

VA OpenNotes: exploring the experiences of early patient adopters with access to clinical notes

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ABSTRACT

Objective To explore the experience of early patient adopters who accessed their clinical notes online using the Blue Button feature of the My HealthVet portal.

Methods A web-based survey of VA patient portal users from June 22 to September 15, 2013.

Results 33.5% of respondents knew that clinical notes could be viewed, and nearly one in four (23.5%) said that they had viewed their notes at least once. The majority of VA Notes users agreed that accessing their notes will help them to do a better job of taking medications as prescribed (80.1%) and be better prepared for clinic visits (88.6%). Nine out of 10 users agreed that use of visit notes will help them understand their conditions better (91.8%), and better remember the plan for their care (91.9%). In contrast, 87% disagreed that VA Notes will make them worry more, and 88.4% disagreed that access to VA Notes will be more confusing than helpful. Users who had either contacted their provider or healthcare team (11.9%) or planned to (13.5%) primarily wanted to learn more about a health issue, medication, or test results (53.7%).

Conclusions Initial assessment of the patient experience within the first 9 months of availability provides evidence that patients both value and benefit from online access to clinical notes. These findings are congruent with OpenNotes study findings on a broader scale. Additional outreach and education is needed to enhance patient awareness. Healthcare professionals should author notes keeping in mind the opportunity patient access presents for enhanced communication.

Key words: access; patient portal; eHealth; Open Notes; communication; veteran

INTRODUCTION

Although patients have a legal right to access the information contained in their medical record¹ and many express the desire to do so,^{2–4} historically patient access to personal health information has been constrained both culturally and technologically.^{5,6} With the advent of personal health records (PHRs) and patient portal systems, a growing number of healthcare organizations are providing patients with access to information contained in their medical record.^{7–12} While previous studies suggest the potential for benefits such as enhanced patient satisfaction, the impact of such access is only beginning to be understood.^{6,7,13,14–17} Additional research is needed, especially given Meaningful Use incentives that promote patient access to medical record data.^{18,19} The Blue Button concept emerged in 2010, aimed at enabling more direct consumer access to personal health information by adding a ‘Download My Data’ button to patient portal systems. The Blue Button is directly aligned with stage 2 of Meaningful Use, which requires that patients be provided with the ability to view, download, and transmit their health data electronically.

Providing patients with easy access to their health information may be a critical step in building a foundation to support patient engagement and empowerment. Enhancing the flow of information between patients and their healthcare providers can help to reduce errors and improve healthcare quality.²⁰ Indeed, patients may also play a crucial role in mediating the exchange of information to support effective care coordination.²¹ Yet, healthcare providers have expressed concerns that patient access to clinical notes, in particular, will lead to confusion or worry, while creating additional workload. These concerns also warrant additional research. Understanding the experiences of early patient adopters will be important in beginning to assess the impact of unprecedented broad scale patient access to clinical notes, but to also illuminate challenges and key strategies to address them that will be crucial to optimize a patient-centered approach to healthcare.

Background

The My HealthVet portal (<http://www.myhealth.va.gov>) is a suite of tools that enables veterans to create a free web-based

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PHR, access health education resources, and refill VA prescriptions. All VA patients are eligible to complete a one time process of identity authentication to obtain an upgraded or premium My HealthVet account. VA patients with a premium account can access data from the VA electronic health record (EHR) and communicate electronically with their healthcare team using secure messaging. The VA Blue Button, added in August 2010, allows veterans to view, print, and download a single electronic file that contains their personal health information.^{22,23} For VA patients with a premium account, this can include both patient self-reported data and information from the VA EHR. As of July 2014, My HealthVet has more than 2.9 million registrants, with more than 1.6 million authenticated VA patients (29% of the VA patient population). Since the VA Blue Button was deployed, it has been used by more than 1 million unique users, with more than 7 million file downloads.²⁴

Building on promising findings from the My HealthVet Pilot Program^{25,26} and the OpenNotes Initiative,^{27–30} in January 2013 VA enabled all VA patients with a premium account to also access their clinical notes online via the VA Blue Button. VA Notes are commonly entered by healthcare professionals at the point of care, and can include templates that bring in tailored information such as specific lab test results. Inpatient and outpatient notes from primary care, specialty care, mental health, nursing, and social work are available to patients three calendar days after they have been completed (signed by all required co-signers). In addition to clinical visit notes, electronic communication between the patient and their healthcare team (referred to as secure messages) that have been copied to the medical record are also included. General informational briefings were conducted from October 2012 through June 2013 to promote awareness of these enhancements; however, these sessions were primarily aimed at clinical leadership.

Objective

In this paper, we report findings from a random survey of My HealthVet visitors to assess the experience of early VA patient adopters with access to their clinical notes (VA OpenNotes). The objective was to understand how and why veterans are reading their clinical notes, and the degree to which reading notes causes patient distress or confusion. We also examine whether patients report contacting their provider in response to reading their clinical notes.

METHODS

The American Customer Satisfaction Index survey

The American Customer Satisfaction Index (ACSI) survey³¹ is an industry standard method for monitoring customer satisfaction and prioritizing areas of improvement using a web-based survey presented to a random sample of website visitors.³² VA uses the ACSI survey to measure satisfaction with My HealthVet and elicit direct feedback from veterans using custom questions.³³ Prior ACSI surveys have explored patient interest in sharing their personal health record information³⁴ and actual use in support of care coordination.^{23,35}

Data collection and analysis

From June 22, 2013 to September 15, 2013, a nationwide web-based survey was offered to a 4% random sample of website visitors who had navigated four or more web pages on My HealthVet during their visit to the portal. Site visitors who accepted the survey invitation were prompted to complete the online survey at the end of their portal visit. Branching logic was used to present custom questions based on participant responses to previous questions (survey available as an online data supplement at <http://www.jamia.org>). Of the 59 843 persons who accepted the survey invitation (acceptance rate approximately 31%), 37 103 answered the custom questions, resulting in a survey completion rate of 62%. To avoid potential duplication, data from respondents who reported that they had (or were not sure if they had) previously taken the survey in the last 3 months were omitted from the analysis, yielding a sample of 34 022 responses. Since My HealthVet is available to all veterans as well as the general public, including veterans who may not be enrolled in VA healthcare, data analysis focused on respondents who reported receiving care at a VA facility (N = 29 191). Slight variations in sample size resulting from non-response to particular survey questions are reported with the data. All respondents were asked general questions about their demographics, health status, knowledge of note availability, and actual use. VA patients who reported accessing their notes were then asked specific questions about their experience. Data collection was managed by ForeSee Results (Ann Arbor, Michigan, USA).

Survey data analysis began with data inspection and evaluation of patient characteristics related to VA Notes use. Survey responses were tallied and examined for values that were missing or out of range. Results are presented primarily as univariate tables describing how patients used VA Notes. Bivariate relationships between patient characteristics and use of VA Notes were conducted using Pearson's χ^2 test. All statistical analyses were conducted using SAS V.9.3. The study was reviewed by the local institutional review board (IRB) and deemed program evaluation for quality improvement.

RESULTS

Knowledge and use of VA Notes

One third of respondents (33.5%) reported knowing that clinical notes could be viewed with a premium My HealthVet account, while 47.4% were not aware and 19.1% were not sure. When asked to describe their actual use of the VA Blue Button to access their VA Notes, nearly one in four (23.5%) said that they had viewed their notes at least once (N = 6861); however, 27.0% were not sure.

VA Notes users' characteristics

Respondents were categorized as VA Notes users (N = 6861) or non-users (N = 22 330) for further analysis. Table 1 presents basic characteristics of VA Notes users and non-users. Both users and non-users were reflective of the veteran population in that they were predominantly male and aged 50–79 years.³⁶ When comparing users and non-users,

Table 1: VA Notes user and non-user demographics and characteristics

Variable	VA Notes, users N (%)	VA Notes, non-users N (%)	p Value
Age (years)	N = 6810	N = 22 157	0.0001
<40	115 (1.7)	528 (2.4)	
40–49	441 (6.5)	1497 (6.8)	
50–59	1356 (19.9)	4041 (18.2)	
60–69	3615 (53.1)	10 985 (49.6)	
70–79	1007 (14.8)	3782 (17.1)	
≥80	276 (4.1)	1324 (6.0)	
Gender	N = 6389	N = 20 819	0.17
Male	5718 (89.5)	18 505 (88.9)	
Female	671 (10.5)	2314 (11.1)	
Education	N = 6861	N = 22 330	0.0006
Did not complete high school	165 (2.4)	622 (2.8)	
High school graduate	835 (12.2)	3081 (13.8)	
Some college or vocational school	3017 (44.0)	9920 (44.4)	
College graduate	1550 (22.6)	4713 (21.1)	
Some postgraduate school	429 (6.3)	1308 (5.9)	
Graduate or professional degree	865 (12.6)	2686 (12.0)	
Self-rated health status	N = 6743	N = 21 893	0.02
Excellent	221 (3.3)	711 (3.3)	
Very good	1067 (15.8)	3857 (17.6)	
Good	2636 (39.1)	8361 (38.2)	
Fair	2170 (32.2)	6900 (31.5)	
Poor	649 (9.6)	2064 (9.4)	
Frequency of VA use in past year	N = 6812	N = 22 149	0.0001
Never	33 (0.5)	199 (0.9)	
Once in the past year	415 (6.1)	2024 (9.1)	
2–11 times in the past year	4580 (67.2)	15 352 (69.3)	
12 or more times in the past year	1784 (26.2)	4574 (20.7)	
Frequency of My Health eVet use	N = 6530	N = 21 023	0.0001
First time	195 (3.0)	2140 (10.2)	
More than once a day	183 (2.8)	259 (1.2)	
Daily	562 (8.6)	769 (3.7)	
About once a week	2604 (39.9)	5432 (25.8)	
About once a month	2591 (39.7)	10 063 (47.9)	
About every 6 months	311 (4.8)	1682 (8.0)	
Less often than every 6 months	84 (1.3)	678 (3.2)	
Previously requested medical records	N = 6861	N = 22 330	0.0001
Yes	3931 (57.3)	11 441 (51.2)	
No	2930 (42.7)	10 889 (48.8)	

veterans who used VA Notes had more education and tended to be middle-aged rather than in the youngest and oldest age groups. While 39.1% rated their health as good, a significant number reported fair (32.2%) or poor (9.6%) health. As previously described, all respondents included in the analysis reported receiving care at a VA facility. While the majority of VA Notes users (67.2%) reported using a VA medical facility or service 2–11 times in the past year, a greater proportion of VA Notes users reported receiving VA services 12 or more times in the past year (26.2%) in comparison to non-users (20.7%). Most VA Notes users (91%) reported visiting the My HealthVet website at least once a month, with more than half (51.3%) visiting once a week or more frequently. The majority of all respondents had previously requested a copy of their medical record from a VA facility, with an even greater proportion of VA Notes users having done so (57.3%).

Motivation for accessing VA Notes

As shown in [table 2](#), the primary reasons users reported viewing their VA Notes was because they wanted to know more about their health (26.4%), were curious (21.0%), or wanted to be sure that they understood what their provider

said (20.9%). When asked to identify the types of information they were seeking in their notes, 46.7% were looking for information describing a clinic visit, nearly one in three were seeking to learn more about what their provider or healthcare team thinks about their health issues (31.4%), and 31.0% were seeking specific recommendations or treatment advice.

Use of VA Notes

As shown in [table 3](#), most users reported viewing visit notes from a primary care clinic visit (68.3%), although 38.9% viewed specialist notes, and 17.9% viewed notes from a visit with a mental health professional. When asked what they did with their VA Notes, about one fourth downloaded a copy (26.3%). Only 10.5% reported sharing their information with a family member, relative, or friend, and 6.9% shared the information with a non-VA provider. Three quarters of VA Notes users said that they did not contact their VA healthcare provider or team about the notes (74.7%), primarily because there was no reason to do so (82.4%). Users who had either contacted their provider or healthcare team (11.9%) or planned to (13.5%) indicated that they wanted to learn more about a

Table 2: Reasons for using VA Notes

	N	%
Primary reason for viewing VA Notes	5152	
I wanted to know more about my health	1361	26.4
I was curious	1082	21.0
I wanted to be sure I understood what my provider said	1076	20.9
I wanted to remember what happened in the visit	651	12.6
I wanted to check the notes to see if they were right	476	9.2
I wanted to know what my provider was thinking	313	6.1
Other	193	3.8
Information sought in VA Notes*	5339	
The note written by a provider or healthcare team after a clinic visit	2494	46.7
What my provider or healthcare team thinks about my health issues	1675	31.4
Recommendations or treatment advice from my provider or healthcare team	1655	31.0
Changes that were discussed during a visit	948	17.8
When I'm supposed to come back for my next appointment	848	15.9
I'm not sure what I was looking for	741	13.9
A referral to a specialist or for further testing	632	11.8
The note written by a provider or healthcare team after a hospital stay	423	7.9
The note written by a provider or healthcare team after an emergency room visit	378	7.1
Other	291	5.5

*Multiple response choices allowed.

Table 3: VA Notes use

	N	%
Type of VA Notes viewed*	6861	
Visit notes from a clinic visit with a primary care provider	4684	68.3
Visit notes from a clinic visit with a specialist (medical or surgical)	2672	38.9
VA Notes from Secure Messaging	2330	34.0
Visit notes from a mental health professional	1231	17.9
Notes from a hospital visit or stay (eg, discharge summary)	994	14.5
Don't remember	973	14.2
Actions taken with VA Notes*	5339	
I read it	3869	72.5
I downloaded it to keep a copy for myself	1404	26.3
I printed it	719	13.5
I shared it with a family member, relative or friend who takes care of me	562	10.5
I shared it with a healthcare provider outside of VA	346	6.9
I discussed it with a VA provider or other healthcare team member	303	5.7
Other	117	2.2
I don't remember	76	1.4
Follow-up contact (or plan to contact) with provider or healthcare team	5339	
No, I did not talk to or contact my provider or team about the notes	3987	74.7
I plan to contact my provider or healthcare team about the notes	719	13.5
Yes, I did contact my provider or healthcare team about the notes	633	11.9
If yes, reason contacted (or plan to contact)*	1352	
To learn more about my health issue, medications, or test results	726	53.7
To get an explanation about something in the note	449	33.2
To discuss something I was worried about in the note	296	21.9
To discuss something that I thought was not correct in the note	283	20.9
To ask about removing or changing something in the note	110	8.1
Other	122	9.0
If no, reason did not contact (or plan to contact)*	3987	
I had no reason to contact my provider or healthcare team about the notes	3287	82.4
I didn't want to waste my provider or healthcare team's time	203	4.5
I didn't think it was important	180	4.5
Other reason	170	4.3
I did not feel I knew enough to talk with my doctor about my concerns	76	1.9
I didn't want my provider or healthcare team to be upset with me	54	1.4
It was too much of a bother for me	17	<1%

*Multiple response choices allowed.

health issue, medication, or test results (53.7%), or to get an explanation about something in the note (33.2%).

User experience with VA Notes

VA Notes users were asked questions about their experience accessing their notes. Four out of five (80.5%) found it easy to find their VA Notes using the VA Blue Button on My Health@Vet. The majority also agreed that the display of VA Notes is easy to read (88.2%), and that the notes correctly describe their clinic or hospital visit (87.9%). Most users (69.5%) disagreed with the statement ‘I did not understand the information in my VA Notes’, however 21.5% indicated that they somewhat agreed, and 5.7% agreed. Lastly, 85.6% disagreed with a statement that there was too much information in the notes.

User perspectives on impact

VA Notes users were also asked to respond to a series of statements using a five-point Likert scale (see figure 1). Predominantly users agreed that visit notes will help them do a better job of taking medications as prescribed (80.1%) and be better prepared for clinic visits (88.6%). Nine out of 10 VA Notes users also agreed that visit notes will help them feel more in control of their healthcare (91.2%), take better care of themselves (91.3%), understand their health and medical conditions better (91.8%), and remember the plan for their care better (91.9%). In contrast, 87% disagreed that access to VA Notes will make them worry more, and 88.4% disagreed that VA Notes will be more confusing than helpful. VA Notes users were also asked to rate their overall satisfaction with access to their notes on a scale of 1 (lowest satisfaction) to 10 (highest satisfaction). The majority (91.2%) rated their satisfaction with

access to VA Notes at 6 or greater, with 28.4% selecting the highest rating of 10 (see figure 2).

DISCUSSION

VA OpenNotes early adopters

In this initial assessment of the first 9 months of full clinical note availability for VA patients, many My Health@Vet users were unaware that VA Notes were available online, however one in four VA patient respondents (23.5%) had viewed their notes at least once. Patients who viewed notes were largely motivated by wanting to know more about their health or review what their provider communicated; some were simply curious. Users were seeking to read notes about recent clinic visits, with many wanting to better understand what their provider thought about their medical issues or to review treatment plans. Primary and specialty care notes were read most often, although more than one out of six VA Notes users reported reading mental health notes. Further research is warranted to closely examine patient access to different types of clinical notes.

In comparing VA Notes users to non-users, we found modest but significant differences in age, education, and frequency of portal use (due to a large sample size, even fairly small differences were statistically significant). While note viewing was associated with a history of requesting medical records, the majority of non-users also reported obtaining records previously, indicating high interest in obtaining medical records among all patient My Health@Vet users. Accessing notes was associated with patients having more clinical visits in the past year, but not with self-reported health status, suggesting that clinical encounters may prompt patients to view their visit documentation. Given that many survey respondents were as yet

Figure 1: VA Notes user perspectives, N = 6861.

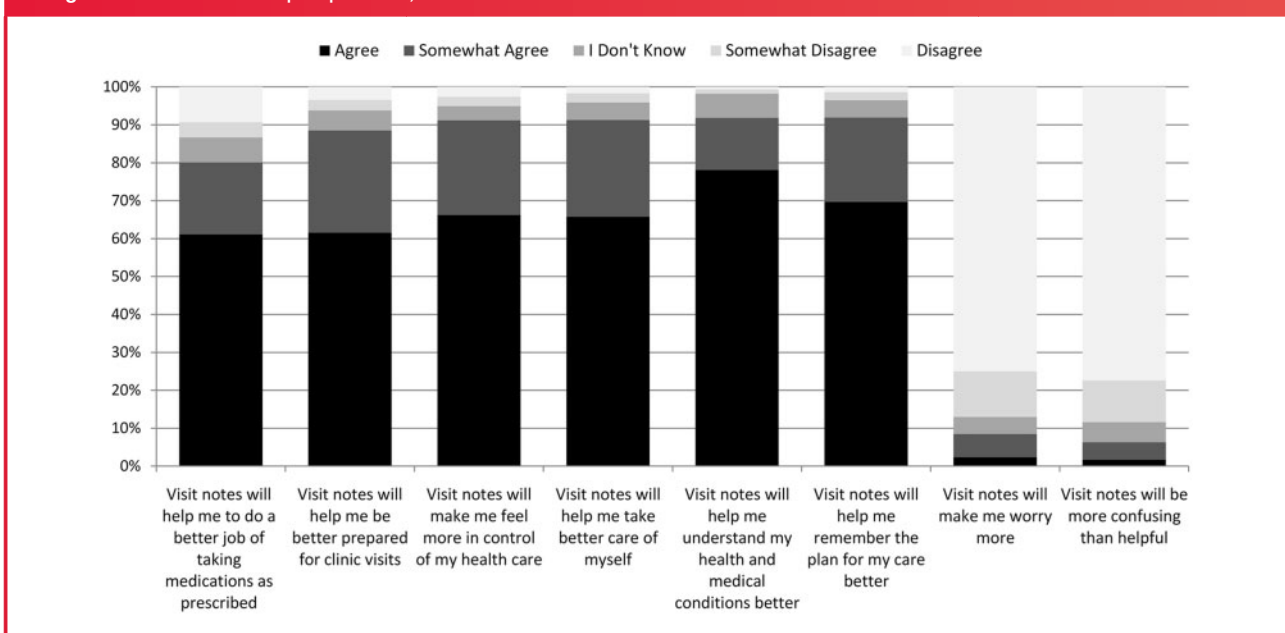
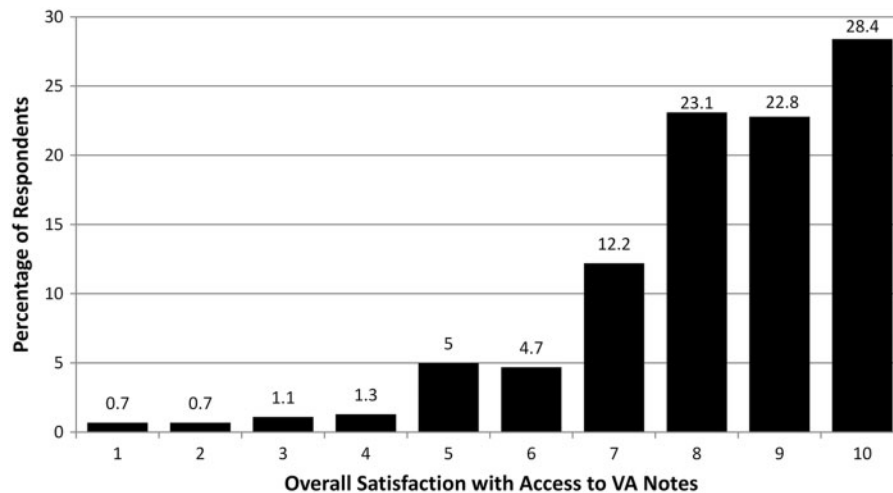


Figure 2: VA Notes users' overall satisfaction with access to VA Notes, N = 6861.



unaware of the availability of clinical notes in the VA Blue Button, cobranding the concept of Blue Button (Download My Data) with additional emphasis on patient access to specific medical record data, including clinical notes, is needed. This may be especially important since currently VA Notes is only available via the Blue Button feature. Participatory research can help to identify optimal language that may be needed to enhance patient awareness and understanding.

VA Notes users' experience

Patients who viewed their clinical notes reported considerable benefits, similar to the OpenNotes study,^{27–30} from preparing for in-person visits, to greater understanding about their conditions and recall of care plans, improved medication adherence, and feeling more in control of their health. While the OpenNotes initiative offered study patients access to primary care visit notes written by volunteering physicians, our survey provides a first look among a large national sample of VA patients having online access to all of their clinical notes. Our efforts to further investigate providers' concerns about the content of clinical notes causing patient confusion and worry were also congruent with OpenNotes study findings. In our study, a small minority of patients who had accessed their notes agreed that notes are more confusing than helpful (6.3%), and that reading notes will make them worry more (8.5%); while 2–8% of OpenNotes patients reported these concerns.

While the majority of VA Note users found it easy to access their notes and felt that the display of notes was easy to read, a significant proportion (27.2%) still agreed that some information in the notes was difficult to understand. Despite these challenges, patients reported overall benefits from accessing their clinical notes online. Given the broad scope of clinical notes available to VA patients, these findings are particularly important. Providing patients with additional education and resources will be an important strategy to address challenges

in health literacy, and to support their understanding of medical terms and complex concepts. Continuing to improve documentation practices for health professionals authoring notes will be an important strategy for organizations,³⁷ especially given the prevalence of 'uncertainty terms' in clinical documentation³⁸ as clinicians document differential diagnoses and probabilities, and the frequent use of templates in EHR systems.³⁹ Healthcare systems may need to provide additional clinical training to staff to emphasize patient-centered documentation practices. Research is underway to explore complementing notes with supplemental information to augment patient understanding.⁴⁰

VA Notes users' actions

Since providers have expressed concerns about possible negative effects on patient–provider communication and duration of visits,²⁹ we were particularly interested in patient reports of purposeful interactions with their providers. Importantly, the majority of patients (74.7%) reported that they did not contact their provider after reading their notes, essentially because they had no reason to do so. Moreover, patients who planned to contact their healthcare team were mostly motivated by wanting to learn more about a health issue, medication, or test result; or to get an explanation about something in the note, representing an opportunity to enhance patient understanding. These findings may alleviate some uneasiness about follow-up telephone calls, longer visits, and changes in documentation.

Areas for further research

As Walker *et al*⁴¹ conclude, as open notes continue to spread, strategies and safeguards will continue to evolve. Additional research is clearly needed to inform this evolution and to support the inherent 'mutual transformation',⁴² including institutional and cultural change, and documentation practices that recognize the patient as an audience for the clinical note.

A March 2013 poll revealed that 65% of US physicians still believe that patients should only have limited access to their EHR.⁴³ Effectively empowering people as active participants in their health requires a paradigm shift from historically paternalistic medicine to patient-centered care in which the locus of control and decision-making is centered on the patient, and aligned with their individual needs and preferences.⁴⁴ The results we report here, along with patient's enthusiasm for greater transparency and access to information in the medical record, are promising in light of the potential for increased patient satisfaction, engagement, patient safety, and quality of care.

Yet as Cahill and Gilbert point out,⁴⁵ increased patient access to information must be contextualized as a complement to existing patient/provider communication practices in order to reduce the potential for negative unanticipated consequences. Notably, the potential for patient distress warrants further study, especially for those with critical conditions such as cancer diagnoses⁶ or acutely emergent illnesses³⁰; striking the balance between patient desire for timely access to information and the need for proactive communication by the healthcare team.³⁷ Transparency in objective documentation using 'descriptive, nonjudgmental summarizing', for even sensitive topics such as mental health, may have additional therapeutic benefit.⁴⁶

Patient access to clinical notes through a secure portal offers transformational opportunity while simultaneously raising questions about adoption, effects on patient and clinician behavior, and health outcomes. As noted by Milne and Morris, 'record access provides most benefit if used as an integral part of the care process. If patients access their records, particularly in the content of joint decision-making in partnership with their health professionals, the result can lead to improvements in their care'.⁴⁷ Novel areas of development and research continue to unfold. As an early exception to the rule for mental health note transparency,⁴⁶ VA remains an important site of inquiry to understand the effect of access to clinical notes. Also, while a significant number of patients downloaded or printed a copy of their notes, relatively few shared their notes with a family member, caregiver, or other healthcare provider. Given that approximately 70% of VA patients receive care in non-VA care settings,⁴⁸ there could be considerable value in encouraging and educating patients to share recent notes with non-VA providers in order to facilitate information sharing and hence promote improved care coordination.

Study limitations

There are several limitations to this study. First, results were gathered from a random sample of website visitors and may not be representative of all My HealthVet users. Survey acceptance and completion rates are comparable to other studies using the ACSI survey method however,^{23,34,35} and exceeded completion rates of similar surveys. Second, early adopters may be appreciably more tech savvy and engaged in their care, possibly affecting their motivation to view notes or to contact providers. Many survey respondents were not yet

familiar with VA Notes, demonstrating the need for heightened outreach and education, or possibly greater portal usability. Given that initial promotion of VA Notes was minimal, it was not surprising that a sizable number were not yet aware during the survey interval. Efforts to promote patient awareness of VA Notes availability are currently underway.

CONCLUSION

Our initial assessment of the patient experience provides evidence that patients both value and benefit from online access to their clinical notes, and indeed such access may be transformational in the journey towards truly patient centered care. This study also points to some important implications for clinical practice. Our early results clearly indicate the need to raise awareness and educate patients about the ability to access their clinical notes, and the potential role that this can play in their care. Second, healthcare professionals who are authoring clinical notes should keep in mind the opportunity that patient note access presents for communicating with the patient as a supplement to the clinical encounter, for example reinforcing the treatment plan and medication instructions. Challenges related to health literacy may otherwise expand the digital divide. Furthermore, while those who subsequently contact their healthcare provider do so primarily to learn or seek clarification, for some users, contact is made to discuss something that was worrisome or perceived to be incorrect. For these patients, access to clinical notes may represent both an unprecedented opportunity for enhanced communication and also a potential opportunity to improve the quality of the medical record.

CONTRIBUTORS

All authors played a role in the study design, data analysis, writing, and final review.

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COMPETING INTERESTS

None.

ETHICS APPROVAL

Iowa City VA Health Care System Institutional Review Board.

PROVENANCE AND PEER REVIEW

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