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ORIGINAL RESEARCH

Assessment of the Readability of Genetic Counseling Patient Letters

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Abstract Patient letters are a powerful tool that genetic counselors use to communicate with their patients. Patient letters are often sent to provide information on a new diagnosis, reiterate test results, and to serve as a permanent record of the visit. Patient letters, however, are only helpful if the patients can understand them. More than 50 % of the US population reads below a 9th grade reading level and over one-third of the population has low health literacy skills. In this study we evaluate the readability of genetic counseling patient letters by assessing reading level, image use, and terminology use. One hundred forty-nine genetic counselors participated in the survey and of these, 79 submitted a sample patient letter. Analyses of the letters revealed a mean reading level of 10.93. On average, 6 genetic terms were included in each letter, and only 25 % of these terms were defined. Analyses of survey responses revealed over 75 % of the genetic counselors did not include images in their patient letters. These results indicate there is room for improvement in order to make genetic counseling patient letters more accessible to the general population.

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Introduction

Genetic counselors utilize a variety of tools to help patients understand genetic information. One tool is the patient letter; patient letters are often sent to patients after seeing a genetic counselor as a permanent record of the visit, and they have been found to improve recall and comprehension of the session (Smith and Pollin 2007).

Multiple studies have confirmed that patients find it beneficial to receive a letter after their healthcare appointment. Researchers report patients forget anywhere from 25 to 72 % of the information reviewed with them (Ley 2011; Sandberg et al. 2012), and the more information a clinician tells a patient, the more they forget (Ley 2011). Receiving a written summary of the visit improves retention rates. One study, conducted in the anesthesiology department, found that patients who were given recall cues such as written materials remembered more than twice as much information as those who received no written materials (Sandberg et al. 2012).

In addition to improving retention rates, patient letters improve the patient's understanding of the information. Research has shown that receiving a letter after a healthcare appointment increases the patient's knowledge of their condition (Treacy et al. 2008; White et al. 2004). Hallowell and Murton (1998) specifically studied the role of patient letters in a genetics clinic and found that 92 % of the patients indicated the letter helped them better understand the information. Additionally, Roggenbuck et al. (2014) found over 50 % of their sample of genetic counseling patients reported understanding their child's condition better after receiving a genetic counseling letter.

Patients also find letters helpful to accurately explain the information to other family members. In the Hallowell and Murton (1998) study, 85 % of their participants stated that they had shown or would show the genetic counseling letter to a family member to help them understand the information. Furthermore, patients use the letters as a means to explain the risks to other family members (Green et al. 1997; Hallowell and Murton 1998; Roggenbuck et al. 2014).

Patient letters, however, are only helpful if patients are able to understand them. Around 50 % of the general population in the United States reads below a ninth grade reading level (Nielsen-Bohlman et al. 2004) and over one-third of the population has "basic" or "below basic" health literacy skills (Kutner et al. 2006). Therefore, patient letters should be written at a low reading level and contain minimal medical terminology.

Readability of patient letters can also be increased by including images. Images have been shown to increase comprehension (Delp and Jones 1996; Karan et al. 2011). For example, Delp and Jones (1996) found that patients who were given medical information with visual aids were not only more likely to read the information, they were also more likely to understand the information.

Genetic counseling patient letters can be especially challenging to write because genomic literacy, which is defined as the "working knowledge of genomic science and its role in society" (p. 658) by the National Human Genome Institute (Hurle et al. 2013), is also low within the general population. One study reported approximately 50 % of participants did not know genes are part of chromosomes (Molster et al. 2009), and another study found people use the terms "gene," "chromosome," and "DNA" interchangeably (Mesters et al. 2005). These results suggest that genetic terms should be defined in the letter in order to increase its readability.

The importance of the readability of genetic counseling patient letters was recognized with the publication of letter-writing guidelines for genetic counselors (Baker et al. 2002). These guidelines state that letters should be written in clear and concise prose, medical jargon should be avoided, and the patient's level of education and comprehension should be taken into consideration.

To date, very little research has studied genetic counseling patient letters. It is unknown how well counselors follow the guidelines published by Baker et al. (2002), and the degree of readability of genetic counseling patient letters remains unclear. Little to no research has been conducted on the average reading level, whether or not images are included, or on the amount of genetic terminology included in each patient letter. In this study, we evaluated the readability of genetic counseling patient letters by determining reading level, terminology usage, inclusion of images, and whether or not terms are defined. Given that patient letters can be an effective way to communicate with patients, it is important to evaluate the likelihood that patients will be able to comprehend them.

Methods

Participants and Procedures

Exempt status for this study was granted by the University of Maryland's institutional review board; the survey was distributed via the National Society of Genetic Counselors (NSGC) listserv to an estimated 3,132 members. Invitations to participate were posted twice on a general discussion board on NSGC's website. A total of 204 genetic counselors consented to participate in the survey (estimated response rate = 6.5 %). One hundred forty-nine completed the survey and indicated they currently worked in a clinical setting at least 50 % of the time. Fifty-five respondents either did not complete the survey or did not work in a clinical setting at least 50 % of the time. Of the 149 respondents, 79 (53 %) submitted a sample genetic counseling patient letter. Participants submitted a variety of types of letters including result letters (24 %), new diagnosis letters (27 %), and clinic summaries (49 %).

Instrumentation

An online, anonymous survey was developed and distributed using Survey Monkey (www.surveymonkey.com). The survey had a consent form followed by 17 close ended questions. Many of the questions had an option to provide additional comments. The first question determined the amount of time the genetic counselor practiced in a clinical setting. In order to be eligible to complete the survey, participants needed to practice in a clinical setting at least 50 % of the time. Demographic data (gender, region of the US, primary specialty, number of years practicing in his/her primary specialty, and primary work setting) were collected. Five questions elicited information on the use of images in patient letters, four questions gathered information on who has input on the content and wording of the patient letters, and one question gathered information on the average education level of the patients seen at the participant's clinic. This latter question was based on the counselor's opinion. A final question asked the participant to paste a sample, de-identified patient letter into a text box. There were no restrictions on the type of letter the participants could submit.

Data Analysis

Readability of the patient letters was partially determined using the Flesch-Kincaid grade score. The Flesch-Kincaid grade score has been used as a measure of readability since its development in 1975, is the standard used in Department of Defense manuals (McClure 1987) and is recommended by the

Centers for Disease Control and Prevention as a way to determine readability (2009). The Flesch-Kincade grade calculates the reading level (US school grade level) at which the reader can comprehend at least 50 % of the document. The score is calculated using the following equation:

$$\text{Flesch-Kincaid Grade Level} = 1/4\,(0.39 \text{ X ASL}) + (11.8 \text{ X ASW}) - 15.59$$

where ASL = average sentence length and ASW = average syllable per word. If a term was defined in the letter, the term was replaced with the word "cat" in order to prevent erroneous inflation of the grade level.

Because the Flesch-Kincaid formula only takes into account sentence length and average syllables per word, letters were independently analyzed for genetic terms and images. Patient letters were analyzed for 18 genetic terms (Table 1) which have previously been shown to be used in at least 20 % of genetic counseling sessions, frequently in genetic counseling educational aids, and were unknown to at least 60 % of the general population with a sixth grade reading level or lower (Erby et al. 2008). All of the terms except "gene" met all three criteria. In a previous study (Erby et al. 2008), "gene" was known to 70 % of the general population with a sixth grade reading level or lower. "Syndrome" and "cystic" were only counted if they were not used as proper nouns. The length, formatting, and organization of the letters were not analyzed.

Statistical analyses were completed using SPSS version 21; the tests included the Chi-square test, Fisher's exact test, Wilcoxon rank sum test, and the Kruskal-Wallis test.

Results

Sample Demographics

Participant demographics are reported in Table 2. The majority of genetic counselors who participated in the survey were female (95 %, n=143). Over half of the survey participants had worked in their primary specialty for less than 5 years (56 %, n=84). The most common specialty for study participants was prenatal (41 %, n=61). The most common work setting was a university hospital (43 %, n=65).

The majority of genetic counselors who submitted a letter were female (92 %, n=73). Over half of the participants who submitted a letter had worked in their primary specialty for less than 5 years (58 %, n=46). The most common specialty was prenatal (41 %, n=32) and the most common work setting was a university hospital (45 %, n=35).

The demographics of the study participants are significantly different from the demographics of the genetic counseling field as a whole based on the 2012 Professional Status Survey (www.nsgc.org). A significantly larger proportion of the sample population had worked for 1–4 years than the proportion reflected in the Professional Status Survey (p=0.0004). The sample population also had significantly more respondents who worked in the prenatal specialty than is reported in the Professional Status Survey (p=0.001) and a smaller proportion of respondents worked in "other" specialties in the study population compared to the Professional Status Survey (p=0.0036).

Table 1 Patient letters were analyzed for these genetic terms

Term	
Syndrome	Carrier
Sporadic	Variation
Mutation	Abnormality
Retardation	Ethnic
Genetic	Uterus
Hereditary	Susceptibility
Trait	Severe
Cystic	Affected
Gene	Chromosome

Reading Level

The reported reading level of submitted letters was 10.93 (standard deviation = 1.33, range = 7.3-12.0). The amount of experience the genetic counselor had in his/her primary specialty, education level of the patient population, the amount of standard language used in the letter, who signed the letter, and who had input on the content of the letter were not significantly related to the mean reading level.

While there was no statistically significant difference in mean reading level due to the average education level of the patient population, there was a general trend such that as the patient population's education increased, the reading level increased. Letters written for populations where the majority of patients had not graduated high school were written at a mean reading level of 10.1 (n=8). In contrast, letters written for populations where the majority of patients had a college degree had a mean reading level of 11.6 (n=4) (p=0.055).

Although not statistically significant, as the amount of standard language included in the letter increased, the mean reading level increased (Table 3). The amount of standard language, or language from a template letter, was self-reported by the participant, and the amount used in each letter ranged from 0 % to 75 % (mode = 0 %).

Letters written solely by genetic counselors were not written at a statistically significant lower reading lever (10.7, n=39) than letters written by genetic counselors and physicians (11.0, n=38) (p=0.64). Letters signed only by genetic counselors (10.7, n=36) were not written at a statistically

Table 2 Participant demographics

	Survey respondents *n* (%)	Respondents who submitted a letter *n* (%)
Gender		
Female	143 (95)	73 (92)
Male	6 (5)	6 (8)
Primary specialty		
Prenatal	61 (41)	32 (41)
Pediatric	31 (21)	14 (17)
Cancer	37 (25)	22 (28)
Other[a]	20 (13)	11 (14)
Primary work setting		
University hospital	65 (43)	35 (45)
Public hospital	42 (28.5)	21 (27)
Private hospital	27 (18)	18 (22)
Private practice	7 (5)	2 (2)
Other[b]	8 (5.5)	3 (4)
Years of experience in primary specialty		
0–4	84 (56)	46 (58)
5–9	26 (17)	14 (18)
10–14	17 (11)	10 (13)
15+	22 (16)	9 (11)

[a] Other included cardiovascular, neuromuscular, infertility, adult, and general specialties

[b] Other included infertility clinics, nonprofits, and veteran affairs (VA) hospitals

significant lower reading level than letters signed by genetic counselors and physicians (11.1, n=41) (p=0.22) (Fig. 1). Two participants indicated the physician alone or the physician, genetic counselor, and geneticist had input on the content of the letter and/or signed the letter.

Significant differences were seen in the mean reading levels of letters submitted by genetic counselors of different specialties. Letters written by cancer genetic counselors (n=22) were written at a significantly higher mean reading level than letters written by pediatric genetic counselors (n=14) (p=0.001) and counselors in "other" specialties (n=11) (p=0.031). Letters written by prenatal genetic counselors (n=32) were written at significantly higher mean reading level than letters written by pediatric genetic counselors (p=0.007) (Table 4).

Genetic counselors who stated they include images in their letters wrote letters at a significantly lower mean reading level (9.82) than genetic counselors who stated they do not include images in their letters (11.33) (p=0.0001).

Table 3 The effect of the use of standard language on the reading level

Amount of standard language	*n*	Mean reading level
0 %	63	10.8
1–25 %	5	10.96
26–50 %	5	11.26
51–75 %	6	11.43

There were no statistical differences between the groups

Images

Twenty two percent of genetic counselors (n=33) said they included images in their letters. The majority stated they included images to aid in comprehension (82 %, n=27). Over 20 % (n=7) stated they included images of test results. The most common reasons genetic counselors stated they did not include images were that they already had shown images during the counseling session (30 %, n=35), they had never

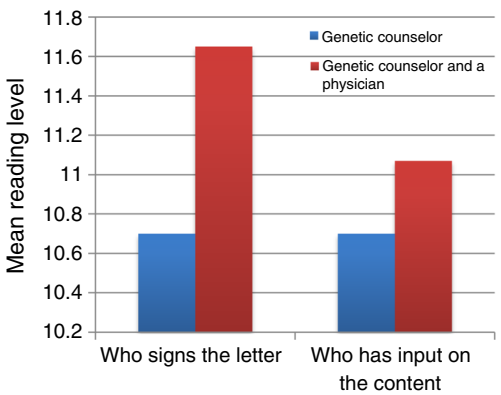

Fig. 1 The effect of physician input and signature on the reading level. The differences are not statistically significant

Table 4 Effect of specialty on the mean reading level of genetic counseling patient letters

Specialty	*n*	Mean reading level
Prenatal	32	11.17[a]
Pediatric	22	10.01
Cancer	14	12.00[b]
Other	11	10.35

[a] Prenatal letters were written at a significantly higher mean reading level than "other" specialty letters

[b] Cancer letters were written at a significantly higher mean reading level than pediatric or "other" specialty letters

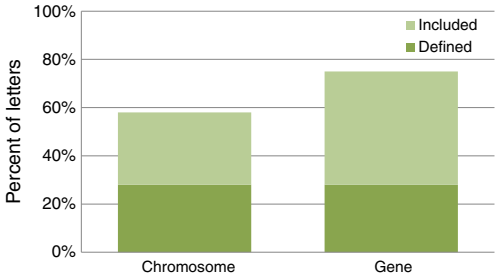

Fig. 2 Inclusion of terms "chromosome" and "gene" in patient letters and how often they were defined

thought about it (20 %, *n*=23), and/or they believe it would not be helpful (14 %, *n*=16). Eight percent (*n*=9) said they did not include images because images were not compatible with their electronic medical record system.

Years of experience, specialty, average patient education level, and terminology usage were not significantly associated with whether or not the genetic counselor included images in their genetic counseling letters.

Terminology

On average, six of the 18 genetics terms listed in Table 1 were used in each letter and 25 %, or 1in 4 of these terms was defined. The most common terms were "genetic," "gene," "chromosome," "affected," and "carrier." The most commonly defined terms were "carrier," "chromosome," "gene," "mutation," and "trait." "Chromosome" was used in 58 % (*n*=46) of the letters and defined in 50 % of these documents. "Gene" was used in 75 % (*n*=58) of letters, and defined in 37 % (*n*=28) of them (see Fig. 2).

There were no significant differences in the number of genetic terms used or the number of genetic terms defined as a function of average patient education level, specialty, years of experience, which health professionals had input on letter content, and which health professionals signed the patient letter.

Discussion

Readability

These data indicate that genetic counseling patient letters are written at a reading level that may not be optimal for the general population. Despite this, the results suggest that genetic counselors may tailor letters' reading level to the education level of their patient population, as seen in the non-significant trends. While the small sample size likely affects the ability to detect significance, these results demonstrate that there is room for improvement. Letters written to patient populations in which the majority of individuals had not graduated high school were at a 10th grade reading level and 50 % of the general population in the United States reads below a ninth grade reading level (Nielsen-Bohlman et al. 2004).

The data also show a difference in reading level between specialties. There are multiple possible reasons for this difference including differences in average letter length and in the complexity of concepts discussed (e.g., advanced maternal age, family history of breast cancer).

Results from this study show a significant relationship between inclusion of images and a lower reading level among survey respondents. Letters written by genetic counselors that included images had, on average, a lower reading level than those that did not include images. This finding is consistent with previous research (Delp and Jones 1996; Karan et al. 2011) that found including images improves comprehension. Because images have been shown to have a correlation with increasing readability, it is concerning that 20 % of respondents had never thought about including images in patient letters and 14 % believed it would not be helpful. These data indicate more education on the benefits of images may be helpful.

The data also suggest that too many genetic terms are being used without being defined, which would increase maximum comprehension. Only 25 % of genetic terms were defined in the patient letters, and the terms "gene" and "chromosome" were defined at most 50 % of the time. The lack of definitions is concerning given previous research findings that people use the terms "gene," "chromosome," and "DNA" interchangeably (Mesters et al. 2005) and that genomic literacy is low in the general population (Hurle et al. 2013; Molster et al. 2009). Others have recommended keeping medical and genetic terminology to a minimum and defining said terms (Baker et al. 2002). To improve comprehension and reduce confusion, genetic counselors may consider defining genetic terms more often in their letters.

Practice Implications

The findings suggest there is room for improvement in the readability of genetic counseling patient letters. In this study,

over 75 % of genetic terms were not defined in patient letters, and the average reading level was almost 11th grade. Improving readability of patient letters may allow genetic information to be more accessible and understandable to the general population.

Given that the majority of the letters submitted in this study were written at a high reading level and contained too much jargon for maximum readability (as defined in the literature), further student and practitioner training in writing genetic counseling letters may be helpful. Genetic counseling training programs could add lectures and/or readings, such as the guidelines by Baker et al. (2002) on writing effective, readable patient letters if they are not already doing so. Training programs could also provide opportunities for students to practice writing letters in different specialties and for different indications.

There are significant barriers to improving readability including genetic counselors having limited time to work on each letter, limitations with electronic medical records, and limitations with respect to more easily understood synonyms for medical terms. One simple way to improve readability would be to include a glossary of terms with each letter. Glossaries have been shown to increase comprehension (Irwin and Davis 1980). The glossary could define terms such as "chromosome," "gene," and "mutation," resulting in less time spent defining these terms in the letter.

Another way to improve readability would be to have copies of commonly used images (e.g., inheritance patterns, translocations) which could be included as an attachment to the letter. Then time would not have to be spent trying to format the image in the body of the letter. However, this solution is only applicable if the patient is being sent the letter and not accessing it via the electronic medical record. Given most hospitals and clinics are adapting the electronic medical record, we recommend electronic medical record systems are designed to allow the easy insertion of pictures into the letter.

The transition to electronic medical record systems adds further complications to increasing the readability of the patient's health information. Previously, notes in the patient's medical record were written with medical jargon and abbreviations because only other health professionals had access to read the notes. However, now that patients have access to these documents, readability needs to be taken into account in these notes as well, and this poses new challenges (Debanco et al. 2012).

Research Recommendations

This study focused on readability of genetic counseling patient letters based on the Flesh-Kincade grade score, image inclusion, terminology inclusion, and whether or not terminology was defined. These are indirect measures of comprehension. Future research could include direct assessment of patient comprehension of the letter. Additionally, genetic counselors generally explain genomic terms during a counseling session, and consequently individuals who have received genetic counseling may have a higher genomic literacy than the general population. Research should be done on the genomic literacy of individuals prior to and after they have had genetic counseling because this could help clarify which genomic terms need to be defined in patient letters. Also, research should be done to see if the type of letter (new diagnosis, clinic summary, test result) impacts the readability.

Furthermore, with the transition to electronic medical records, there are new challenges for the readability of letters because the letters are written to the physician and the patient, and many systems allow patients to access their results directly before speaking with a genetic counselor. Research should be done on how this change in technology is affecting letter writing in the genetic counseling field.

Study Limitations

There are a few limitations of this study that affect the generalizability of these results. The survey was only advertised to members of NSGC, and consequently, participants only represent a subset of the genetic counseling population as a whole.

Additionally, the Flesh-Kincade grade score is an estimate of reading level based on sentence and word length and does not take into account formatting, length, organization of the letter or use of active versus passive voice. All of these factors have been shown to affect readability (Meade and Smith 1991; Ownby 2005; Roggenbuck et al. 2014). Furthermore, because the formula solely looks at sentence and word length, it does not take into account the reader's background knowledge or cultural schema which affect a reader's comprehension (Kazemek 1984).

The biggest limitation is the low response rate (6.5 % for total respondents and 2.5 % for respondents who submitted a sample letter) and that the participant demographics were significantly different from the National Society of Genetic Counselor membership. Consequently, the survey responses and sample letters may not be an accurate representation of the genetic counselor population. Thus conclusions can only be drawn about the participants and not on the genetic counselor population as a whole.

Finally, the sample sizes for certain variables reduced the power of the statistical analyses. Furthermore, numerous univariate tests were conducted to assess relationships between major study variables. Although appropriate for an exploratory study, this approach increases the family-wise error rate, thus increasing the likelihood that some of the significant findings were due to chance. Future studies with larger samples would be sufficiently powered to detect significant differences and would also allow for multiple variable analyses.

Conclusion

The findings of this study suggest there is room for improvement in the readability of genetic counseling patient letters. To ensure maximum readability for the general population, genetic terms should be defined, images included, and the reading level should be less than 9th grade. There is a need for further education/awareness about how to increase the readability of patient letters. It should be noted that conclusions based on the present data are tentative because the survey responses may not be representative of the genetic counselor population as a whole.

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Conflict of Interest Emily Brown, Megan Skinner, Stephanie Ashley, Kate Reed, and Shannan DeLany Dixon declare that they have no conflict of interest.

Human Studies and Informed Consent Statement All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards. Informed consent was obtained from all participants for being included in the study.

Animal Studies This article does not contain any studies with animals performed by any of the authors.

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