THE CANADIAN GUIDELINES AND THE INTERDISCIPLINARY CLINICAL CAPACITY OF CANADA TO DIAGNOSE FETAL ALCOHOL SPECTRUM DISORDER

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ABSTRACT

Background

In 2005, the CMAJ published the *Fetal alcohol spectrum disorder: Canadian guidelines for diagnosis*. The intent of this publication was to encourage a more consistent interdisciplinary team approach and diagnostic procedure for FASD diagnoses. That same year, the Canada Northwest FASD Research Network (CanFASD Northwest) determined the locations and capacity for interdisciplinary FASD diagnosis across Canada. Six years later, we wondered how successfully these Guidelines had been in bringing consistency to FASD clinical work.

Method

All clinical programs in Canada that routinely performed FASD evaluations were identified through membership in either our Network Action Team on FASD Diagnosis, professional meetings, organizational memberships, websites, programs lists available from Provincial or Federal offices or by word of mouth. Surveys were sent to all of the programs identified.

Results

A total of 55 clinics had been identified in seven provinces and one territory in 2005 that did FASD multidisciplinary diagnostics. In 2011 only 44 clinics were identified in six provinces and one territory using the same methodology. Survey responses were completed by 89% of these 44 clinics identified in 2011. The Guidelines were well known to all programs and actively referred to by most. Only 46% of respondents had a full staff of professionals on site for diagnosis, however 90% did use the team approach in determining final FASD diagnosis, while 79% used the team to help in developing a treatment plan. Among the clinics reporting, 74% of them used the new diagnostic schema proposed in the Guidelines and another 12% report using both the Guidelines and another system for diagnosis.

Interpretation

The Guidelines have become well known to the medical community. They have contributed to increased consistency in approach and in diagnosis. The variations in clinical ability to fully staff themselves, and the 20% decline in clinic numbers suggest important funding gaps. Many provinces and territories still have no local interdisciplinary programs for FASD diagnosis, and the need across Canada is still many times greater than what is currently available.

Key Words: *Fetal Alcohol Spectrum Disorder, diagnosis, guidelines, Canadian, capacity*

In 2005, “Fetal alcohol spectrum disorder: Canadian guidelines for diagnosis” (the Guidelines) were written by a panel of Canadian experts sponsored by the Public Health Agency of Canada (PHAC).[1] These experts were well aware of the diagnostic approaches in the literature and knew that there were three on going problems in fetal alcohol diagnoses: a) determining the probability that the gestation was exposed to alcohol at potentially teratogenic levels; b) discerning the probability that the brain was dysfunctional due to cognitive and processing abnormalities (organically deranged as differentiated from psychiatric conditions and environmental disturbances); and c) calculating the degree of the patient's functional abnormality as within or beyond the normal range of performance. The panel believed the clinical range of approaches was wide enough that "guidelines" were needed to bring consistency to the clinical work across Canada, but that enough data was not yet available to produce a true "clinical standard of care" or a "best practice."

The Guidelines proposed a new diagnostic scheme, which was based on other diagnostic systems that had been previously developed in the United States.[2,3] The Guidelines emphasized that an interdisciplinary team rather than a single practitioner was preferred for completing a diagnostic assessment. They recommended that the team required a coordinator, a physician who could identify the physical features of FAS and/or other conditions that might be present leading to brain dysfunction, and a "brain assessment group" composed of a clinical psychologist, speech pathologist and occupational therapist. The Guidelines reminded the reader that the evaluation of strengths and weaknesses used to establish the diagnosis could also be used to develop an appropriate individual treatment plan for education, social service, community and other arenas of concern. Finally, the authors emphasized that the information from one team member could inform or alter the recommendations of another team member thus justifying a team meeting to resolve issues. The Guidelines have been referenced regularly in the literature since their publication in 2005. A quick scan from scholar.google.com shows a consistent growth in referring to the Guidelines each year since publication (Table 1). The Guidelines are also the second most often cited publication of the PHAC according to a recent search of Google Scholar.com.

The Guidelines were published in the same year (2005) that CanFASD Northwest was established to inform government with data that might improve public policy around the issues of FASD.[4] That same year, PHAC funded a study by the CanFASD Northwest to determine the number of sites that were already doing FASD diagnoses by using an interdisciplinary team approach.

Across the north and the west (British Columbia, Alberta, Saskatchewan, Manitoba and the Northern Territories), 27 programs were identified and 15 programs responded to the questionnaire. These programs were determined to have seen about 85% of the patients evaluated by all the programs. The full capacity for FASD diagnosis was 816 evaluations in 2005, and projected to be 975 in 2006.[4] A similar survey was then conducted in the rest of Canada where 28 programs had been identified (Ontario, New Brunswick and Nova Scotia), but poor response made interpretation impossible. Nevertheless, 55 clinical programs were identified as seeing FASD patients to at least some extent six years ago.

In 2010, PHAC became interested in the dissemination and use of the Guidelines and requested that CanFASD Northwest undertake a more extensive survey and to evaluate the impact of the Guidelines on the development of FASD clinical programming over the last five years.

CanFASD Northwest attempted to identify all clinical programs that represented themselves as diagnosing FASD, either in a program devoted solely to that purpose, or in a program evaluating other developmental conditions that also relied on a neurodevelopmental team approach. These programs were identified through membership in our Network Action Team on FASD Diagnosis, from professional meetings, organizational memberships, websites; program lists available from Provincial or Federal offices or by word of mouth. We accepted all programs, whether they saw individuals at only specific ages (e.g. Pre-school, school age or adult) or saw patients across the lifespan, and whether they were open to the general public or focused on a specific community. Some programs had more than one team – one that assesses children and youth and another to assess adults. If these teams functioned as separate clinical programs then, each program was counted separately. Through this process, which was the same as the process used in the previous 2005 study to locate clinics, we identified 56 Clinics in British Columbia, Alberta, Saskatchewan, Manitoba, Ontario, New Brunswick and the Yukon. No programs were identified in the other provinces or territories. Of these 56 clinics, 44 were determined to be operational at present or would be operational within calendar year 2011. The others had either closed prior to 2010 or had a delay in opening. This was generally due to funding limitations.

The objectives of this study were then to identify the availability and impact of the Canadian Guidelines in clinics that purport to routinely do FASD diagnosis and then determine the capacity of Canada to perform these necessary medical evaluations.

METHODS

The survey was conducted in two parts. Part 1 was sent to the coordinator or designated leader of each clinical program. As part of that survey, the interviewee identified specific professionals on their team who could answer Part 2. Ideally, they identified a physician, psychologist, speech pathologist and occupational therapist. Although many teams had more than one professional sharing a role on the team, only one respondent per team, per profession, was recruited. Some teams within the clinical programs did not have all positions filled, and so their responses were limited. The survey form is appended.

RESULTS AND DISCUSSION

Of the 44 clinics identified, 39(89%) responded to Part 1 of the survey. All of the programs in British Columbia, Saskatchewan, Manitoba, New Brunswick and the Yukon responded. Most, but not all of the programs in Ontario and Alberta responded (Table 2). One of these non-responding clinics was within a large medical center that may see as many as 50 children per year for an FASD assessment, the others were all small community clinics that were not anticipated to have the capacity to assess more than 10 to 15 people per year. From within the 39 clinics responding to Part 1, at least 61 respondents from 37 clinics then answered the questions in Part 2 of the survey.

TABLE 1 Unique references to the Fetal alcohol spectrum disorder: Canadian guidelines for diagnosis per year since publication as found on Google Scholar (scholar.google.com)

Publication Year	<2005	2005	2006	2007	2008	2009	2010
Number of References	0	6	14	17	18	32	29

TABLE 2 FASD Clinical Capacity in 2010 and 2011 in clinics ascribing to the Guidelines for FASD Diagnosis in Canada

Province or Territory	N of Programs Responding	N of Programs Declining	2010	2011	Known Capacity*
British Columbia	9	0	767	765	1.69
Alberta	14	4	418	387	1.04
Saskatchewan	5	0	370	280	2.68
Manitoba	1	0	198	198	1.61
Ontario	6	1	482	512	0.39
New Brunswick	2	0	27	16	0.21
Yukon	2	0	20	20	5.84
All Canada	39	5	2282	2178	0.64
Estimated additional slots			110	110	
Estimated full capacity in Canada			2392	2288**	

*The maximum number of diagnostic slots available for FASD diagnosis in 2011 that have been identified divided by the population of the jurisdiction multiplied by 10,000; **The final number is the full capacity for FASD diagnosis in Canada as a whole. Populations per Statistics Canada, July 1, 2010.

Clinical capacity per year is the number of assessment slots available for diagnostic purposes. This is the maximum number of cases that can be assessed in any one year. In many clinics, these slots are shared for the diagnosis of complex developmental conditions that utilize a similar diagnostic team. Most commonly, these diagnostic resources are shared for the evaluation of Autism Spectrum Disorder. Therefore, it would be likely that far fewer FASD diagnostic evaluations are actually performed than the maximum number of diagnostic slots would indicate. Further of course, not everyone evaluated for FASD will have FASD so that actual number of new FASD diagnoses would be less (or far less) than these numbers.

Table 2 presents the capacity to evaluate FASD using a team approach across Canada in 2010 as well as the anticipated capacity in 2011. The full capacity, if all slots available were used for FASD diagnosis, would be 2,392 assessments in 2010, and 2,288 in 2011 combining the reported numbers in 39 clinics and the estimates from the other five. The identified capacity per populations of the provinces and territories is also provided in Table 2. Across the four western provinces and the Yukon, capacity has increased from 816 potential assessments in 2005 to 1,773 assessments in 2010. A lack of data from previous years makes comparisons in the rest of Canada difficult.

The clinical capacity can be more fairly compared from jurisdiction to jurisdiction through the use of a "Formula for Capacity" (slots available/jurisdictional population X 10,000). These calculations are available in Table 2. The calculations vary from 0.21 in New Brunswick, to 5.84 in the Yukon. Ontario is under represented by a lack of response. But if their estimated slots were added, Ontario's capacity would only increase to 0.43. The western provinces have a more uniform capacity ranging from 1.04 to 2.68. The mean identified capacity for FASD diagnosis using the team approach in Canada as a whole would be 0.638. Most clinics are organized around diagnosis in children and youth. Less then 10 programs are specifically prepared to see adults.

Jurisdictions across Canada have dealt with building clinical capacity for FASD diagnosis in a number of ways. For example, Manitoba has one large program and is developing satellite programs, British Columbia has one large coordinated program with multiple sites as well as small private programs, and Alberta has a large number of community, government and educational programs supervised in a variety of ways. The Yukon has one program utilizing a local professional team for children, and then brings in a visiting team as needed to assess patients in a second program for adults. We have been told that patients needing FASD diagnosis from the Northwest Territories and Nunavut are flown south for diagnosis, but we had no ability to determine how many individuals that might be, or where they might go. They may be captured in some of the numbers from the clinics that responded.

The Guidelines were written to be "guidelines." They cannot prevent a physician from making an FASD diagnosis alone or with colleagues who conducted their own individual assessments over time. If patients are being diagnosed with FASD in Quebec or the other Maritime Provinces, individual physicians may be seeing them with or without other professional consultation, and without a team review. We did not attempt to identify physicians who might undertake FASD diagnoses by themselves.

The Guidelines suggest that all teams need a physician, a coordinator, and a group to specifically assess the wide range of brain dysfunctions that may be present. This group would generally include, at a minimum, a psychologist, a speech pathologist and an occupational therapist. All 39 clinics reported that they had one or more physicians as regular team members and had coordinators. Pediatricians filled the physician role 67% of the time, family physicians 31%, geneticists 13%, and psychiatrists 31%. This sums to more than 100% because many teams have more than one physician sharing in this role. The coordinators of these clinics are found to take on a good deal of clinical work in interviewing the families and collecting records prior to the visits. Generally, this job is held by a person with an advanced degree in nursing (18%); social work (28%) or psychology, counseling, occupational therapy or another aligned field.

Of these 39 clinics, only 18(46%) have a full complement of staff professionals available to evaluate the brain dysfunction. Of these clinics, 34 had staff in psychology, 25 had occupational therapists, and 28 had speech pathologists. All clinics that did not have these fields covered with staffed positions explained that the work was done as needed through consultation in the community.

Another important recommendation within the Guidelines endorsing previous clinical experience is the general need for a team meeting to determine the final FASD diagnosis, the number of significant functional diagnoses, and the comprehensive treatment plan.

This recommendation is generally followed. Of the responding clinics, 33(90%) meet in person prior to meeting with the family and work as a group to agree on the diagnoses and treatment plan. In 62% of programs, the diagnoses are reached through team consensus, while in the remaining programs the decision rests with one team member, usually the physician, after all information has been discussed among the group. For groups who work in more remote communities, consultants who are not on staff often join the team meetings by phone or video teleconference. In 79% of programs, the team also collaborates on the development of the treatment recommendations.

There is no full agreement on a final diagnostic system. The Canadian Guidelines diagnostic schema is used by 29 clinics (74%), while the University of Washington 4-Digit code system is used by 14(36%). Five of these clinics use either both systems or a hybrid of their own based on the two systems. One clinic uses the older Institute of Medicine approach.

The Guidelines themselves were well known to the clinical staff members. They are available in all of the programs either as a common copy in the program library or through personal copies that are regularly brought to the meetings. “Did the publication of the Canadian Guidelines for FASD Diagnosis change your clinic’s practice in any way?” There were 28 responses to this query, five said the article had helped them to gain support for funding and or staffing a diagnostic team, eight thought the Guidelines had helped to make the diagnostic determinations more consistent, and forethought the Guidelines had helped their programs to develop improved procedural structure. Only three responses said that the Guidelines had not altered practice in their programs. The informants were asked how documents like the Guidelines and other new materials are brought to the attention of the practitioners. The answers to these questions are found in the answers to the survey, Part 2, questions 8 and 9. Most interviewees expected that new information would be identified by professionals on their own, most typically through meetings, independent journal reading and via the Internet (email and websites). Materials sent through the mail by government agencies and professional organization or transmitted through word of mouth, were less than half as likely to be the preferred routes for finding important new information. The lack of enthusiasm for materials sent in the mail by governments and organizations was striking; it is likely that this reflects the current trends in working in a paperless environment, unfortunately, the specific reasons could not be determined from the questions used in this survey.

INTERPRETATION

It is important that people with fetal alcohol spectrum disorder are diagnosed. The diagnostic explanation of adaptive problems caused by a brain based disability, rather than a potentially reversible psychiatric or environmental condition, is central to appropriate treatment planning. The knowledge that ethyl alcohol is an etiologic factor is important in preventing subsequent births and in gauging the effectiveness of prevention efforts.

If there was political will to expand diagnostic programs, availability of materials like the Guidelines would be essential in building programs that reflect the state of the art and would aid in developing appropriate staffing and funding for new programs.

The responses to this survey indicate that the Guidelines were well known to all of the programs (100%) and were regularly referred to. It is likely that the Guidelines were used as a template for building the programs since 2005. Nearly all the programs agreed that the team approach was necessary. The reasons given for a less than full on site team were due to funding restrictions not preference. There remained a substantial minority of programs (about 25%) that were not satisfied with the diagnostic scheme presented in the Guidelines, however. It would appear that further expert review of this situation would be warranted.

The prevalence of fetal alcohol spectrum disorder has not been established in Canada for reasons explained elsewhere, but the prevalence is likely to be one percent of the general population or higher.[5] This means that at least 340,000 Canadians have FASD. If it were a goal of Canada to see everyone who might need a diagnosis of FASD and to do this over a ten-year period, and to assume that the birth rate remained stable and the death rate stayed comparable, and screening permitted very high rates of sensitivity and specificity, then roughly 37,000 diagnostic slots would be needed per year. This year approximately 2,200 slots are available Canada wide using the methods endorsed by the Guidelines and far fewer than this are actually used for FASD diagnoses. A 17-fold increase in FASD diagnostic capacity across Canada is needed without neglecting other neurodevelopmental diagnoses.

In conclusion, the Guidelines have been well distributed to those who need them and they are actively used. The Guidelines have likely been a positive component in the development of appropriate programs in the last five years, although the growth is quite modest compared to the need. The clinicians in the field who work in interdisciplinary teams appear to endorse the need for a team approach to this diagnostic task and the other components within the Guidelines although the diagnostic scheme itself appears to need further refinement to gain universal acceptance.

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