

Patients' Participation on Their On-Site Review of Doctors' Notes: Physicians' OpenNotes Experiences in a Pain Clinic

Christopher Gilligan, Ashish Bhandari, Edgar L. Ross, Victor C. Wang, Ji Hong Lee, Aimaiti Bomaliyamu, Andrew Pisansky Brigham and Women's Hospital, Massachusetts, USA Divya Chirumamilla Memorial Hermann Hospital, Texas, USA Alan Sheydwasser Beth Israel Deaconess Medical Center (BIDMC), Massachusetts, USA Manasi Parikh Boston University, Massachusetts, USA

Inviting patients with chronic pain to read their doctors' visit notes via secure electronic portals may empower them and improve their understanding of their health condition. However, sharing the clinician's perspective on the psychosocial contributors to a patient's pain via transparent medical records could potentially lead to conflicts between patients and providers. Mirroring the OpenNotes study, we investigate and describe here the effects of increased clinic visit note transparency on physician experience in a large outpatient pain medicine clinic. We analyzed pre- and post- intervention questionnaire data from nine chronic pain medicine physicians over a six-month period. During this period, patients were given full access to their clinic visit notes that were not previously available to patients. In this study, we found that previous concerns of the potential risks and workload concerns of OpenNotes were not realized to the degree that the pain medicine providers had predicted but were more prevalent when compared to data from primary care physicians.

Keywords: OpenNotes, chronic pain, pain clinic, intervention, physician's perception

Introduction

Over the past several decades, an increasing number of physicians have advocated for making patient records transparent and easily available to patients (W. V. Slack & C. W. Slack, 1972; Weed, 1968). Electronic

Ashish Bhandari, MBBS, Department of Anesthesia, Brigham and Women's Hospital, Massachusetts, USA.

Victor C. Wang, MD, Ph.D., Department of Anesthesia, Brigham and Women's Hospital, Massachusetts, USA.

Ji Hong Lee, MPH, Department of Anesthesia, Brigham and Women's Hospital, Massachusetts, USA.

Aimaiti Bomaliyamu, MPH, Department of Anesthesia, Brigham and Women's Hospital, Massachusetts, USA.

Divya Chirumamilla, MD, Memorial Hermann Hospital, Texas, USA.

Christopher Gilligan, MD, MBA, Assistant Professor, Department of Anesthesia, Brigham and Women's Hospital, Massachusetts, USA.

Edgar L. Ross, MD, Associate Professor, Department of Anesthesia, Brigham and Women's Hospital, Massachusetts, USA.

Andrew Pisansky, MD, MS, Department of Anesthesia, Brigham and Women's Hospital, Massachusetts, USA.

Alan Sheydwasser, MD, Beth Israel Deaconess Medical Center, Massachusetts, USA.

Manasi Parikh, MBBS, M.Sc., Department N/A, Boston University, Massachusetts, USA.

medical records and secure Internet portals have provided patients with the option to view test results, medication lists, and other selected parts of their medical records. However, only recently has clinical encounter narrative transparency occurred with the introduction of OpenNotes, which invites patients to read the notes generated by their physicians after each visit.

The OpenNotes initiative started in 2010 and detailed the experiences of patients and primary care physicians prior to and 12 months after making physician notes available to patients. The post-intervention survey data showed that greater than 80% of patients opened at least one note, and over two thirds of patients reported having a better understanding of their health and medical conditions, taking better care of themselves, having increased medication adherence, or feeling more control over of their care (Delbanco et al., 2012). Few patients (1-8%) were confused, worried, or offended by what they read. After the intervention, 3% of primary care physicians felt that they spent more time answering patient questions outside of visits, 11% felt they spent more time writing or editing notes, and email volume to patients did not significantly change. About 20% of physicians reported changing the way they wrote about cancer, mental health, substance misuse, or obesity. No physician in the study decided to discontinue the practice.

Introducing OpenNotes in an academic chronic pain medicine practice poses several possible challenges and warrants study given the dissimilarities between the pain medicine environment and that of primary care. The prevalence of psychosocial stressors, mental health disorders, and substance abuse in the chronic pain population is higher when compared to most patients in primary care practices (Carta, Balestrieri, Murru, & Hardoy, 2009; Miller & Cano, 2009; R. A. Sansone & L. A. Sansone, 2012; Sehgal, Manchikanti, & Smith, 2012). Since OpenNotes had been successfully implemented in the primary care setting, we sought to determine whether the same physician experiences generalized to a chronic pain practice.

This is the first study to evaluate online access to full clinic visit notes among chronic pain clinic patients, and the first to report physicians' experience prior to and after this transition.

Methods

Setting

This study included nine pain medicine physicians at the Arnold-Warfield Center for Pain Medicine (Beth Israel Deaconess Medical Center [BIDMC], Boston, Massachusetts). The Arnold-Warfield Center for Pain Medicine is an academic pain medicine clinic with pain medicine specialists trained in anesthesiology, neurology, psychology, and nursing. Close referral patterns are present with primary care physicians, spine orthopedics, and neurosurgeons as well as physical therapists. The clinic treats a case mix composed of patients with common pain disorders as well as patients with complex pain syndromes or common disorders resistant to conventional therapy using multidisciplinary techniques.

Intervention

During the six-calendar month intervention, patients were given full access to their visit notes. Patients who had no prior experience accessing their medical records were given brochures that contained instructions on how to access their clinic notes via web portal. Patients were able to contact the clinic via email to inquire about their notes during the intervention period. Physicians were notified of these queries and either responded directly or with the help of triage nursing staff.

Pre- and Post- intervention Surveys

Prior to the start of the study, physicians at the Pain Center were surveyed in regard to what they expected their experiences would be once patients had access to their clinic visit notes. The pre- and post- intervention physician surveys used standardized and verified questions and were selected based on themes that arose from focus group discussions. A 4-point Likert scale (disagree, somewhat disagree, somewhat agree, and agree) was used for most survey questions. The full physician pre- and post- surveys are available upon request. We did not survey patient experiences, as prior studies involving OpenNotes have shown that patients are strongly in favor of having ready access to their notes and report a wide variety of positive effects (Delbanco et al., 2012).

Results

Pain Medicine Physician and Patient Participation

Of the 10 BIDMC pain medicine physicians who started using OpenNotes, nine completed the study. All of the participants who completed the six-month study submitted pre- and post- intervention surveys. The participants also attended pre- and post- intervention debriefing sessions to discuss issues not directly covered in the survey. Since this study focused on experiences of pain medicine physicians, no patients were contacted during the study period.

Pain Physician Experiences

Of the nine physicians who responded to the post-intervention survey, five estimated that conversations about OpenNotes occurred less than once per month, three felt that patients were calling 1-3 times per month, and one believed their patients were calling 1-6 times per week about the notes. This represents an insignificant change from call volume prior to the intervention. Before the start of the study, the participating pain physicians were generally worried about the increasing workload that OpenNotes could bring to their practices (see Table 1).

Table 1

Pre-intervention		Post-intervention	
Survey item	Physicians (N)	Survey item	Physicians (N)
Patient will worry more		Patients worried more	
Agree	2	Agree	4
Somewhat agree	6	Somewhat agree	1
Somewhat disagree	1	Somewhat disagree	2
Disagree	0	Do not know	2
Will request changes in notes		Frequency changes requested to notes	
Agree	1	> 5 times	1
Somewhat agree	7	2-4 times	4
Somewhat disagree	1	Once	4
Disagree	0	None	0
Longer Visit length		Longer Visits	
Very concerned	1	Yes	0
Moderately concerned	2		0
Minimally concerned	3	No	9
Not concerned	3		

Pre- and Post- intervention Physicians' Perceptions on Effect of OpenNotes Implementation

Increased time addressing concerns		Increased time addressing concerns		
Outside visits		outside visits		
Very concerned	1	Yes	5	
Moderately concerned	6		5	
Minimally concerned	2	No	4	
Not concerned	0		4	
Offend patients		Number of patients offended		
Very concerned	1	0	4	
Moderately concerned	5		4	
Minimally concerned	3	1-3	5	
Not concerned	1		5	
Less candid in documenting		Less candid in documenting		
Very concerned	1	Yes	1	
Moderately concerned	2		1	
Minimally concerned	5	No	9	
Not concerned	1		8	
Change approach to mental health topics		Changed approach to mental health topics		
Agree	2	Yes	2	
Disagree	7	No	7	

Table 1 to be continued

The post-intervention surveys illustrate that the perceived workload did modestly increase. However, the increases were not as significant as these physicians originally believed they would be. Although patient experiences were not directly captured, before the intervention, 89% of the participating physicians "agreed" or "somewhat agreed" that their patients would worry more after being able to read their clinic notes. Following the intervention, 79% "agreed" or "somewhat agreed" that their patients did indeed worry more after having access to their notes (see Figure 1).



Figure 1. Patients would worry more after the OpenNotes session.

Participants were also asked to assess whether they believed that patients would request changes to their notes. In the pre-intervention survey, 89% "agreed" or "somewhat agreed" that patients would request changes. Following the intervention, 44.5% of the physicians reported that they received one request for modification per month, 44.5% reported receiving two to four requests per month, and 11% received more than five requests

for changes per month (see Figure 2). Although 33% of participants were "moderately concerned" or "very concerned" that OpenNotes would increase the average visit length, none of them felt that visit time was increased following the intervention (see Figure 3). In the pre-intervention survey, 78% of providers were "moderately concerned" or "very concerned" that they would spend more time outside of scheduled visits answering questions, while 56% reported actually spending more time answering questions after the intervention (see Figure 4).



Figure 2. Request changes in notes.



Figure 3. Longer visit length.



Figure 4. Increased time addressing concerns outside visits.



Another subset topic on the pre- and post- intervention surveys addressed issues regarding offending patients, candid documentation, and avoidance of subjects likely to produce offense, such as mental health disorders and substance abuse (see Table 1). Regarding offending patients, 56% of the participants were "moderately concerned" before the intervention that their notes would offend patients and 56% reported actually offending 1-3 patients per month after the intervention (see Figure 5). Regarding less candid documentation, 33% of the physicians reported being "moderately concerned" or "very concerned" that their notes would be less candid before the intervention, while only 11% actually reported being less candid in their documentation after the intervention (see Figure 6). Prior to the intervention, 22% of the participating pain

physicians believed that they would have to change the way they address topics like mental health and substance abuse and 22% reported actually changing the way they address these subjects in the post-intervention survey (see Figure 7).

The post-intervention survey also evaluated physician perceptions of patient confusion and provider experiences using OpenNotes (see Table 2). Regarding patient confusion, 56% of participating physicians either "agreed" or "somewhat agreed" that their patients were confused by reading their notes; while 33% were not able to tell. When asked "Is having patients read their notes a good idea?", 67% either "agreed" or "somewhat agreed". When given the prompt, "If OpenNotes were turned off, our physicians would…", 56% of participants stated they "would not care", 11% would be "somewhat pleased", and 33% claimed they would be "very pleased".



Figure 7. Change approach to mental health topics.

Table 2

Survey item	Physicians (N)
Patients brought up notes	
Less than once per month	5
1-3 times per month	4
1-6 times per week	0
Patients called with questions about note	
Less than once per month	5
1-3 times per month	3
1-6 times per week	1
Patients requested changes to notes	
None	0
Once	4
2-4 times	4
> 5 times	1
Thoughts on whether OpenNotes was a good idea	
Disagree	3
Somewhat disagree	0
Somewhat agree	4
Agree	2
Thoughts on discontinuing OpenNotes	
Very pleased	3
Would not care	5
Somewhat pleased	1

Post-Intervention Physicians' Perceptions of Increased Workload Due to OpenNotes Intervention

Post-intervention Comments From Debriefing Sessions

The post-intervention debriefing session allowed the study participants to comment on their experiences using OpenNotes. Some of the challenges of OpenNotes were as follows: Changes in notes requested by patients often lacked clinical significance, documentation was targeted to non-medically trained people which was not effective for professional communication, notes included fewer details of clinical diagnoses, such as mental health and substance abuse, and notes sometimes created confusion and worry for patients over clinically insignificant matters. Some providers felt that OpenNotes could potentially help patients understand their care better but this was not formally assessed. Providers were also given the opportunity to offer feedback on OpenNotes. As this study was conducted at an academic institution, several physicians expressed frustration with the inferior quality of their trainees' notes, feeling they were often inaccurate or poorly written. Limitations in the note writing software program also prevented the participants from directly editing a trainee's note. Furthermore, the faculty also felt that they did not have enough time to write addenda before the clinic notes became available to patients. One asserted that "It would be better if the attending could edit a trainee's notes".

Discussion

Many of the potential risks and workload concerns of OpenNotes were not realized to the degree that the pain medicine providers originally predicted. However, these concerns were more prevalent than previously reported among primary care physicians. Some of the most notable differences were that chronic pain patients were perceived by physicians as much more likely to worry, be offended, become confused, and inquire about their notes outside of visits compared to primary care patients³. Longer visits, an increased frequency of requested changes, and less candid provider documentation were not perceived to be as problematic as originally expected.

Introducing OpenNotes in an academic chronic pain medicine clinic posed several challenges that differ from primary care settings. There is an increased prevalence of mental health disorders, substance abuse, and psychosocial stressors among chronic pain patients compared to the average primary care patient (Miller & Cano, 2009; Sehgal et al., 2012). Chronic pain patients are also known to be hyper vigilant about their care and many are skeptical of the medical community in general (Carta et al., 2009; R. A. Sansone & L. A. Sansone, 2012). This behavior was noted in the post-intervention focus group, when participants observed that some patients became fixated on clinically insignificant matters which seemed to create confusion and worry among patients. Although the patient-level experience was not directly measured in this study, it is possible that OpenNotes had an unanticipated, negative effect on the patient-physician interaction. In comparison, primary care patients generally have been assumed by providers to be more resourceful and respectful of a physician's time (Delbanco et al., 2012). Another reason why relative workload in prior studies did not increase in primary care clinics after implementing OpenNotes could be due to the fact that many primary care patients are reasonably healthy and have no functional deficits. This relative state of health may in turn cause them to be less attentive to the details of an available clinic note as opposed to patients in chronic pain who are often functionally disabled and may exhibit a greater level of interest in what their pain medicine providers are documenting about their illness

Candidly addressing potentially sensitive topics in clinic notes that are made available to patients has long been considered taboo, especially in the fields of psychiatry and pain medicine. Interestingly, a similar percentage of pain medicine physicians (22%) reported changing the way they addressed potentially sensitive topics like substance abuse and mental health when compared to PCPs (20%) (Delbanco et al., 2012). Only 11% of the study participants reported being less candid in their documentation. In a post-intervention focus group, some participants noted that the modifications that occurred from utilizing OpenNotes resulted in a loss of clinical and diagnostic information which in turn lead to less effective communication. One provider asserted that, "OpenNotes creates a bias to satisfy patients and deviates away from true medical communication between providers". The clinical effects of targeting notes to the lay population have not been thoroughly studied. Despite these hurdles, 67% of the pain physicians surveyed felt that having patients read their clinic notes is a good idea, and some providers felt that OpenNotes could potentially help patients develop better understanding of their care. Perhaps more significantly, OpenNotes provides another chapter in the evolution of the shared decision-making process. Models of clinical decision-making have theorized a spectrum: Paternalistic decision-making puts the physician entirely in charge of care decisions, shared decision-making describes and equal partnership between physician and patient, and informed decision-making relies on the patient to make all treatment decisions (Charles, Gafni, & Whelan, 1999). OpenNotes seeks to communicate additional information to the patient in order to facilitate shared decision-making between physician and patient. However, our findings suggest that it may have a complex effect on this process, involving changes to both the patient and physician experience.

Remarkably, the most significant objection to using OpenNotes among the participants stemmed from the complex interaction between attending physicians and trainees in the academic setting, and not the modestly

increased workload that resulted from having patients in chronic pain read their clinic notes. The faculty was largely unsatisfied with the quality of trainee notes. They felt these notes regularly omitted crucial diagnostic and therapeutic details, were poorly written, and were often inaccurate. Software limitations also prevented the faculty from directly editing a trainee's note, and addenda frequently could not be written in a timely manner. Collectively, these issues created tension between the faculty and the trainees.

There are many features of an academic chronic pain clinic that may contribute to poorly written trainee notes. Most pain clinic trainees come from anesthesia residency programs where operating room procedural skills and vigilance are emphasized over detailed narrative documentation. Also, trainees working in a chronic pain clinic often do not have the opportunity to follow the same patients longitudinally which may lead to a lack of longitudinal understanding of the patient's condition.

This study has several limitations. First, with only nine participants, all of whom practice at the same academic chronic pain clinic, the results of this study may not be generalizable to all chronic pain medicine clinics in the U.S. Second, as previously noted by Walker et al. (2011), although the survey questions were specifically designed for this project and had face validity, they did not undergo formal psychometric testing to evaluate future validity and reliability. Third, this study only presents part of the picture, since it lacks the perspectives of patients and trainees. It was not possible to survey all patients involved in this study, so physician perceptions of the intervention's effect on patients was used as a proxy. Prior research has shown that physician perception of patients' disease severity is frequently discordant with a patient's own evaluation of his or her disease state, thus challenging the validity of physician perceptions. Given that research in other areas has shown that physicians consistently under-report symptom severity, it raises the question of how much patient distress may have been provoked by OpenNotes (Efficace et al., 2014). Evaluation of resident anesthesia trainee experiences was not done because they were limited to only rotating through the pain clinic one month out of the year. Pain fellow trainees were not evaluated because of the lack of longitudinal follow up with patients, which was especially limited over the six-month study period. Finally, the nine participants may have a more positive view of OpenNotes compared to the one provider who chose not to participate, which may introduce some bias in this study.

This study represents the start of a journey that explores how pain medicine physicians can communicate more transparently with their patients. However, this study also raises questions about the complex effects of OpenNotes on the patient-physician interaction and how shared decision-making may be facilitated or hampered by this intervention. Thus, it motivates future research into this area to define the patient perspective and answer the question of whether changes in physician workload are quantitative or qualitative. In the future, it will be fascinating to compare patient perspectives with those of our pain medicine faculty and trainees. Despite the challenges of introducing OpenNotes in an academic setting and modestly increasing workloads, the potential benefits provided by increased transparency between patients and pain physicians, such as increased medication adherence, greater understanding of care plans, and empowering patients to improve their pain, make it imperative to explore this fundamental change in practice carefully and creatively.

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