OpenNotes in oncology: oncologists' perceptions and a baseline of the content and style of their clinician notes

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Abstract

Patients' ability to access their provider's clinical notes (OpenNotes) has been well received and has led to greater transparency in health systems. However, the majority of this research has occurred in primary care, and little is known about how patients' access to notes is used in oncology. This study aims to understand oncologists' perceptions of OpenNotes, while also establishing a baseline of the linguistic characteristics and patterns used in notes. Data from 13 in-depth, semistructured interviews with oncologists were thematically analyzed. In addition, the Linguistic Inquiry and Word Count (LIWC) program evaluated over 200 clinician notes, measuring variables encompassing emotions, thinking styles, social concerns, and parts of speech. Analysis from LIWC revealed that notes contained negative emotional tone, low authenticity, high clout, and high analytical writing. Oncologists' use of stigmatized and sensitive words, such as "obese" and "distress," was mainly absent. Themes from interviews revealed that oncologists were uncertain about patients' access to their notes and may edit their notes to avoid problematic terminology. Despite their reluctance to embrace OpenNotes, they envisioned opportunities for an improved patient-provider relationship due to patients initiating interactions from viewing notes. Oncologists believe notes are not intended for patients and altering their content may compromise the integrity of the note. This study established a baseline for further study to compare notes pre-implementation to post-implementation. Further analysis will clarify whether oncologists are altering the style and content of their notes and determine the presence of patient-centered language.

Keywords

Health communication, OpenNotes, Patient portal, Electronic medical record, Patient-provider communication

INTRODUCTION

Written clinical notes are the most commonly used method by clinicians to exchange information with one another and communicate about their patients' care [1]. The sharing of these notes decreases duplicate tests and ensures that relevant information is not overlooked [2]. Although patients have always had a legal right to their notes, patients infrequently requested them due to barriers such as the high cost of printing and lengthy delays in receiving notes [3, 4]. The concomitant lack of transparency associated with these barriers has resulted in negative

Implications

Practice: Patients' access to clinical notes may change the content and style of clinicians' written notes.

Policy: Implementing OpenNotes throughout all areas of health systems, including oncology, requires that clinicians receive training and reconsider the intent of notes.

Research: Future research should determine whether oncologists are changing the manner in which notes that patients access are written now that patients have access.

consequences that promote paternalistic medicine [5] and limit patients' opportunities to control their care [6, 7]. However, in the USA, in recognition of the need to overcome these shortcomings, the Health Insurance Portability and Accountability Act [8] has been enacted and recommendations developed by the Institute of Medicine have been implemented [9], both of which encourage the utilization of web-based patient portals to provide patients with unfettered access to their electronic medical record (EMR). Moreover, \$27 billion in federal financial incentives were made available to health systems that provided patients with such portals [10].

Such portals routinely enable patients to access various components of their EMR, including test results and scans. Additional attention has been given to making written clinical notes available to patients through the portals [11]. In recent years, OpenNotes, an initiative to provide patients access to their written clinical notes, has rapidly spread across the USA. OpenNotes is now utilized in 37 states, making written clinical notes available to 17 million people [12]. Proponents of OpenNotes claim that providing access to clinician's notes promotes greater transparency [13]. The seminal study that is responsible for the surge in health systems implementing

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OpenNotes was a year-long study of more than 100 primary care physicians who shared written notes with nearly 14,000 of their patients [14]. The study provided some preliminary evidence, from the patient and provider perspective, for the effectiveness of OpenNotes. Many participating patients felt more in control of their care and reported being more adherent to medications; only a very small number reported being confused by reading their notes [14]. However, this quasiexperimental study had some notable design limitations such as: (a) only physicians who were positively inclined to share their notes with patients were included in the sample; (b) different portals were used across different sites, which limited the standardization of responses due to variations in functionality and design; (c) there was no way to determine which notes had been read by the patients; and (d) all health-related outcomes were self-reported by patients. Given these limitations, these results do not suggest which factors or content may have contributed to the positive results. A more recent OpenNotes study sought feedback from patients who had used OpenNotes and showed that patients appreciated reviewing their notes because it enabled quicker access to salient records, garnered confidence in providers, created a sense of partnership, and allowed patients to share information with care partners [15]. However, as feedback was only solicited from patients who had previously stated that they found the tool valuable, the lack of a balanced perspective is perhaps unsurprising.

From the physician's perspective, there was an initial caution about OpenNotes because physicians (a) feared making declarative diagnostic statements available to patients due to the potential for legal ramifications in the case of incorrect diagnoses [16], (b) were concerned that patient's access to written notes would generate longer visits [14], and (c) were afraid patients would be offended by their use of terms such as "obese" or commenting on the patient's mental health. Thus far, fears concerning increased workload have not been realized [14]; however, clinician's notes often contain a high prevalence of uncertainty terms, which are ambiguities such as "likely," "probable," and "sometimes" [17]. Adverse consequences may result from patients being exposed to these types of notes [17]. These concerns were underscored by nonparticipating physicians from the original OpenNotes study who stated that they would change the way they approach taking notes if patients had access, especially when addressing cancer or the possibility of cancer [14]. Participating physicians also claimed they would alter their usual clinical practice when writing notes, particularly with regard to noting patient's obesity. Moreover, several of these physicians restricted the content of the notes and excluded postulating alternate diagnoses [14]. A subsequent OpenNotes study confirmed these findings, with about 20% of

physicians reporting changing the way they wrote about potentially offensive terms [18].

An increasing number of health systems are implementing OpenNotes and extending it to the oncology setting. Physicians from specialties that deal with sensitive topics are particularly concerned about the negative implications of patients' viewing notes. As a result, a framework has been recommended to consider before implementation to identify how patients should be informed, the type of notes to be shared, and the timing of sharing notes [19]. This issue is particularly significant in the oncological setting, since notes often contain distressing and sensitive information about patients. Because the cancer care delivery process encompasses fear, stigma, and uncertainty [20], it is unknown whether patient's access to notes may enhance the ability for providers to recognize and address the emotional concerns of patients with cancer, or whether it may exacerbate an existing challenge [21–25]. In addition, the combination of complex medical terminology [26], the fear and ambiguity of prognoses associated with a cancer diagnosis, and providers' time constraints may confuse patients when viewing notes as they often have difficulty retaining important information discussed during the in-person appointment [27].

It is possible that patients' access to oncologists' notes may be just as beneficial as stated in the original OpenNotes study, but there is also the possibility that the manner in which the information is written could produce negative implications. There is no study that analyzes the elements of physician's notes, to gain an understanding of their linguistic content and style. These are both factors that may be highly influential in the patient-provider relationship and affect ongoing communication. Therefore, as part of a larger project about patient portal transparency, this study's objective was to utilize a linguistic tool, Linguistic Inquiry and Word Count (LIWC) 2015 [28], to establish a quantitative baseline set of characteristics of oncologists' notes, so that we can gain an explicit understanding of physician documentation of their patient interactions. In addition, we are seeking to qualitatively assess oncologists' perceptions of OpenNotes to determine whether they plan on altering the manner in which they write notes in the future. Together, qualitative interviews combined with quantitative analysis of oncologists' notes will provide data to better understand attitudes of those using OpenNotes and the linguistic traits of notes contained in patient records. The following research questions are posited:

RQ1: What is the frequency of language patterns used in oncologists' notes prior to the OpenNotes implementation as measured by LIWC?

RQ2: How do oncologists believe availability of their notes will affect the way in which they are

written in the future as measured by qualitative interview?

RQ3: What are oncologists’ perceptions of the advantages and disadvantages of OpenNotes as measured by qualitative interview?

METHODS

Setting

This study took place at a National Cancer Institute–designated center in central Virginia. In June 2015, outpatient provider notes became viewable to patients through the secure patient portal. All areas of the health system participate in OpenNotes, except for psychiatric and psychotherapy services. Recruitment for this study occurred between May and September 2016. This study was approved by the local Institutional Review Board of Virginia Commonwealth University.

Participants

To attain a widespread range of attitudes toward OpenNotes, oncologists were recruited from three areas of service (hematology, radiation, surgery). A broad summary of the study and its goals were presented at departmental meetings. Subsequently, the research team requested a list of oncologists present at each meeting and then used a random number generator to randomly select oncologists to be contacted for participation. Oncologists selected received an email invitation to enroll in the study. Informed consent was reviewed, and written consent was required before interviews and to access their notes from the electronic health record (EHR) system.

Procedure

This study employed mixed methodology: qualitative in-depth respondent interviews [29, 30] and descriptive statistics of clinician notes.

Notes

To establish a baseline, notes from January to May 2014 were aggregated from participating oncologists. This time period was over a year in advance of the OpenNotes implementation, even before announcements that the program was forthcoming. Due to some oncologists seeing more patients than

others, and different numbers of notes depending on the complexity of a patients’ illness at the time of consultation, we accounted for this variation by randomly selecting percentages of notes from each oncologist. To ensure that selected notes were representative from a variety of oncologists, while also making sure that a sufficient amount of data was collected for analysis, higher percentages of notes were collected from oncologists with fewer notes than oncologists with a greater number of notes. A random number generator was used for each set of notes per oncologist, and the average number of notes selected was 17. All notes were maintained in a spreadsheet that included an ID number associated with the oncologist, date of the note, oncologists’ department, and the note’s section header. Summaries of laboratory tests were not included, but the following five sections were selected for analysis because they often contained subjective information written by the clinician: “Assessment,” “Plan,” “Interval history,” “Impression,” and “Free Summary.” Once a note was selected, each section was separated for individual analysis. “Assessment” was the most frequently used category by oncologists and therefore was included the most in analysis.

Interviews

A subset of questions about OpenNotes was included in a semistructured interview guide from a larger study about patient portal transparency. OpenNotes was already implemented at the time of the interviews, allowing oncologists’ attitudes and initial experiences of this new technological feature to be captured. Questions focused on attitudes toward OpenNotes and how notes were written and may be interpreted. A sample of selected questions from the interview guide can be found in Table 1. Interviews were conducted by a member of the research team (J.M.A.) and audio recorded. Atlas.ti v. 7.5.17 [31] managed the verbatim transcripts.

Data analysis

Analysis of notes

Notes were randomly selected from each provider, and the five sections previously indicated were extracted and then input into the LIWC 2015 [32]

Table 1 | Selected interview questions

What are your views about the recent adoption of OpenNotes, the ability for patients to access provider’s notes via the patient portal?
Who do you primarily write notes for (patients or providers)?
How has your objective of writing notes changed with OpenNotes now in place?
How do you feel about the possibility of patients discovering errors in your notes?
How do you think OpenNotes will contribute to quality of care and making for a safer patient experience in and out of the hospital?
OpenNotes has been very well received by patients and physicians in primary care settings. In your view, what differences, if any, exist between the primary care and oncology in regard to OpenNotes?
How do you feel that the OpenNotes policy will affect levels of trust between you and your patients?

to identify language patterns. LIWC is a text analysis computer program that calculates words that reflect different emotions, thinking styles, social concerns, and parts of speech within a given text. The tool is empirically verified and widely used in the social sciences, particularly to analyze medical language [33–38]. LIWC helps to reveal how individuals are thinking as they write about events, since language is a marker of cognitive processes, style, and social integration [39]. It measures variables that affect the patient–provider relationship, for example: (a) analytical thinking, which is important because patients prefer providers who communicate in clear, simple terms without technical jargon [40], and (b) emotional tone, as clinicians’ expressions of hope and optimism have reduced patients’ anxiety and helped foster stronger relationships [41]. Frequencies among word categories reflect how individuals make sense of their environment and indicate attentional focus, emotionality, social relationships, and thinking styles [42]. LIWC was developed to be used on a wide variety of texts and not specifically for medical language. Although the program yields scores for 14 categories of variables, the research team reviewed all of the available categories and discussed which would be most relevant based on the aims and scope of this study. The research team collectively identified variables from across several categories: four summary variables and five language dimension variables. The four summary variables were based on algorithms ranging from 0 to 100:

- (1) Analytical thinking: The degree to which people use words that suggest formal, logical, and hierarchical thinking patterns. High scores indicate very formal writing, whereas low analytical thinking scores tend to indicate narrative language focused on personal experiences [43].
- (2) Clout: Relative social status and confidence displayed through writing. Communication that enhances the patient’s confidence may provide motivation and allow the patient to enjoy greater quality of life despite their disease [44]. Scores close to 100 indicate high levels of clout.
- (3) Authenticity: Text presented personally and straightforward. The authenticity algorithm was derived from a series of deception studies to discern candid text entries [45, 46]. The higher the score, the greater the amount of authenticity.
- (4) Emotional tone: The higher the number, the more positive the tone. Numbers below 50 suggest a negative emotional tone.

Five language dimension variables were also included (word count, words per sentence, words greater than six letters, personal pronouns, and anxiety). It was necessary to include these measures as high or low counts on any of these dimensions increase the likelihood of patient misunderstanding.

For instance, when online health information is written below sixth-grade reading levels, consumer comprehension may increase [47]. Each dimension was calculated by counting as follows:

- (1) Word count: The raw number of words contained in a note.
- (2) Words per sentence: The mean number of words within each sentence of the note.
- (3) Words greater than six letters.
- (4) Personal pronouns: The total number of personal pronouns within a note, along with subcategories of specific types of personal pronouns, such as “I,” “we,” “you,” “he/she,” and “they.” Previous research has found that providers predominantly use partnership-building language like “we” to reference the patient–provider relationship [48].
- (5) Anxiety: The inclusion of words associated with anxiety, such as “worried,” “fearful,” and “nervous.” Linguistic analysis has been previously applied to clinical notes associated with veterans who died from suicide, finding that keywords related to distancing language emerged as suicide date neared among mental health service users [49]. In oncology, clinicians may document prognostic information such as life expectancy [50], and in doing so, words associated with anxiety may be used.

In addition, frequencies for the following stigmatized and sensitive terminology cited from previous studies were counted: “obese”/“obesity”; “patient,” as in “the patient” in lieu of the patient’s name; “distress”/“stress”; “alcohol”/“alcoholic”; and “depressed”/“depression.”

After the scores were generated for all of the variables, two of the authors (J.M.A., B.B.M.) randomly selected 10 notes from each variable to validate their scores. We checked to ensure that the score aligned with the context of the note. Means and standard deviations were calculated using JMP® version 13.

Interviews

Using an interpretivist lens [51] with a grounded theory approach [52], two members of the research team (J.M.A., B.B.M.) reviewed the verbatim transcripts for emergent themes and conducted initial coding. J.M.A. and B.B.M. met weekly after three transcripts were coded to discuss discrepancies. Next, axial coding [53] took place in which codes were consolidated and expanded through constant comparison [54]. The entire research team discussed the codes, and a codebook was developed, which guided subsequent rounds of focused coding [53] conducted by J.M.A. and B.B.M. During the ongoing analysis process, member checks [55] were performed, by presenting preliminary themes to subsequent oncologists as a method of seeking

feedback and validating findings. At the conclusion of the interviews, the entire research team discussed the meaning of each theme.

RESULTS

Demographics

Thirteen oncologists from hematology/oncology ($n = 8$, 62%), radiation oncology ($n = 4$, 30%), and surgical oncology ($n = 1$, 8%) were enrolled in the study. The average age was 47, gender was almost equal (54% female), and most participants were White (77%). The enrollment rate was 59%.

LIWC analysis

A total of 207 notes were collected and used for quantitative analysis. Nearly all of the notes were from medical oncologists (45%, $n = 93$) and radiation oncologists (51%, $n = 106$). Most notes were “Assessments” ($n = 92$, 44%), followed by “Interval History” ($n = 39$, 19%), “Plan” ($n = 35$, 17%), “Impression” ($n = 21$, 10%), and “Free Summary” ($n = 20$, 10%). The mean Emotional Tone was 36.1 ($SD = 26.43$), reflecting a negative emotional tone. Authenticity was similarly low ($M = 25.1$, $SD = 28.66$), indicating a lack of clear writing. The high Clout score ($M = 64.8$, $SD = 18.12$) meant that notes conveyed confidence. The last summary variable, Analytical Thinking, was high ($M = 77.5$, $SD = 21.50$), meaning that notes generally lacked personal experiences and were written more formally. Examples of notes from each variable can be found in Table 2.

The average words per sentence was 15.1 ($SD = 6.42$), and 26.9% of text contained words with more than six letters ($SD = 7.91$). The mean percent of personal pronouns was 6.2 ($SD = 4.14$), with “he” or “she” being the most prevalent. Language signifying worry or fear as part of the Anxiety category was infrequent ($M = 0.3$, $SD = 0.67$).

Nearly all of the sensitive terms were absent (obesity, distress, alcohol, mental health, and depression). Only the “patient” was regularly used ($M = 3.0$, $SD = 3.06$). A summary of the LIWC and sensitive terms results can be found in Tables 3 and 4.

Interview themes

Qualitative interviews with oncologists averaged 28 min in length and were conducted face-to-face in the private offices of each oncologist, except for one phone interview. Two main themes related to their perceptions of OpenNotes and the content of their notes were revealed: (i) audience uncertainty, because oncologists question the purpose of patients reading notes as they are primarily meant to be used for communications between treating clinicians, with a subtheme of possible censorship of notes and (ii) relationship building, as notes may enable increased trust and enhanced interaction.

Audience uncertainty

OpenNotes was viewed with doubt, as oncologists believed patient’s access could bring about potential harm due to the complexity of cancer. A medical oncologist compared oncology with primary care and stated, “With primary care, certainly they’ve got a lot of chronic diseases that they’re managing, but I think it’s the nature of how potentially terminal cancer can be that is the big difference.” Other oncologists downplayed the potential impact of OpenNotes and did not believe that patients would greatly benefit. For example, a medical oncologist said, “I’m pretty open with my patients already. I mean I’m very honest...so I can’t imagine much that would be of discovery to [patients] in the notes.” Overall, mixed feelings were expressed, with one oncologist stating,

In some ways it’s helpful to patients to be able to see their information and access it whenever they want. I think that’s very valuable as long as they are able to accurately interpret what those results mean, which is not always necessarily easy.

When asked whether oncologists were mindful of patients when writing notes, 77% ($n = 10$) declared that notes were not and should not be written for patients. Most oncologists agreed with a radiation oncologist who said, “I primarily write them for myself and then as a communication to another provider.” Oncologists did not view notes as a method of communication with patients and considered a quality note one that could be understood by a colleague that conveyed the oncologists’ thought process.

Censorship due to social terms

One of the reasons why oncologists did not consider notes as an advantage for themselves or patients was because of the necessity to include sensitive terminology. For instance, a medical oncologist said, “We’re going to be a bit leery because if a patient is somewhat troubled, difficult or disruptive, a physician might not put that in their note because the patient is going to be reading that.” Similarly, a medical term like obese was viewed as problematic because of patients’ sensitivities. The medical record software used at the hospital interprets patients’ height and weight to automatically calculate obesity, but a surgical oncologist suggested, “I suppose one thing I will change is not checking off obesity or morbid obesity if I know patients are reading my notes.”

However, there was steadfast agreement to not compromise the note further. For instance, even though one oncologist was cognizant to substitute “esophagitis” with “soreness in throat” on informed consent forms for patients, she would still use the medical term in her notes, even though patients

Table 2 | Excerpts of summary variables

Summary variable	Note	Score
Analytic		
	<ol style="list-style-type: none"> 1. Discussion today with patient and family regarding her scans. The lung lesions are essentially stable. There is minimal to no changes of the disease. The liver lesions are much better. They are easy to measure and there has been an excellent response to treatment there. Given that information will plan on doing another 3 cycles of Taxotere and gemcitabine. May have some additional issues with how well her counts tolerate this. However, it is showing to work and that is good for her. Other options if this does not work would be temozolomide. She has had Adriamycin in the past, so we would need to check cardiac function if we wanted to try drugs such as Doxil, but there may be limited room to use this given the past history. 2. Pain seems to be under much better control which is good. That should give her more energy. 3. Hypertension is under good control which also makes it easier to both treat her and to provide supportive care at this time. 4. She is doing well. We will see her again in three weeks. Will arrange for her chemotherapy and then see her again with her next cycle. 	29.3
	The patient reports that she has been having pain under her left shoulder blade for the past 6–8 months. The patient states that this pain radiates to her left chest wall and down her left arm. The patient reports that the pain is worse when she is sitting in a slough post position or when she is lying down. The patient has been using Tylenol, Flector pain patch, and Votaren gel for pain relief. The patient states that when her pain is at its worst is a scale of 10/10, and when she takes the pain medication the pain resolves to a 2/10. The patient however typically waits until she is in severe pain before taking any pain medication.	71.0
Clout		
	We received a notification from the lab about the critical calcium value later in the day on 5/13/14. We had Mr. ___ return to the clinic to be admitted to the medicine service for treatment and evaluation to determine the cause of this problem. At this point, multiple myeloma seems to be the leading candidate, given his hypercalcemia, renal insufficiency, anemia, proteinuria and bone lesions on plane films. Will follow.	85.2
	1. No evidence of metastatic disease to the abdomen or pelvis. 2. Hepatic steatosis. 3. Stable renal hypodensities, too small to characterize but likely benign.	14.2
Authentic		
	I reviewed Mr. ___ CT of the chest with the patient and I showed him the large right upper lung opacity as a result of the radiation treatment. I also showed him the disk changes at T8 level that are most likely responsible for the current pain. I also discussed with him the pulmonary nodules that are at present indeterminate.	55.6
	Ms. ___ is a ___ year-old lady with newly diagnosed non-Hodgkin lymphoma. She has transformed diffuse large B-cell lymphoma as at diagnosed low grade follicular lymphoma was also present. We spent much of the visit discussing the nature of the disease and goals of therapy. Our goal would be cure of the large cell component and remission of follicular component. She has likely had the bulk of her diffuse large B-cell lymphoma removed but still has follicular disease (serosal surface disease is likely follicular lymphoma). She should complete staging with bone marrow and positron emission tomography. She will also need multiple-gated acquisition and port placement. We will also obtain some baseline blood work today including LDH. Her International Prognostic Index score will likely be intermediate risk high (IPI 3).	4.7
Emotional tone		
	She has seen Dr. ___ in ___ who plans palliative chemotherapy. Given her developing obstructive symptoms and chronic constipation over a period of 3 years, I think she would benefit from palliative stent placement as well as radiotherapy to the rectum concomitant with chemotherapy. If she wishes Dr. ___ can arranged the radiotherapy to be done in ___ or she can have this done here while he is administering his chemotherapy. I spent approximately 30 min talking to the patient, her daughter and her son-in-law about her prognosis. We discussed the issue of the colon stenting and the possible need for colostomy down the road. I think her best chance for remaining colostomy free with her incurable rectal cancer is to have a stent placed and then to undergo chemo + radiotherapy. According to the patient's family doctor much ___ was planning to treat her with Xeloda. This would hopefully impact her liver metastases as well as potentiate the efficacy of radiation to the primary lesion in the rectum. We have contacted gastroenterology and arranged for her to have a flexible sigmoidoscopy or colonoscopy and stent placement in the near future. They will contact her to set a day.	91.5
	Ms. ___ returns to the clinic for routine followup visit. She was last seen in ___. Ms. ___ reports that she has fair appetite and poor energy. She has the impression that she has lost some weight. However, she has no scale and has not been able to measure that. However, she was buying new clothes as her old ones were becoming too large. She denies any hemoptysis or shortness of breath, but continues to have dyspnea, unchanged from previous visit. She also has some cough with yellow sputum, but no fevers. She denies any dysphagia or esophagitis. Ms. ___ comes in with a cast on her left leg. She explains that about 3 weeks ago she noticed a black spot on her left big toe that turned out to be an ulceration. Dr. ___ is currently taking care of this lesion. Ms. ___ reports that she is often constipated and is taking Senokot on a regular basis, otherwise she has bowel movements only once per week. She continues to have pain mostly in her left back and flank as well as her lower back, and knees with a history of arthritis. She was recently seen by Dr. ___ from Pulmonology and continues on several inhalers.	34.1

Table 3 | Summary of linguistic analysis

	Mean	Standard deviation
Word count	133.6	103.27
Analytic	77.5	21.50
Clout	64.8	18.12
Authentic	25.1	28.66
Emotional tone	36.1	26.43
Words per sentence	15.1	6.42
Words >6 letters	26.9	7.91
Personal pronouns	6.2	4.14
“I”	0.9	1.33
“We”	0.9	1.47
“You”	0.003	0.036
“He/she”	4.2	3.82
“They”	0.1	0.34
Anxiety	0.3	0.67

were reading it. Despite oncologists’ intentions to use the note to communicate effectively, notes often must include certain terms for billing purposes, and oncologists anticipated being confronted by patients to eliminate diagnoses from their chart due to possibly compromising their health insurance.

Relationship building

Oncologists also recognized the power of their language to enhance or erode trust with patients. As notes were often written succinctly, there was the possibility that OpenNotes would be a disadvantage because they could be misinterpreted as being judgmental or harsh. As a medical oncologist said, “My notes aren’t warm, so I worry that could potentially cause trust issues.” Conversely, a radiation oncologist understood how the note holds the possibility to strengthen the patient-provider relationship. Relaying patient concerns in the note demonstrates that the oncologist listened and paid attention. However, oncologists stated the importance of ensuring that the note reinforced what occurred during the visit. The same radiation oncologist said, “If I’m telling a patient that they look great, but then I put in the note, ‘remains obese,’ that’s not good.”

Another way oncologists expected notes to improve the patient-provider relationship was their ability to foster increased interactions. A medical oncologist viewed OpenNotes as an advantage and said, “It’s a good thing” if patients come

to consultations with very specific questions because they have time to “digest” more information. Similarly, a different medical oncologist thought that patients reading the note could lead to them initiating more conversations, instead of waiting to be contacted. However, oncologists were mindful of the potential increase OpenNotes could generate to their already burdensome workloads. A radiation oncologist said, “I don’t want to spend all night reading my resident’s note in full detail and making sure my addendum is beautifully eloquent and charming because anything can be misconstrued.” Another radiation oncologist acknowledged that though it may contribute to their workload, giving patients access to notes adds pressure to make sure that what is documented in the note “actually gets done,” which can benefit both patients and oncologists.

DISCUSSION

The nascent trend toward greater transparency of medical information through their widespread availability via the adoption of patient portals is likely to continue. The OpenNotes initiative was founded to leverage the ease of accessing medical information using portals, to make records as comprehensive as possible by including clinician notes. The mission of OpenNotes, stated on their website, declares, “We believe that providing ready access to notes can empower patients, families, and caregivers to feel more in control of their health care decisions, and improve the quality and safety of care” [12]. While studies utilizing OpenNotes have demonstrated that patients value transparency and believe it contributes to more productive discussions with providers [56], apprehension still exists among providers, especially when complex and sensitive information is involved.

Our study did not focus on a comparison of notes before and after implementation of OpenNotes, but instead took a dual approach by combining qualitative and quantitative analysis to understand the content and style of clinician notes in oncology while establishing a baseline. Key variables within the framework of the LIWC tool were quantitatively analyzed to establish a baseline of LIWC measures. We also supplemented the data with a qualitative analysis of oncologists’ initial impressions and attitudes toward OpenNotes. This mixed methods approach helped to triangulate the data and validate our findings.

We discovered that before the implementation of OpenNotes, oncologists’ style of writing did not account for the way in which the notes would be received by patients, revealed by the negative emotional tone, low authenticity scores, lack of personal pronouns, and long sentences. These quantitative results coupled with oncologists’ attitudes toward OpenNotes from the qualitative interviews indicate a belief that the note’s purpose is to facilitate

Table 4 | Summary of stigmatized and sensitive words

	Frequency	Mean	Standard deviation
Obesity	0	0.0	0.00
“Patient”	315	3.0	3.06
Distress/stress	1	0.0	0.07
Mental	11	0.1	0.22
Alcohol	3	0.0	0.16
Depression	0	0.0	0.0

communication with other providers and not educate patients. Our findings suggest that oncologists favor paternalistic approaches in regard to patient's access to notes. This aligns with a 2013 poll which found that 65% of U.S. physicians believe that patients should have restricted access to their EHR [57]. Nonetheless, patients have the legal right to their notes, and greater transparency can lead to improved shared decision making, which is essential to delivering patient-centric care [58].

However, our qualitative results revealed that oncologists were very aware of the potential impact sensitive terminology, such as "obese," could have when read by patients. Quantitative findings from the LIWC indicated that hardly any oncologists actually used such stigmatized terminology. A fine line exists between transparency and the inclusion of terminology that could trigger patient anxiety, fear, or anger. Honesty, openness, and disclosure are integral to patient-centered communication (PCC), which can contribute to fostering a positive relationship between patients and providers [59]. Although patients with cancer want information presented in a clear and an open manner [60, 61], oncologists should be aware of patient preferences toward involvement and information related to their care [62]. This is especially crucial because most patients prefer to be informed in a face-to-face setting rather than using web portals, especially when a diagnosis is being communicated [63]. Although OpenNotes can benefit patients by providing a summary of the visit and the topics discussed, it should not replace personal communication. This is especially important because many patients may not be able to fully understand notes, as more than 20% of adults read at the fifth grade level or lower [64]. However, OpenNotes may be most valuable as a means to help patients determine their preferences, in which reading notes after consultations prompts future discussions between patients and oncologists about topics of confusion, such as technical jargon.

Our knowledge of best practices for PCC in the electronic age is emerging. Yet, we do know that when patients are able to conduct a dialogue with providers using secure messaging, few providers responded using PCC practices [65]. However, advocates of OpenNotes report that patient's access to notes facilitates their ability to share information with care partners, correct mistakes, and partner with providers [66]. There is potential for oncologists to benefit as well, as availability of notes may make face-to-face time more effective [66] and can reduce burnout by strengthening morale and creating positive culture change [66].

In the minds of oncologists, OpenNotes changes the nature of the clinician note from a method to communication with colleagues and as a "note to self" about their patient. Redundant information that is not intended for patients is often included, and most of the text is usually copied or imported from other providers [67]. Moreover, clinicians in general

are frustrated with the emphasis placed on EHR because for every hour of in-person consultations with patients, nearly two additional hours are spent updating the record [68]. Therefore, it is important to understand the attitudes of clinicians who have reservations about OpenNotes and to identify how their notes may be altered if forced to participate. It should be noted that the current study was a subset of a larger study examining general transparency of medical data between patients and providers. It is possible that oncologists' feelings toward greater transparency of laboratory or scan results may have influenced their attitudes toward OpenNotes.

Further studies are planned, such as comparing the baseline data from the current study with data collected after OpenNotes was introduced, to determine whether clinicians are changing the style of their notes. In addition, the manner in which other providers utilize OpenNotes should be studied, as nurses frequently use patient portals to communicate with patients [69]. Limitations of the current study include that the results are confined to one health system and therefore cannot be generalized. Moreover, quantitative analysis using LIWC was a reflection on certain characteristics of oncologists' notes and may not have captured the individual character of how communication occurs between patients and oncologists. Also, the small sample size of oncologists may not indicate the writing style of oncologists in general. Moreover, it may be that oncologists are more likely to report certain feedback, either positive or negative, given their own note-writing styles.

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Ethical Approval: 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. This study was approved by the local Institutional Review Board of Virginia Commonwealth University. This article does not contain any studies with animals performed by any of the authors.

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Compliance with Ethical Standards

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