Interoperability and Patient Electronic Health Record Accessibility: Opportunities to Improve Care Delivery for Dialysis Patients

Yvelynne P. Kelly, Gilad J. Kuperman, David J.R. Steele, and Mallika L. Mendu

Patients with kidney failure requiring dialysis often receive fragmented care, hindered by disparate primary care, specialist, hospital, and dialysis facility electronic health record (EHR) systems. In this editorial, we present an example of the siloed care that may result from interoperability limitations, examine the current state of care delivery fragmentation in dialysis, and advocate for increased interoperability in dialysis patient care.

In our example case, a 60-year-old African American requiring maintenance hemodialysis (HD) presents to an emergency department (ED) with shortness of breath due to pneumonia. This hospital does not have a shared EHR with her outpatient dialysis facility, so data from that facility are not available to her hospital providers. She receives a generic HD prescription with goal fluid removal to an undefined dry weight and workup for anemia. Her dialysis treatment is complicated by severe cramping. Ultimately, following contact with her dialysis facility, important details are conveyed: her dry weight was recently adjusted; ultrafiltration has been challenging, and she is on cooled dialysate with higher than typical dialysate calcium concentration; and blood work was performed last week, with similar results to those in the ED. This leads to significant frustration for the patient given that she has experienced a complicated dialysis treatment and unnecessary testing.

In February 2019, the Centers for Medicare & Medicaid Services (CMS) proposed an updated policy to improve patient access and advance electronic data exchange throughout the US health care system. The goal is to make patient data transferable through open secure standardized formats. They proposed care coordination through “trusted exchange networks by integrating more plans and healthcare providers into these networks nationwide.” Notably, dialysis patients and providers are not specifically referenced, which is a missed opportunity.

Interoperability is crucial for all dialysis patients—in-center HD, home HD, and peritoneal dialysis—given the fragmentation of data among various sites of care, including primary care providers, home, dialysis clinics, other specialists, and hospitals. Gaps in dialysis patient care can lead to missed opportunities for clinical intervention and to increased health care utilization, specifically hospitalizations, ED visits, and prolonged lengths of stay. More than half (55%) of dialysis patients visit an ED during their first year of dialysis, with most having 2 to 3 such visits per year in their first 3 years of dialysis.

Frequent hospital readmissions contribute to both high mortality rates and poor health-related quality of life. The dialysis population is particularly vulnerable to fragmented information transfer in the setting of frequent transitions of care. Fragmentation is associated with an increased risk for infections and emergency admissions for patients with chronic diseases. Substantial care coordination gaps exist due to lack of interoperability, resulting in barriers in our ability to transfer information and facilitate transitions, essential elements in care delivery for dialysis patients.

Treating patients without complete information can increase the opportunity for medical errors, duplicative laboratory tests and procedures, and increased health care costs. The opportunities to improve care through health information exchange (HIE) were noted in the mid-2000s when a focus on health information technology began to take hold. Kaelber and Bates identified key areas in which HIE can improve patient safety, including improved medication, laboratory, radiology, and public health information processing and improved provider-patient and provider-provider communication. To date, there has not been a comprehensive assessment of the challenges and potential solutions in achieving interoperability for dialysis patients. As detailed in Table 1 and summarized next, several barriers have prevented interoperability for dialysis patients. However, these are potentially surmountable with technological innovation, policy changes, and improved patient engagement.

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Interoperability Incentivization and Information Blocking

The US Health Information Technology for Economic and Clinical Health (HITECH) Act promoted EHR adoption nationally. However, HIE has not become commonplace. As of 2012, a total of 63% of physicians were using faxes as a primary means of information transfer; this rings true for many dialysis providers. Although EHRs have now been widely adopted, there is no standard interoperability format for sharing data. Also, the standpoint of organizations treating data as a strategic asset has resulted in “information blocking,” with providers and vendors tacitly interfering with exchange of health-related information. Examples include EHR products designed not to interact with other technologies and requirements for health care providers to adopt one specific EHR technology.

CMS has taken steps to incentivize coordination between disparate dialysis stakeholders, namely through the Comprehensive End-Stage Renal Disease Care model of the Affordable Care Act, which incentivizes partnerships between dialysis units and other providers to reduce utilization. Success in this model relies on timely inter-provider communication. Interoperability is not directly incentivized, but dialysis units, providers, and hospitals that take steps toward HIE are more likely to succeed. Similarly, the Advancing American Kidney Health Initiative, launched in July 2019, espouses enhanced coordination to facilitate home dialysis and kidney transplantation, with the success of new payment models reliant on improved coordination, thereby offering indirect incentives promoting interoperability. Critically, of dialysis providers participating in the models, those that embrace interoperability will be better positioned to achieve financial success, particularly in shifting care delivery to more home care.

We advocate for CMS and policy makers to directly incentivize interoperability for dialysis patients, similar to the Promoting Interoperability programs that are in place for hospitals (through the Medicare Hospital Inpatient Prospective Payment System) and clinicians (through the Merit-Based Incentive Payment System). These programs include measures such as “support electronic referral loops by sending health information” and “provider to patient

Table 1. Challenges and Solutions for Improving EHR Accessibility for Dialysis Patients

<table>
<thead>
<tr>
<th>Challenges</th>
<th>Implications for Dialysis Patients</th>
<th>Proposed Solutions</th>
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<tbody>
<tr>
<td>Insufficient incentives to advance interoperability and address information blocking</td>
<td>• Difficulty sharing health care data between different settings, contributing to increased health care utilization, unnecessary repeat procedures, and potential adverse events</td>
<td>• Direct financial incentives for interoperability included in AAKH CMMI models and/or future iterations of the ESRD CEC model</td>
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<td>Technical and financial barriers</td>
<td>• Lack of standardization of dialysis patient data, poor data quality, and inadequate ability to match patients and providers across organizations</td>
<td>• Development of FHIR-based open standard APIs by the ONC</td>
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<td>Patient perceptions of HIE</td>
<td>• Costs to providers and vendors of updating and maintaining interoperable systems</td>
<td>• Payer + Provider (P2) FHIR Task Force (2017-2020) to improve the environment and infrastructure for adoption of interoperability</td>
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<td>• Worries regarding privacy and security of data being shared</td>
<td>• Blue Button 2.0 allowing Medicare beneficiaries to control and link their own claims to other applications, services, or research programs</td>
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<td>• Concerns regarding increased use of health IT for those who are not computer literate</td>
<td>• Financial incentives for EHR vendors to adopt FHIR technology</td>
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<td>The current landscape of dialysis care EHRs</td>
<td>• Multiple vendors and platforms used by varied large and small dialysis organizations</td>
<td>• Increased education regarding benefits of data interoperability</td>
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<td>• Confusion and information gaps when patients from a single dialysis unit attend multiple hospitals, and when a hospital receives patients from multiple dialysis units</td>
<td>• Increased education regarding privacy and security of data being transferred</td>
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<td>• Improving interprovider communication by expanding existing trusted HIE networks</td>
<td>• User-friendly patient portals</td>
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<td>• Creating new HIE networks that incorporate large dialysis organizations (eg, the eHealth Exchange)</td>
<td>• Electronic consent simplification for patients who are not computer literate</td>
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<td>• Support for TEFCA, to minimize the need to join multiple exchange networks</td>
<td>• Consumer councils to voice concerns and aid customization of user interface</td>
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Abbreviations: AAKH, Advancing American Kidney Health; API, application program interface; CMMI, Center for Medicare and Medicaid Innovation; CEC, comprehensive end-stage renal disease care; CMS, Centers for Medicare & Medicaid Services; EHR, electronic health record; ESRD, end-stage renal disease; FHIR, Fast Healthcare Interoperability Resources; HIE, health information exchange; IT, information technology; ONC, Office of National Coordinator; QIP, quality incentive program; TEFCA, trusted exchange framework and common agreement.
exchange.” Financial incentives could be included in the Advancing American Kidney Health Center for Medicare and Medicaid Innovation models or the End-Stage Renal Disease Quality Incentive Program, with clearly defined metrics regarding exchange of data. Given the technical and financial barriers, we would advocate for incentive payments as opposed to penalties. Notably the 21st Century Cures Act prohibits and penalizes information blocking when “knowing and unreasonable interference” has taken place.12

Technical and Financial Barriers

The 2018 Report to Congress by the Office of the National Coordinator (ONC) for Health Information Technology outlines current technical barriers to health data sharing.11 They include lack of standardization of electronic health information, varied data quality, and the inability to match patients and providers across organizations. In addition, financial barriers hindering interoperability are identified, including significant costs to develop, implement, and optimize EHRs to meet frequently changing needs of health systems.

The ONC is encouraging the advancement of Fast Healthcare Interoperability Resource (FHIR)-based application programming interfaces (APIs) by making APIs part of the definition of “certified EHR technology.” FHIR is an evolving standard that presents health care data in a way that is easier for providers to share, while APIs allow an application to access data from another application. ONC has convened a Payer + Provider FHIR Task Force focused on optimizing the infrastructure for wide-scale adoption of interoperability, using FHIR-based open source solutions. This includes Blue Button 2.0, an API enabling access to Medicare claims data. Applications that make use of Blue Button 2.0 can empower Medicare beneficiaries by giving them access to their own claims data. The efforts of the ONC are a step in the right direction, but EHR vendors must also embrace FHIR technology development.

Patient Perceptions of HIE

Patients’ comfort with the exchange of health information is affected by perceived benefits and concerns associated with the use of HIE.13 Privacy and security concerns can be mitigated by more robust patient engagement. Notably for dialysis care, racial minorities are likely to have greater concern about sharing information with HIE.14

Patient education should describe potential benefits of HIE, including expedited care, higher quality care, and lower medical charges.15 For those expressing privacy and security concerns, education needs to be provided about the authorization process and patients’ rights. Consumer councils should be developed so patients can voice concerns. Electronic consent needs to be optimized and made user friendly, particularly for those less familiar with information technology.16

The Current Landscape of Dialysis Care EHRs

Large dialysis organizations frequently use their own proprietary EHRs, while smaller dialysis organizations rely on a variety of commercially available EHRs.17 Given that the current landscape for dialysis patients involves a myriad of vendors, information gaps arise when patients from a single dialysis facility visit multiple hospitals and also when a hospital receives patients from multiple dialysis facilities.

Many health care provider organizations belong to HIE networks.18 Fragmentation of care for dialysis patients could be mitigated if dialysis organizations, nephrologists, and hospitals were to participate in these emerging models of HIE. Efforts have already been made, such as the eHealth Exchange, which now connects 5,200 dialysis facilities to 70,000 medical groups and 75% of US hospitals as part of a data use and reciprocal support agreement.19 Currently, to exchange data with all “information trading partners,” providers may need to belong to more than 1 exchange network. To address this problem, the federal government is advancing the idea of a “Trusted Exchange Framework and Common Agreement,” which would allow networks to share data with each other.20

In summary, the CMS Interoperability and Patient Access Rule seeks to advance electronic data exchange by making patient data more transferable. This is particularly applicable to dialysis given the existing fragmentation of care in this complex patient population. In our example case, improved interoperability would allow for immediate access to dialysis prescriptions and laboratory data to facilitate decision making and avoid unnecessary repeat testing. In addition, the hospital should be able to share vital information with the dialysis facility regarding discharge orders. Emerging HIE should be used to maximize interoperability between all stakeholders to optimize dialysis care.

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