Adults With Severe Reading and Learning Difficulties: A Challenge for the Family Physician

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Background: **An estimated 40 to 44 million adults living in the United States have severe difficulty reading, writing, spelling, and doing arithmetic. These deficiencies interfere with their receiving adequate health care. Many of these adults have reading or other learning disabilities that further compromise their ability to understand their medical conditions and to participate fully in their own care.**

Methods: **The literature on the cognitive and affective characteristics of adults with reading and learning disabilities was searched using the MEDLINE, PsychLIT, and ERIC databases. This literature is reviewed with an emphasis placed on how these characteristics might challenge a family physician's ability to provide optimal patient care, and what can be done to meet these challenges. Illustrative case vignettes of adults with these disabilities are described.**

Results **and** ***Conclusions:*** **The cognitive and affective characteristics of this patient population make it difficult for the family physician to provide optimal medical services. Suggestions are given to make medical care more accessible and appropriate for these patients. (J Am Board Fam Pract 1997;10:199-205.)**

It is estimated that more than 20 percent of adults living in the United States have severe difficulty in reading, writing, spelling, and mathematics. These deficiencies interfere with their ability to obtain adequate medical care. Many of these adults have learning disabilities that further compromise their ability to understand their medical conditions and to participate appropriately in their own medical care.

Methods

We searched the MEDLINE files from 1990 to the present using the key words "learning disorders," "dyslexia," "adult," and "English language." We conducted similar searches in the PsychLIT and ERIC databases. Earlier articles were obtained through examination of the references from more recent articles.

Background

Persons with severe reading difficulties constitute a sizable portion of the adult population of the United States. In a comprehensive study of literacy levels and practices, Kirsch et al[1] profiled a nationally representative sample of more than 13,000 US adults. Their results suggest that 40 to 44 million American adults cannot perform the simplest reading and writing tasks because their reading, writing, and mathematics skills are below those of the average elementary school student. They have great difficulty performing such tasks as locating and matching a specific piece of information in a brief news article, signing their name in the appropriate place on a form, or computing simple, one-step arithmetic problems. Kirsch et al found that these persons are far less likely to work full-time, earn adequate wages, or vote; in other words, they are far less likely to participate fully and productively in our society. Furthermore, this low-literacy group had a higher incidence of health-related problems than did the literate population, a finding similar to those of researchers and practitioners in family medicine.[2,3]

In a survey of nearly 3000 patients from two urban public hospitals, Williams and colleagues[4] found a surprisingly high proportion (22 to 62 percent) who did not have the reading skills necessary to function in the health care environment. Most were unable to read and understand vital health care information, such as instructions on medication bottles or appointment slips.

Recent research suggests that many of these patients might have reading and other learning disabilities that compound their difficulties in ac-

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cessing and learning information, thus making it even harder for them to understand their medical conditions and comply with their physician's instructions. In a study of 280 adults who sought help from a clinic-based adult literacy program, Gottesman et al[5] found that the overwhelming majority (78 percent) met diagnostic criteria for reading or other learning disabilities. This group was similar to those patients studied by Williams et al on a number of variables, including ethnic and racial diversity and socioeconomic status. These findings indicate that many adults with low literacy levels suffer from a constellation of problems rather than an isolated reading deficit.

Why should family physicians be particularly concerned with this population? As a number of researchers and clinicians suggest, inadequate literacy is an obstacle to providing medical care.[4,6,7] Illiteracy and learning disabilities pose a tremendous challenge to the physician because they are silent and extremely difficult to detect without an awareness of the major signs and symptoms. In this article we describe the relevant characteristics of learning disabilities, explain how these characteristics can make it difficult for the family physician to provide optimal medical services, and offer suggestions for patient care.

Characteristics

Learning disabilities are difficult to diagnose because no single symptom or characteristic is shared by every person with a learning disability. There is great heterogeneity in this population,[8,9] and each individual will have a different constellation of specific symptoms. The term *learning disability* is defined in federal law as

> ...a disorder in one or more basic psychological processes involved in understanding or using language, spoken or written, which may manifest itself in an imperfect ability to listen, speak, read, write, spell, or do mathematical calculations. The term includes such conditions as perceptual handicaps, brain injury, minimal brain dysfunction, dyslexia, and developmental aphasia. Such terms do not include children who have learning disabilities which are primarily the result of visual, hearing, or motor handicaps, of mental retardation, of emotional disturbance, or of environmental, cultural, or economic disadvantage.[10]

As this definition implies, in addition to severe problems with reading, writing, and mathematics, many learning-disabled persons have difficulties in other areas, including general information, oral language, memory and attention, auditory processing, visual perception and directionality, and social and emotional adjustment.

General Information

People with reading and learning disabilities are less informed than more proficient readers. Many have never been able to use reading as a tool for learning and are highly dependent upon others for basic information. They can lack common knowledge, such as the names of their political representatives and the name of the state or even the name of the country in which they live. They might not be able to perform tasks that children do easily, such as using coupons in a grocery store, taking a measurement with a 12-inch ruler, or locating a street on a simple map. They might not be able to follow uncomplicated instructions, such as how to take their medications, or lack basic information that would allow them, for example, to follow a low-fat or low-sodium diet.

Elena was asked to monitor her daughter's temperature during a bout of chicken pox. She was too embarrassed to tell the physician or nurse that she did not know how to take a temperature or even what the thermometer was called.

Jasmine's daughter had an ear infection. An oral medication was prescribed. When she tried to administer this medication, Jasmine asked, "How am I supposed to get this in her ear with a spoon?"

Memory and Attention

Memory deficits interfere with the rote learning of such material as the days of the week, months of the year, or times tables.[11,12] Both long-term and short-term memory can be affected by learning disabilities, and often multiple exposures are needed before a learning-disabled person can remember new information. Similarly, deficits in attention can impede learning by interfering with the ability to focus and concentrate on tasks. Attention deficit-hyperactivity disorder frequently accompanies reading disabilities, and estimates of the comorbidity range from 35 to 50 percent.[13] Memory and attention deficits result in difficulties in daily functioning, such as keeping appointments, remembering oral instructions or explanations from a physician, or remembering to take a prescribed medication.

When Paul goes to his clinic, he cannot sit still in the waiting area. He paces; sometimes he walks out and is not present when his name is called. He is not trying to avoid seeing the physician, he just does not have the attentional capacity to wait patiently.

A veteran of Operation Desert Storm, Alphonse suffers from severe back and neck pain, migraines, and severe depression, and he needs several medications to alleviate these symptoms. He frequently confuses the time and amount of dosages and several times has had to be taken to the emergency department. He complains, "I can never remember what the doctor says."

Attention problems can also lead to impulsive behavior. We have clients who, if they do not have immediate relief from a prescribed medication, stop taking it in the belief that the medication is not helping. They do not understand that the medication might need time to work. Other clients report taking more than their prescribed dosages, thinking that doing so will make them better faster.

Marie was given a prescription for a sleeping medication. The first night she took it, she did not sleep any better. The next night she drank four beers to help her fall asleep rather than take the medication again.

Lucille was prescribed medication for high blood pressure. One day she felt as if she were having heart palpitations. She took three capsules instead of the one prescribed to relieve those symptoms. "It all has to do with my heart, doesn't it," she said when asked why she had increased her dose.

Oral Language

Persons with reading and learning disabilities can have oral language delays or impairments. As a result, they often have small vocabularies, mispronounce words, use words incorrectly, have difficulty using and understanding complex sentences, and organize their thoughts poorly,[14,15] all of which are profound impediments to learning. Many in this group might not understand simple, commonly known words. Their oral language skills can also be characterized by dysfluency and word-finding problems.

Because oral language is the major vehicle for communication, restricted or flawed language skills can hamper interpersonal relationships by affecting the person's ability to recognize figurative language or the subtle linguistic cues associated with exaggerating, teasing, or joking. Poor language skills make it hard to share feelings or even to engage in everyday conversation.

In a medical setting these oral language deficits can have serious consequences. Patients who have trouble expressing themselves might not be able to describe their symptoms completely or clearly, and they might not be able to give a thorough and coherent medical history. They are not reliable informants.

Lillian was told to eat before she took her medication. She did not know what before meant, so she stopped taking her medication because she had stomach pains whenever she took it.

When asked during a review of symptoms, Bill denied having angina, but at the end of the visit he asked the physician if there was anything he could do for his chest pains.

Auditory Processing

Many patients with reading and spelling difficulties have an underlying problem discriminating among similar speech sounds. For example, pin might sound like pen or big might sound like pig despite adequate hearing.[16-18] Such difficulties frequently result in misunderstood messages or trouble understanding directions and can particularly compromise their ability to get information by telephone. These patients do not benefit from directions given on the telephone because they cannot hear the directions properly, might not be able to remember what was said, and might not be able to write information down.

Visual Perception and Directionality

Poor or inconsistent visual perception can result in difficulties with spatial relations, difficulties detecting similarities and differences in drawings or written material (eg, letters), and directional confusion. Adults with visual perceptual problems might have difficulty with such tasks as copying geometric designs, putting puzzles together, or staying on the line when writing. They can also encounter problems interpreting common facial expressions, such as frowns, grimaces, or looks of annoyance (which are spatial cues) and respond inappropriately. Often they are not on time for their appointments because, in addition to a poor sense of time, they experience confusion with directions such as right or left and north or south.[19-21]

Judy, a woman with diabetes, has very poor visual perception. She often confuses letters that are similar (eg, b, d, p, q) and transposes numbers (eg, writing 25

Table 1. Behavioral Characteristics Often Found in Adults With Learning Disabilities.*

Memory and attention	Trouble learning material by rote Needs multiple presentations to learn new information Trouble remembering appointments or instructions Easily distracted Excessively disorganized Difficulty with sustained concentration Difficulty sitting still; fidgety, restless Acts without concern about consequences (impulsive)
Oral language	Difficulty following verbal directions Poor grasp of grammar and syntax Limited receptive and expressive vocabulary Word-finding problems Difficulty conveying information in logical and understandable manner
Visual and auditory processing	Confuses right and left Confuses words that sound similar Reverses letters or numbers Difficulty following directions
Social relationships	Difficulty in conversational skills Reacts inappropriately to other people's tone of voice or facial expressions Inappropriate responses to other people's use of humor or sarcasm
Survival skills	Difficulty telling time Difficulty making change Difficulty using public transportation Difficulty using maps and schedules
Reading, spelling, writing, and mathematics	Long-standing history of reading difficulties from the early grades in school History of special education classes, repeating grades, or dropping out of school Great difficulty learning and remembering new reading vocabulary and learning sound-letter and letter-sound relations Difficulty with spelling Difficulty with simple number calculations Frequent reversal of letters or numbers Difficulty keeping numbers correctly aligned in a column

*Categories are not discrete and might overlap.

for 52). It has been difficult to treat her diabetes because she transposes the numbers when writing down her blood glucose levels.

Social and Emotional Adjustment

Perhaps the most devastating consequences of reading and learning disabilities result from the many frustrations and failures experienced throughout and well beyond the school years. Feelings of inadequacy, low self-esteem, lack of confidence, shame, embarrassment, and depression are almost universally experienced.[22] Interviews with patients indicate that poor literacy skills are accompanied by profound shame and fear of admitting to any difficulty.[23] Parikh and colleagues[7] found that 67 percent of a low-literate urban population did not reveal their reading problems to anyone, including their spouses. These adults frequently believe they will be taken advantage of and distrust strangers. Thus, many patients are simply too embarrassed to seek help from their health care providers. They are afraid to ask questions; they are afraid they will appear stupid or not in control. This barrier might be the most important to overcome when treating learning-disabled adults.

Forming and maintaining relationships can be further complicated by deficiencies in language and social judgment, including poor perception of others' feelings.[8,20,21,24,25] Sometimes those with learning disabilities are unaware of personal boundaries and invade a person's space by moving in too closely. Sometimes speech patterns are affected, and a patient might talk in a monotone voice, which could convey a lack of interest.

Depression is ubiquitous in the adult learning-disabled population, and some speculate that this depression is not a secondary reaction, but part of the learning disability syndrome. Depression might in fact be the primary complaint of this population.

When Hank was asked to read during an evaluation session in our clinic, he pulled out two pairs of over-the-counter eyeglasses that he had cobbled together. He stated that he knew he needed glasses to see print, but he was too afraid he would be asked to name letters during a vision examination to go to an optometrist.

Max's back injuries prevented him from finding work that did not require reading and writing. When he applied for social security benefits, he avoided telling his lawyer and his physician that he was unable to read. "I didn't want them to think I was stupid," he said. He was denied social security on the basis of being capable of holding a sedentary job.

A summary of the behavioral characteristics of adults with learning disabilities is displayed in Table 1. This table can also be used as a checklist. It is possible that a patient who has a number of these characteristics is learning disabled.

Role of the Family Physician

Awareness

Perhaps most important, family physicians should be aware that reading and learning disabilities are common and that the cognitive and behavioral characteristics of learning-disabled patients can hamper productive physician-patient relationships.

During the delivery of medical care, the physician, other health care workers, and office staff have many opportunities to observe symptoms associated with reading and learning disabilities. Special attention can be directed toward observing waiting room behavior, how the patient fills out forms, the adequacy of the history or description of symptoms, whether the patient comprehends the physician's instructions, and patient compliance with the physician's orders. If a patient consistently fails to comply with medical instructions or advice, a possible learning disability should be suspected.

If a parent requests information about a child having a learning disability, there is a strong possibility the parent has difficulty too. Ample evidence suggests a genetic component to reading and learning disabilities.[26]

Many visits to family physicians result from vague symptoms that could be psychosomatic or caused by depression. An estimated 20 percent of patients who visit family physicians suffer from mental, emotional, or behavioral disorders.[27-29] When these problems are encountered, they could be reactions to severe learning problems.[30]

The shame and embarrassment that so often accompany learning disabilities must be acknowledged when a physician suspects learning disabilities are interfering with the patient's medical care. There might be no compelling reason to discuss this diagnosis with the patient, although such a diagnosis makes a patient eligible for special accommodations and government assistance (eg, vocational rehabilitation services). If such a diagnosis is suspected, however, changes in patient care could be initiated that would not be offensive to a non-learning-disabled patient.

Table 2. Enhancing Care of Patients With Learning Disabilities.

Awareness and recognition	Observe waiting-room behaviors Check ability to fill out forms Observe coherence or adequacy of history Monitor comprehension
Communication	Ask simply worded, direct questions Use simple vocabulary Avoid use of medical terminology or acronyms Speak slowly Encourage questions Encourage office staff to help with forms
Giving instructions	Review instructions Ask the patient to repeat instructions Explain graphic or pictorial information Include other family members to improve comprehension and compliance Limit amount of information given to patient in each visit
Checking compliance	Ask in detail how patients are taking medications Use weekly medication dispenser with compartments Have office staff telephone patients the day before to remind them of appointments Schedule follow-up appointment or telephone call

Medical Care

A number of strategies can help the learning-disabled adult obtain appropriate medical care.[6,31-34] When taking a history, ask direct questions and monitor comprehension. Patients might know, for example, that they were sick at some point but might not be able to name their condition. They might, however, recognize the name when asked directly. Simply worded, specific, yes-or-no questions can elicit reliable information from patients with receptive or expressive language difficulties. With the permission of the patient, family members can be recruited to help with the medical history.

Poor readers might avoid a new physician because of the many forms encountered at the first visit. Assistance with these tasks can help establish rapport and gain a patient's confidence. Office and clinic staff should be made aware that some patients need special help and extra patience, that they are not trying to be difficult or are not unconcerned about their health.

The most important strategy for the family physician is to present new information to a learning-disabled patient in a slow, patient manner and to encourage questions. The physician should not assume an absence of questions means that such patients understand their conditions or are following instructions. Carefully check compliance at the start of each visit. Consider making only one point clear or prescribing or adjusting only one medication at each visit, using a simple vocabulary and avoiding medical terminology and acronyms. Persons with learning disabilities learn best when information is presented slowly and repeated frequently.

If using simple written handouts to help patients remember instructions, review the materials with the patients before expecting them to use the handout independently. Provide pictorial materials, if possible and appropriate. Check patient comprehension or memory by asking patients to repeat instructions. Repeat the information if necessary. Again, a family member can be enlisted to monitor comprehension and compliance.

When prescribing medications for learning-disabled patients or their children, dosages and times should be reviewed carefully. Patients who cannot read also profit from such aids as pictures or drawings showing dosages and when medications should be taken. Whenever any instructions are given, the patient should be asked to repeat them or to demonstrate what they are supposed to do. A weekly medication dispenser with four compartments for each day can enhance compliance with both simple and complicated medication regimens. Alternatively, some pharmacies will package medications into weekly four-times-a-day blister packs. Schedule a follow-up appointment or follow up by telephone to ensure that medications are taken properly and that other medical interventions are being undertaken as directed.

Vision and hearing screening should be a part of a complete physical examination to rule out sensory deficits, which are sometimes easily correctable underlying causes of reading failure.

The depression that often accompanies low literacy should be monitored carefully. Medication can help, but referral for psychiatric and psychoeducational interventions is also important.

If a reading or learning disability is suspected, and if the patient indicates a desire for help, the physician should refer the patient to a program that serves adults with learning difficulties. Local programs can be found by contacting the Learning Disabilities Association of America, 4156 Library Road, Pittsburgh, PA 15234 (telephone: 412-341-1515, fax: 412-344-0224) or the National Center for Learning Disabilities, 381 Park Avenue South, Suite 1420, New York, NY 10016 (telephone: 212-545-7510).

Table 2 summarizes some suggestions for recognizing and treating learning disabilities in patients.

Conclusion

Providing high-quality medical care to adults with severe reading difficulties is a challenge to family physicians, particularly because reading and other learning difficulties are silent syndromes that are difficult to detect. Awareness of the symptoms, use of appropriate accommodations, and knowledge of available referral sources will help the physician care for patients with these difficulties more effectively.

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