

Refereed paper

Leveraging electronic health records to support chronic disease management: the need for temporal data views

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ABSTRACT

Background The ageing population worldwide is increasingly acquiring multiple chronic diseases. The complex management of chronic diseases could be improved with electronic health records (EHRs) tailored to chronic disease care, but most EHRs in use today do not adequately support longitudinal data management. A key aspect of chronic disease management is that it takes place over long periods, but the way that most EHRs display longitudinal data makes it difficult to trend changes over time and slows providers as they review each patient's unique course.

Methods We present five clinical scenarios illustrating longitudinal data needs in complex chronic disease management. These scenarios may function as example cases for software development.

Outputs For each scenario, we describe and illustrate improvements in temporal data views. Two potential solutions are visualisation for numerical data and disease-oriented text summaries for non-numerical data.

Conclusions We believe that development and widespread implementation of improved temporal data views in EHRs will improve the efficiency and quality of chronic disease management in primary care.

Keywords: clinical documentation, electronic medical record, human factors, primary care, patient-centred medical home

Introduction

Chronic diseases such as diabetes, coronary artery disease, hypertension, cerebrovascular disease, congestive heart failure (CHF) and chronic obstructive

pulmonary disease account for as much as 75% of US healthcare costs and will eventually outpace infectious diseases in terms of costs worldwide.^{1,2} Management

of diabetes alone cost \$116 billion in 2007 in the USA, and diabetes is now epidemic in south Asia.³ However, our current healthcare system manages chronic diseases poorly in the outpatient setting. For example, up to two-thirds of the money spent on diabetes hospitalisations could be saved with improved primary care management.⁴

Electronic health records (EHRs) may improve primary care management and care co-ordination. However, studies have failed to consistently show improved quality with EHRs in chronic disease care. For example, diabetes disease management programmes using physician reminders, performance feedback and nurse-driven structured care have been shown to improve process outcomes such as rates of haemoglobin A1c testing, but not intermediate clinical outcomes, such as glycaemic control.⁵ Recent reviews show positive results from about two-thirds of trials of clinical decision support, but absolute changes in clinical outcomes are small; a Cochrane systematic review of point-of-care reminders for hypertension management reported a median reduction in systolic blood pressure of only 1.0 mmHg in intervention groups.^{6–9} Finally, some studies have shown that EHRs have failed to improve care when implemented as part of a disease management programme, when clinical decision support is incorporated, or when used for care co-ordination across settings.^{10–13}

EHRs may have failed to improve chronic disease care in these studies in part because most EHRs in use today do not facilitate longitudinal data management.¹⁴ We believe that the contribution of health information technology has been limited because EHRs are largely visit oriented and clinicians need contextual information for each data point. For example, a provider treating a patient for hypertension needs not only the medication list, but also context about how the patient's blood pressure has responded to each medication that the patient has tried in the past.¹⁵ To attempt to provide context, systems designed for clinical care have attempted to display all patient data on one screen, but this causes cognitive overload from the presence of extraneous data.¹⁶ Chronic disease management requires filtering pertinent diagnosis-oriented information. For this reason, we propose the term 'temporal data views' to mean both an improved interface and a filtered view of patient data. Chronic disease management requires numerical data, best displayed using visualisation, as well as non-numerical data, best displayed using diagnosis-oriented text summaries. Neither data visualisation nor diagnosis-oriented text summaries have been widely adopted into the EHRs commonly used in primary care practices today.

Currently, patient data are organised in EHRs by source, i.e. clinic notes, phone notes, laboratory results,

radiology results, medication lists and problem lists. While providers used to flip back and forth between sections of a paper chart in order to recognise trends or create a mental timeline, they now must click on multiple screens to accomplish the same goal. In the Methods section we use clinical scenarios to explain how temporal data views can aid providers in this goal and we define two types of temporal data views: visualisation and diagnosis-oriented summaries. In the Outputs section we illustrate the potential of visualisations and diagnosis-oriented summaries in chronic disease management. In the Discussion section we summarise our argument for improved longitudinal data management and review prior literature.

Methods

Data visualisation and chronic disease management

A data visualisation, which may be as simple as a graph of a patient's creatinine, is more efficient than reviewing a series of laboratory reports. As opposed to flowsheets in which there is little visual association between the individual values, graphs reveal connections between data points. Using graphs, the visual detection and assembly of data points to recognise a trend can be exceedingly fast. Many EHRs offer the ability to graph laboratory results over time, but this tool is not commonly used by primary care providers (PCPs) because of usability issues. For example, some systems do not automatically adjust the *y*-axis to the range of values. Other systems do not indicate the normal range, which leaves interpretation to the memory of the provider. These graphs should be improved in EHRs that are currently widely used. More advanced designs could be added, such as Sparklines, small information graphics embedded in the context of text to show temporal data in a condensed way.¹⁷ Previously evaluated in an intensive care setting, they should be available to primary care clinicians to display numerical data intuitively and compactly.¹⁸ Another study reported a visualisation which used stacked timelines of information from different sources such as medications and subjective complaints, which allows clinicians to recognise correlations between disparate information, such as initiation of a new drug and development of an adverse drug reaction.¹⁹

The clinical scenarios below describe common problems encountered by PCPs which may be improved by data visualisation.

Scenario 1: Emergency room visit for gout flare

Dr Phair's patient, Mr Taylor, calls the office after an emergency room visit for a gout flare. She reviews his electronic chart, but does not notice that his last flare had occurred a number of years ago and that it was related to a medication change. Nor does she realise that he was recently started on Ibuprofen.

In the Outputs section, we explain how data visualisation could improve the efficiency of this task and help the PCP to discover a likely cause of Mr Taylor's gout flare. When assessing a gradual decline in status, data visualisations may aid physicians in recognising subtle changes over time as described in the following scenario.

Scenario 2: Early chronic kidney disease

One year later, Dr Phair sees Mr Taylor for his annual physical. She reviews his past notes and health-monitoring flowsheet, but fails to notice that he is slowly developing worsening chronic kidney disease.

In the Outputs section, we explain how a data visualisation may improve quality of care in this scenario by raising awareness of a change from baseline and providing clues to potential causes. We also suggest how data visualisation tools may increase use of clinical decision support of electronic reminders.

Scenario 3: Weight loss in end-stage cancer

An 87-year-old man, Mr Radley, comes in for a follow-up visit with his longtime PCP, Dr Holtzman. Mr Radley has end-stage cancer and has failed multiple treatment regimens. In past discussions, he has asked that Dr Holtzman refer him to an inpatient hospice 'close to the end' because his wife's arthritis will make it hard for her to care for him at home. Dr Holtzman reviews the patient's symptoms and determines that his clinical condition is stable. He schedules a follow-up visit in two months. Unfortunately, he fails to note that Mr Radley has been losing weight rapidly and that his last routine blood test showed a decrease in albumin level. Two weeks later, Mr Radley acutely decompensates and is hospitalised rather than being admitted to an inpatient hospice.

The addition of a patient-specific data visualisation would make it easier for this busy PCP to recognise a crucial turning point in this patient's course and to make recommendations that are consistent with the patient's previously stated wishes. We present an example of such data visualisation in the Outputs section.

The next section describes the opportunities for text summaries and how a diagnosis-oriented text summary

may be superior to data visualisations when narrative information is present in notes, labs, radiology, problem lists and medication lists.

Disease-oriented text summaries for chronic disease management

When assessing time intervals between events or observing a trend in numeric data, visualisation is superior to other approaches. By contrast, in situations where narrative information is dispersed throughout the record, diagnosis-oriented text summaries are superior.²⁰

The following scenario describes a common situation in which a PCP is searching for pertinent diagnosis-oriented data in narrative documents.

Scenario 4: Source-oriented review of low back pain data

Mrs Hyatt is a 31-year-old woman who has been seen by her PCP Dr Mackay for a number of years. Recently, she began to complain of low back pain. Today she leaves a message for Dr Mackay requesting a referral for an MRI. Dr Mackay begins to search through her chart in order to find data from radiology, notes and referrals. After scrolling up and down through multiple screens, he sees a phone note where he noted that Mrs Hyatt was having so much pain that she could no longer do heavy housework. He opens the referral section and sees a referral to neurology. He decides to order an MRI because it is reasonable, because it may be a requirement for a neurology assessment and because gathering more information would be too time-consuming.

Dr Mackay should be able to access all data pertinent to low back pain with one click as described in the revised scenario in the Outputs section.

Combined visualisation and disease-oriented text summaries for chronic disease management

A temporal patient data view, as we have described it, differs from a disease registry or dashboard in that it is not a cross-sectional data view. Since the most recent LDL value and current dose of medication is often all that is needed for lipid management decisions, a cross-sectional view for lipid management may increase quality and efficiency of medical decision making.²¹ However, the management of complex chronic diseases requires more context than the most recent value.²² For example, CHF management may require recent and distant data about medication changes, symptoms,

diagnostic test results and vital signs, as illustrated in the next scenario.

Scenario 5: Source-oriented review of CHF data

Mr Davis is a 76-year-old man who has been hospitalised multiple times and has coronary artery disease and CHF. Dr Floyd, who is covering for his PCP, is called by a visiting nurse for a blood pressure of 78/42. Dr Floyd clicks on multiple screens to review Mr Davis's medical problems and medications, but soon decides to send him to the emergency department where he is admitted.

In order to avoid an unnecessary emergency department visit and hospitalisation, Dr Floyd needs to feel confident that the low blood pressure is not due to worsening CHF. Ideally, she would be able to read a text summary of his CHF course and open a visualisation of medications, clinical assessments of New York Heart Association (NYHA) functional class, weight, blood pressure and gain access to reports of non-invasive diagnostic studies such as echocardiograms. We illustrate a combined data visualisation and CHF-based text summary in the Outputs section.

These five clinical scenarios illustrate common situations in primary care. Unlike intensive care settings, in which physicians review dense, uniform data over short periods, primary care physicians must review sparse, incongruous data spanning many years.

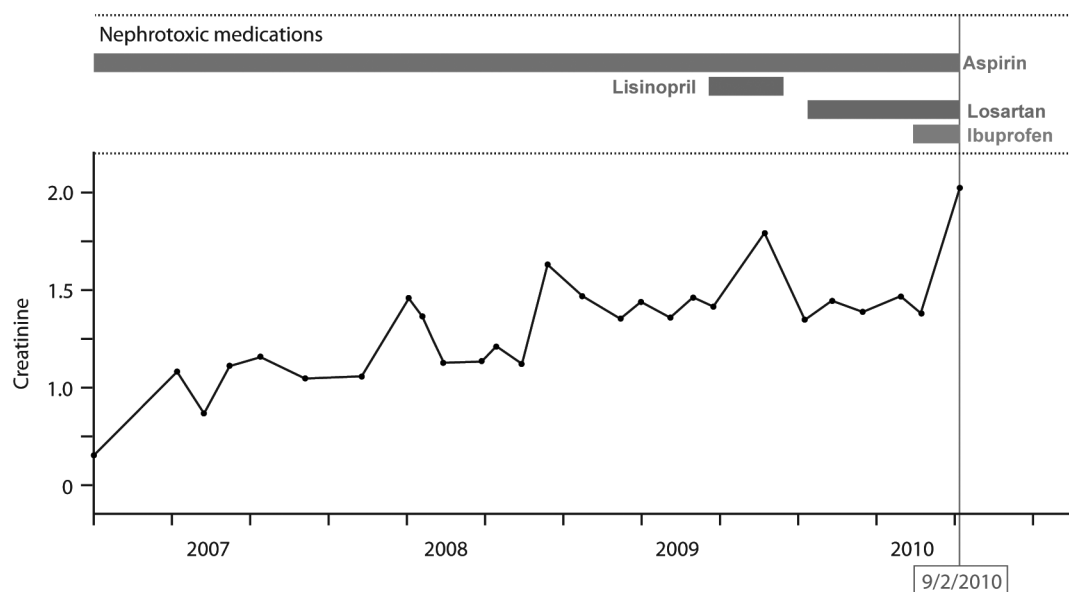
Outputs

In this section, we review the current method of longitudinal data review in each scenario and provide a figure illustrating an innovative temporal data view.

Scenario 1: Diagnosing the cause of gout flare using a visualisation of creatinine peaks

Mr Taylor's gout flare could be related to renal function. Knowing this, his PCP decides to examine how Mr Taylor's serum creatinine has changed over time. The EHR displays a flowsheet of results from basic metabolic panels. She must scroll through multiple screens to find his last high creatinine value. She then must close the lab results section of the chart in order to open his medication list and display all of his past medication changes. She is not able to quickly determine that his last creatinine rise was related to medication changes and also does not notice that he has recently been started on a new nephrotoxic medication.

With a temporal data view, Dr Phair would be aided in the task of finding pertinent information. Using the data visualisation in Figure 1, she realises that Mr Taylor's last creatinine peak coincided with the addition of Lisinopril in 2009 and that his creatinine improved when Lisinopril was stopped. She also realises that his current spike in creatinine coincides with the addition of Ibuprofen. She concludes that this new medication may be contributing to his problem by



reducing his creatinine clearance. She discontinues it and substitutes Acetaminophen.

Reviewing this data visualisation is more efficient than chart review because the graph condenses more data onto one screen compared with a flowsheet and juxtaposes nephrotoxic medications with laboratory data.

Our proposed improvement in Scenario 2 includes both a data visualisation and actionable clinical decision support to remind the PCP of an appropriate next step.

Scenario 2: Diagnosing chronic kidney disease using a visualisation of change in rate of glomerular filtration decline

When Mr Taylor returns for his physical, Dr Phair checks under the lab results tab to make sure that his creatinine improved after the gout flare. She does not notice that he is rapidly approaching chronic kidney disease.

With an improved temporal data view, Dr Phair would be able to synthesise data about his mild chronic kidney disease. This data visualisation plots his trend in estimated glomerular filtration rate alongside a plot of expected change due to rising age alone, which is derived from population data (Figure 2). Although he has not yet crossed a predefined threshold for stage 3 chronic kidney disease, she sees that his renal function has declined substantially from his own baseline and from the population trend. In this case,

the interface not only shows her the pertinent information, but also provides a link to an actionable order to check for proteinuria. A positive proteinuria test classifies him as having chronic kidney disease, she institutes measures to delay progression of chronic kidney disease, and his condition stabilises.

This type of data visualisation raises the awareness of a change from baseline, provides clues to potential causes, and may make providers more likely to use clinical decision support, which has been cited as a barrier to quality improvement.¹¹

Similar to Scenario 2, the outcome of Scenario 3 would be improved with a data visualisation and illustrates the potential for patient-specific alerts.

Scenario 3: Respecting patient end-of-life wishes using a visualisation of weight loss

Dr Holtzman was unable to follow Mr Radley's wishes because it was difficult to detect a change in status. A temporal data display could be customised to include the data he needs to recognise a change in status, for example, with a graph of weight loss including a pre-specified alert (Figure 3). The data visualisation makes it clear to Dr Holtzman that Mr Radley is declining rapidly and, after checking for reversible causes, he refers him to hospice.

Scenario 4 illustrates how inefficient source-oriented review is when a provider is searching for data from different sources over a long period of time. Unlike the preceding scenarios, Scenario 4 does not

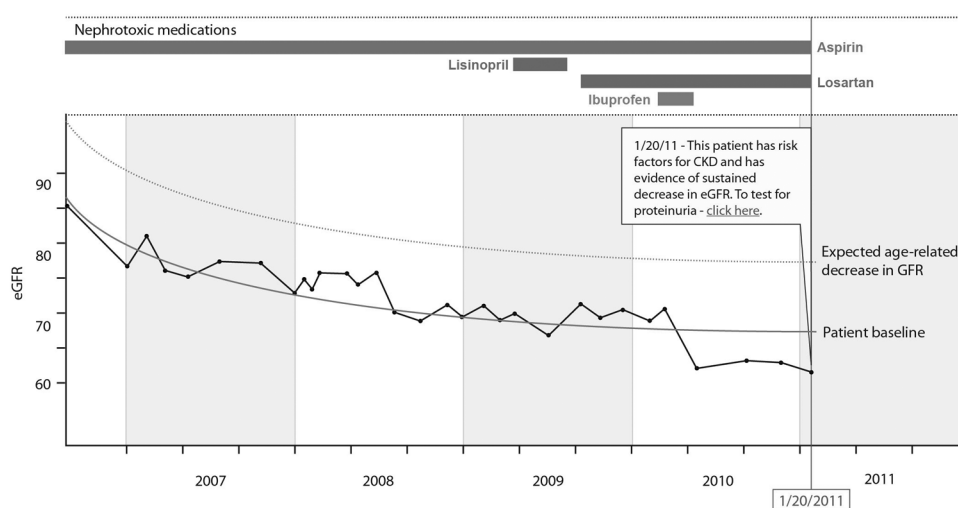


Figure 2 Visualisation of rate change, benchmark data, nephrotoxic medications, actionable order. The benchmark data of expected age-related change in glomerular filtration rate makes it clear that not only has there been a gradual decline in renal function, but it is greater than that expected due to age alone. A stacked timeline infers that the Ibuprofen was likely the inciting event. Clinical decision support with an actionable order is embedded directly into the visualisation

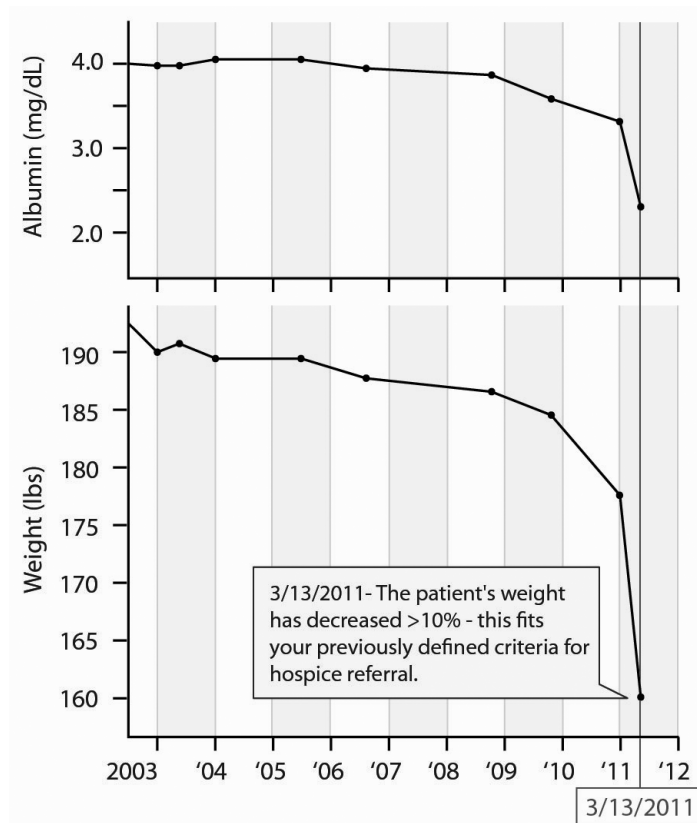


Figure 3 Visualisation of weight loss. An individualised display alerts Dr Holtzman to the fact that the rate of weight loss has accelerated

lend itself to data visualisation because the information is not numeric. A potential improvement is a diagnosis-oriented text summary.

Scenario 4: Using a disease-oriented text summary of low back pain data to approve a request for an MRI

In most EHRs in use today, Dr Mackay would need to open the radiology section to review previous back imaging. He would then check the notes section and go to multiple notes searching for mention of low back pain. Eventually he would see that he has referred Mrs Hyatt to physical therapy and then neurology.

In an EHR with improved temporal data views, Dr Mackay would be able to click on 'low back pain' from her problem list. All information pertinent to an evidence-based work-up of low back pain would be included in one temporal data view. He would be able to see excerpts of text by rolling over each note and quickly determine that an MRI is indicated (Figure 4).

Dr Mackay may come to the same decision in this case, but since he is able to locate information more efficiently, this tool may also help him to decrease

unnecessary utilisation. Also, another member of the team could use this tool to gather appropriate information for him or for a prior authorisation request to an insurance company.

Currently, the design and implementation of such a summary would require free text searching, but in the future, EHRs could be designed to produce diagnosis-oriented data displays by tagging all patient data with diagnosis-oriented metadata.

Another opportunity to reduce healthcare costs and improve quality of care is illustrated in the following scenario with a data visualisation and a CHF-oriented text summary.

Scenario 5: Determining the cause of hypotension using a visualisation and text summary for CHF

Although the visiting nurse reports that Mr Davis is not symptomatic with his low blood pressure, Dr Floyd is too unfamiliar with his case to feel comfortable waiting for a routine follow-up visit.

The situation would be improved with a temporal data view specific to CHF (Figure 5). Dr Floyd would

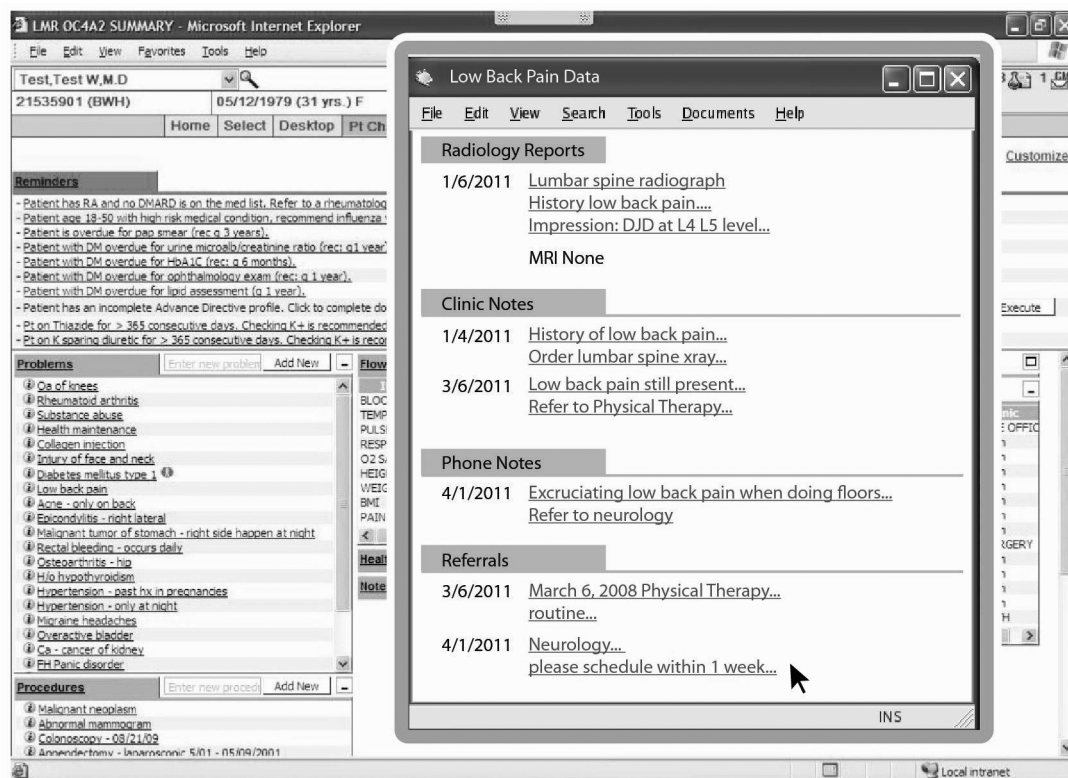


Figure 4 Disease-oriented text summary. Dr Mackay may access diverse data using hyperlinks to the original document. The temporal data view improves efficiency of navigation and may impact MRI utilisation

be able to open the temporal data view while speaking to the nurse. The brief text summary at the top of the figure tells her that, 'This is a 76-year-old man with ischemic cardiomyopathy resulting from a myocardial infarction on March 13, 2008. His most recent systolic ejection fraction was 25% as measured by echocardiogram on September 28, 2010. He is NYHA Class II. He has declined an implantable cardioverter defibrillator'. She would quickly note that his NYHA class has recently increased, which indicates a recent decompensation, and that he was subsequently started on Spironolactone. She believes that this contributed to his current low blood pressure. She stops this new medication, he does not go to the emergency department, is not readmitted, and is able to attend his next scheduled clinic visit with his PCP as planned.

In this case of an abrupt change in patient status, the temporal data view helped the physician to identify a potential cause. We propose that EHRs should be designed to produce such disease-oriented text summaries for all chronic diseases.

If we solve the problem of data overload in primary care, we may be able to provide real value to the healthcare system and society. Temporal data views such as the ones we have illustrated are appropriate to the task, but are not yet commonplace in primary care settings.

Discussion

Principal findings

We have explained that the management of chronic diseases can be complex using five clinical scenarios. We have illustrated five temporal data views that can assist physicians by providing pertinent information. In these scenarios, improvements in the representation of longitudinal data led to improvements in healthcare costs, efficiency and quality. EHRs can be used as tools for analysis and we should leverage these capabilities in clinical care.

Implications of findings

Poorly designed EHRs have unintended consequences including cognitive overload during clinic visits and increased workload for PCPs. In the USA, the meaningful use criteria promote patient-centredness and the ability to produce chart summaries, both of which depend on the ability of EHRs to not only retrieve vast quantities of data, but also to synthesise it in ways that make it useful for physicians and patients.²³ Diagnosis-oriented text summaries could be a key platform

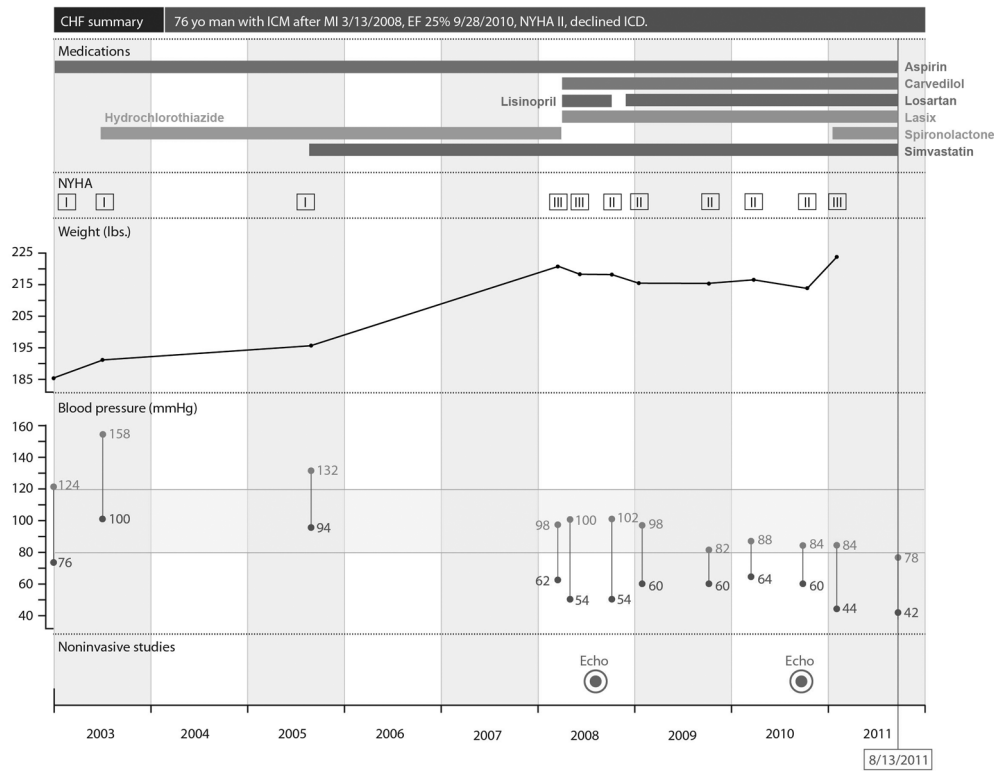


Figure 5 Visualisation and disease-oriented text summary. A CHF temporal data view brings together diverse data in anticipation of changes in patient status so that Dr Floyd is able to manage the patient as if she were his PCP. She is aided by a succinct one-line text summary at the top of the display and links to pertinent information such as echocardiogram reports

for co-management in accountable care organisations so that the responsibility for appropriate test utilisation may be shared between primary care and specialist providers. Such a tool could also be designed to anchor the patient data to a clinical algorithm, thereby driving practice improvement.

Comparisons with the prior literature

Medical informatics studies have established that current human–computer interfaces adversely impact provider efficiency while reviewing patient data.^{24–26} A seminal work in the area of temporal data representation was the LifeLines project which was first reported over a decade ago and was the first to present data visualisation as a solution to longitudinal data needs.¹⁹ This system and others were designed for clinical research informatics and have not been widely adopted in clinical care settings.^{27–29} Only two systems have been designed to display longitudinal data

filtered by diagnosis; both display anti-hypertensive medications alongside blood pressure measurements.^{30,31} A tool for reviewing laboratory results has been developed at Regenstrief Institute and presents information such as historical test results, medication-dispensing events, visit information and clinical reminders.³² However, there is not yet widespread implementation of such tools.

Limitations of the method

Our theory has not been tested with empirical research. There may be other conditions that are more costly or more profoundly impact a patient's quality of life than those we have used to illustrate temporal data views. A time–motion study may identify other management scenarios that are time-consuming and would benefit from such views. A qualitative research study might identify different provider preferences for temporal data views.

Call for further research

Academic researchers should pursue research to improve longitudinal data management. EHR vendors for primary care EHRs may not have the capacity or market to develop highly innovative solutions. Both clinical decision support and population disease registry functions may improve care and they will likely be accompanied by team-based care and payment reform. If accountable care organisations are to be successful, they will need to improve co-ordination of chronic disease management across settings, perhaps through care redesign efforts such as patient-centred medical homes.^{33,34} Accountable care organisations would represent an ideal environment for trials of such tools in chronic disease management. A variety of approaches should be evaluated and the most valuable ones should be incorporated in new EHRs.

Conclusions

PCPs need better tools in order to improve longitudinal chronic disease management. We propose that incorporating temporal patient data views into EHRs will reduce costs and improve efficiency and quality of care.

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CONFLICT OF INTEREST

None.

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Accepted September 2011