WHY JOHNNY CAN'T REHAB: OPENING THE BOOK ON LITERACY AND REHAB

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INTRODUCTION

The challenge for medical and rehabilitation specialists is to promptly, efficiently and effectively return a client to a functional level that is as close as possible to her pre-injury level. One of the most misunderstood conditions that impedes recovery is illiteracy. Illiteracy affects a large percentage of those needing medical attention and, in fact, is often a primary reason for a person to need medical and/or rehabilitation assistance. It is unlikely that a professional will be able to tell which client is illiterate. He must use an approach to all clients that will allow them to understand clearly the information that must be presented.

ASSESSMENT OF ADULT LITERACY IN THE UNITED STATES

Literacy is defined by the National Center for Education Statistics as "using printed and written information to function in society, to achieve one's goals, and to develop one's knowledge and potential." Low literacy affects approximately 93 million people in the United States – and that is probably a low estimate, because illiteracy carries a stigma that not many are willing to incur.

The National Center for Education Statistics has devised a tool for assessing literacy levels in the United States. The NAAL (National Assessment of Adult Literacy) assessed a representative sample of adults (aged 16 or over) in their homes or in penal institutions in 1985,1992 and 2003 (National Center for Education Statistics, 2010a). They cite four levels of literacy (National Center for Education Statistics, 2010b) –

- Below Basic – unable to use more than the most simple and concrete literacy and numeracy skills.
- Basic – able to perform simple and everyday literacy activities
- Intermediate – able to perform moderately challenging literacy activities
- Proficient – able to perform complex and challenging literacy activities

Sample questions included – check the correct box on a Social Security application; write a date on a check with numbers; using a chart, find the projected percentage of Black people who will be considered middle class for the year 2000; read a brochure or pamphlet and extract specific information.

Their 2003 results indicated that 22% of adults tested Below Basic level in quantitative literacy, 14% in prose literacy and 12% in document literacy. This meant that, among other tasks, they could not derive information from documents, balance a checkbook, interpret a telephone bill, or fill out an application.

An additional 11 million adults, 7 million of whom are native English speakers, are considered non-literate. They could not answer simple test questions.

Causes of Illiteracy

Illiteracy has multiple causes. A primary reason for a person's inability to read is often because illiteracy was a part of his childhood environment (ProLiteracy, 2014). It may also be a result of interrupted education, a learning disorder such as dyslexia, or emotional issues that impede learning.

Being successful and wealthy does not preclude illiteracy. In the article "Overcoming Dyslexia" by Betsy Morris, published in *Fortune Magazine* in 2002 (Morris, 2002), several prominent business leaders explain how they work with their dyslexia by using alternate strategies in visualizing and solving problems.

Fortune Magazine notwithstanding, most people who cannot read are unwilling to let others know. They do not want to incur the scorn and derision that too often accompanies the revelation. They conceal their illiteracy from their families, friends, co-workers and employees, and are often unwilling to disclose this limitation to their doctors and therapists. This impedes their interactions with medical, legal, educational and social services.

The Results of Illiteracy

The results of an inability to read or calculate can be devastating. Low health literacy, poor health maintenance, poorly paid jobs, and increased poverty levels can reduce quality of life to a significant degree. The incidence of incarceration also increases significantly among low-level readers.

However, a low-level reader can learn to live fairly well within the routine of daily life. Most develop support systems that allow them a tenuous level of functionality. Family members, church members or workplace colleagues may provide a safety net. But an unexpected lost of support such as the death of a spouse may destroy one's ability to cope.

The Effects of Illiteracy on Health

Those who are unable to read above a Basic level frequently are unable to read instructions for medical tests or prescriptions or to read and understand permission/disclosures for medical procedures.

This inability to read can result in a lack of knowledge of when to seek medical help. It also contributes to medication errors, postponed procedures and prolonged hospital stays, not to mention greatly increased readmission rates. It is estimated that low literary issues increase direct health care costs by up to $238 billion per year in the United States (Vernon, Trujillo, Rosenbaum, & DeBuono, 2007).

Importance in Acute Care

A health provider's first contact with an illiterate patient or client may be following the patient's injury, stroke, or debilitating surgery. This is a catastrophic event that may trigger disclosure of a patient's inability to access information accurately. In the intensive care unit, the patient may be intubated and on a ventilator. The assumed solution is to provide a pad and pencil to express needs to the staff. An elderly deaf patient who is unable to understand spoken instructions may be shown written messages by medical personnel instead. The patient may nod cooperatively with no idea what of what she is agreeing to. The teenager who is unable to read the sign at the foot of his bed – "Call for help before getting out of bed." – may sustain a fall, increasing the extent of injury.

All these have the potential for adding further injury or complications to an existing condition - requiring additional rehabilitation before the patient can go home.

Illiteracy and Rehabilitation

A rehab stay may also be prolonged for a variety of reasons. The client may be unable to read important brochures relating to his medications or medical equipment. He may not be able to function well with certain assistive technology. She may have lost vocal function and therefore her best and last method of communication. Incomplete understanding of instructions may increase the risk for re-injury. The ability of even a proficient reader to access and retain information can be reduced simply because of stress or the effects of illness. "Simpler is better" applies to everybody.

WHAT TO DO?

The best way to improve communication with any client is to ask how she learns best. "Do you learn best by reading, video, or hands-on?" is a non-invasive question that covers most learning strategies.

If there is a procedure to learn, then the "teach back" method of demonstration is quite effective. Demonstrate the procedure, have the client or caregiver return the demonstration, and repeat daily or more often until the client is able to competently perform the task.

It is at this point you may discover that the potential caregiver is also unable to read. Similar accommodations may need to be made for him.

Writing Instructions and Information

At times, information must be provided to a client in written form.

Recognizing that the literacy level of the individual may never have been high, or might be reduced by stress, medication, or as a side effect of an injury, the following guidelines are recommended (National Institute of Health, 2013; PlainLanguage.gov, 2011) for instructions that must be written:

- Keep it short.
- Use a sans serif font, such as Helvetica, Arial or Geneva. Consider special fonts for dyslexia, such as APHont or Dyslexie.
- Check your written instructions against a readability scoring tool such as that found on https://readability-score.com . Try to keep the reading level at about a fourth-grade level.
- Use lots of white space.
- Include illustrations if at all possible. Make sure they are culture-neutral and clearly represent the issue. A "rising sun" motif to remind a patient to take his medications in the morning may well be interpreted as a "setting sun" – bedtime.

Follow up at a later time to be sure the client is still clear about what to do. Answer any questions clearly and simply. Include a caregiver if possible.

CONCLUSION

Since illiteracy is a condition rarely, if ever, disclosed by the client, it is the responsibility of the professional to provide information in a manner easily understood by everyone. Simple and clear explanations, instructions written in plain language, return demonstrations of procedures - all these can reduce the tremendous readmission rates current among clients with low literacy.

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