The Time is Now: Informatics Research Opportunities in Home Health Care

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Home health care (HHC) agencies face numerous challenges as they care for sicker patients due to shortened hospital stays and the discharge of patients before they are able to care for themselves.[1] The agencies face rehospitalization penalties,[1,2] shortened episodes due to payment reform via the Patient-Driven Groupings Model,[3] and other pressures regarding quality and efficiency.[4] More recently, agencies face increased financial pressures due to reduced admissions, patient refusal of services, and costs for personal protective equipment due to the COVID-19 pandemic.[5,6]

These challenges call for the productivity and quality gains offered by health information technology (HIT).[7,8] While over 11,800 Medicare-certified HHC agencies[9] provide valued care across the United States, HHC, and other post-acute care settings were unfortunately omitted from Meaningful Use regulations requiring basic HIT functionality.[10] Thus, progress in supporting smooth information transfer and associated decision support lag behind acute and ambulatory care. While the Office of the National Coordinator for Health Information Technology initially funded longitudinal care coordination and electronic health information exchange (HIE) standards development for HHC, the funding was discontinued to address national health information network-to-network exchange.[11] This is unfortunate because the networks rarely include HHC agencies.

Current applications that are integrated into hospital electronic health record systems (EHRs) cannot be repurposed for HHC due to the unique home environment. Unlike in acute care settings, HHC clinicians operate independently under physician orders, to function effectively they need information to make specific decisions while in the home, and they often lack stable access to the internet.

The purpose of this editorial is to highlight for the health informatics community specific HHC informatics challenges to encourage more HIT development in the fast growing health care sector caring for disabled and vulnerable aging populations. Current HHC point-of-care EHR functionality tends to focus on the documentation of clinical data for reimbursement and compliance, requiring extensive (sometimes duplicative) data entry burdens. HIT solutions are needed to enhance data access, data processing and analysis, and information representation to increase efficiency, accuracy, and effectiveness. Although some state-of-the-art HHC HIT systems may enable interoperability of demographics and medication lists from hospital EHRs,[12] or documentation

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Table 1 Scenario of the informatics challenges during the transition and admission process from acute care to home health care

Mrs. Jones, 70-year-old, is discharged from hospital to home where she lives alone. Like most older adults, she has multiple chronic conditions and takes more than 12 prescribed and over the counter medications. Upon hospital discharge, she is given a paper discharge summary. The HHC agency—lacking interoperability with the hospital—receives referral documents consisting of 40 pages without a standardized format, content, or computability. With this information and without associated decision support, agency staff tries to identify high-risk patients to be scheduled for admission visits within 24 to 48 hours by the nurse.
To prepare for the first visit, and in the anticipation of unreliable internet service in the patient home, the nurse works at home the evening or morning before the visit to peruse through the 40 pages of referral documents. Lacking guidance from a comprehensive problem list or decision support integrated into the EHR, the nurse tries to discern from among the many chronic conditions and acute exacerbations which problems are active, resolved, or potential to determine the focus of the HHC episode.
The nurse enters the home, hopeful to find an uncluttered place to sit, and place her laptop. Because of the patient's fatigue from her hospital stay and self-care demands, the nurse has limited time (usually 1 hour) to:
(1) Gather the information to answer the Centers for Medicare and Medicaid Services mandated 90 question admission assessment (OASIS)
(2) Conduct a physical assessment and assessment of the home environment
(3) Find the prescription and over the counter medications in the home and reconcile them with the hospital discharge medication list located in different documents
(4) Call the physician or pharmacy to resolve medication discrepancies and potential adverse effects
(5) Assess Mrs. Jones' medication self-management capability
(6) Determine which of Mrs. Jones' many problems spread across different documents and identified during the assessment to include on the HHC plan of care
(7) Recommend to the HHC care team which, if any, other HHC services Mrs. Jones needs (e.g., physical therapy)
(8) Check the current and trended vital sign data on Mrs. Jones' home blood pressure monitor
(9) Educate the patient and/or caregiver in how to access current and trended vital sign data
(10) Elicit from Mrs. Jones her upcoming medical appointments, negotiate with her the timing and frequency of follow-up nursing visits, and schedule these appointments
(11) Document these aspects of the admission in the EHR. The nurse leaves to see five more patients for follow-up visits scheduled for that day, and Mrs. Jones tries to get some rest.
At the end of the day, the nurse, now at home with reliable internet access and remembering to check for a reply from the physician about the medication issue, finalizes the admission. Completing the documentation will entail transcription of information from hospital referral documents and duplicative data entry. Team members who will subsequently visit Mrs. Jones will now be able to see the plan of care and summary note.
The admission documentation will also be reviewed by additional agency staff to assure internal consistency for reimbursement, in lieu of clinical decision support, as the nurse documents. Further analysis of the data collected and noted by the nurse to proactively identify clinical trends or identify cohorts for care management is not possible as important data are stored as text, and the EHR lacks the needed HIT tools for synthesis and reporting.
The agency, seeking new knowledge while ensuring patient privacy, seeks to provide de-identified structured data (e.g., OASIS data) to researchers who use statistical or machine learning techniques to help them prioritize patient visits for the rest of the week.

Abbreviations: HHC, home health care; HIT, health information technology; EHR, electronic health record; OASIS, Outcome and Assessment Information Data Set.
Note: Fictional patient names used.

using clinical guidelines, these capabilities are not universal and do not address the range of capabilities needed.

The scenario in ►Table 1 illustrates the informatics challenges present during the transition and admission process from acute to HHC and to set the stage for discussion regarding needed HIT solutions. Then the authors discuss major HIT challenges at the health care system level (interoperability and data standardization), at the HHC agency level (data analytics), at the clinician level (workflow and human factors), and at the society level (patient access and privacy).

Health System Level Challenge: Data Acquisition

Interoperability

The ►Table 1 scenario highlights the nurse's inability to have the information needed readily available to support decision-making. In a study examining three different electronic health record (EHR) systems, problems and medication information, if communicated from referring site to HHC, were scattered across pages of printed or scanned referral documents, thus forcing nurses to search the EHR for them.[13]

Interoperability would address this issue of information scatter. Here we utilize a widely used interoperability definition: the "ability to correctly interpret data across information systems or organizational boundaries."[14] The patient's clinical information did not arrive in an organized, usable format: a pervasive HHC issue. A survey of 17 leading HIT organizations found no examples of interoperability between acute and postacute settings, and reported that this absence forced clinicians to perform clerical work such as transcription.[15]

Despite the existence of data communication exchange standards, interoperability deficits persist due to the absence of policies to support adoption in HHC.[16] For example, the Continuity of Care Document (CCD) is an existing health level 7 (HL7) communication exchange standard, which contains most of the clinical data needed by HHC nurses including problems and medications with the exception of patient medication self-management capability information.[13] However, the CCD—intended to be generated at hospital discharge—is not mandated to be transmitted to HHC and therefore is rarely sent, and, if received, is sent as a static PDF (personal communication with leading HHC EHR software vendor) that is not structured or interoperable data.

The absence of policies to support data communication exchange standards in HHC is also an impediment to the use of third-party applications to transfer information to HHC EHRs. The adoption of available standards such as the next generation interoperability standards framework, HL7 Fast Healthcare Interoperability Resources (FHIR) will facilitate implementation of external applications into EHRs.[17]

Structured data comprise a set of records, each with a set of fields of defined data types. Text can be extracted from a PDF file by using tools such as Apache PDFBox[18]; can be preprocessed by using tools such as tokenizers, filters, and annotators; and then can be indexed to support search. But a busy clinician cannot stop—and should not be expected to stop—to use these tools, nor are these tools available on hand-held devices such as tablets.

Two recent interoperability mandates also overlook HHC. The Improving Medicare Post-Acute Care Transformation (IMPACT) Act of 2014 specifies structured communication standards for quality and assessment measures among long-term care hospitals, skilled nursing facilities, HHC agencies, and inpatient rehabilitation facilities,[19] not between hospitals and HHC. The new Centers for Medicare and Medicaid Services (CMS) standard, U.S. Core Data for Interoperability, is an interoperable HIE dataset intended for third parties including HHC. However, implicit for interoperability is HIE participation which tends to exclude HHC. In response to these missed HHC interoperability opportunities, we recommend informatics research to investigate interoperability standards (►Table 2) and promote policy changes to support HIE in HHC.

Table 2 Summary of research recommendations by domain

Domain	Research priority recommendation
Interoperability	• Investigate the applicability of interoperability standards (e.g., continuity of care document, U.S. core data for interoperability) for transitions in care to community settings and make related policy recommendations to standard-setting organizations • Assess the efficacy of implementation of interoperability standards in regards to patient outcomes and clinician workflow
Standardization of patient data	• Identify and evaluate a parsimonious set of data elements to be communicated to HHC from the referral source. These data elements should include historical and current medical and psychosocial information, medications, caregiver details, and functional status. Make related policy recommendations to standard-setting organizations • Apply and test the use of standardized terminologies for transitions in care to promote structured exchange and measurement of information • Examine the impact of HHC nurse access to structured data as compared with nonstructured data
Natural language processing	• Develop or adapt to the HHC domain, and apply natural language processing tools to parse interoperable text data and clinician-entered data to create structured data
Clinical decision support	• Identify areas where clinical decision support tools can have the largest impact on patient outcomes in HHC • Develop and assess the impact of clinical decision support tools integrated into HHC workflows • Develop and test implementation strategies to integrate and scale clinical decision support tools into diverse HHC EHRs
Predictive analytics	• Build and test predictive models for better care coordination, utilization outcomes, provider, and patient satisfaction • Qualitatively study the contextual characteristics of decision making in HHC and build and test models accordingly (e.g., by balancing model complexity and interpretability as needed)
Workflow support/ human factors	• Adapt best practices for the application of user-centered design that address the constraints of HHC environments • Design portable, hygienic, secure, and efficient devices/methods for EHR data entry and data retrieval • Develop visualizations for accurately and efficiently communicating information to support nurse decision-making
Privacy and security	• Explore data sharing and publishing opportunities via data de-identification that complies with privacy constraints to facilitate predictive analytics • Build information privacy and security into the design of healthcare systems and software • Reserve IT budgets for continuous assessment of information privacy and security risks along with mitigating and eliminating those risks

Abbreviations: HHC, home health care; EHR, electronic health record.

Standardization of Patient Data

Clinical data received by HHC admission nurses from referrers are not always targeted nor sufficient for their information needs. The different perspectives[20,21] (i.e., acute vs. chronic care and medical vs. nursing diagnoses) between the referring and HHC sites impact the information each site collects, produces, and shares.[20] HHC needs a comprehensive summary of patient needs and history from the referral source,[13] written using standard terminology which enables the information to be interoperable and retrievable. Innovative methods and further research are needed to determine whether the current user interface standardized terminologies, such as the Omaha System which is used in community-based settings,[22] are adequate and appropriate for transitions in care. Previous work on this topic was a small study completed 20 years ago.[23] Data communication, reporting, and analytics could be greatly enhanced by electronically mapping user interface terms from both the referral source and HHC to a reference terminology, such as the Systematized Nomenclature of Medicine: Clinical Terms (SNOMED-CT). For example, this work has begun in Denmark, where the focus is on patient problems. Research should address the HHC need for comprehensive, structured, and formatted information to support patient care in the home, as specified in ►Table 2.

Home Health Care Agency Level Challenge: Data Analytics

Natural Language Processing

A portion of HHC referral and admission data are unstructured and free text (including for example care and follow/up recommendations section of hospital discharge summaries) which presents data analytic challenges.[13] An exception is the standardized Outcome and Assessment Information Data Set (OASIS)[24] used by CMS and others for quality measurement, care improvement,[25] research,[26,27] and identification of hospitalization risk factors.[28]

Unstructured narrative data are included in nursing, therapy, and social work visit notes, care coordination documentation, and clinical notes from referral settings (e.g., discharge summaries). NLP can identify information within the documentation to understand and address unique patient care challenges such as risk factors for patient hospitalizations and emergency department visits[29] and provider communication to support care coordination.[30] Pioneering studies include extracting fall-related information,[31] recognizing sexual orientation and gender identity,[32] and exploring failed communication attempts between HHC nurses and physicians.[33] However, the application of NLP in HHC is nascent and it is unclear whether current NLP methods are able to process HHC data effectively. More NLP development and testing in HHC are needed to extract useful EHR narrative information to support patient care.

Clinical Decision Support

CDS tools use structured data to provide clinicians, staff, patients, or other individuals with knowledge and person-specific information, intelligently filtered or presented at appropriate times, to enhance health care.[34] Such tools are becoming increasingly prevalent in inpatient settings, with some providers having used CDS tools for several decades (e.g., physician order entry systems).[35] In HHC, CDS tools can help the nurse in ►Table 1 prioritize Mrs. Jones's visit based on her unique clinical characteristics documented in structured interoperable data. Topaz et al suggest that patient prioritization with CDS has the potential to significantly reduce rehospitalizations.[36,37] For example, CDS tools can help nurses identify patients who are deteriorating during the HHC episode and should be prioritized for timely nursing interventions. In addition, CDS tools can help identify patients who experience lack of social support and connect them to social services, such as meals, housing, or financial support. However, validated and well-studied HHC CDS tools are rare, and more research is urgently needed to develop and test CDS impact on improving decision-making[38] and patient outcomes.

Predictive Analytics

Recent changes in CMS policies about value-based reimbursement and the Patient-Driven Groupings Model[3] drive industry competition and cost containment by continuously demanding improved effectiveness and efficiency from HHC providers. Availability of structured data presents research opportunities to explore potential HHC clinical and administrative improvements by building models that predict future outcomes. For example, Koru et al application of a tool to predict unplanned emergency room visits[37] uses statistical techniques[39,40] to build interpretable models of relationships between a set of predictors and the outcome. Additional predictive analytic applications include: logistic regression analyses to predict falls[41,42] and live discharge from home-hospice[43]; and machine learning to streamline documentation,[44] and predict falls[45]; along with discriminant analysis to predict patient satisfaction.[46] HHC machine learning examples, while infrequent, are increasing, due in part to these analytic methods' ability to adapt to various data patterns and distributions with minimal human intervention. Examples include Bowles et al use of penalized logistic regression and regression trees to predict referral to HHC[47]; use of lasso regularization of Generalized Linear Models predicting maternal risk among HHC patients[44]; and use of gradient boosted trees, random forests, and neural networks predicting HHC patients' hospital and emergency department utilization.[48] In the HHC future, the development and adoption of predictive models can substantially increase our understanding of the relationships among clinical data and outcomes, and improve the ability to make predictions and apply the resulting innovative models to support decision-making and achieve better care, improved outcomes, and reduced costs.[49] Accordingly, HHC researchers and professionals should continue to focus on improving the data standards for these models, predictive performance and model interpretability, as well as how to apply models to facilitate human judgment and decision making. Continuously building models in different locales and sharing the performance results would contribute to a potentially generalizable body of knowledge leading to the development and use of even more optimized models in the future.

Clinician Level Challenge: Work Flow Support/Human Factors

The nurse in ►Table 1 encountered workflow issues including having insufficient information at the first home visit, an inability to find a clean, uncluttered place to set up a laptop, the need for redundant data entry, and lack of task management support (e.g., track phone calls to physicians). These issues cause the nurse to spend time finding, eliciting, and documenting information, including making telephone calls to physicians and pharmacists.[12] These workflow issues persist in HHC EHRs despite work done over 10 years ago on the human (recipient, provider), task, technology (including HIT), and environmental factors influencing HHC effectiveness, quality, and safety.[50] At that time, funded workshops and consensus studies[51,52] highlighted the need to explore HHC issues from a human factors perspective and to make recommendations for improving care provided in the home.[53]

While end user involvement in the development of health-related technology is a growing trend,[54,55] and novel methods continue to be introduced to improve the process[56,57]; the pace at which human factors methods and knowledge are being integrated into HIT could be increased. Regarding technology, limited strides have been made regarding requiring the application of user-centered design and validation methods during EHR development and certification, especially for HHC. Limited efforts have been made to develop and to use design guidelines and standards for content, accessibility, functionality, and usability related to HHC. While documents[58–61] have been presented, none were specifically targeted at HHC. With respect to the display of information, data visualization methods[57] potentially may support provision of the best possible care, communication among clinicians, and implementation of new care delivery models. Related recommendations are specified in ►Table 2.

Society Level Challenges

Patient/Caregiver View and Remote Monitoring Data

The expanding use of telehealth in HHC, due in part to the COVID-19 response,[6] may enable both formal and informal caregivers to monitor patients. For example, caregivers may be able to view telehealth vital sign data, as noted in the ►Table 1 scenario. This could be of particular value to caregivers who live a distance from the patient. However, telehealth devices are subject to data breaches, as discussed below.

Privacy and Security in the Unique Home Health Care Environment

The off-site and in-home nature of HHC often involves clinicians' use of multiple mobile devices (e.g., laptop, phone) which increases risks for data breach.[62,63] Protecting HHC patient information privacy and security is an achievable goal. However, it requires investment of resources which is often relatively more limited in HHC.[63] To be effective in addressing this societal challenge, privacy and security need to be built into design[64] during HIT development and adoption.[65] Consequently, the chances for data leaks or ransomware attacks, which recently took HHC data hostage by encrypting it without authorization,[66,67] can be reduced. Careful computer-supported processes and patient data handling both during care delivery and after are necessary. Therefore, continuous risk assessment, risk mitigation, training, and raising awareness are required. Appropriate data de-identification techniques[68] used to balance privacy and utility can facilitate statistical and machine learning techniques by providing de-identified datasets to researchers. Recommendations are shown in ►Table 2.

Conclusion

In conclusion, we have a timely and exceptional opportunity to augment the HHC informatics ecosystem by applying existing standards to facilitate transitions-in-care data flow necessary for advances in HHC informatics and patient care. Now is the time to implement available informatics methodologies for use in HHC and to evaluate their impact on the ecosystem including patient outcomes, agency quality measures, and clinician workflow. The authors welcome informaticians and HHC researchers and clinicians to join us in the important opportunities described herein.

Multiple Choice Questions

1. What are the effects of the absence of policies to support data communication exchange standards in HHC?
   a. Over reliance on hospital discharge information formatted using the Continuity of Care Document
   b. Wide implementation of third party applications to communicate data to the HHC EHR
   c. Adoption of IMPACT Act standards for communication of data from hospitals to HHC
   d. Persistence of interoperability deficits

   Correct Answer: The standards specified in a to c have not been widely implemented due to lack of policies to support adoption of these standards. Hence, interoperability deficits persist (d).

2. Predictive analytics can guide identification of potential clinical and administrative improvements. Which of the following is a prerequisite for development of predictive models in HHC?
   a. Structured data
   b. Standardized data
   c. Narrative data
   d. Improved model predictability

   Correct Answer: Computable data are a necessary condition for predictive models. Structured data are computable. Narrative data are not computable and therefore cannot be used in predictive models. While having standardized data would facilitate model development, it is not a necessary condition. Improved model predictability is not a necessary condition: instead it is a goal.

Protection of Human and Animal Subjects

No human subjects were involved in the project.

Conflict of Interest

None declared.

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