Managing complexity in care of patients with intellectual and developmental disabilities

Natural fit for the family physician as an expert generalist

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Abstract

Objective To delineate the factors inherent in caring for patients with intellectual and developmental disabilities (IDD) that lead to complexity and to provide perspectives and techniques mapped to the phases of the clinical encounter.

Sources of information The authors of the physical health section of the 2018 Canadian consensus guidelines on the primary care of adults with IDD consisted of family physicians, all of whom practise comprehensive family medicine with additional clinical experience in care of adults with IDD. These authors reviewed evidence on which their recommendations are based and these recommendations have undergone a rigorous peer review to ensure that they deserve special attention because they highlight what is different from what a family physician would consider to constitute "normal care" for the general population.

Main message Additional factors across the phases of clinical encounters with patients with IDD include the need for the following: an initial assessment that identifies genetic or neurologic conditions to guide anticipatory care and isolates unique barriers to health promotion and chronic disease management; adaptations to history taking, particularly for patients who are unable to describe symptoms owing to cognitive and communication deficits; overcoming challenges to performing physical examinations and certain investigations; addressing uncertainty in the formulation of hypotheses to establish an appropriate diagnosis; and involvement of resources of the developmental services sector to provide a management plan as well as an adapted empathetic approach in order to integrate the patient's illness experience.

Editor's key points

- Medical complexity presents considerable challenges in the treatment of patients with intellectual and developmental disabilities (IDD) and contributes in part to the health inequities they face. Specific and identifiable factors contribute to complexity in the health care of patients with IDD and affect all phases of the clinical encounter.
- Some of these factors, such as an inability to communicate symptoms, a tendency toward undifferentiated presentations, and sensitivity to medication, might be found in other special populations (eg, pediatric or geriatric patients), while others are unique to people with IDD.
- Family physicians are well suited to managing complexity in patients with IDD given their experience with diagnostic uncertainty, continuing comprehensive care, and integration of the patient's illness experience.

Points de repère du rédacteur

- Les complexités médicales représentent une énorme difficulté dans le traitement des patients ayant des déficiences intellectuelles et développementales (DID) et elles contribuent en partie à l'inégalité en matière de santé dont ces personnes sont la cible. Certains facteurs précis et identifiables contribuent à la complexité des soins de santé aux patients ayant des DID et concernent toutes les phases de la rencontre clinique.
- Certains de ces facteurs, comme l'incapacité de communiquer les symptômes, la tendance aux présentations non différenciées et la sensibilité aux médicaments, se retrouvent aussi dans d'autres populations particulières (p. ex. en pédiatrie ou gériatrie), alors que d'autres sont uniques aux patients ayant des DID.
- Les médecins de famille sont bien placés pour gérer les complexités chez les patients ayant des DID, compte tenu de leur expérience avec l'incertitude diagnostique, les soins continus complets et l'intégration du vécu du patient avec sa maladie.

Conclusion Although each patient with IDD is unique, and care of patients with IDD requires knowledge of certain conditions, these considerations are readily identifiable, and family physicians as expert generalists are well equipped to provide excellent care to patients with IDD.

Gérer la complexité des soins des patients ayant des déficiences intellectuelles et développementales

La place naturelle du médecin de famille à titre d'expert généraliste

Résumé

Objectif Définir les facteurs qui compliquent les soins et qui sont inhérents aux soins des patients ayant des déficiences intellectuelles et développementales (DID) et qui engendrent la complexité, et proposer un point de vue et des techniques s'insérant dans les différentes phases de la rencontre clinique.

Sources d'information Les auteurs de la section sur la santé physique des Lignes directrices consensuelles canadiennes 2018 en matière de soins primaires aux adultes ayant une déficience développementale étaient des médecins de famille qui avaient tous pratiqué la médecine familiale complète et avaient de l'expertise clinique en soins aux adultes ayant des DID. Ces auteurs ont examiné les données probantes sur lesquelles s'appuient leurs recommandations, et ces recommandations ont été soumises à un processus rigoureux de revue par les pairs afin d'assurer qu'elles méritent bien une attention particulière puisqu'elles mettent en lumière les différences par rapport à ce qu'un médecin de famille jugerait être «normal» dans la population générale.

Message principal Les autres facteurs qui interviennent durant toutes les phases de la rencontre clinique avec les patients ayant des DID sont: le besoin d'une évaluation initiale qui discerne les affections génétiques et neurologiques afin d'orienter les soins préventifs et d'isoler les obstacles uniques à la promotion de la santé et à la prise en charge des maladies chroniques; l'adaptation de la prise de l'anamnèse, en particulier auprès des patients qui sont incapables de décrire leurs symptômes en raison de déficits cognitifs et de la difficulté à communiquer; surmonter les difficultés liées à l'examen physique et à certaines investigations; surmonter l'incertitude liée à la formulation des hypothèses visant à établir un diagnostic approprié; et la participation de ressources du secteur des services développementaux pour fournir un plan de prise en charge de même qu'une approche empathique adaptée afin d'intégrer le vécu du patient avec sa maladie.

Conclusion Même si chaque patient ayant des DID est unique, et même si les soins des patients ayant des DID exigent de connaître certaines affections, ces considérations sont facilement identifiables, et les médecins de famille, à titre d'experts généralistes, sont bien équipés pour dispenser des soins d'excellence aux patients ayant des DID.

Case

Marie is a 19-year-old woman with severe intellectual disability and autism spectrum disorder. She has minimal verbal communication and can respond yes or no only for certain well-known day-to-day choices. Marie does not appear to be able to localize pain or describe symptoms. Marie lives with her very supportive mother and older brother in a small duplex and attends a day program 3 days a week. An occupational therapist has worked closely with her over many years owing to difficulties with sensory integration, including sensitivity to fluorescent lighting, crowds, loud noises, and unfamiliar touch. She is very soothed by certain tactile inputs (eg, touching certain fabrics or strings of beads) and loves music. She wears noise-canceling headphones with her MP3 player when she is taken to unfamiliar places. Selective eating is also an issue, and Marie's only type of fluid intake is full-strength fruit juice. She has severe episodic constipation that has been well managed with 2 tablespoons of polyethylene glycol 3350 a daily.

Earlier this year, Marie showed a change in behaviour involving new agitation and loss of functional skills (including use of a picture-exchange communication system). Over a 2-month period of appointments and investigations, Marie was eventually diagnosed with biliary colic and underwent cholecystectomy. Following surgery, Marie's behaviour stabilized, only to deteriorate again 3 months later. This second episode consisted of a pattern of banging the dinner table with her hand then running to the washroom to urinate. Urinary tract infection was suspected and urine culture showed enterococcal species. Two courses of antibiotics did not resolve her behaviour and, although follow-up cultures showed persistent bacteriuria, this was concluded to be chronic and asymptomatic. Marie's agitation continued to worsen until she was no longer able to attend her day program and her mother had to take an extended leave from work to care for her at home. Marie developed reduced appetite and a new behaviour of accumulating saliva in her mouth, then painting it with her finger across her cheeks and forehead, which was particularly distressing to her mother when it occurred in public. Marie was prescribed 50 mg of pregabalin twice daily, as well as 40 mg of pantoprazole daily for possible irritable bowel syndrome and gastroesophageal reflux

disease. She developed worsening agitation on these medications and both were discontinued. Marie's mother went on to purchase ranitidine over the counter and discovered that 150 mg given before meals was well tolerated and substantially reduced agitation. Over the next 2 months, Marie was able to gradually transition back into day programming through the support of calming sensory interventions, as the time away had disrupted her regular routine.

Newer definitions of complexity in medicine stretch beyond simply the number of conditions with which a patient is diagnosed and incorporate mental health and socioeconomic factors.[1] In 2015, Loeb et al used qualitative analysis of in-depth interviews with primary care providers to develop a "typology" of patient complexity. Four categories of complexity were identified, including medical (ie, discordant conditions, chronic pain, medication intolerance, unexplained symptoms, and cognitive issues); socioeconomic (eg, the unaffordability of medication, family stressors, and low levels of health literacy); mental health (eg, depression or addictions resulting in poor medication adherence); and behavioural issues (eg, anxiety about one's symptoms).[1]

Generalism as a clinical method includes skill at evaluating undifferentiated symptoms presenting early in the course of a disease. The generalist also integrates cumulative knowledge of the patient and uses the continuity of the physician-patient relationship to improve judgment and manage diagnostic uncertainty. Generalism ensures a process that is patient-centred and that integrates the illness experience with a broader understanding of the patient's context.[2] A generalist approach has been shown to be particularly effective in improving outcomes in situations where a high degree of comorbidity and complexity exist.[3] Dr Ian McWhinney is well known for his foundational thinking regarding family medicine and what he called "generalist expertise."[2] Given that patients with intellectual and developmental disabilities (IDD) have higher degrees of comorbid physical and mental health conditions, and experience factors that influence communication, care coordination, and social determinants of health, the generalist expert approach is important and well suited to managing their primary care.

Sources of information

The authors of the physical health section of the "Primary care of adults with intellectual and developmental disabilities. 2018 Canadian consensus guidelines"[4] (hereafter, *the guidelines*) consisted of family physicians, all of whom practise comprehensive family medicine with additional clinical experience in care of adults with IDD. The recommendations in these guidelines are formatted around specific conditions or systems (eg, epilepsy, gastrointestinal conditions, sleep disorders). The authors of the guidelines have reviewed evidence on which their recommendations are based, and these recommendations have undergone a rigorous peer review to ensure that they deserve special attention because they highlight what is different from what a family physician would consider to constitute "normal care" for the general population. Recommendations in the guidelines are practical suggestions outlining what to do and when. The guidelines are also linked to point-of-care online tools to enable integration into the clinical setting. This article acts as a complement to the guidelines, by delineating the broader factors inherent in the care of this population that lead to complexity and by going on to provide perspectives and techniques mapped to the phases of the clinical encounter.

Main message

Phase 1: First visit and intake assessment. Intake appointments for new patients typically involve setting up the patient file with basic information on existing medical conditions, current medications, and past hospitalizations and surgeries, and reviewing the status of preventive care and chronic disease management. Additional considerations at intake for a patient with IDD include the following.

Specific background medical information is needed to inform the family physician's care: This includes a pathogenic genetic assessment, identifying the presence of congenital anomalies, and identifying the co-occurrence of certain neurologic conditions (eg, cerebral palsy, autism spectrum disorder). Knowing the cause or pathogenesis of an IDD allows the family physician to anticipate certain physical or mental health conditions that he or she might not normally consider. For example, Down syndrome is associated with a 7% likelihood of developing celiac disease,[5] while Prader-Willi syndrome is associated with hypogonadism, which requires monitoring and potential treatment to preserve bone health.[6]

Congenital anomalies might also exist, such as cardiac and renal anomalies or cranial and spinal cord malformations (sometimes associated with hydrocephalus). These anomalies affect treatment and ongoing monitoring in different ways (eg, managing seizure disorders associated with cranial malformations is often more challenging).[7] Patients with myelodysplastic disorders, such as spina bifida, require special vigilance concerning neurogenic bowel and bladder conditions, including pyelonephritis or bowel obstructions.[8]

Neurologic conditions that are diagnosed in early childhood, such as cerebral palsy and autism spectrum disorder, are important comorbidities that influence ongoing primary care. For example, people with cerebral palsy often have substantial muscle spasticity and loss of mobility, which affects positioning and skin care.[9] Patients with an autism spectrum disorder often have sensory integration difficulties or hypersensitivities that affect sleep or require very restricted diets.[10]

Syndrome-specific clinical tools, called *Health Watch Tables*, are available to inform a system of regular anticipatory care.[5,6,10] A record of genetic assessments, neuroimaging, echocardiography, imaging of the urinary tract, and other assessments might not be easily accessible, especially if the patient has moved cities. Clerical staff play a key role in obtaining old records from various sources, such as children's hospitals.

Unique barriers to health promotion, risk factor modification, and optimization of chronic disease exist for patients with IDD and benefit from proactive identification: Patients with IDD often rely on others to access health promotion and illness prevention, such as making lifestyle changes. For example, the home "food environment" might be out of the patient's control and sugar-dense foods might be used to reward "good behaviour"; the patient might be given open access to cigarettes, yet will struggle with the cognitive capacity to weigh the pros and cons of smoking; or the patient might be unable to independently access gym facilities alone for safety or supervisory reasons. Further, many health promotion pamphlets are not adapted to the literacy level of patients with IDD and lack pictures to aid comprehension. In addition, adult day programs might be unavailable or too expensive for these patients, with the result that they become very isolated and sedentary. Increased rates of obesity, diabetes, and other cardiovascular risk factors are therefore more common in this population and warrant more intensive and earlier screening.[11] Patients with IDD often rely on others for skin care and general hygiene and are particularly prone to dental disease.[12] Some patients reside in group-living situations with associated increased risks of infections such as those transmitted by the fecal-oral route.[13]

Patients with IDD experience increased risk of chronic disease as a result of medication use, particularly owing to the deleterious effects of long-term use of psychotropic medications and medications used to control seizures and spasticity.[14] The use of psychotropic medications considerably increases the risk of metabolic conditions, especially diabetes in women.[11] This is especially problematic in settings where access to exercise and healthy eating is limited. Anticholinergic drugs cause dry mouth and gastroesophageal reflux, which can exacerbate other conditions such as dysphagia and tooth decay.[12]

The status of chronic diseases is often poorer in patients with IDD owing to issues around self-monitoring and self-advocacy. Patients with IDD are often unable to self-monitor for and report signs of deterioration of chronic conditions, such as decompensation of congenital heart disease and development of symptoms of heart failure.[15] Patients might not be able to self-monitor for initial signs of cancer, such as by detecting breast lumps or abnormal moles.[16] This has led the authors of the guidelines to recommend proactive guidance on regular breast examinations and skin surveys. Patients with IDD also experience difficulties with the cognitive and communication skills needed for self-advocacy and are at risk of receiving as acceptable a lower standard of chronic disease detection and management. This is apparent in management of constipation,[17] menstrual regulation,[18] and seizure in epilepsy.[19] Fortunately, monitoring tools exist for bowel movements, menses, seizures, and other chronic diseases, which can be facilitated by physicians and caregivers,[20] and adapted health promotion materials are also available.[10]

In summary, setting up primary care for a new patient with IDD in a family practice will often reveal an identifiable set of important and sometimes unique comorbidities and risk factors acquired congenitally or owing to environmental factors. Such an understanding is critical to a comprehensive exploration of pertinent positive and negative findings when evaluating new presenting symptoms, assessing the pretest probabilities for investigations, and evaluating risks and benefits of interventions.

Phase 2: History of presenting illness. Patients with IDD face difficulties in describing and answering questions about their symptoms. These difficulties might be owing to limited receptive and expressive language skills, motor apraxia affecting speech, or challenges with time concepts and difficulties with abstract language.[21] Symptom descriptions with an abstract or metaphorical component, such as "shortness of breath," "burning or crushing pain," or "low mood," might be particularly challenging for some patients with autism spectrum disorder.[10] Difficulties reporting symptoms can lead to several phenomena that affect the history of presenting illness:

Problems that would normally present as a specific complaint or symptom might instead present as an undifferentiated change in behaviour: Family physicians are very familiar with undifferentiated presentations of illnesses, such as nonspecific weakness or tiredness. In patients with IDD who cannot report their symptoms, a typically differentiated complaint, such as vision or hearing loss, might present instead as withdrawal, lethargy, or even agitation.[22]

Some undifferentiated presentations might be atypical in their morphology: A patient with IDD might present with new stereotypic behaviour, loss of a previously learned skill, or refusal to eat owing to an underlying illness. For example, gastroesophageal reflux might present as repetitive hand-tapping on the chest, while new dysphagia and aspiration might present as behaviours that challenge at meal times or sudden preference for a favourite caregiver to assist with meals.[23]

A single behavioural morphology might be the only expression of distress available to the individual with IDD and might be the result of unrelated, temporally overlapping processes: For example, a stereotypic facial grimace, which might indicate discomfort from a continence pad that requires changing or which might be an indication of

hunger or other day-to-day need, might also be the same distress sign the person with IDD uses to indicate new pain or substantial emotional distress. An astute caregiver often can observe these different patterns in behaviour. The family physician must listen carefully to the caregiver in order to differentiate possible causes based on provoking factors, new intensity or duration, temporal relation to mealtime or transfers, or lack of response to interventions that are usually successful. Sometimes it might be difficult for the caregiver to tease out what is different, yet the physician must trust the caregiver's "sixth sense" that there is a subtle, yet concerning, change in the function or appearance of the patient. A common phrase that caregivers will use is, "Something is wrong; he [or she] is just not himself [or herself]."

Late presentations at more advanced stages are common: Family physicians should be aware that presentations of illnesses are less likely to represent recent or transient conditions and that the period of safe watchful waiting might have already passed. For example, an initial presentation of gastroesophageal reflux disease might represent longstanding, untreated reflux that has progressed to severe erosive esophagitis.[24] A patient presenting with constipation might already be at the stage of severe fecal impaction.[17] Urinary frequency or new incontinence that presents with fever might be beyond an uncomplicated urinary tract infection and verging on urosepsis.[25]

Phase 3: Physical examinations and investigations. Multiple issues factor in when carrying out physical examinations and investigations, and in the decision making involved.

Challenges with positioning and interpreting patient posturing might limit certain tests: For example, bone mineral density measurement might be limited by scoliosis, hip contractures, or fixed rotation of the lumbar spine. Observable physical postures that would typically contribute to diagnostic impressions might be absent or altered. For example, a patient with a neuromuscular condition that causes truncal weakness or hypotonia might not show typical signs of respiratory distress, such as sitting upright to maximize vital capacity or use of accessory respiratory muscles.[9] A patient with a fracture might present as agitated and moving an injured limb rather than staying immobile in the way one would expect. A patient with acute peritonitis might be restless on the examination table instead of lying still and guarding their abdomen when examined.[22]

Physical examination maneuvers that require the patient to follow commands might be limited by reduced comprehension and communication barriers: Neurologic examinations might be limited by an inability to assess an active range of motion of limbs or conduct special tests of coordination. Investigations involving complex directions such as pulmonary function tests are often not possible for patients with a severe level of IDD.

Sensory integration issues, unfamiliar environments, and procedures, as well as difficulty understanding the rationale for tests, affects tolerance of intrusive assessments: Sensory integration issues often affect tolerance of touch, the use of bright lights during examinations, or the acceptance of equipment that makes loud, unfamiliar sounds. A lack of experience with the procedure, the place, and the people involved, and the sensation of being held or even restrained to have a procedure done safely, all elicit an alarm response from patients with IDD and sensory sensitivities. The behavioural manifestations of posttraumatic stress disorder from previous traumatic experiences might also affect assessment.

Given the challenges defining symptoms on history and performing physical examinations, patients with IDD are at risk of both overinvestigation and underinvestigation: Overinvestigation carries the risk of unnecessary sedation (including general anesthesia), as well as radiation exposure, which is made more important by the relatively young age at which patients with IDD undergo many imaging tests. Underinvestigation, and the resultant risk of missed diagnoses, most commonly occurs owing to lack of available information on history or examination. Caregiver reluctance to pursue indicated tests is another factor contributing to underinvestigation and it can result from fears regarding possible negative diagnoses. For example, substitute decision makers (SDMs) might worry that a cancer diagnosis would be too frightening for a patient with IDD or that the cancer treatments would be too challenging to cope with. As a result, some SDMs might refuse screening tests like mammography that are considered to be standard care for people without IDD.[26] It is helpful for the physician to explore an SDM's fears around potential test results and to discuss, for example, how a patient with IDD could receive special supports throughout a cancer treatment experience. **Table 1** outlines practical tips to address the above barriers to physical examinations and investigations.

Phase 4: Diagnostic formulation. Generating a diagnostic formulation for patients with IDD is challenging for several reasons.

Comorbidities seen in this population interact and result in unique multifactorial presentations, which are less commonly seen in general practice: Family physicians are very familiar with managing multifactorial conditions in patients—for example, defining and treating acute dyspnea in a patient who has both chronic obstructive pulmonary disease and congestive heart failure. However, a patient with Down syndrome presenting with acute dyspnea requires the family physician to additionally consider impaired immune function, reduced cough reflex, and overlay of obstructive sleep apnea associated with higher rates of obesity, small craniofacial structures, and macroglossia, all characteristic of people with this genetic condition.[5]

Table 1. Tips for physical examinations and investigations in patients with IDD

TIP	EXPLANATION
Prepare	Ask caregivers to outline the steps of the procedure in advance by using a picture schedule or other communication tool
Desensitize	Design protocols (eg, a home kit including a tourniquet, alcohol swab) to safely practise some of the steps of a procedure. Include parts of a basic physical examination in every office visit to build familiarity with procedures
Model	Model the desired physical examination movement and encourage the patient to imitate it. Alternatively, replicate the desired movement indirectly by having the patient reach for a favourite object or mimic a known routine (eg, arms up to take off a shirt)
De-stress the environment	Make sensory-calming items available to the patient and minimize common sensory insults such as loud noises or fluorescent lighting. Allow time to accommodate to the clinic room before entering
Use sedation mindfully	Sedation, such as low-dose sublingual lorazepam, can facilitate examination or investigations. Complete a trial dose at home some time before the actual procedure. Owing to lack of understanding and anticipation of the sedative effect, patients with IDD might be alarmed at the feeling of sedation and react with agitation before becoming calmer. If a general anesthetic is planned for one reason (eg, an eye examination), consider trying to do bloodwork and other tests at the same time
Use alternatives	Use alternative tests when positioning of the patient is an obstacle. For example, use arm span to estimate height measurement for a patient who is unable to stand or distal one-third radius bone density for a patient with hip contractures or scoliosis who cannot have testing at femoral and lumbar sites

IDD—intellectual and developmental disabilities.

Diagnostic uncertainty can compound when one hypothesis is built on a previous diagnosis that is uncertain: This "compounding" of diagnostic uncertainty requires family physicians to diligently revisit the validity of previous diagnoses using a systematic approach. For example, agitation and irritability might have led to a preliminary diagnosis of depression in a patient with IDD. When he or she subsequently refuses to eat, it might then be assumed that the patient has loss of appetite commonly associated with a depressive episode. A family physician who stops and reconsiders a broad differential for the presentation of irritability and subsequent refusal to eat in such a patient might uncover the correct diagnosis of an occult dental abscess causing pain with chewing.

Therapeutic trials of medications are often necessary to confirm a diagnostic hypothesis when evaluating patients with IDD: This can be challenging, however, when there are several active hypotheses owing to simultaneous, yet unrelated, processes. Given the multiple variables and dynamic interactions that affect the use of medications in people with IDD, it is ideal to only make one medication change at a time and to evaluate the patient frequently. For example, a presentation of recent onset of insomnia in a patient with cerebral palsy might be due to malpositioning that causes trouble clearing secretions, gastroesophageal reflux, which is worsened lying in the supine position, or simply primary insomnia. The family physician might consider prescribing both a proton pump inhibitor for reflux and a hypnotic sedative, while also instructing caregivers to try different bolstering pillows. Such a plan, however, risks unnecessary polypharmacy. Maintaining a careful log of medication trials is helpful in avoiding polypharmacy and repeating failed medication trials, particularly of psychotropic, antiepileptic, and other medications used for chronic conditions such as constipation and dysmenorrhea.

Patients with IDD are susceptible to unique types of diagnostic overshadowing: Diagnostic overshadowing is a term commonly used in psychiatry to indicate when symptoms of an underlying physical health problem are incorrectly attributed to a chronic mental illness.[27] In caring for people with IDD, family physicians might similarly misattribute signs and symptoms of illness to the IDD. For example, a blank or staring behaviour might mistakenly be attributed to having a profound intellectual disability and low responsiveness, when in fact such behaviour represents a new onset of partial seizures. Similarly, a new hand-mouthing behaviour might be misattributed to sensory seeking or repetitive behaviour in a patient with an autism spectrum disorder when in fact it is owing to new onset of gastroesophageal reflux.[28]

Phase 5: Management and follow-up plan. Treatment recommendations including important "return to care" instructions are affected by several important factors.

Patients with IDD are more susceptible to central nervous system and gastrointestinal adverse effects of medications: A prescribing strategy of "start low and go slow" is recommended in geriatric medicine, which takes into account reductions in muscle mass and renal function that affect drug metabolism.[29] This is an important strategy for prescribing medications for patients with IDD who experience similar sensitivity (not due to changes in renal function, but rather due to primary neuromuscular or genetic conditions). Patients with IDD are highly sensitive to central nervous system and gastrointestinal adverse effects of psychotropic medications (including selective serotonin reuptake inhibitors), as well as medications

frequently used to treat pain or spasticity, and might be unable to communicate about such adverse effects.[14]

Comprehension difficulties might limit treatment adherence, while barriers to self-monitoring and symptom recognition might result in missing important signs requiring reassessment: Owing to high degrees of comorbidity and overall fragility, patients with IDD might undergo accelerated symptom progression and rapid deterioration. It is important to instruct caregivers to monitor for subtle signs of deterioration and have a low threshold for returning for reassessment. For more independent patients with IDD, it is helpful to provide treatment and follow-up instructions using pictures with simple text, which can be reviewed at home several times again with family members or caregivers. It is important to ensure short-term follow-up is booked, perhaps with a reminder call, and that a patient with IDD who does not show up is contacted to check in.

Referrals to other specialists or to a specialty multidisciplinary team involve facilitating collaboration, sometimes across different sectors: Family physicians might need to access subspecialty rehabilitation services such as occupational therapists qualified in sensory integration therapy, or seating clinics specializing in care of patients with cerebral palsy. Financial programs specific to the developmental service sector might be available, and social workers from developmental agencies or children's hospitals can provide helpful suggestions for applying for these financial resources. A particular health service might need facilitated access to developmental service professionals to support patients with IDD. For example, a woman with IDD who has just had a baby might need her adult protective service worker to collaborate with a public health nurse to ensure that patient communication and education resources are adapted for a woman with IDD.

The process of finding common ground through aligning the disease presentation with the patient's illness experience requires a special empathetic approach: The term *empathy*, when used in medicine, is generally defined as an effort to appreciate the patient's experience from his or her perspective.[30] Weston et al define the components of the illness experience, which are elicited by exploration of patients' feelings and ideas, and the effect of their symptoms on their functioning.[31] They describe how aligning this information with the physician's understanding of the disease presentation considerably improves management plans, as evidenced by enhanced adherence to treatment plans.[32] For patients with IDD and their caregivers, the *ideas and feelings* related to an illness are strongly shaped by previous health experiences, which involve challenges with communicating symptoms, tolerating assessments, and diagnostic uncertainty. Appreciating the effect of symptoms on *function* also requires a unique understanding of the broader context of the patient with IDD in a caregiving or group-living situation. For example, new insomnia might have minimal effects on the patient but might affect adequate sleep and the ability to function for the caregiver. This can then affect the caregiver's ability to manage other chronic illnesses for the patient with IDD during the day. Discussions aimed at finding a common ground for supporting the patient with IDD must therefore be highly sensitive to such contextual factors. Management plans should ideally tap into factors that enable resiliency and coping skills of the patient-caregiver team.

Conclusion

Complexity in caring for patients with IDD carries the risk of causing health professionals to experience uncertainty and feel overwhelmed ("I'm not sure what's going on or where to start") and can lead to frustration ("I'm not sure how to help").[33] Worse, such complexity can eventually lead to a sense of futility ("I can't really help here"). However, by unpacking additional considerations that contribute to the complexities of caring for a patient with IDD, family physicians can apply their strong generalist skills in providing such care, thus enabling assessment, diagnosis, and treatment. This approach, coupled with a strong relationship with the patient with IDD and caregivers, creates an effective strategy for addressing the complex health care needs of people with IDD and is rewarding for the entire care team.

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Contributors

All authors contributed to the literature review and interpretation, and to preparing the manuscript for submission.

Competing interests

None declared

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This article has been peer reviewed.
Cet article a fait l'objet d'une révision par des pairs.
Can Fam Physician 2018;64(Suppl 2):S15-22