INTERNISTS' PERCEPTIONS REGARDING PATIENT ACCESS TO PROGRESS NOTES

by

Alfredo Almerares, MD

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This is to certify that the Master's Thesis of

<u>Alfredo Anibal Almerares</u>

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Has been approved

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Thesis Advisor: Justin Fletcher PhD

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Committee Member: Homer Chin MD

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Committee Member: Paula Otero MD

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Abstract

In many countries allowing patients access to physician progress notes regarding their care is not only considered important for improving patient engagement but is a legal requirement. While most efforts and analysis have been focused on providing such access in the outpatient setting comparatively little is known about the impacts in the inpatient setting.. Furthermore, in a country like Argentina with its own healthcare model where no such access, in either inpatient or outpatient settings, has ever been given before, at any level, implementing open progress notes will require a systematic approach that considers providers fears and expectations.

This qualitative study explores Internists' general perceptions on opening progress notes to patients during inpatient hospitalization.

Three focus group sessions with a total of twenty participating Hospital Italiano internists' were conducted. Grounded theory approach was use to analyze the data. The themes that emerged were: (1) Increase workload; (2) effect on patient-physician relationships; (3) Communication between providers; (4) Security and information privacy; and (5) Usefulness. I found that Internists' are not in favor of giving patient access to the progress notes. They perceive the progress notes primarly as tools for communicating between providers and therefore see little use in allowing patients to read them and see this as an extra burden for providers

Description

Title: Internists' perceptions regarding patient access to progress notes

Objective: The main goal of this project is to answer the question of what are Argentinian Internists' general perceptions about sharing progress notes with their patients.

We seek to identify local Hospital Italiano internists' willingness to give this open access, understand what are the internists' fears, concerns and perceived consequences of giving real-time unrestricted access.

Knowing Internists' perceptions is fundamental in the implementation process of open access progress notes. It facilitates and allows for a better approach of the implementation, reducing their concerns and increasing internists' participation.

Main terms:

-**Consumer health informatics:** One of the major topics within consumer health informatics is empowering consumers to manage their own health, by providing methods to make information accessible to consumers.

-**Patient access to medical records;** under article 14 of Argentinian federal laws 26.529[1]patients are the owners of their health records and they can demand access to their health information. Healthcare institutions must provide the means for such access.

-**Focus Group:** A group of individuals selected by researchers to discuss and comment on, from personal experience, the topic that has been a subject of the research.

-**Grounded Theory**: A systematic, qualitative procedure used to generate a theory that explains, at a broad conceptual level, a process, an action, or interaction about a substantive topic

Introduction

United States federal law establish a patient's right over their health information, including rights to examine and obtain a copy of their health records .[2] Concurrently under Argentina federal law[1] patients are the owners of their medical records and upon request they should be given access to them. However, this is frequently time consuming for patients who often have to face many challenges until they receive their information.

It has been 40 years since Bud Shenkin and Robert Warner made a call to give patients unrestricted access to their medical records, stating it would increase patient engagement and lead to more appropriate utilization of physicians.[3] Only now has health information technology developed as a way to reduce existing barriers between patients and their health information, giving more transparency to healthcare. Electronic health records (EHR) and personal health records (PHR) can bring patients and physician closer. Core functions of PHRs include: secure messaging, delivery of personalized health information, appointment scheduling, bill management and access to EHR. Giving patients immediate open access to their physicians' progress notes seems to be the final frontier when it comes to full access to medical records. Opening progress notes have the potential to be a driver of better health outcomes augmenting patient engagement and adherence to therapeutic plans, [4,5,6]favoring self-management and reinforcing collaborative relationships between clinicians and patients.[7.8,9]

Despite initial concerns,[10] physicians' experience with granting access to clinical notes has been positive, with studies showing open notes implementation had little affect over physicians workloads[6] or any significant impact in their writing patterns[6,11,12]. However, the majority of the research and implementation efforts regarding patient access to progress notes has been undertaken in North America. There is a paucity of data from other settings specifically Latin America. Furthermore in reading the meaningful 2

objectives there is no delineation regarding ambulatory versus inpatient care setting for the origin of the notes and thus an implied requirement for patient access to inpatient clinical notes within the four days appears to exist. It is of vital importance to understand and address the subjective perspectives of internists prior to implementing such access. By doing so we can better understand possible unintended consequences (both good and bad), identify potential risks and leverage this to avoid barriers in adoption, reducing physicians concerns and increasing their participation.

The focus of this study is to understand Internists' perceptions regarding patient access to progress notes.

Methods

Reality is subjective; people do not experience the world identically. To consider individual views and look for patterns in those views, we performed a qualitative study at Hospital Italiano de Buenos Aires, in Argentina. In order to capitalize on debate and to better understand Internists' perception and beliefs, we conducted a series of focus groups. Discussion was centered on the topic of "giving patient access to their medical records." Data gathered during focus groups was validated through the use of member checking, to that end, after concluding with the sessions, field notes were shared with participants to validate findings.

Setting

Hospital Italiano de Buenos Aires (HIBA) is a tertiary care academic medical center with 750 inpatient beds. It is part of a health network that includes a second hospital, 25 outpatient centers and 150 private clinics. In 1998, HIBA began to implement a Healthcare Information System (HIS) that was completely developed in-house. The HIBA information

infrastructure includes a PHR, which was launched in 2007. In October 2013, approximately 80,000 patients were enrolled in the personal health records (PHR), representing more than 50% of enrolment rate[13]. The core functions of HIBA´s PHR include: secure messaging, delivery of personalized health information, appointment scheduling, bill management and access to limited EHR data which, for the moment, does not include progress notes.[14]

Sampling

Three focus groups were conducted (n=3). Each group consisted of between 6 to 8 Internists which totaled up to 20 participants. Internists were invited to participate in person, and were offered no compensation for their time. Oral consent for participation was elicited and given:

Inclusion criteria: Physician needed to be working as Internists in HIBA for greater than two years.

Exclusion criteria: those internists who concurrently worked in the clinical informatics department.

Focus group format

Each group was engaged in conversation for no more than an hour. Audio tapes and field notes were taken. One experienced moderator and one assistant moderator formulated opened ended questions to guide the discussion when needed, however even as the moderator engaged the group to discuss neither he nor the assistant joined the

conversation as participants. Focus group outline and guidelines can be found in **Appendix A.**

Analysis

Data gathered from the focus groups transcripts was evaluated and analyzed using grounded theory coding. Themes were generated from the focus group transcript data in order to understand physicians' perception about the topic.

We used a systematic approach to the analysis and data interpretation. This involved coding strategies, breaking down the data into distinct units of meaning which were labeled to generate concepts. Concepts were then re-evaluated for their interrelationships and developed into higher-order categories.

The process can be summarize in three coding steps[15];

- **Open Coding and Analysis**: analyze the data line-by-line and allocate codes to the text. From the initial focus group, a list of codes emerges and this list will then use to code subsequent interviews

- **Axial coding;** process of relating the categories

- **Selective coding;** consolidating the themes

Results

Demographics

In all, three focus groups sessions were conducted, with a total of twenty participant internists. Of those, thirteen were female and seven were male. Six subjects had more than ten years of work experience in the inpatient setting, while fourteen had less than ten. Table 1 shows the characteristics of the subjects.

Total participants	20
Females	13
Males	7
More than 10 years since grad.	6
Less than 10 years since grad.	14

Table 1. Participant characteristics

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Theme analysis

The overwhelming sentiment between participants was negative with scarce positive perceptions regarding the topic. After analyzing the transcripts from all three focus groups five themes emerged (Table 2). The themes related to the lack of perceived benefit for the patient and how open access to progress notes would affect current workflows, added to a sense of increase burden and little recognition of patient as owner of the medical record. A description of themes and selected quotes from participants are described in this section, within some these major themes, a number of sub-themes were identified. Sub-themes will be discussed within the presentation of each theme.

Table 2: Overarching focus group themes

1) Increase workload

2) Effect on patient-physician relation

3) Communication between providers

4) Usefulness

5) Security issues and information privacy

Increase Workload

Across all focus groups, participants reported fear for an increase in their workload if patient were to have access to the progress notes. Participants discussed a common feeling of dissatisfaction for the potential at having to spend more time addressing patient demands or documenting. A prominent sub-theme identified within this overarching theme related to documenting. Many respondents reported that they would have to write longer more detailed progress notes hence having to spend more time in their stations documenting. As noted by quotes like the following:

"I will have to write long progress notes in order for none clinicians to understand, patients don't follow clinicians logic when reading"

Similarly, another respondent stated:

"All ready we spend most of our time in the EHR, this will only make things worse"

While the majority of respondents perceived this change in documentation as a having a negative impact on their workload, there was one participant who saw this as an opportunity to improve the way progress notes were written, stating:

"Maybe that is better [that we spend more time documenting] Sometimes I don't even understand what other clinicians write"

However his view was unique and not supported by other participants.

The increase of demands from patients and relatives was the other sub-theme as it affected workload.

Participants considered the language used in progress notes as suited only for the understanding of other members of the healthcare team. The confusion created by information that would not be understood by patients or relatives would lead to increase anxiety and having to address more demands at any time. This was noted by comments such as the following:

"They will look into Google to try to understand what is written and that is bad for me. It creates fear increases anxiety and I have to deal with that. I will spend more time correcting them than actually explaining what is relevant"

"We will have to spend more time explaining ourselves to patients that read things they just don't understand".

Security issues and information privacy

A topic that was raised in every encounter related to data security and information privacy. Giving patient access to the progress notes was deemed unsafe by many participants, as a new way of access to progress notes could lead to patient privacy being

compromised. Participants express concern with issues like having care givers demanding access and patient feeling pressed to grant that access.

 "There will certainly be a demand from family members and caregivers to have access to the progress notes, and patients might find themselves in an uncomfortable and feel that they to give this access to them"

The point was made that, while access was controlled by providers, patients could avoid these demands, and this would be no longer. Also concern for a patient who is in a fragile state might not be fit to guard his information. The simple act of leaving a mobile device unattended could lead to security breaches, simply stated by one participant:

"What if they leave the iPads unlocked and somebody reads their information?"

Consideration of security issues was representative of how unaware internists were of how open access to progress notes would be implemented or and the anxiety it caused:

"So who will access? Patients only? Guardians? All the family? How do you control who has access".

Communication between providers

The effect on communication between providers was highlighted across all focus group sessions. Participants considered sharing information with each other as one of the main functions of the progress notes and were concerned on how changing documentation patterns would affect that process. Change on communication patterns would be not only a consequence of having to write longer notes but also secondary to fear on how patients would react to certain information. Participants considered that this change had the potential of creating progress notes empty of content that would miss valuable information. For instance stating:

"This will generate defensive documentation; we won't write vital information for fear of a reaction from patients or caregivers, for instance if I suspect abuse of some sort I don't know if I would document it"

"Medical records don't belong JUST to the patients. Progress notes are dialogs between clinicians; they are not composed for the patient"

Comments such as these revealed internist perception of medical records as belonging more to them than to patients and their perception of medical records as tools thought and designed to support their work.

Effect on patient patient-physician relation

The effect that patient access to progress notes would have on patient-physician relationship emerged as a prominent theme. Concerns on how patients would react to information and how this would affect their relationship with patients were common, as expressed by one of the participating internist:

"This is a horrible idea! Can you imagen if patients read what we put into the progress notes? It will diminish patient-physician relationship. Many times I write information that is important for other physicians but that I don't want the patient to see. If they did who knows how they would react. I remember they did this on a TV show [Seinfeld] the patient was offended by what she read and demanded it was erased later she changed physicians, this is no joke"

How face to face communication between patient and internists would be affected was a sub-theme. Some participants were concerned that knowing patients would have full access to the medical records might be perceived by other physicians as an excuse not to spend time orally informing patients. With one participant stating:

"Progress notes lack the context that face to face communication brings; this is the basis of patient-physician relationship. Many of my colleagues will expect patients to get the information from the progress notes and won't spend time talking with them"

This perception was somehow contradictory as many participants had expressed that they would have to in fact spend more time addressing demands, which would imply more face to face time.

Usefulness

The perception that there was no potential usefulness in giving patient open access to the progress notes was the most significant expression of how negative participants view on the topic of open access is.

Participants were unaware or did not perceive there was any benefit that could come from implementing unrestricted access to progress notes. With expressions like:

"It's pointless"

"Why would you do this? Nobody would access their records. Patients want to be explained their condition verbally and up to a certain point, they don't want to know everything"

In one of the focus group session a participant commented:

"Just because we are at Hospital Italiano, we have electronic health records and we have the technology to do it, doesn't mean we should, why should we go first let someone else take the first step, I mean nobody is doing it, nobody is asking for this because nobody wants it"

No perception of benefit and the belief that patient would not want to access their progress notes were the building blocks of the overall negativity towards the topic.

Discussion

The greatest value behind focus group research is that allows us to learn from participant interaction and debate, when there is not much information available from a certain topic. After completing the focus group sessions, and before undertaking the analysis, it was self-evident that participants overall perception is very negative when it comes to allowing patients to have full access to their medical records. Participants were eager to express their opinion but there was little debate, as perceptions were clearly one sided.

Although some comments may apply only to the inpatient setting, most participants' perceptions were generalizable to the outpatient setting. This may be indicative that any implementation of open notes, regardless of setting, would face opposition from providers. Participants expressed similar concerns to those discuss in the health literature in the United States[10, 12, 19], topics like increase workload, change in documentation patterns and its consequences are common, local practitioners much like those who practice medicine elsewhere, express some degree of fear with allowing patients to access the notes as well as concern for the security of the information and possible negative effects on patient-physician relationship that include less face to face communication. However, in our evaluation the strong sentiment against opening progress notes seemed to be moved by a general lack of perceived usefulness. On top of considering that they would face increase burden, participants saw little to no benefit in sharing the information on progress notes with patients, which would explain their opposition to any change in current practices. Participants views, supported also by ignorance or disregard of governing laws, indicate their belief that medical records in general and progress notes in particular are tools thought and designed for practitioners and not fit for the use of non-

clinicians. Participants claim ownership of the records and believe it is them who should decide what and how much information is given to the patient, this reinforces the physician centered mentality and paternalistic take on medicine that is common in Latin American countries[16,17].

Our intention throughout the sessions was to allow participants to express their views with as little intervention from the research team as possible, in order not affect their views with our own. However, upon completion of the focus groups participants would ask for the rationale behind the initiative. After explaining global experiences, measured consequences and benefits from similar implementation, it became evident general perceptions begun to change with some recognition of use and backing of the open notes initiative. This would support the concept that often the greater our ignorance about something the greater our resistance to change.

Patients are increasingly aware of their rights and more willing to exert control of their healthcare and decisions. Open access to medical records at every setting is no longer a technological issue but a cultural one, sooner rather than later patients will demand what is theirs. With this in mind it becomes necessary to study how best to implement open access. This study results indicate that before any implementation can take place locally, a strong education campaign among providers must be conducted. Knowing internists perceptions is vital for the implementation process to go as smoothly as possible, but is not enough, the rationale of open notes must be explained if meaningful cultural change is to be expected and implementation of open notes is to be successful.

Study implications and future work

Several studies have looked into the benefits of giving patient access to their progress in the outpatient setting, concurrently, it has been shown that allowing patients to access some of personal health Information during hospitalization, through mobile devices such as tablets, can increase inpatient engagement in care with high satisfaction and little need of any form of training[18], however the impact of full unrestricted access that would include progress notes in the inpatient setting has not yet been evaluated.

This study is, to our knowledge, the first published evaluation of internists' perception on opening progress notes, particularly in Latin America where patient access to progress notes has not been implemented at any level. We hope it will be the starting point for further evaluation in the topic and that it would be of value when designing an open notes implementation.

Future work should focus on understanding local patient's expectations as well as perceptions from other member of the healthcare team who also are involve in the documentation process. This, together with the information that we found in our work, will allow guiding efforts to achieve unrestricted access to medical record. We believe further steps should include a reduced pilot implementation with a prospective cohort study to evaluate the experiences of patients, and providers with real-time patient access to progress notes. To this end, and similarly to what was done when evaluating the impact of open access in the ambulatory setting [6,10,12] or limited access in the impatient enviroment[19], before and after survey need to be developed based on the findings of the qualitative research.

During the research phase and prior to conducting the focus group we discover several projects are being conducted globally that had no communication plan, we believe a systematic review of the topic is also needed, this will allow us to share experiences and capitalize with what is being learn on the topic.

Limitations

Focus groups are a qualitative research method, and therefore subject to some limitations implicit in this methodology, we tried to diminish them by the use of member checking to increase result validity.

Internists were recruited from a single academic medical center that has a long standing tradition for adopting health information technology therefore participant's views may not be generalizable to the rest of the region, however we believe that the concept of open progress notes is not technological but instead cultural, hence HIBA internists' perception are of great value.

Conclusion

Internists are not in favor of giving patient access to the progress notes. Perceived ownership over the medical records, no recognition of usefulness and expectation of increase burden together with security concerns will be obstacles to any implementation of open notes in the inpatient setting.

Physician concerns should be addressed before implementing full access to progress notes. This will require education on open notes concepts, value of patient engagement and overall patient rights as well as strong leadership.

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APENDIX A: Focus group outline and guidelines

Welcome and thank you for participating.

(Introduce moderator and assistant)

Our topic is patient's access to the progress notes.

The results will be used to guide the implementation of this access within our Institution. You were selected because you are a physician working as an Internist in Hospital Italiano for over 1 year; we value your perceptions as we are considering implementing open access to progress notes in the inpatient setting.

Guidelines: *these guidelines were communicated orally and in written form*

There is no right or wrong answers, only differing points of view

We're taking notes and also tape recording; please only one person speak at a time

We're on a first name basis

You don't need to agree with others, but you must listen respectfully as others share their views

This is a voluntary process. You have the right to pass answering any or all questions

My role as moderator will be to guide the discussion

We encourage you to talk to each other

Open questions for this project

What do you think about opening progress notes to the patients?

What are your concerns about giving patients access to the progress notes?

What is your opinion on how opening progress notes will affect communication with the patient?

How do you think your workload will be affected?