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Patient-Reported Value of a Standardized Welcome Letter for Huntington Disease Clinic

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Introduction

Patient-centered care is a multi-faceted approach, defined by a focus and respect for patients' values, coordination of care, communication, adequate education, physical and emotional comfort, and involvement of family and friends.¹ Patient-centered care has steadily grown in its utilization in clinical settings, and is described by the Institute of Medicine as one of the 6 key elements constituting high-quality care.¹ Of the various elements of personalized care, communication has consistently proven to be a driver of patient satisfaction.² Providers who work to communicate with and educate patients regarding their illnesses, subsequently show greater evidence for improved patient involvement, health outcomes, and efficient use of resources.³

The use of a clinic letter or patient welcome letter (PWL) has shown to be an effective form of communication in terms of positively influencing patient satisfaction and future compliance.⁴ However, while well-written patient letters may be of great benefit to patients, they must be carefully crafted to benefit patients with wide-ranging literacy levels. Research has shown that many forms of patient education are of limited utility as the readability exceeds the average reading skill level of adults in the U.S.⁵ Thus, the concept of health literacy is of crucial importance when implementing patient-centered care.

For neurologists, health literacy is an essential component of patient education. The prevalence, complexity, and often severity of the neurological disease can lead to a wide array of health literacy, highlighting the need for improvement of patient education practices that can lead to increased patient satisfaction, involvement, and outcomes. For instance, Huntington disease (HD) is a hereditary neurodegenerative disorder characterized by a triad of abnormal movement, psychiatric problems, and behavioral and cognitive symptoms.⁶ Neurobehavioral symptoms can manifest early in the course of the disease and deteriorate with disease progression, which makes patient-physician

communication more challenging. In this short report, we evaluated the satisfaction of patients with HD regarding a PWL prepared based on readability and suitability standards.

Methods

This study was performed in the HD clinic of The University of Texas Health Science Center at Houston, a Huntington's Disease Society of America (HDSA) center of excellence. To prepare the letter, we used the expert view of our multidisciplinary team specialized in HD. The PWL included the following sections:

- A brief introduction to HD and HD clinic, including assessment, genetic testing, treatment, rehabilitation, and research.
- A complete description of HD multidisciplinary team members, including movement disorder neurologist, psychiatrist, neuropsychologist, genetic counselor, social worker, physical therapist, medical assistant, and research staff.
- Introduction of the staff, their responsibilities, and important contact information.
- Appointment and visit day information, including the front desk number and the process of check-in, visit, and check-out.
- Financial information such as insurance and costs.
- Directions, parking, and the costs.
- Communication with HD clinic, including contact numbers, email, and patient portal information.

After group discussion and a consensus process, the draft was assessed for readability and suitability using established metrics.

Readability

We used the Flesch-Kincaid (FK) and Simple Measure of Gobbledygook (SMOG) for readability.⁷⁻⁹ The FK utilizes information such as the total number of words per sentence and syllables per word to assess the grade level of the material.⁹ The SMOG index is a readability tool aimed specifically at assessing health-related writing.⁷ Like FK, the SMOG index uses a formula that checks for sentences and the number of syllables when ascertaining the grade level of the written matter. Certain studies even prefer the SMOG index to the more widely used FK due to the potential underestimation of reading difficulty when compared to the SMOG index.¹⁰ Because certain technical words in the PWL such as “neuropsychology” skewed readability due to the nature of the subject matter, these words were omitted from the PWL when performing readability assessments.

It is typically accepted that the general US public reads at an 8th-grade level and so we aimed for this statistic when creating the PWL.¹¹ Once readability was assessed by two independent reviewers (KSR & SAZ), the PWL was reevaluated to lower the reading level of the material under or as close to the accepted mark of an 8th-grade level.

Suitability

Assessing how suitable patient education materials are for their intended audience was accomplished through the Suitability Assessment of Materials (SAM).¹¹ We utilized SAM by independently reviewing the PWL according to the SAM criteria and ascertaining an average score. SAM scores were evaluated according to the following criteria: a score of 0-39% is not suitable, 40-69% is adequate, and 70-100% is superior.

The survey

The PWLs were distributed to the patients referred to our clinic between June 2021 and July 2022. Before meeting with the attending physician, a PWL and a survey were handed to each patient. The survey contained 5 general

demographical questions (Table 1), 7 quality-related questions (Table 2), and one comment field to collect patients' feedback on improving the PWL. The quality-specific questions were designed on a five-point Likert scale (Strongly agree, agree, uncertain, disagree, and strongly disagree). The survey was completed after reading the PWL and collected from the patients upon checkout. The help of a caregiver was used for the process if required.

Results

Of the 80 patients that received PWL, 47 filled out the survey (59% response rate). The mean age of participants was 56 years with a female-to-male ratio of 0.8:1. Regarding education level, 93.6% of the participants had at least a bachelor's degree. Most of the patients were known to the clinic, with 87.2% corresponding to follow-up visits (Table 1). When asked about the time it took them to read the PWL, most of the participants stated that they needed less than 10 minutes (Mean: 8.65 ± 5.06), and described the letter as understandable, easy to remember, and organized. The patients had no trouble locating the information they needed. As well, most of the participants agreed that the PWL was either valuable or very valuable. A detailed report of the questionnaire's results is presented in Table 2.

Table 1. Demographic information from the participants

| Factor | <i>n</i> | % |
|------------|----------|-------|
| Sex | | |
| Male | 26 | 55.32 |
| Female | 21 | 44.68 |
| Age | | |
| 18-30 | 2 | 4.26 |
| 31-40 | 5 | 10.64 |
| 41-50 | 9 | 19.15 |
| >50 | 31 | 65.96 |

| Education Level | | |
|--|----|-------|
| Less than High School | 1 | 2.13 |
| High School or equivalent | 17 | 36.17 |
| Associate degree | 3 | 6.38 |
| Bachelor's degree | 13 | 27.66 |
| Master's degree | 3 | 6.38 |
| Professional degree | 4 | 8.51 |
| Doctorate | 4 | 8.51 |
| Other | 2 | 4.26 |
| Type of Visit | | |
| New patient | 6 | 12.77 |
| Follow up | 41 | 87.23 |
| Used help of a family member to fill the survey | | |
| Yes | 16 | 34.04 |
| No | 31 | 65.96 |

Table 2. Results from the survey regarding the participant's perception about the PWL

| Survey questions | <i>n</i> | % |
|---|-----------------|----------|
| Q1. The PWL was clear and understandable | | |
| Strongly Agree | 31 | 65.96 |
| Agree | 15 | 31.91 |
| Uncertain | 0 | 0 |
| Disagree | 0 | 0 |
| Strongly Disagree | 1 | 2.13 |
| Q2. The PWL was easy to remember | | |
| Strongly Agree | 25 | 53.19 |
| Agree | 16 | 34.04 |
| Uncertain | 4 | 8.51 |
| Disagree | 1 | 2.13 |
| Strongly Disagree | 1 | 2.13 |
| Q3. I am able to find information in the PWL | | |
| Strongly Agree | 31 | 65.96 |

| | | |
|---|----|-------|
| Agree | 14 | 29.79 |
| Uncertain | 1 | 2.13 |
| Disagree | 0 | 0 |
| Strongly Disagree | 1 | 2.13 |
| Q4. The PWL is organized | | |
| Strongly Agree | 31 | 65.96 |
| Agree | 15 | 31.91 |
| Uncertain | 0 | 0 |
| Disagree | 0 | 0 |
| Strongly Disagree | 1 | 2.13 |
| Q5. I would know where to go for my appointment | | |
| Strongly Agree | 32 | 68.09 |
| Agree | 12 | 25.53 |
| Uncertain | 0 | 0 |
| Disagree | 0 | 0 |
| Strongly Disagree | 2 | 4.26 |
| Missing | 1 | 2.13 |
| Q6. I would know how to contact the office and my provider | | |
| Strongly Agree | 33 | 70.21 |
| Agree | 12 | 25.53 |
| Uncertain | 0 | 0 |
| Disagree | 0 | 0 |
| Strongly Disagree | 2 | 4.26 |
| Q7. Overall value of the PWL | | |
| Very valuable | 27 | 57.45 |
| Valuable | 16 | 34.04 |
| Moderately valuable | 1 | 2.13 |
| Somewhat valuable | 0 | 0 |
| Not valuable | 1 | 2.13 |
| Missing | 2 | 4.26 |

PWL = Patient Welcome Letter

The participants' feedbacks were generally positive. The PWL was described as:

“Very informative and useful. More clinics should implement.”

“The letter is perfect. I think the explanation is perfect.”

“No improvement. It was great!”

“Pretty thorough.”

“Looks great!”

The second most common feedback was sending the PWL before the appointment and/or giving it on the first appointment.

“Email it to people before their appointment”

“To be emailed directions ahead of time”

“This letter would have been handy if provided to us on our first introductory visit”

The comments regarding the technical aspects of the PWL were limited to two comments, including the size and coloring of the graphics.

Discussion

In this study, we designed a PWL using the standard readability and suitability measures, which resulted in widespread acceptability among our patients. A majority of patients (97.8%) answered agree or strongly agree with the clarity and understandability of the PWL. Overall, 91.4% of participants found the PWL valuable or very valuable.

A study by Busl et al. investigated patient-perceived value for an ambulatory neurology clinic PWL. They found that the original PWL was written at a literacy level exceeding the recommended level of readability. After seeking patient feedback and amending the letter to increase readability, they reported a marked positive increase in patient satisfaction, quantitated by the percentage of satisfied patients and levels of satisfaction.¹² Our report adds to this evidence in a setting where cognitive impairment can be determinant given the specific

population of patients with HD and their known potential cognitive difficulties. Our study shows that a PWL is useful, informative, and well-received by the patients who attend the HD clinic. It also proved to be understandable and did not require significant time from the visit to be read.

Patient education materials such as clinic welcome letters are important steps to ensure that patients are adequately informed. To fulfill this task, they require approachability for those of various backgrounds. Thus, assessments such as readability and suitability allow patients with varying levels of literacy to comprehend the information given. There are also other factors such as the organization of the letter, content, graphics, and cultural appropriateness, which in our study, they were achieved by the expert view of a multidisciplinary team specialized in HD. The current study aimed to assess the acceptability of PWL among patients. The next step in improving the health care service in our clinic is PWL implementation, and subsequently, assessing its impact on the clinical experience of the patients. As one of the most important patient feedback items, having the letter before the first visit to the clinic is an important factor when implementing the PWL. Using the patient portal as a new and interactive means of communication with patients can help in distributing the PWL before the initial visit.

This study had several limitations. Although high school or an equivalent degree was the most common level of education, more than half of the participants had an associate degree or higher, which may affect the results due to a higher level of literacy. The lack of classification by functional scores was another limitation of our study, as there could be a difference between mild and moderate-to-severe cognitive decline. Also, most of the participants were returning to the clinic instead of attending a first visit, which could be a source of bias since they have already experienced the clinic setting. The study could also benefit from a control group, which would provide further information

regarding specific differences between individuals who received the letter and those who did not.

Conclusions

A PWL could be a very useful tool in a neurology subspecialty clinic. Empowering the patients and their families by providing information in advance could improve their experience with the healthcare system, enhance their communication with the provider, and ultimately increase their level of satisfaction. Assuring the readability, suitability, and cross-cultural application of a PWL represents an essential requirement to increase its success.

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