

Using AI for Accessible Medical Reports for Patients with Intellectual Disabilities

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Abstract

Introduction

Research has established that individuals with Intellectual and Developmental Disabilities (IDD) struggle with reading comprehension and processing of spoken and written language. They also experience increased co-morbidities and poorer health outcomes than the general population. **To close this gap, patients with IDD need to understand their medical conditions and their providers' instructions.**

To address these inequities in care, an AI-based application was developed to summarize patient-focused elements of physicians' medical reports so patients with IDD could read and understand them. Principles of Minimized Text Complexity (MTC), developed in conjunction with the CDC during the Covid-19 pandemic, were employed.

Methods

A pilot study conducted by a team from Georgia Tech and Adult Disability Medical Healthcare (ADMH) involved three individuals with Down syndrome and two with autism. Participatory needs assessments were conducted with patients using their latest medical reports. Message testing was then conducted with the MTCAI summarized version of the report and supporting medical condition information sheets. Data was collected to assess comprehension and preferences for presentation of medical information.

Key Findings/Results

All participants reported that unfamiliar vocabulary, acronyms, and medical jargon made original reports difficult to understand. All participants found the MTCAI summaries of the reports preferable in both structure and content. Data collected on comprehension suggested that all participants understood the MTCAI summaries.

Conclusions/Significance/Discussion

Patients reported that the MTCAI medical reports and information sheets were significantly easier to understand. Further research is needed to evaluate this AI tool.

Objectives

1. Describe how reading comprehension challenges faced by people with IDD impact their healthcare outcomes.
2. List three components of Minimized Text Complexity
3. Identify three differences between Plain Language and Minimized Text Complexity.
4. List 3 observations participants made about how MTCAI report summaries of their medical reports.

Background

It is well documented that individuals with IDD struggle to read with comprehension (Wagner et al., 2006; Allor et al., 2014; McIntyre et al., 2021; Benson-Goldberg et al., 2022). They also often experience poorer health outcomes than their peers without disabilities. **This may be partially explained by the complexity of health care communication**, including physicians after-visit reports. Unfortunately, many existing approaches to simplifying text (i.e., Plain Language Guidelines) are insufficient to meet the needs of this population.(Benson-Goldberg et al., 2022)

During the COVID-19 pandemic, it became apparent that this population was especially vulnerable due to their unmet health communications needs. In partnership with the CDC, researchers at Georgia Tech and UNC Chapel Hill developed a process for summarizing medical advice called the Minimized Text Complexity Guidelines (MTC; Erickson et. al., 2020). Unlike Plain Language Guidelines, which are aimed at sixth grade level readers, MTC guidelines create texts that can be read and understood by individuals who read at the third-grade level or below. **These guidelines are evidence-based, relevant to the audience, and have been folded into the CDC's Clear Communication Index. However, the process remains manually intensive and as a result, infrequently used.**

To address this gap in implementation, we have created an AI tool that simplifies texts in compliance with the MTC guidelines called MTCAI. The goal in the design of MTCAI was to create an instrument that produces an accessible, readable summary of a physician's medical report for an adult with IDD to read and understand. This tool takes medical records and transforms them from highly complicated, often college-level text to a second-grade level for those with IDD. The tool itself can be thought of as an automation of the well-established MTC guidelines already accepted and supported by CDC.

Sample & Methodology

Sample

Six individuals were selected from among 15 adult patients with IDD who were identified from among patients served by the ADMH in Marietta, GA. which provides medical services to adults with IDD according to the Patient Centered Medical Home (PCMH) model.

The individuals were selected around the following criteria:

- At least 18 years old
- Currently residing in the United States
- Having a diagnosis of an Intellectual or Developmental Disability
- Ability to read at some level
- Ability to communicate their preferences (AAC permitted)

ADMH assisted in recruiting these participants and obtaining their consent to participate. The protocol for this project was reviewed and approved by the Georgia Institute of Technology Institutional Review Board (Protocol H24462). Patients provided permission for the research team to obtain a redacted version of their latest medical report from their physician and to summarize it using the MTCAI process. ADMH assisted in the redaction of these reports.

The limited budget and timeline for this project permitted the team to work with 5 of the 6 participants.

Participants

ID	Disability	Gender	Age
A1	Autism	F	25
A2	Autism	M	30
D1	Down Syndrome	M	25
D2	Down Syndrome	M	24
D3	Down Syndrome	F	24
C1 ¹	Cerebral Palsy	F	20

¹ This participant was not able to participate further due to time constraints.

Methodology

Each participant agreed to take part in two semi-structured interviews:

The first was a **Participatory Needs Assessment** where the individual reviewed a redacted version of their latest medical report. The research team observed this review and asked questions to discover the level of understanding and comprehension that was evident. We asked patients to identify sections of their report (diagnosis, physician instructions, medications, etc.) and discuss that aspect of their lives. We asked each to read the narrative section that described their history (to get a sense of reading fluency) then asked questions to ascertain comprehension. We also asked them to identify unfamiliar words.

The second was a **Message Testing interview**, where the MTCAI summary was presented to the patient. The research team observed as the individual reviewed the report, asking questions to ascertain comprehension. The questions used were modelled after those used in the first interview. Each report involved different conditions, so questions varied somewhat according to the individual's situation. Again, we asked the patient to read a narrative section and to identify difficult words. We asked the patient to tell us which version of their report they preferred and why.

Minimized Text Complexity

The Minimized Text Complexity guidelines are designed such that **written passages might be comprehended by adults with IDD who read at or below a third grade reading level.** They present research-based recommendations at multiple levels: word, sentence, and content. These guidelines suggest the language be simplified by having 92% of the words used in any passage be drawn from among the 3000 most common words in written English. Beyond this there are guidelines that inform design, arrangement, and the inclusion of images (Erickson, et al., 2020; Benson-Goldberg, et al., 2022).

An example of an MTCAI Summary

NIH: Sleep Apnea - Original Text	MTCAI Summary
Sleep apnea is a common condition that occurs when your breathing stops and restarts many times while you sleep. This can prevent your body from getting enough oxygen. If someone tells you that you snore or gasp for air during sleep, you may want to talk to your healthcare provider. You may also want to ask your provider about sleep apnea if you experience other symptoms of poor sleep quality, such as excessive daytime sleepiness. There are two types of sleep apnea. Obstructive sleep apnea, also called OSA, happens when your upper airway becomes blocked many times while you sleep. The blockage can reduce or completely stop airflow. This is the most common type of sleep apnea. Factors such as obesity, large tonsils, or changes in your hormone levels can narrow your airway. Any of these factors could increase your risk for obstructive sleep apnea. Central sleep apnea occurs when your brain does not send the signals needed to breathe. Health conditions that affect how your brain controls your airways and chest muscles can cause central sleep apnea. To diagnose sleep apnea, your provider may have you do a sleep study. Breathing devices, such as continuous positive air pressure (CPAP) machines, and lifestyle changes are common sleep apnea treatments. If these treatments do not work, your provider may recommend surgery to correct the problem that is causing your sleep apnea. If your sleep apnea is not diagnosed or treated, you may not get enough quality sleep. This can lead to issues with concentrating, making decisions, remembering things, or controlling your behavior. Untreated sleep apnea increases the risk for stroke, heart attack, and other serious problems.	Sleep Apnea ----- You may have sleep apnea. It is when your breath stops. This happens many times while you sleep. Your body may not get enough air. You may snore or gasp for air during sleep. Talk to your doctor. You may have other issues. You may feel sleepy during the day. There are two types of sleep apnea. Obstructive sleep apnea happens when your airway becomes blocked. This is the most common type. Central sleep apnea happens when your brain does not send the signals needed to breathe. Your doctor may have you do a sleep study. Breathing devices can help treat sleep apnea Changing what you eat can help treat sleep apnea. Changing your daily activities can also help. If these treatments do not work, your doctor may suggest surgery. If you have sleep apnea and you don't find out, or if your sleep apnea is not treated, you may not get enough good sleep. Sleep apnea that is not treated can lead to more problems.

<https://www.nhlbi.nih.gov/health/sleep-apnea>

Comparing Medical Reports to MTCAI Summaries

When analyzed as a group, **the original physician's medical reports for these participants were written at a reading level higher than an 8th grade**, and with low score for reading ease (50.5%). The reports employed relatively long sentences and complex and unfamiliar wording. In contrast, metrics for the MTC summaries of these reports conformed to the recommended MTC guidelines providing shorter sentences, less complex and more familiar words, greater ease of reading (86.3), and lower grade-level equivalent (2.5) on average.

Summaries Compared

Metric	Mean for Original Report(SD)	MTC Mean (SD)
Total Words ¹	533 (214.02)	360.6 (98.19)*
Words per Sentence ¹	9.22 (1.28)	5.04 (0.61)**
Syllables per Sentence ¹	1.72 (0.04)	1.36 (0.05)**
Type Token Ratio ¹	54% (4%)	43% (4%)*
% of Words Among 3k Most Frequent ²	80% (2%)	89% (3%)*
Flesh Kincaid Reading Ease Score ¹	50.50 (23.4)	86.3 (3.47)**
Grade Level Equivalent Score ¹	8.18 (0.75)	2.48 (0.4)**

¹Metric generated at <https://seoscout.com/tools/text-analyzer>

²Metric generated at <https://www.english-corpora.org/cocao/>

*Indicates a significant difference p < .05

** Indicates a significant difference p < .001

MTC and Plain Language

Ratz and Lenhard (2013) found that **as much as a third of people with IDD read with comprehension below 3rd grade level and that another third cannot read with any effectiveness.** Plain language evolved as a response to national reports indicating declining reading ability among people in the United States. The use of Plain language in Healthcare has been advocated by federal agencies like CDC and NIH.

Plain language is aimed at a 6th grade reading level. While the use of Plain Language in medical reports and healthcare information is more common, its application is still far from universal. **Inconsistent quality, irregular formatting, and wide variability in reading difficulty persists in the application of PL to health literacy** (Berkman, et al., 2011). The use of Plain Language techniques has proven insufficient for most readers with IDD. (Benson-Goldberg, 2022).

Participant Interviews

Participatory Needs Assessments

Participants were asked to review their original physician's reports and locate specific information on their reports. They were asked to identify unfamiliar words and to read a passage out loud, followed by comprehension questions.

- Only 40% reported having previously read one of their reports.
- 60% said they did not personally receive a copy of their previous reports.
- 60% said they were not sure they wanted to read their report.
- 100% said they looked to their parents for medical information.
- Only 20% said that they thought it was important for them to read their report.
- 80% said they understood some of what they read in their report.
- 100% described reading the report as hard, confusing,
- 100% listed at least 5 words that they did not recognize.
- 100% identified acronyms with which they were unfamiliar.
- 60% found the section with their doctor's instructions without assistance.
- 100% report being unsure that they understood the doctor's instructions.
- 20% were able to locate their diagnosis without assistance.
- 60% said they understood their diagnosis.
- 60% found the section with their medications without assistance.
- 40% recognized their medications.
- 80% reported being unclear as to the purpose of their medications.

Message Testing

A second interview provided the participants with a chance to review the MTC summaries of their physician's reports. Participants were asked to comment on the report, identify unfamiliar words, and to answer questions about their comprehension of what they read.

100% of the participants reported that they:

- Could read the summary.
- Would read this if it was given to them by their doctor.
- Would not need help reading the summary.
- Saw a reduction in unfamiliar or difficult words.
- Made correct statements regarding the doctor's *general* instructions to them.
- Made correct statements regarding the doctor's *specific* instructions to them.
- Made correct statements regarding their medications.
- **Would rather read the MTC summary than the physician's report**

Conclusions

The results of this preliminary study suggest that the MTC-AI tool simplified the original medical reports and information sheets such that they could be better read and understood by individuals with IDD. Both the metrics and the results of the message testing support this conclusion. Future work is warranted to investigate the use of the MTC-AI with a broader range of participants to ensure the generalizability of these preliminary findings. The results are promising that the MTCAI tool might be used clinically to support individuals with IDD in reading and understanding their medical reports as well as information sheets about their medical diagnoses.

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