alcohol Spectrum Disorder (LCFASD) in northeastern Alberta has been providing community-based, mobile diagnostic and assessment services for adults prenatally exposed to alcohol. This article describes the community-based model developed by the LCFASD, the clinical findings of the diagnostic team and the successes and challenges experienced by the team.

L'accès à des services de diagnostic et d'évaluation des troubles du spectre de l'alcoolisation foetale chez les adultes est relativement rare dans le monde. Depuis 2002, le Lakeland Centre for Fetal Alcohol Spectrum Disorder (LCFASD), au nord-est de l'Alberta, fournit des services communautaires mobiles de diagnostic et de traitement des adultes qui ont été exposés à l'alcool avant la naissance. Cet article décrit le modèle communautaire créé par le LCFASD et les constatations cliniques de l'équipe de diagnostic, ses succès et les défis auxquels elle est confrontée.

INTRODUCTION

The Lakeland Centre for Fetal Alcohol Spectrum Disorder (LCFASD) in Cold Lake, Alta., opened in 2001 to support a local group of hard-working and dedicated professionals who were contributing to a community-based diagnostic team to serve children. The team had been trained in Seattle at the Fetal Alcohol Syndrome Diagnostic and Prevention Network at the University of Washington.¹ The training prepared the team of local professionals to use the 4-digit code developed at the University of Washington to provide clear diagnoses for those prenatally exposed to alcohol. The local team worked together to adapt the diagnostic model to meet a rural need. They were able to develop and deliver this service with the support of the Lakeland Fetal Alcohol Syndrome Committee, which began in 1994.

The LCFASD provides services to

the Lakeland region, which is an area in northeastern Alberta that includes 1 small city, 25 small towns or villages, 7 First Nations communities, 4 Métis settlements (land-based Métis peoples, unique to Alberta) and 1 military base, with a total population of about 80 000. From Edmonton, the closest community is a 1-hour drive and the farthest is a 3.5-hour drive. All communities are accessible by road. The LCFASD is based in Cold Lake, Alta., but provides its services to the region's communities through mobile diagnostic and assessment teams and follow-up support personnel.

The LCFASD diagnostic team began with a community-based diagnostic and assessment team for children in 2000² and had always planned to serve adults. However, it became apparent that to serve adults, a different grouping of professionals was required for the clinical team. Adults who have

been prenatally exposed to alcohol are in desperate need of an accurate diagnosis and support; there are few diagnostic clinics that serve adults, and many adults with fetal alcohol spectrum disorder (FASD) have received treatment for symptoms and not the diagnosis, which has led to substantial maladaptations to life. In 2002, the FASD diagnostic team for adults was developed, team members were trained and the diagnostic service was implemented. To our knowledge, this was the first diagnostic service for adult FASD in Canada. Published literature for diagnosis in adults is minimal, as is the depth of literature on delivery of services or development of community-based programs in support of adults with FASD living in rural areas. The Lakeland Fetal Alcohol Syndrome Committee became the Lakeland FASD Society in 2003. The society operates the LCFASD and also oversees a variety of training and prevention programs, including mentorship programs for women at high risk of alcohol use during pregnancy, transition planning, employment coordination and a summer camp for children with FASD.

The diagnosis of what is now known as FASD was first recognized by Lemoine⁵ and subsequently elaborated on by Jones and Smith.⁴ The diagnosis was a “gestalt” diagnosis based on the presence of physical abnormalities involving facial formation, growth patterns and central nervous system or neurobehavioural disorders. In 1996, the Institute of Medicine⁵ further delineated the spectrum of damage caused by alcohol to the growing fetus in its diagnostic criteria. The effects were further refined by Astley and Clarren,¹ leading to the introduction of the 4-digit code system of diagnostic management. The 4-digit code system is a formula used to assess the 4 key components of diagnosis: growth deficiencies, facial features, brain function and alcohol consumption. The diagnostic criteria highlighted the need for a multidisciplinary team to be involved in the diagnostic process. These professionals, each with their individual expertise, could provide a comprehensive assessment unique to the patient, providing the team with the necessary information to support that patient across the full spectrum of the disabilities identified. In 2005, Chudley and colleagues⁶ reviewed the Canadian approach to the 4-digit code to develop the Canadian guidelines for diagnosing and assessing FASD.

DESCRIPTION

The delivery model for diagnostic services used by the LCFASD is based on the model of the Universi-

ty of Washington Diagnostic Clinic¹ and uses the Canadian diagnostic guidelines for FASD.⁶ The focus of the LCFASD model of service delivery is the diagnostic team of local service providers who come together from throughout the region on predetermined clinic days in a variety of communities for the purpose of assessment and diagnosis.

All information flows to and through a team coordinator. She ensures that the information is collected and the patient and site prepared. She controls the flow of the clinic day, engages and delegates all the team members in their various roles and manages the details of the day. The team coordinator also ensures that the participating agencies are satisfied with the outcomes, and she deals with any arising issues immediately.

This community-based multidisciplinary team is made up of a physician, neuropsychologist, mental health therapist, psychiatrist, career counsellor, addictions counsellor, cultural liaison, legal representative, disability services coordinator, team coordinator and postdiagnostic outreach worker. A specialized hospital or specialized services are often not available in rural communities, thus forcing patients and families to travel to larger centres for service. This creates many barriers to accessing services, including limited transportation, fear of cities, lack of financial resources and a feeling that one is ill if they must travel to see a specialist. Whether real or perceived, these barriers have prevented adults from accessing diagnostic services for FASD.

This model brings local professionals together once a month who have been specifically selected and trained to participate on the LCFASD diagnostic and assessment team. Their contributing agencies provide them with a salary to participate in the team. The Lakeland service area does not have a neuropsychologist that it can borrow for a day. A fee-for-service arrangement has been made with a neuropsychologist who provides service for other agencies in the region and so has some understanding of the rural area. The service area also does not have a psychiatrist to work on the team, and a special arrangement has been made with an interested psychiatrist from Saskatchewan, again on a fee-for-service arrangement. An honorarium is provided to the physician, who is in private practice, thus giving recognition to his commitment and loss of salary for the day. The team coordinator and postdiagnostic outreach workers are employed by the LCFASD. To prevent cancellations by the clinic, each team member has an identified and trained backup to address employee turnover, holidays and sick leave.

The team dedicated to adult patients is mobile and sees one adult per month, because the volume of information needed for adult patients is very extensive and the testing is all done in one day.

SIX PHASES OF DIAGNOSIS

Phase 0: preclinic

Referrals are received by the team coordinator, who determines eligibility (i.e., residence in the service area and confirmation of mothers' drinking habits during pregnancy). An advocate (e.g., community worker, public health nurse, women's shelter, parent, spouse) is identified to assist the patient in completing the application and consent forms. The team coordinator may assist the patient with this if the patient has no support system. Most referrals come from social workers, employment counsellors, families, employers, lawyers or the LCFASD itself. The LCFASD may find that parents of diagnosed children need diagnosis and assessment for FASD themselves, or the women within a mentorship program for those at high risk of alcohol use during pregnancy may need to be seen for diagnosis and are referred to the team coordinator.

On receiving the application package, the team coordinator reviews all information and collects any missing documentation. When the file is complete, a clinic date is selected, with an average wait of 3 months. The cultural liaison or the team coordinator may assist the patient and members of the support system in understanding the process of clinic day. The team coordinator also ensures that all team members have information about location, dates, times and a very brief overview of the patient for each clinic day. The team moves around to different communities in the region, so it is critical that everyone knows the correct location.

Phase 1: clinic days

Most patients like the in-clinic process to occur in one day; they may have difficulty waiting for results or may have problems returning for a second clinic day. The neuropsychologist completes a battery of tests depending on what assessments have been completed in the past. This is the most time-consuming part of the clinic day and begins before the rest of the team arrives.

The team is provided with a history of the patient. Information gaps are identified and questions generated for the clinical interviews. The clinical interviews are conducted by a variety of team members

with the patient and members of the support system (e.g., parent, spouse, case worker). The interviews provide valuable information about the current situation, functional difficulties, areas of strengths and any heretofore undocumented information. This process helps the patient and family to identify what they want to get out of a diagnosis. Clinical interviews are followed by examination by the physician, which includes facial measurements, head circumference, height and weight, and a soft neurologic assessment.

Phase 2: diagnosis and recommendations

The team meets to review all of the gathered information and to make a determination of diagnosis and recommendations. Input from all members has equal consideration, and each member may contribute his or her ideas and thoughts to the process. Consensus must be reached in all areas (growth, face, brain and alcohol) by all members before conclusion. Using the 4-digit code and translating to language used by the Institute of Medicine, all diagnoses are listed (e.g., learning disabilities, language deficits, memory problems). Then the team formulates the recommendations, which will be given to the patient and family that day.

During this phase, the postdiagnostic outreach worker will meet with the patient and members of the support system to inform them about what will happen during the next phase, the case conference, and to tell them that they will meet in 1 or 2 weeks to begin working on the recommendations.

Phase 3: case conference

A case conference held the same day with the patient and members of the support system provides the diagnostic information and recommendations. A written copy of the diagnosis and recommendations is provided, which helps the patient remember what was discussed and begin to address the recommendations. The patient and the people supporting him or her have an opportunity to ask the team questions and are given some resources to take home, such as *Rainy & Red*,⁷ a story book developed by the LCFASD that is designed to assist adults in better understanding their disability.

Phase 4: emotional support

The mental health therapist meets with the patient privately to again review diagnostic and recommendation information and to emotionally debrief the

patient. The psychiatrist will meet privately with the people supporting the patient for the same purpose. It is important to provide clear direction for patients and those supporting them to ensure that they know where to seek emotional support if needed. In most instances, the patient is relieved to have a reason for the way things have happened in their lives.

Phase 5: team debriefing

Many community-based team members are not accustomed to the process of diagnosis and may have to emotionally debrief particularly difficult patient histories. This helps to keep team members healthy and able to continue their work.

Phase 6: outreach support

The LCFASD believes that every family requires some form of additional support following a diagnosis. The centre employs postdiagnostic outreach workers to connect the patient to the local community supports and assist the patient with following through on recommendations. The outreach worker will remain involved with the patient as long as is required.

The team coordinator combines the completed

reports from the team members into one document. A copy of the report is sent to the referring organization, family physician, team physician and others as identified by the patient. The team of professionals is not required to provide any follow-up as part of their team involvement.

CLINICAL OBSERVATIONS

Since 2002, the LCFASD team has attempted to diagnose one adult per month. This has not always occurred because of patients unexpectedly leaving the community, being incarcerated, being homeless or moving to stay with the next family member or friend, or team members being unavailable because of unscheduled events. Table 1 shows characteristics of the 57 assessed adults who were given diagnoses by the LCFASD team.

DISCUSSION

Model of service

Assessment and diagnosis of adults with FASD is a new practice in Canada, with only a handful of clinics attempting this work. The LCFASD has taken

Table 1. Characteristics of 57 adults seen at the Lakeland Centre for Fetal Alcohol Spectrum Disorder from 2002 to 2010

Characteristic	% of patients	Characteristic	% of patients
Diagnosis*		Living situation	
ARND	85	Independent	14
Partial FAS	12	With spouse	18
FAS	0	With biological parent	25
No diagnosis	3	With adoptive or foster parent	15
Sex		Homeless	2
Male	48	Jail	2
Female	52	Extended family	25
Ethnic background		Had children†	42
White	26	Had children who were in the	29
Aboriginal	74	care of others	
Marital status		Legal involvement‡	40
Single	70	Employed at time of diagnosis	14
Married	11	Health concerns§	58
Common-law	16		
Separated or widowed	3		

ARND = alcohol-related neurodevelopmental disorder; FAS = fetal alcohol syndrome.

*Fetal alcohol spectrum disorder is an umbrella term used to encompass all of the alcohol-related diagnoses, which include FAS, partial FAS and ARND. All of these diagnoses can include a range of maladaptation, intelligence and ability levels. In FAS, the patient presents with substantial growth deficiencies, characteristic facial features and brain dysfunction, whereas patients with partial FAS have a less severe expression of these characteristics and ARND patients present with only the brain dysfunction.

†Many of the patients' children were not in their care, so an accurate number was difficult to obtain.

‡Includes only charges against patients, not involvement with justice system (e.g., as a victim or involvement with child welfare).

§Important health issues that needed treatment, such as untreated diabetes, brain tumour, obesity, eating disorder, malnutrition and pregnancy.

the community-based model that it developed for children and expanded the application to serve adults. The use of in-kind donations from community agencies allows rural areas to deliver specialized services in a cost-effective and confident manner. Team members from community agencies have a unique perspective in being able to make recommendations regarding the services of their agency and from their knowledge of other local services. This allows patients and members of their support systems to receive practical and relevant recommendations.

With the use of this model, team members report a less stressful workload because they are a part of a team dealing with complex cases and they are not on their own, cross-training of various disciplines has proven very helpful in everyday work, agencies have a specialized service that they can refer patients to and agencies have confidence in the services being provided. The contributing agencies benefit from their involvement with LCFASD because they are able to use the expertise of their employee trained in FASD.

The use of mobile teams has reduced many real and perceived barriers for patients. The smallest of communities have been host to FASD diagnostic services, and it has been the clinic's experience that additional referrals will follow after a visit to a community.

In a postclinic survey,⁸ families and patients indicated that postdiagnostic outreach support was the most useful aspect of the diagnostic process. The postdiagnostic outreach worker visits patients in their homes and provides support using philosophies in harm reduction and relational theory.

The LCFASD has a patient-focused approach rather than a research focus, like the FASD diagnostic clinic at the University of Washington,¹ and its patients provide data for FASD research. A patient-centred approach means that the needs of the patient and family come before the needs of the team or the need for research. This commitment to patient care and respect is likely the largest contributing factor to the overwhelmingly positive patient feedback the LCFASD receives.

Successes

Several factors have been identified as critical to the LCFASD's success in providing diagnostic services for adults. These include selection, management and coordination of the team; patient focus; cultural connections; community readiness; and political visibility.

The conscious development of an effective team

is critical. Team members request to be part of the team (indicating an interest in FASD), work well together and are dedicated professionals. Team dynamics are critical to the success of the work. Every team member's input is considered equally important, and decisions are made through team consensus. Passion for the cause is critical. Team members are all trained in FASD, specifically its diagnostic components, and their role on the team by the LCFASD. Each team member also has an identified and trained backup who can substitute in the event of sickness, holidays or staff turnover so that clinic appointments can still proceed.

Establishing an effective network of regional and community partners with a broad, integrated view is a priority. Communities are prepared to support and participate with the diagnostic teams. A diagnostic clinic may not "parachute" as well into communities that are not prepared. A strong indicator of readiness would be if many community agencies were asking for FASD diagnostic service.

A commitment to patient-focused services ensures better services and more enthusiastic participation from staff.

Good working relationships, based on cultural knowledge and respect, are established with all communities. Aboriginal professionals are included as team members to advise the team and give clarification about cultural issues, and to support the families of patients when appropriate. People from many other cultures in our region are accessing services, and every effort is made to find a cultural liaison to the team.

Political visibility and partnerships with all levels of government are cultivated and are critical for funding and support. For example, the LCFASD organizes fundraisers, is visible at conferences and liaises with federal, provincial and local representatives to put forth the needs of people with FASD.

Challenges

One of the major challenges in implementing this model has been the availability of rural professionals, both as primary team members and in filling backup positions. Finding the right person (i.e., someone with an interest and background in FASD, the ability to work effectively in a team and a good sense of humour) can be challenging. Having agency partners appoint employees to join the team is less effective than if employees request to be a part of the service. The LCFASD provides team training sessions annually to train new members, as well as

for communities who wish to train their own teams. This training has proven to be critical to the functioning of teams.

Adult patients present the challenge of not always having a stable support network. In the event that a scheduled patient is unavailable on the clinic day, every clinic must be prepared with 1 or 2 patients who can be called in to be assessed. This instability also presents many challenges to the provision of postdiagnostic support, because outreach workers often need to help patients meet basic needs before addressing more supportive or treatment options of the recommendations.

In the beginning, there was concern that the 4-digit code would not be effective in diagnosing adults; however, it has worked very well. The characteristic facial features are just as prominent in adults as they are in children when we specifically look for them. One challenge is measurement of the philtrum when the patient has a moustache or beard.

CONCLUSION

The service delivery model developed by the LCFASD has turned out to be appropriate and effective for the rural areas in northeastern Alberta. It addresses the need for professional, timely assessment and diagnosis with an emphasis on patient support in a rural setting. The LCFASD believes that this service model can be adopted by other communities wishing to provide diagnostic services for FASD in adults.

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