

# Is My Patient Non-Compliant or Do They Have Low Literacy Skills? A Case Report

By Christina Ritchey, MS, RD, LD, CNSC  
critchey1@optum.com



## ABSTRACT

**Introduction:** Literacy is the ability to understand, evaluate, use, and engage with written texts to participate in society, to achieve one's goals, and to develop one's knowledge. Home parenteral nutrition (HPN) patients with low literacy may be considered non-compliant if they are unable to follow their prescription, have negative outcomes, or are readmitted to the hospital often. Studies show patients with low literacy have poorer health, higher hospitalization rates, and increased health care costs. The purpose of this study is to examine the effect of low literacy on compliance for a home infusion patient.

**Case Description:** A 62-year-old male with a high output enterocutaneous fistula (ECF) was readmitted for acute kidney injury (AKI) related to dehydration, then referred to a national home infusion provider for HPN. The patient had been with another provider and nursing agency, but neither wanted to resume care due to reported non-compliance. The new HPN team reviewed the case and accepted the patient. He was discharged home with HPN, intravenous (IV) antibiotics, and IV hydration. After a short time, the nursing agency reported the patient missed several antibiotic doses and HPN. During the

nutrition assessment, the patient revealed to the dietitian he could barely read, and therefore, mixed up his medications.

**Results:** The nursing agency provided hands-on patient education and daily visits. The patient became independent, confident, and successfully administered all prescribed therapies at home without further readmissions.

**Discussion:** HPN is a complex therapy requiring significant patient education, reinforcement, and support for success. When additional IV medications are prescribed, complexity increases, especially with low literacy.

**Conclusion:** The home infusion team can be integral in identifying literacy barriers. The Single Item Literacy Screener (SILS) is a validated tool that may be useful in home care where the patient assumes responsibilities for self administration. It includes a single verbal question and identifies patients needing assistance reading health-related materials. Additional research should be conducted on the home infusion population utilizing the SILS to gain information on literacy.

## Introduction

Roughly, 1 in 5 U.S. adults (21%) have low literacy skills.<sup>1</sup> According to the National Center for Education, literacy is the ability to understand, evaluate, use and engage with written texts to participate in society, to achieve one's goals, and to develop one's knowledge.<sup>1</sup> Low literacy also correlates with an individual's health literacy.<sup>2,3</sup> Health literacy is defined as the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions.<sup>4,5</sup> Health literacy has been shown to be significantly worse than a patient's literacy skills due to the complexity of health-related information.<sup>6</sup> As health professionals, we play an integral role in identifying patients who may have low literacy skills which impacts one's ability to play an active role in their health care.

Low literacy is not unique to one specific demographic, therefore identifying a patient with low literacy skills can be a challenge. Research shows low literacy is more common in patients with lower socioeconomic status, lower education levels, elderly, immigrants, the disabled, and minorities. However, many patients with low literacy skills have adapted and know how to compensate to function in society.<sup>1,5,7,8</sup>

Most patients with literacy challenges do not share this information with others, including family and friends. Marcus reported "more than two-thirds of patients with low literacy in public hospitals said they had never told their spouses about it. Nearly one-fifth said they had "never told anyone."<sup>9</sup> Patients often feel ashamed or embarrassed to admit they are unable to read. It is common for health professionals to treat patients with low literacy and never know the struggle their patient

is going through. Individuals with low literacy may react to complex learning situations by withdrawing or avoiding because it is intimidating and difficult to process. When providing patient education or discussing their health care, patients with low literacy will usually say they understand the material even if they did not.<sup>5,10</sup>

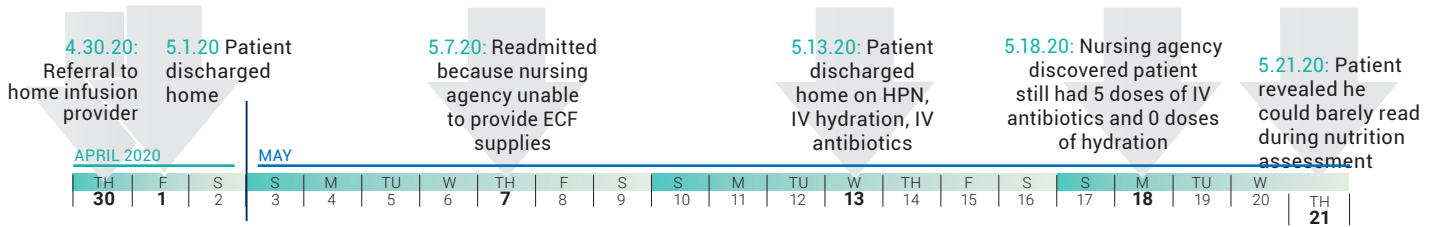
Patients with low literacy skills had poorer health, higher hospitalization rates and higher health care costs.<sup>5,7</sup> The *American Journal of Public Health* reports that, "the inability to read and understand health information accounts for \$232 billion spent in health care costs each year."<sup>11</sup> DeWalt and colleagues conducted a systematic review of multiple observational studies investigating the relationship between literacy and health outcomes. They found 16 studies that measured this relationship and found a positive significant association between reading ability and health outcomes.<sup>12</sup> Individuals with lower literacy were 1.5 to 3 times more likely to have an adverse outcome compared to those with higher literacy. Two studies by Baker and colleagues showed the likelihood of being hospitalized was significantly higher for patients with lower literacy than for those with higher literacy; specifically, 1.69 times higher at a public hospital and 1.29 times higher for Medicare enrollees.<sup>5,12</sup>

In addition, patients with low literacy are less likely to understand information about their chronic medical conditions, less likely to understand discharge instructions following an emergency department visit and are more likely to experience medication errors because they are unable to read the prescription labels. According to Baker, 54% of patients with low literacy were unable to answer a specific question about when they should take their medication because they could not read the label. Further, these patients may stop taking a medication or decrease their dose if they do not understand the importance of compliance.<sup>13</sup> These

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EXHIBIT 1

Case Description Timeline



patients are a high risk for medication errors whether it is missed doses or mixing up their medications.<sup>5</sup> According to the Institute of Medicine (IOM) and The Joint Commission (TJC), miscommunication between health professionals and patients significantly contributes to medication errors, and was the cause of 3,000 sentinel events reported to TJC.<sup>5,14</sup> Another study by Davis et al examined patients' ability to read and understand 5 different label instructions on prescription bottles. Patients with low literacy were less able to understand all 5 labels. Only 34.7% could indicate the number of pills to be taken daily. The results also showed a significant correlation between a greater number of prescription medications and patient misunderstanding of instructions.<sup>15</sup>

Home infusion, specifically home parenteral nutrition (HPN), requires patients to process a significant amount of health-related information, learn how to self-administer, and manage a complex therapy. HPN patients with low literacy skills may be labeled as non-compliant if they are unable to follow their prescription, have negative outcomes, or are readmitted back to the hospital. The purpose of this case report is to examine the effect of low literacy on compliance for a home infusion patient.

Case Description

A 62-year-old male with a high-output enterocutaneous fistula (ECF) was readmitted to the hospital for acute kidney injury (AKI) related to dehydration and high output ECF. On April 30, 2020 a national home infusion provider received a referral from the hospital to provide HPN for this patient. He had a complex medical history which included diabetes mellitus type 2, hypertension, small bowel obstruction, and ventral hernia repair. His high-output ECF was a post-operative complication of his ventral hernia repair (see Exhibit 1 for timeline). The patient had been with another home infusion

provider and nursing agency receiving HPN, but neither wanted to resume care due to reported non-compliance. The patient had recently been in the hospital 4 times prior to the current admission. The new home infusion team met to review the case, which included the general manager, intake coordinator, nutrition support dietitian, pharmacist, nurse, clinical liaison, and acute care specialist (sales representative). The team agreed to accept the patient on service if he expressed willingness to participate in his care and had a safe home environment. He lived alone and did not have a caregiver to assist with his home infusions, but he was assessed as competent to self infuse and manage his therapy. The hospital discharge planner was notified of the decision and arranged a new nursing agency for the patient.

On May 1, 2020, the home infusion nurse met with the patient in the hospital to complete a nursing assessment, review expectations, and provide education regarding administration of HPN. He verbalized understanding, performed return demonstration, and was discharged home. On May 7, 2020, the patient was readmitted back to the hospital because the nursing agency was unable to provide supplies to manage his ECF. While the patient was in the hospital, he was diagnosed with an infection at his ECF site. He was started on intravenous (IV) antibiotics. In preparation for discharge, the provider received updated HPN orders and new orders for IV antibiotics and hydration (Exhibit 2). The home infusion provider set the patient up with a new nursing agency who was experienced in complex cases and IV therapy. On May 13, 2020, the home infusion nurse met with the patient

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EXHIBIT 2

Home Infusion Orders for May 13 Discharge

Admitting Diagnosis	Past Medical History	Home Infusion Medications
<ul style="list-style-type: none"><li>• AKI</li><li>• Dehydration</li><li>• High output ECF</li></ul>	<ul style="list-style-type: none"><li>• DM2</li><li>• HTN</li><li>• SBO</li><li>• Ventral hernia repair</li></ul>	<ul style="list-style-type: none"><li>• 3 in 1 Parenteral Nutrition</li><li>• Vancomycin 1750mg IV q 24 hours</li><li>• NS 500ml 3x/week</li></ul>

in the hospital again to complete a nursing assessment, provide education regarding administration of the two new IV therapies, the antibiotic, and hydration. The home infusion nurse also reinforced education regarding HPN administration. The patient verbalized understanding, performed return demonstration, and was discharged home.

On May 18, 2020, the nursing agency reported the patient had mixed up the IV antibiotics with the IV hydration. He missed several doses of IV antibiotics and instead infused multiple doses of IV hydration daily. Although the patient infused more hydration bags than ordered, there were no adverse effects identified. In addition, the nurse was not sure if the patient was administering his HPN correctly because he had extra doses on hand. The home infusion provider notified the infectious disease (ID) physician that the patient missed several doses of IV antibiotics. The ID physician stated he was aware of the patient's non-compliance but would like him to finish out his IV antibiotics. The home infusion provider sent more hydration to the patient and the nursing agency provided additional hands-on education.

On May 21, 2020, the nutrition support dietitian called the patient for his routine nutrition assessment and was aware of the situation earlier in the week. During the nutrition assessment, the dietitian asked the patient to count how many doses of each medication he had at the time to determine if he had been able to infuse all 3 medications properly since May 18th. The patient then revealed to the dietitian that he could barely read. He explained he accidentally infused multiple doses of hydration, missed the antibiotics, and had difficulty hooking up the PN because he was unable to read the labels on the medications.

## Results

The dietitian let the patient know a new plan would be developed to help him with his complex regimen. The dietitian immediately informed the home infusion team of the patient's literacy challenges. The team discussed alternative methods to ensure the patient could decipher between his medications such as color coding each medication and changing the method of administration as applicable. The nursing agency was also notified of the patient's low literacy skills. It agreed to provide additional hands-on patient education and daily visits to ensure the patient was infusing as prescribed. The dietitian reinforced education and reviewed HPN administration during weekly calls. The patient became independent, confident in his abilities, and successfully administered all prescribed therapies at home without further readmissions to the hospital. Ultimately this patient's outcome was successful; his ECF output decreased and healed enough to where he was able to have surgery to repair it and was discharged from home infusion therapy as "therapy complete."

## Discussion

HPN is a complex therapy requiring significant patient education, reinforcement, and support for success. When additional IV medications are prescribed, the complexity greatly increases along with the likelihood that patients will have difficulty. This is especially true in patients with low literacy skills. Understanding the needs of this patient and adapting to his literacy level allowed the home infusion provider to support the best outcome possible. This positive outcome also decreased health care costs for him and the health care system.

The home infusion team can be integral in identifying literacy barriers. Patients should be screened and identified at the beginning of care to determine their literacy level. There are various types of instruments used to measure reading ability in health care. The most common validated tools are the Rapid Estimate of Adult Literacy in Medicine (REALM), Test of Functional Health Literacy in Adults (TOFHLA) or short version (S-TOFHLA). The REALM only takes 2-3 minutes to complete. It uses word recognition and pronunciation but does not test reading comprehension or functional literacy. REALM was intended for primary care or public health settings and measures literacy levels of patients

EXHIBIT 3

Single Item Literacy Screener (SILS)

Question	Response Range	Scoring Criteria
How often do you need to have someone help you when you read instructions, pamphlets, or other written material from your doctor or pharmacist?	1 = Never 2 = Rarely 3 = Sometimes 4 = Often 5 = Always	Scores greater than "2" are considered positive, indicating some difficulty with reading printed health related material.

who read below the 9th grade level. The TOFHLA or S-TOFHLA measures functional health literacy using health-related materials. TOFHLA takes approximately 20-25 minutes and S-TOFHLA takes 5-10 minutes to complete. They are available in Spanish and English.<sup>12,13</sup>

Another validated tool to measure reading ability is The Single Item Literacy Screener (SILS) (Exhibit 3).<sup>4</sup> The SILS was developed from the S-TOFHLA into a single verbal question to identify patients needing assistance reading health-related materials. The SILS question is "How often do you need to have someone help you when you read instructions, pamphlets, or other written material from your doctor or pharmacy?" Responses range from 1 to 5 (1-Never, 2-Rarely, 3-Sometimes, 4-Often, 5-Always). A score of 3 or higher indicates a patient has some difficulty with reading printed health-related material. To measure the validity of the SILS, Morris et al compared the diagnostic accuracy to the S-TOFHLA and analyzed the sensitivity and specificity. Their results indicated a score of 3 or higher provides a sensitivity of 54% and specificity of 83%.<sup>16</sup> The SILS could be useful in home care and could be utilized during the initial evaluation prior to HPN education. Nguyen et al evaluated the association between the SILS and health outcomes in patients with lung cancer. Results showed one-third of patients had limited health literacy, which was more prevalent in patients 70 years and older. Patients with limited health literacy had a higher number of emergency department visits (p = 0.0156) and unplanned hospitalizations (p = 0.0044); and were more likely to have these events sooner (p < 0.0001) (Nguyen et al).<sup>17</sup>

Andrus and Roth suggest routine literacy evaluation be conducted in a private setting since many low literacy patients feel shame and embarrassment.<sup>6</sup> In addition to the above validated tools, some clinicians carry

around a prescription bottle and ask the patient to read it.<sup>5,6</sup> Patients may hide their literacy issues by making statements such as "I forgot my reading glasses," "I'll read through this when I get home," "I'd like to discuss this with my family first," or "May I take the instructions home?"<sup>6</sup> These should all be warning signs that an individual may be masking a literacy issue. Once a patient with low literacy skills is identified, it is critical that health care professionals communicate and educate effectively.

### Conclusions

Patient education is a critical component of compliance and safety for those with low literacy skills. Oftentimes these patients require more time to learn and understand concepts.<sup>6</sup> With 43 million adults in the U.S. having low literacy skills, this is an important consideration for all health care professionals.<sup>1</sup> Understanding literacy levels in the home infusion population, can help determine the type of patient education, ultimately improving medication adherence, preventing unnecessary hospitalizations, and improving outcomes. There is limited data regarding literacy levels amongst home infusion patients. Additional research needs to be conducted specifically on the home infusion patient population to gain information on literacy. The SILS as a literacy screening tool should be studied in home infusion since it has been successfully used in other patient care settings. In addition, investigating the rates of rehospitalizations and compliance among home infusion patients with low literacy would also provide data to show the impact on health care outcomes and cost.

**Christina Ritchey, MS, RD, LD, CNSC** is a dietitian and clinical program manager for Optum Infusion Pharmacy in San Antonio, Texas.

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