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PROGRAM DESCRIPTION:
Implementing the Canadian Consensus Guidelines for the Primary Care of Adults with Developmental Disabilities: Clinical and Educational Enhancements in an Academic Family Medicine Practice

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This article describes a pilot program of clinical and educational enhancements in developmental disabilities (DD) that has been launched by Queen's University's Department of Family Medicine (DFM) postgraduate medical education (residency) program and its teaching practice, the Queen's Family Health Team (QFHT). The goals of this program are to enhance the care of patients with DD served by our academic family health team, to teach family medicine residents about the care of adults with developmental disabilities and to design a concurrent program evaluation.

Background:

Many studies confirm that adults with DD experience significant health disparities compared to the general population.[1,2] With Family Medicine's emphasis on providing a community-based, comprehensive approach to the management of disease in patients throughout the lifecycle, Canadian family physicians are well-positioned to effectively oversee the health care of patients with DD, yet many feel poorly prepared for this role as do their colleagues in Australia and the United States.[3,4,5] It is increasingly evident that there is a need for improved clinical training in the care of individuals with DD at all levels and across specialties, including Family Medicine postgraduate programs, in particular, whose trainees must be prepared with the knowledge, skills, and attitudes to meet the needs of patients with DD in their future clinical practices.[6,7,8,9,10]

Clinical Enhancements:

The primary objective of the clinical enhancements is to ensure that QFHT patients who have DD are receiving optimal care based on current recommendations. The strongest recommendation made by the Canadian Consensus Guidelines for the Primary Care of Adults with Developmental Disabilities[11] is that family physicians adopt an anticipatory care model, whereby patients with DD should be actively screened on a regular basis for a number of health concerns that are of higher prevalence in this population. This recommendation is based on evidence from randomized clinical trials which found that the implementation of a directed health assessment plan in family clinics can significantly improve the quality of health care received by patients with DD.[12,13] Queen's Family Health Team has recently adopted the use of a program based on the "Cumulative Patient Profile" (CPP) and "Preventative Care Checklist" (PCC), which are part of a set of Tools[14] developed by the Developmental Disabilities Primary Care Initiative (DDPCI) in Ontario to help implementation of the Guidelines.

A practical first step in establishing these clinical enhancements was identifying the patients in the QFHT roster who had a diagnosis of a developmental disability. This was done using disease registry codes that had been entered into the clinic's electronic medical record system in the course of routine patient care. The list of patients that was generated was double-checked by the clinic receptionists and the patients' primary physicians for completeness and accuracy. The receptionists use this list to contact patients and their caregivers to invite them to come to the clinic for a comprehensive health review.

Various members of the interdisciplinary health care team of QFHT share in the tasks involved in completing each comprehensive health review. The clinic receptionists proactively contact the patients who have been identified as having a developmental disability, or their caregivers, and invite them for an “annual check-up” or medical review. The receptionists also mail out a pre-appointment health questionnaire for the patients and their caregivers to fill out in advance and bring with them to the clinic. A member of the clerical staff searches for previous genetic and psychological/functional assessments in the patient’s past records. The initial appointment to go over the questionnaire and begin the comprehensive health review is booked with one of the clinic’s nurse practitioners. Another appointment (or appointments, as needed) is made with a physician, often a resident, to complete the health review. The appointments are facilitated by a health review form integrated into the patient’s electronic medical record and annotated with resources and explanations. At Queen’s Family Health Team, there is the opportunity to involve others—pharmacist, social worker, and nutritionist—in developing follow-up care plans. Interdisciplinary input and participation have been essential to both the planning and execution of the program, making for better, more effective care of patients with complex medical needs.

Curricular and Assessment Enhancements:

The new curriculum aims to give residents the confidence that they can provide the best possible care to their patients with DD. It combines experiential learning with reflective activities. The curriculum is centered on the clinical encounters between residents and adult patients with a developmental disability, which occur as part of the routine clinical care of this population. In their first postgraduate year, each resident will perform at least one comprehensive health review of a person with DD and oversee their follow-up care. To prepare them for this task, the residents are provided with an introduction to current guidelines for the care of adults with DD, as well as structured tools and interprofessional supports available to help physicians meet the needs of this population.

As part of their program orientation, residents are introduced to existing resources designed for family physicians, namely the Canadian Consensus Guidelines for the Primary Care of Adults with Developmental Disabilities,[11] and the Tools designed by the DDPCI to help translate the recommendations into clinical practice.[14] At Queen's, these resources have been adapted into the health review form and accompanying resource sheet noted above, that can be accessed on the patient's electronic medical record system for learning at the point of care.

Each resident is assigned at least two adults with DD who are patients of QFHT for whose care they are responsible. In addition to providing routine care for these patients, they are required to perform a comprehensive health review using the resources that were introduced. This gives the residents the experience of developing an approach to putting the guidelines into practice while meeting the specific needs of their patient (for example, inability to tolerate a long clinical appointment) and the demands and time constraints of the clinic. They also have an opportunity to work collaboratively with other members of the clinical team, including the clinic nurse practitioners who perform part of the comprehensive health review. The residents receive active supervision and support from their clinical teachers and the interdisciplinary healthcare team of the clinic.

The residents' learning is reinforced through guided self-reflection and formative feedback. After completing the health review of a patient with DD, they must complete a reflective piece of writing based on an encounter with a patient with DD. The reflections are then submitted as part of the residents' electronic "portfolio," which is a collection of evidence of competencies that is part of the assessment system for residents at Queen's. Each resident will review their reflection with their Academic Advisor. The clinical teachers also assess the residents' ability to display competencies related to the care of adults with DD using a "Field Note." Field Notes are tools that are part of the current teaching and assessment system for residents at Queen's DFM, through which the clinical teachers document their feedback on the residents' performance in clinical encounters. These can be connected to an "Entrustable Professional Activity" (EPA), which is a method of assessing residents' competency in performing routine clinical activities.[15] Since the initiation of this program, the residents receive Field Notes, based on their encounters with a person with DD in their Family Medicine practice. The EPA describes different levels of performance for each phase of the clinical encounter for the care of adults with DD. The Field Notes are written and can be linked to the appropriate part of the EPA. This allows for a clear road map of expectations for the resident in terms of every aspect of their performance in the encounter.

Program Evaluation:

This novel program will be evaluated using multisource feedback from patients, the learners, and the teaching faculty to make improvements in subsequent iterations. The planned program evaluation will include a patient chart audit and patient and caregiver satisfaction surveys. Assessments of the program's educational value, specifically, will be recruited from both the residents and their teachers. This will include a qualitative review of resident feedback surveys, residents' written self-assessments and reflections, and the assessments of resident learning by their clinical teachers. The feasibility of the program will be assessed by an audit of rates of participation and completion of its various elements and the resources required to run the program.

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RESOURCES

http://www.cfpc.ca/SBIR_addresses_harmful_alcohol_consumption/

New Alcohol Screening, Intervention and Referral Resource addresses harmful alcohol consumption

(November 22, 2012, Mississauga, ON) Together with the Canadian Centre on Substance Abuse (CCSA), the College of Family Physicians of Canada (CFPC) is pleased to announce a valuable new resource to assist family physicians and other health professionals detect and address harmful alcohol consumption among their patients.

The Screening, Brief Intervention and Referral (SBIR) resource is a practical, web-based guide that offers a three-step alcohol assessment and referral process, supported by related online resources.

Screening, Brief Intervention and Referral: A Clinical Guide can be accessed at http://www.sbir-diba.ca/

Even a Little Alcohol When Pregnant Puts a Child's IQ at Risk
http://www.thedoctorwillseeyounow.com/content/womens_health/art3879.html
The Doctor will See you Now, New York
or
http://www.plosone.org/article/info%3Adoi%2F10.1371%2Fjournal.pone.0049407
"Despite contradictory advice to pregnant women about alcohol consumption, the Centers for Disease Control and Prevention advocates complete abstinence during pregnancy and calls alcohol consumption the leading cause of preventable birth defects and developmental disabilities. A new study adds credence to the CDC's advice, suggesting that even a small amount of alcohol during pregnancy can lower IQ levels in children."
Beth Fontenot, MS, RD, LDN November 22, 2012

100 best special needs resources on the web at
http://phdinspecialeducation.com/special-needs/
by Amy Ellison amy@phdinspecialeducation.com
Covers sites dealing with Autism, Down Syndrome, Batten Disease and overall special education knowledge.
Some sites simply chronicle an individual's or family's journey with Down Syndrome or other condition. Some sites offer advice or links to other resources for those doing research about special education or a specific type of special need.

https://gene.sfari.org/
SFARI GENE Home: A Modular Database for Autism Research

A special issue of the International Journal of Integrated Care is focused on a series of articles on bridging aging and disabilities. You can see this by following this link: www.ijic.org/index.php/ijic

City of Hope Pain & Palliative Care Resource Center (City of Hope is an independent research and medical institution in Duarte, Calif, devoted to comprehensive cancer care and improving care through research and innovation.) http://prc.coh.org/pain_assessment.asp

IV. Pain and Symptom Management
A. Pain Assessment Tools (Also see Research Instruments http://prc.coh.org/res_inst.asp)
This section includes various tools to assess pain. Specifically, pocket reference cards, rating scales, assessment packets, chart forms, database tools, home health flow sheets, chart documentation packets, and tools for infant and pediatric pain assessment are among the resources available. **See especially Section 11**

Friday, April 12th, 2013: Ontario Association on Developmental Disabilities (OADD) Research Special Interest Group (RSIG) Annual Conference

Location: DoubleTree Fallsview Resort & Spa, Niagara Falls, Ontario

The Ontario Association on Developmental Disabilities (OADD) Research Special Interest Group (RSIG) is inviting proposals for presentations and posters for its annual research conference. RSIG was formed to provide an opportunity for researchers, professionals, and other interested individuals, working in the field of developmental disabilities to exchange research, ideas, resources, and concerns. We welcome research from all disciplines and areas of research related to developmental disabilities. We accept both quantitative and qualitative research. The deadline for submissions is **December 17th, 2012.**

For more information about RSIG and OADD, please visit our website at: www.oadd.org
rsigsubmission@oadd.org

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Many resources can be found at *ddd@uwo.ca* *www.ddd.uwo.ca*