

Cooperative Documentation: The Patient Problem List as a Nexus in Electronic Health Records

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ABSTRACT

The patient Problem List (PL) is a mandated documentation component of electronic health records supporting the longitudinal summarization of patient information in addition to facilitating the coordination of care by multidisciplinary medical teams. In this paper, we report an ethnographic study that examined the institutionalization of the PL. Specifically, we explored: (1) how different groups (primary care providers, inpatient hospitalists, specialists, and emergency doctors) perceived the purposes of the PL differently; (2) how these deviated perceptions might affect their use of the PL; and (3) how the technical design of the PL facilitated or hindered the clinical practices of these groups. We found significant ambiguity regarding the definition, benefits, and use of the PL across different groups. We also found that certain groups (e.g. primary care providers) had developed effective cooperative strategies regarding the use of the PL; however, suboptimal usage was common among other user types, which could have a profound impact on quality of care and safety. Based on these findings, we provide suggestions to improve the design of the PL, particularly in strengthening its support for longitudinal and cooperative clinical practices.

Author Keywords

Patient problem list, electronic medical records, EMR, EHR, patient-centered medical records, documentation, coordination, CSCW.

ACM Classification Keywords

H.0 [information systems]; K.4.3 [organizational impacts]: Computer-supported cooperative work.

General Terms

Human Factors; Design; Documentation.

INTRODUCTION

The Problem List (PL), as the name suggests, is a place where essential descriptors about a patient's illness are recorded. In practice, the PL not only serves as an index and summary of the patient's presented symptoms and differential (tentative) or final diagnoses (i.e., "problems"),

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but also provides clinicians a quick access to other types of critical patient information such as allergies and medication prescriptions and treatments. Given its direct relevance to quality of care and patient safety, a comprehensive and timely documentation of the PL is mandated by the Joint Commission,¹ and therefore constitutes an essential function electronic health records (EHR) system [4].

An appropriately structured and documented PL is instrumental in facilitating the coordination of care and enhancing clinicians' ability to understand patient cases more effectively and efficiently—by eliminating the need to peruse every document in a large collection of historical patient records. It also plays a key role in proactively arranging long-term care plans both for the benefit of patients and for the cost containment goals of healthcare providers [3, 5]. Nonetheless, while the PL is mandated by the Joint Commission, how it should be implemented is largely a decision by individual healthcare institutions. Therefore, its designed objectives, actual usage, and quality of implementation can vary greatly from setting to setting. Existing research has shown that in many healthcare institutions, the implementation of the PL is very problematic which is partially responsible for its suboptimal usage and consequently underachieved value [5].

The PL's documentation summarizes a patient's information after an ambulatory visit or hospitalization to provide a comprehensive overview of this patient for future care. Therefore, it does not directly support the current episode of care. Furthermore, the "documenters" of the PL are, sometimes, not going to be the *direct* beneficiaries of the information in the future. This unique nature introduces many interesting dynamics into how different clinicians may perceive differently their anticipated responsibilities and rewards in this cooperative documentation activity, in which reciprocal benefits, tacit negotiation, and other types of incentives may all play critical roles.

To better understand this cooperative nature that has profound implications on the design and use of the PL, we conducted an ethnographically based study at a large teaching hospital in a Midwestern state in the U.S. Our

¹ Formerly JCAHO, i.e. Joint Commission on Accreditation of Healthcare Organization. It is an independent and non-profit organization that accredits and certifies more than 19,000 health care organizations and programs in the United States.

investigation involved observations of and interviews with different types of clinicians (e.g., specialists, general medicine hospitalists, primary care physicians, and nurse practitioners), and was focused on how the PL functions supports, as well as hinders, their group practices. The central objective of our research was to further examine the issues involved in information sharing – to examine the critically important differences between local settings and the needs for standardized processes, particularly in providing for the long term while dealing with short-term needs and incentives.

In the next section, we describe the PL in more detail and present a review of the extant research literature related to its design, implementation, and use, and similar research issues documented in CSCW. Then, we describe our empirical study setting and the data collection processes. In the following sections, we present our research findings and discuss how these findings further our understanding of the necessity of acknowledging local practices [17] in relation to standardization, and how the findings from the healthcare context may inform CSCW research in general. We conclude the paper with several design implications that may contribute to improving the PL function in EHRs.

BACKGROUND AND LITERATURE REVIEW

The PL, either on paper forms or in electronic systems, is often presented in a “table of contents” format serving as an index to most essential patient data. The entries on the “table of contents” provide not only pointers to the referenced information, but also high-level summaries of a cogently selected set of patient data to help clinicians quickly build an accurate and comprehensive understanding of the patient’s illnesses, conditions, and treatments. Because of this nature, the PL represents a patient-centered, problem-oriented medical records approach (which requires careful thinking and synthesis) as opposed to a “laundry list” approach documenting data according to discrete clinical processes. Previous research has shown that these two different document practices could lead to distinct outcomes [14], and that identifying an optimal balance between describing the patient vs. medical processes that occur to the patient is vitally important [18].

First introduced by Weed in 1969 [16], the concept of the PL has been widely adopted in healthcare and is now mandated by the Joint Commission as a key component of patient records. However, there has been a lack of general consensus in the medical community with regard to what should be included on the PL in order to effectively and comprehensively present a patient case. Some emphasize “significant diagnoses and treatments” [2], while others argue for the inclusion of additional relevant information elements such as patients’ psychosocial histories [10]. Due to a lack of agreement, the institutionalization of the PL has been very problematic, which has resulted in varied practices, inaccuracy (and thus distrust) of the data recorded, and consequently lack of user acceptance and suboptimal use [5].

Researchers and practitioners have strived to address these issues in order to unleash the true power of the PL. Such efforts include studies on automated construction of the PL by extracting medical concepts from narrative patient records, development of more pertinent taxonomies and vocabularies to help formalize the PL in structured and codified formats [3], and incorporation of the PL in the clinicians’ sign-out process to improve efficiency and patient safety [15].

However, significant gaps remain in understanding clinicians’ perception of *how* the PL should be designed and used to better support their cooperative work. For example, what are the medical and social implications that may result when the PL is missing certain information? How should the PL be constructed and presented more effectively to help clinicians make sense of patient cases? For chronically ill patients whose medical records may accumulate to an unmanageable amount over time, can the PL serve the function of helping clinicians quickly identify most critical areas in the data? Such gaps have severely constrained our ability to design more useful and usable PL functions in EHRs to help clinicians manage complex data [18]. While the study described in this paper attempted to answer these questions based on an investigation conducted in one hospital, we believe the research findings may be generalizable to other settings.

The use of the PL in a health care setting is an ideal case to further examine information sharing in a collaborative setting. Information sharing has been a consistent theme within CSCW. For example, Grudin noted that when an information object is shared across multiple parties, there are always tensions between different parties due to the unevenly distributed workload and benefits [7]. Further, Ackerman and Halverson, in their study of a hotline [1], found that when the same information object is maintained by multiple parties, there can be tensions between information provenance, i.e. who creates it, and information governance, i.e., who manages it. This is especially true when an information object is shared across communities whose expertise and practice are inherently different, and is even more complex when such information is politically or psychosocially sensitive in medical settings [18].

Long-term use of information has become more a prevalent interest in recent years. Medical care is an especially good place to examine this problem, not only because of the need but also because of the relative complexity of the work. Patients often present ‘one-off’ problems, and care is contingent and situated. On the other hand, medical care is not ad-hoc; it consists of sequences of standardized routines [11]. Furthermore, this work is done within a complex landscape involving a large number of clinicians from distinct specialties and backgrounds cooperating over a long period of time to provide high quality care services to patients. As such, the PL both documents those routines and the problems as well as attempts to provide an overall view of the patient.

This study was informed, then, by the research findings from both medical informatics and organizational studies in CSCW. We believed that a close examination of the PL problem would not only benefit medical practice, but could also lead to a better understanding of information sharing and reuse—specifically in trying to balance localized versus standardized practice and in ameliorating tensions between long-term and short-term needs.

STUDY SETTING

Our observation field site was an internal medicine unit at a large teaching hospital. An in-house developed electronic health records system, eCare, has been implemented in this hospital for over a decade. It allows clinicians to document various kinds of clinical notes, such as Emergency Department (ER) notes, (inpatient) admission notes, progress notes, nursing notes, discharge notes, and (outpatient) clinic visit notes. In an inpatient setting, discharger planners and social workers also document patients' discharge and long-term care plan and any social issues that may be discovered and affect patient illness management. In addition, eCare also serves as interface to pull lab/radiology results and medication information from the clinical data repository (CDR) so that clinicians largely can do their information work within eCare.

The research reported in this paper is part of our larger study which aims to explore any issues related to medical information reuse from a long-term perspective. This objective led us to search for a research site that could provide rich data related to patients with chronic illness trajectories. We selected an internal medicine unit that hosts four internal medicine doctor teams and one nursing team. The unit receives a diverse range of patients. Many patients have a long history of chronic illness accompanied by various psychosocial issues in their daily lives.

Among the four doctor teams, one general medicine team granted us the opportunity to shadow their work almost without any restriction. The nursing manager also provided us access to all aspects of the nurses' work. Therefore, our field observation focused on this general medicine team (3 attending doctors and 21 residents working on a monthly rotation) and nursing team (56 nurses).

DATA COLLECTION

The data collected and reported in this paper consist of field-based observations augmented by the examination of patients' medical records and clinicians' working documents, including both paper and electronic due to the transition to a more computerized environment. In addition, we also conducted semi-structured formal interviews with the clinicians from several units of the hospital system, such as specialists, primary care doctors, and nurse practitioners in order to get a much broader understanding of the issues.

The first author performed the field observations, semi-structured interviews, and all other data collection. She shadowed clinicians' day-to-day work, including doctors' morning rounds, diagnostic interviews, constructing notes,

nursing shift-change, etc. She often engaged the clinicians to conduct informal interviews with them during quiet periods. Her fieldwork was typically from three to five hours per each session. In total, she spent over 750 hours through 18 months.

Our semi-structured interviews about the issues of PL use included 13 physicians (including inpatient general medicine, ER and specialized services, and outpatient primary care) and 2 nurse practitioners, who were all required to contribute to the PL. We also included an IT project manager who was responsible for improving the PL design and for implementing a structured PL, and who had a broad perspective about PL use across the hospital.

We employed the grounded theory [6] approach to begin our data analysis. This approach allowed us to identify emerging themes from broad observational activities and to gradually evolve into more focused data collection. For instance, the issues with PL use appeared repeatedly during our observations of work activities in the general medicine team, such as the attending doctor pushing residents multiple times to document certain information on the PL. This theme gradually emerged as an interesting research topic that led us to focus on the PL when we interviewed the clinicians, and we extended our interviewees to include a spectrum of caregivers who are all required to use the PL in their patient care. Therefore, the grounded theory method served not only as an approach for analyzing the data but also a guide for data collection. In this paper, field notes, interview transcripts, and examination of the PL function within eCare were used to corroborate one another during the data analysis process.

PROBLEM LIST IN MEDICAL PRACTICE

To comply with the Joint Commission regulations, the institution we studied requires that a Problem List (PL) be maintained for any patient who has had more than three encounters in the health system (including hospitalizations and clinic visits), and that the PL must be shared among clinicians. It is the responsibility for every clinician who treats the patient to document any "major" problems based on the categories defined.

The PL in this health system is a large table divided into six sections: Diagnoses, Procedures, Medications, Allergies, Health Maintenance/Chronic Care, and Patient Education / Counseling. For simple patients, the PL can be viewed on a couple of screen pages; but for complex patients with a long past medical history, the PL will require many pages. The first four categories are mandatory. The Health Maintenance section became primarily an automated process, pulling relevant data entries from CDR and populating them on the PL, which includes whether the patient gets services such as mammography, cholesterol screening, Pap smears, immunizations, etc. Patient Education/Counseling is not required, and is almost never used. All of the other categories require clinicians to manually enter the data. For instance, Diagnoses should

contain the “significant” medical diagnoses or other problems for a patient through her or his entire lifetime for which knowledge of the items could impact future medical decision making; Procedures records a patient’s surgical history and other “significant” medical procedures; Medications should list a patient’s current and past medications; Allergies should contain a list of all allergies and intolerances to not only medications but foods and environmental exposures as well.

The PL was initially begun with free-text entry for all sections. Gradually, Allergies and Medications required structured input in order to build a foundation upon which inpatient computerized provider order entry (CPOE) and outpatient electronic prescribing (E-prescribing) could be implemented. Currently, the hospital system is preparing for a transition from free text to coded diagnoses as well. In this study, we will focus on the Diagnoses section.

In the rest of this section, we attempt provide a rich account of the use of the PL from different stakeholders. We report 1) how the PL provides an overview of a patient’s medical record, 2) how primary care, specialists, inpatient doctors, and ER doctors perceive and use the PL differently, 3) how the PL can be over- or under-documented, depending on the type of clinician, 4) how it has become the primary care clinicians’ responsibility to maintain and clean up duplicate entries on the PL, and 5) the upcoming transition to coded diagnoses from the current free text.

Mixed Perceptions and Uses of the Problem List

Our findings reveal that clinicians have mixed perceptions of what the PL is about, which further manifested in how they use the PL in their practice. It is interesting to note, for all primary care clinicians (including pediatricians) we interviewed, when asked what was their last time they used a PL, they all said something like “five minutes ago” or “I use it for every single patient I see,” whereas the specialists answered the same question, “a long time ago” or “honestly I don’t use it very much.” In this section, we introduce how several groups of clinicians use the PL, focusing on how their perceptions are dramatically different and how these perceptions and uses may affect the continuity of care.

Primary care clinicians—heavy users

In a clinic environment, primary care clinicians almost always look at the PL just before meeting a patient (unless the patient is new and has no data in the system yet). The PL allows for a quick review of the patient’s overall medical issues and helps prompt the clinicians to consider further evaluations or tests for the patient.

For primary care physicians, support staff such as nurses or medical assistants (MAs) print out a paper PL when the patients are being prepared for the physician. The physicians often update the paper PL *during* the clinical encounter and return it to the support staff for adding or updating the entries in the electronic PL. One of our interviews was with a physician who sees patients three days a week and 20 patients a day. She largely relies on her

assistants to maintain her patients’ electronic PL via handwritten notes, and admitted that she usually would not go back to check whether the new problems were appropriately interpreted and documented. Further, sometimes the paper PLs were just left behind and thus the official electronic PL was never updated.

Some physicians update the PL electronically by themselves due to concerns that their assistants may not understand what they wrote or to allow for more contemplation before adding the diagnoses to the records. Their use of the PL is often streamlined into their practices while they are seeing patients. One nurse practitioner reported,

[For] “any patient I take my laptop into the room and the problem summary list is the first thing I look at, with the patient, I have them looking at the screen actually. So, they can see the diagnoses they can see the medications and they are the ones who will say no, no that’s not right I am not on that medicine anymore.... Then the patient knows what’s in the system and can help me update it.”

This nurse practitioner reported that usually after a patient’s visit she would dictate the clinic visit notes and sometimes forget to update the PL. In one of the most recent peer audits (which is an institutionalized activity for nurse practitioners), among ten of her patients’ records, her peer found out two cases where the diagnoses weren’t updated on the PL. Since then, she has double-checked to ensure that everything is entered.

For primary care services, clinicians reported that updating a single patient’s PL required an average of 1–3 minutes for an existing patient, and about 5 minutes or longer for a patient who is new to the system. However, considering that they need to see up to 20 to 30 patients per day, updating the PL within their routine workflow indeed adds significant documentation time.

Regardless, primary care clinicians recognize that the PL is essential for them because they can save a lot of time for a patient’s next visit and avoid reading through the clinical notes. For them, the PL will be beneficial to whomever will see the patient subsequently, including themselves. Updating the PL, while time consuming, is a process they “pay forward” in order to maintain the continuity of care.

Specialists’ view of the problem list

In contrast with the primary care clinicians, the specialists in the hospital systems seem to find that the PL requires too much “additional work,” is “redundant,” or is “doing the same thing two times.” While we only interviewed two specialists in this study, primary care clinicians also commented on the lack of input to the PL from specialists.

It is interesting that one of the specialists (a developmental behavioral pediatrician) labeled herself as “the other end of the spectrum” of PL users. She created a template to remind her of work activities. During the interview, she recalled a

recent case in which she did not enter a diagnosis of ADHD in the PL because “I haven’t been careful to do that.”

Another specialist (a pediatric cardiologist) commented that the PL has no direct role in the workflow of his unit. As specialists, the information they want to capture is of a very precise nature. They spend a lot of time creating precise clinical notes, and thus heavily rely on the notes when they see the patients. Their method of documentation is through dictation with subsequent refinement of their notes. In this context, documenting in the PL is perceived as an extra effort with no direct benefit for their practice. Doctors in this division never look at PL for diagnostic information.

This specialist also pointed out that what is considered as a “significant” problem is very local to each service. For instance, in their work the most significant birth defect should always be listed first with subsequent complications labeled with lower priorities. The new “problems” in their field may include a series of anatomic diagnosis of a patient’s heart (e.g. certain abnormal vessels of the heart), whereas a primary care physician may only need to know that the patient has a “heart problem.”

One specialist commented that unless there was a way to automatically populate the PL directly from their detailed notes, it was just not compelling for them to take extra time out of their workflow to summarize a patient’s medical problems during the visit in a note and then manually key the significant problems into the patient’s PL, because all they need is the detailed clinical note from the patient’s last visit. However, summarized information about a patient’s recent visit to a specialist and the subsequent diagnosis is critical for the patient’s primary care clinicians to know.

It should be noted that not all specialists or special units have the same practice or attitude towards the PL. One primary care physician observed that certain special units (e.g. pulmonary) are “doing better” than the others.

Inpatient doctors—using the PL as hospitalization summary
Our observations, based on one general internal medicine team using informal and formal interviews, showed mixed use of the PL among inpatient doctors.

When admitting a patient who needs to be hospitalized, some of the doctors like to start gathering information from the PL to get a brief overview about the patient’s prior conditions, whereas others may read the admission or discharge note from the patient’s *last* hospitalization, since these notes contain more detailed information. Updating a patient’s PL only takes place as the patient is being discharged from the hospital. It is the doctor who took direct care of the patient, i.e. usually the resident in a teaching hospital with the attending doctor’s supervision, who is responsible for documenting in the PL for the major issues arising from the hospitalization.

For an internal medicine team, which normally consists of one attending doctor, one or two residents, and two interns (i.e. first year residents), they admit about eight patients

every four days. Summarizing and documenting new diagnoses should not be a huge burden for them; however, some admit that they neglect to do this. Regardless, issues arise in considering which specific diagnoses should be included or excluded (which we will discuss in detail later) in order to make the PL useful, but not overwhelming, to other inpatient, primary care, and ER doctors.

Emergency Department doctors’ use of the PL

About 80% of the patient admissions for hospitalization come through the ER in this health system. In order to make an informed decision about a patient, ER doctors need to see a quick overview of their past medical history due to the time pressures. The first priority of their work is to address the patient’s acute situation and then move them to an inpatient unit or send them home.

For ER doctors, obtaining the most critical information about a patient’s medical history in a highly time-sensitive fashion is a concern. A well-maintained, concise PL is ideal for this purpose. However, due to the inconsistent use across the hospital system and different interpretations of what a PL should contain (which we will discuss in detail next), certain critical information is often not documented. This information can be either medical or psychosocial. (For instance, some patients may have serious behavioral issues and they come to ER only to receive a controlled substance). On the other hand, a patient’s single diagnosis can be recorded multiple times if they have had multiple prior encounters, which results in a PL that is many pages long. This situation often frustrates ER doctors who then have to sift through many non-essential items.

During our observations, one general medicine attending doctor was very upset when he made a special warning in a patient’s admission note not to prescribe narcotic to a patient because she was abusing it with no diagnosis found (after multiple hospitalizations), but ER doctors missed the warning, prescribed large doses of the drug, and admitted the patient for further treatment. One ER doctor responded why they often missed a warning and did not read the note,

“If you have millions notes (in eCare), I don’t know where to start.”

Indeed, an ER doctor may only have a few seconds to glance at the information about a patient’s critical problems (either medical or psychosocial) in their decision making process. How to construct a PL that fits into ER doctors’ needs is still an open question. During our interviews, acknowledging that the PL may be constructed at different levels, some argued that a PL should only include the most important elements for a patient such that if they came into an emergency room unconscious, the ER doctors could still make informed decisions without causing harm.

Different Interpretation of ‘Problem’ on the PL

What is considered an appropriate “problem” that should be on a patient’s PL and should it be presented? Surprisingly, there is no common agreement among clinicians, which partially explains why certain critical information is

missing while other entries are repeatedly documented. However, for some physicians, the redundancy in certain contexts has great utility [13]. In this section, we focus on how clinicians interpret the notion of a ‘problem.’

As described earlier, a patient’s PL has four sections that clinicians must manually update. Among these four, Medication, Allergies, and Procedures are clearly defined. However, clinicians have very different opinions about what should be put in the Diagnoses section, which is presented at the top of the PL page.

For some clinicians, only significant medical diagnoses that may affect how *later* doctors may treat the patient should be documented in the Diagnoses section. For instance, a patient’s diabetes should always be on the PL. However, inpatient doctors tend to list every single diagnosis that the patient received during the hospitalization, such as ‘dehydration,’ ‘respiratory distress,’ ‘diarrhea,’ and ‘vomiting.’ Some of these diagnoses, such as dehydration may be secondary to a more important primary diagnosis, or may have resolved quickly; these may not be critical for subsequent caregivers to know.

This situation became worse after the eCare implemented a function last year that automatically extracts items from the diagnoses section from a patient’s inpatient discharge note and subsequently updates the PL. The feature was a remedy for the lack of contribution to PL from inpatient doctors (only about 30%). However, it created many duplicate PL entries, because it simply included each visit-level diagnosis rather than a general summarized overview about a patient’s medical history. In fact, the new feature requires the doctors who discharge the patient to synthesize and refine the PL rather than just leave it as it is after the automatic extraction.

In addition to the issue with duplicate diagnoses, many clinicians may also interpret the PL differently depending on what other information is on the PL. As the name Problem List suggests, any observed problematic situations (e.g. symptoms, patients’ complaints, diagnoses) relevant to a patient hospitalization or clinic visit could be documented as a means to inform other care providers. The IT manager we interviewed, who was in charge of the improvement of PL design and use, also commented on this extended use. For instance, symptoms such as ‘throat pain’ and ‘headache’ in the PL may not be related to a clear diagnosis or may be simply a manifestation of an encompassing diagnosis such as ‘strep throat.’ One primary care physician pointed out that having symptoms documented provided one more dimension of the information to understand a patient’s illness situation.

However, this extended use of the PL can go too far, as one primary care physician said,

“We use that for anything that we think is important because no one else is going to look at any other part. We will use it even for a reminder to ourselves you know, (such as) ‘parents have

chosen not to vaccinate this child’ or ‘remember to do serology at the nine-month visit’.”

In this situation, a group of physicians used it as a place to put comments about the patient that they wanted someone else in the group to know about. Surprisingly, the use of PL as a sort of quick work list is not uncommon. For these clinicians, “these are the *key* things that we need to know whether it’s a problem or not.”

The lack of the consensus of what should be documented in the PL results in a messy PL that is not universally accepted by all clinicians. However, inflexible rules may not be the best way to solve the problem, as one physician said,

“I don’t think that we want to restrict clinicians from entering a problem. It is always good when people enter problems. We want it as complete as possible, and the key is how to display and summarize it...if your rules are ‘we don’t want you entering this problem because we don’t want the list cluttered’, I think that’s a problem. I think the better way is consider how we can make a scattered list manageable. Because if you basically say ‘don’t enter a problem’, you are losing information.”

Information Provenance vs. Governance

As described above, the PL should be a shared responsibility so that each clinician has a different role for updating the list—primary care clinicians focus on the general situation, inpatient doctors contribute the hospitalization summary, and specialists add detailed diagnoses. The PL should help coordinate care activities and maintain the continuity of patient care.

In preparation to transition from the free-text based PL into a structured format entry list, the administration has asked all clinicians to take some effort to clean up their patients’ PLs by removing redundant or minor diagnoses, or other elements that will not transition well to a structured format such as comments. This task eventually was delegated to primary care clinicians, whom the patients see most often. As a result, many primary care clinicians are frustrated because a lot of this work is perceived to be clerical, even though they acknowledge that those without enough medical background could not do the work.

However, deleting or altering “problems” someone else created (as part of maintenance) raises important issues about data provenance and governance. One may not fully understand another person’s intention and may remove or edit important information. This further escalates clinicians’ distrust about the PL. One primary care nurse practitioner reported that she had been actively deleting duplicate entries in the PL. For instance, if she saw multiple entries of ‘asthma’ or ‘hypertension,’ she would delete the duplicates then add ‘multiple’ before the diagnosis. However, another clinician had a strong reservation about this practice:

“Was it (multiple) three times or 30 times? Was it just all in the last month or was it within the last five years? I think it helps to know frequency and intervals because if you had no problems and then all of a sudden you’re having

the same problem five times in the last month, then something is very wrong; if you had it every other year for the last ten years maybe it's not a big deal, but the context of timing matters."

In this context, a certain level of redundancy conveys much more meaning than a single mention of diagnosis.

While some primary care clinicians were actively cleaning up the 'mess' on the PL, others were hesitant because they were "afraid to get rid of somebody else's entry." In addition to the additional meanings resulting from duplicate diagnoses provided by different care providers, the use of the PL as a reminder or work list further complicates the situation. For instance, whereas one physician may enter "depression secondary to physical abuse" as a reminder about the patient's problematic situation, another physician may think such an entry is inappropriate because the Diagnosis section of a PL should only include pure medical diagnoses. If the second physician deletes the entry, the first physician will lose the valuable reminder. As described in last section, these data entries, although not clearly defined medical diagnoses, depict a richer picture about a patient, which are all important for physicians to know in order to provide appropriate care.

The conflicts between information provenance and governance created distrust about the veracity of data in the PL. One primary care physician stated that she would only print out the PL for *her own* patients when the patients need to visit other health organizations and request a copy of their PLs because she had carefully gone through their PLs manually and made sure every data element was correct.

Psychosocial Context of the Problem List

In eCare, the design for documenting a patient's major social history is a separate page accessible via a tab on the primary page, requiring an extra click. Due to this separate click, poor interface design, and perceived lack of overall utility, the page is rarely used. Documenting psychosocial history as a reminder to other care providers usually occurs either in the hospital admission notes or clinic visit notes. In addition, physicians also key in entries as a diagnosis in the PL when a patient's psychosocial issues become critical and worthy of warning to other care providers whom the patients may see.

For instance, along with some medical diagnoses, "domestic violence" also appeared on a patient's PL. The nurse practitioner who documented it wanted other care providers to know about the patient situation right at the front page of the PL. In the context of pediatric practice, entries such as "Parents divorced" or "Child adopted from another country" are not medical diagnoses, but they are very important for pediatricians to know.

The use of the PL for psychosocial problems has raised concerns among some clinicians. One primary care physician worried that information like "depression" and "anxiety" on the PL would affect the patient's ability to receive disability insurance later, because the insurers may

request the patient's entire medical records, and since the PL is an overview of the patient, the company is likely to look at it first. This physician expressed,

"I don't feel comfortable putting this in the problem list; I don't think we should do that. The opposite argument is this is really important information that we need to know about that patient and we need to have it in some place where other people who are taking care of this patient can easily find it."

In the inpatient setting, the internal medicine unit deals with a large number of the patients who have chronic medical conditions with a psychosocial issue. If their frequent hospital visits are driven more by their psychosocial issues related to managing their illness rather than the illness itself, the attending doctors often push the residents to document critical and problematic psychosocial issues in the PL. In an extreme case, one attending doctor put his warning message in all capital letters at the very top of the PL, saying:

"DO NOT EVER PRESCRIBE CONTROLLED SUBSTANCES FOR THIS PATIENT. HE IS A DRUG DEALER AND FORGES PRESCRIPTIONS."

This is a way to warn ER doctors not to give certain controlled substances to patients who are drug seeking. This active and alarming description ensures that no one who reads the patient's PL will miss it. However, some residents still hesitate to enter this. One resident said while the person indeed exhibited some pain-medicine-seeking behavior that should not be encouraged, a similar warning might prevent someone in actual pain from receiving appropriate care. The subjective interpretation about a patient's psychosocial behavior has presented a unique account about the complex use of the PL. As one physician put it, "we haven't come up with an answer to that question yet."

Looking Forward: Structured Problem List

The hospital is in the process of implementing a transition to a structured Diagnoses section on the PL, preparing for the transfer of eCare data to a newly purchased commercial EHR that will be in practice next year. The new system requires structured data entry for many components.

In anticipation of the new system, some clinicians are optimistic because it has the potential to automatically populate data from clinical notes to the PL; others have a lot of concerns. The structured PL will be substantially different from how the PL is used right now. For instance, a large portion of psychosocial problems will not get transferred into the new system. Clinicians are concerned that they would lose valuable information that would affect their understanding of the patients.

DISCUSSION

Our findings provide a detailed account of clinicians' perceptions about the value of the PL and consequently how they may use the PL function in an EHR system differently. We found that while the use of the PL does support patient care among certain clinician groups, the

practices are highly variable due to the lack of a common agreement on the intended purposes of the PL, which is caused by, and perhaps also a cause of, the technical design of the PL function in the EHR system used in the site.

We believe that these findings can be readily applied to better understand the tensions originating in the use of shared information objects in cooperative clinical work, in addition to informing better designs of the PL in clinical settings. This study also speaks to collaborative issues in information sharing, balancing local differences and standardization, and information reuse from a long-term perspective.

First, the use of the PL among the primary care clinicians has been well institutionalized and well integrated into their workflow. These primary care clinicians highly appreciate the value of well-constructed summary data in the PL, in supporting their patient care activities across multiple episodes. This is indeed a reflection of the nature of the longitudinal, holistic patient care services that primary care clinicians are primed to render. The reason that specialists and inpatient hospitalists are poor contributors to the PL is multifold, such as the PL not being adapted to their workflow nor specific enough. Most importantly, the lack of systematic contribution to the PL by other types of clinicians (specialists and inpatient hospitalists) echoes a classic CSCW story: people are reluctant to contribute unless they see direct rewards for them in return [7].

Second, there are situations where the PL has been “over-documented,” i.e., populated with redundant data entries. This issue may be a result of the lack of a consensus what to include (and what not to) in the PL in the institution. Some clinicians adhere to the “general PL” concept, such as primary care clinicians who see that the PL documentation should be patient-centric, a snapshot of a patient, only presenting significant issues. Other clinicians, however, such as inpatient doctors, adopt the episodic approach and thereby choose to record all issues presented during the hospitalization, which can be repeating from last hospitalization or temporary symptoms quickly solved. This deviated understanding of the purposes of the PL has resulted in conflicts frustrations and suboptimal utilization. Increasingly, EHR systems are required to have a dual PL design that is intended to support both needs (and beyond, unique needs by ER doctors).

Relatedly, because eCare is shared among all patient care services in the hospital system, our field investigation uncovered interesting behaviors regarding how clinicians maintain and manage information created by other people, particularly other types of clinicians. For instance, primary care clinicians attempt and sometime are obligated to remove duplicate entries created by other care providers (inpatient doctors) further discouraging their already limited contributions. This also creates tensions between the people who generate the data (provenance) and those who manage the data (governance) [1]. The politics of information in this

context not only involves the debates on data ownership but also interpretations of what is considered to be appropriate as integral parts of the PL.

Third, in both health informatics and CSCW, researchers have paid close attention to the complex use of patients’ psychosocial information to facilitate patient care [10, 17, 18]. The deficiencies identified have led to arguments whether a separate set of codes for accurate and comprehensive description of patients’ psychosocial information should be developed [10]. In our study, the hesitation from certain clinicians about documenting sensitive information in the PL (the judgmental comments such as “patient needy for pain medications”) is reasonable, which reflects their concerns about anticipated future use of the information (e.g., seen by other clinicians, insurance company, or patients themselves through personal health records or patient portals in the future). That is, when one decides what information should be entered in a shared information object, the nuance of expressing the information is subject to anticipated downstream use [9]. If there is no clear anticipated downstream use, or there may be uncertainties with regard to how the information will be used later, clinicians are inclined not to document the information into patient records. These findings hence suggest that the PL should be considerably designed to accommodate such sensitive psychosocial information, or it will be lost. This may be an indication that there is a tension in everyday practice between short-term, specialized use and long-term use. Earlier CSCW studies have suggested to allow more flexibility in providing “informal” information and establishing communication channels to handle work-in-progress or sensitive data ([e.g. 8, 17, 18]).

Fourth, in the context of the PL, the key challenge is how to connect the dots (critical yet fragmented information from multiple episodes) into a bird’s-eye view of patient cases (understanding the patient’s illnesses and conditions as a meaningful whole). To have clinicians construct and maintain the PL in a manner that is primed for long-term use would require substantial effort, and this effort fails much of the time. The tensions that occur between localized practice and standardized procedures, and between acute (short-term) and chronic (long-term) issues, warrant further study. In this study, however, it is apparent that they make one unified PL difficult.

In addition, while significant progress has been made on structuring the PL, which provides the promise of automated populating the PL using existing patient records data [12], automation will not be able to deliver desirable results if no consensus has been achieved on how the PL should be constructed, as illustrated in this study. On the contrary, automation could exacerbate the situation if there is not a mindful strategy of what to include in the PL and what not to, as well as the nuances in how to properly present certain information such as patients’ psychosocial data. After all, a task cannot be effectively automated if human experts do not know how to handle it properly.

Automated approaches that are capable of meeting this objective will still require significant future research.

Finally, our study not only describes the complexity of long-term information use in healthcare. It also speaks to the issues in designing a computerized system to accommodate the differences of local settings (e.g. primary care, ER, specialized care, and inpatient care) in order to better support the cooperation in future work (e.g. collaboratively documenting the patient's critical information to be used as a whole in the future). As our results show, even within the same local setting, information requirements and practices can deviate to a great extent. For instance, general medicine in inpatient care may have more patients with complicated psychosocial issues and therefore have a greater need for mechanisms to communicate psychosocial information to future care teams. Our study hence provides insights about the issues and tensions in creating information for 'work in the future', i.e. how multiple groups (with distinct expertise) can collaborate in an attempt to maintain the continuity of the work over time. We believe a better understanding of cooperation in light of work in the future is critically important in both healthcare and non-healthcare settings.

DESIGN IMPLICATIONS

Based on our findings we can suggest several design elements, including user interface modifications, to enhance the functionality, usability, and usefulness of the PL across clinical domains, ranging from general practitioners to specialists. Many of the elements we suggest would depend on significant amounts metadata to enrich the diagnoses, some of which might still have to be developed..

First, diagnoses should be coded and should provide a hierarchy so that generalists can pick higher-level codes (e.g., 'heart disease') whereas specialists could select more granular codes (e.g., 'double outlet right ventricle,' a subset of 'heart disease'). The PL itself could then include a 'slider' to adjust the level of granularity as needed, based on the clinical hierarchies, for the clinician reviewing the list. Additionally, having coded data could allow grouping by categories including 'organ system' (e.g., 'heart') or even 'disease process' (e.g., 'diabetes').

Second, diagnoses should support labels such as

- *acute* or *chronic*, so that episodic diagnoses can be distinguished from long-standing diagnoses. This is to acknowledge the differences in disease processes that may affect patients for just a short period of time versus many years.
- *active* or *resolved*, dates, relative dates, or ages at disease onset or resolution should be selectable if known. This is to record the times at which different disease processes occurred which helps clinicians determine whether they may or may not still be affecting the patient.
- *major* or *minor*, or potentially a continuum, to allow for the ranking of diagnoses in terms of perceived

importance for a patient. Such labels should be modifiable over time so that if a major issue is corrected, or a minor issue flares, the PL can accurately reflect that.

- *department*, from which the diagnoses was entered in or to which it pertains. This would allow for specialists to quickly filter out the diagnoses that may not primarily be of interest to them.
- *clinician*, who entered the diagnosis or who saw the patient in which the diagnosis was made. This would allow a clinician to view everyone who may have taken care of the patient for a specific diagnosis which may be important when interdisciplinary teams are involved.

Third, diagnoses should support the ability to view the *number* of times a diagnosis was entered, especially for acute issues. This contrasts with some policies that either discourage the entry of such diagnoses or require that they be entered only once, to avoid clutter. This could be done by simply appending a number in parentheses next to the diagnosis (e.g., 'acute otitis media (10)', ear infection ten times in the past). This can provide valuable information for diagnoses in which the frequency of an event can provoke further work-up or investigation (e.g., ear tubes for too many ear infections, or a tonsillectomy for too many strep throat infections). Furthermore, the list should be expandable so that each individual episode with time stamps can be viewed individually. Even in cases where a repeated diagnosis probably has no clinical significance, such as the case with 'seasonal allergies', it may still be worthwhile to show all of the care episodes in which the diagnoses was addressed. Multiple instances for such diagnoses might suggest either a misdiagnosis or help identify a patient that is not being treated adequately.

Fourth, diagnoses should be linked to the original care episode in which each diagnosis was made, so that clicking on the diagnosis would bring up a display of the detailed note, such as an admission note by an inpatient doctor, or an outpatient clinic note by a primary care doctor.

Fifth, one should enable embedded displays of ancillary data associated with a subset of common diagnoses. For example, if a diagnosis of obesity were added, one should be able to click a link to view all weights for a patient in tabular or graphic form trended over time. Similarly, blood pressures could be displayed for patients with a diagnosis of hypertension (high blood pressure), or kidney failure so that the trends are evident immediately. Lab data could also be incorporated. This represents a hybrid model between a PL and what is often viewable on dashboards, but it would enhance the value of the PL for many clinicians.

Sixth, one should allow specific diagnoses to be flagged for internal viewing only. This is important at institutions where the PL is accessible by patients through a portal, or even by insurance companies. While the merit of such a practice is debatable, some clinicians may be reluctant to add certain diagnoses to the PL if they know that the patient will view them. This is especially true in adolescent

medicine in which sensitive information (e.g., sexually transmitted infection) is supposed to be kept confidential from parents. Additionally, concerns about affecting a patient's eligibility for insurance might also drive this decision.

Last, in a rigid, structured approach, we suggest having an area where free text notes can be added. Previously, clinicians often added notes that were important for themselves or other clinicians to view on subsequent visits. These included reminders about tests that needed to be done, or even details about the patient that were important to always remember (e.g., 'tremendous fear of white coats—take off before seeing patient' or other types of psychosocial issues). With the move from paper to electronic documentation, and from free text to structured data entry, the ability to add such small notations is diminishing even though the need still exists.

In summary, we believe that while maintaining an accurate and complete problem list may require extra work by some clinicians, if such a list were constructed properly, it would become a more central source of patient-centered information for all clinicians, and thus greater incentives would exist to maintain up-to-date documentation. Our findings provide rich insights for redesigning the PL in a much more general context.

CONCLUSION

The patient Problem List (PL) is a mandated documentation component of electronic health records supporting the longitudinal summarization of patient information, in addition to facilitating the coordination of care by multidisciplinary teams. We conducted an ethnographic investigation that examined the institutionalization of the PL, investigating the use of the PL among primary care clinicians, inpatient internal medicine doctors, specialists, and emergency doctors. We found significant ambiguity regarding the definition, benefits, and use of the PL from different clinician groups. Additionally, we found that some clinician groups (e.g. primary care) had developed effective cooperative practices regarding the use of the PL; however, suboptimal usage was common in other groups which could impact quality of care and safety. We studied various issues related to information sharing, integrity, and long-term reuse in the context of clinician use of electronic health records (EHR). We described in-depth issues and tensions involved in designing a computerized system that can enable multiple user groups to collaboratively document information to support 'work in the future.' Based on the findings, we provided several design suggestions to improve the PL, particularly regarding the longitudinal cooperative clinical practices that the function should support.

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