The Role of Personal Health Information Management in Promoting Patient Safety in the Home: A Qualitative Analysis

George Demiris[a], Shih-Yin Lin[b], Anne M. Turner[b,c]

[a] Department of Biostatistics, Epidemiology and Informatics, University of Pennsylvania, Philadelphia, PA, USA,
[b] Department of Biomedical Informatics and Medical Education, University of Washington, Seattle, WA, USA,
[c] Department of Health Services, University of Washington, Seattle, WA, USA

Abstract

Patient safety is a critical component of health care services; however, it has beent mostly conceptualized for the hospital sector. As home health care expands, it is important to examine the concept of patient safety in the home and identify opportunity for personal health information management (PHIM) tools to support and maximize patient safety. The goal of this study is to explore how PHIM can be a facilitator for patient safety in the home. We explore a comprehensive framework of patient safety in the home and identify the role of PHIM in this context. We analyzed the coded transcripts of in-depth interviews with 88 older adults (60 year and older), 56 family members or informal caregivers and 27 clinicians. Findings demonstrate the physical, emotional, social and functional dimensions of patient safety in the home and concrete ways for informatics tools to maximize safety aspects.

Keywords:

Patient Safety; Home Care Services; Health Records, Personal

Introduction

Home health care is the fastest growing segment of the US health care system with a rapidly increasing number of patients receiving care services in their home and a well-documented shift from acute to home care for patient populations across the lifespan. As patients with complex needs and their families are faced with challenges of care coordination in the residential setting, patient safety in the home needs to be examined to identify barriers and facilitators in this unique context. A significant body of literature has examined patient safety in clinical settings, mostly in the hospital setting, and various frameworks and instruments have been developed to define, measure and track patient safety in in-patient settings. Less emphasis has been placed on a formal examination of patient safety in the home setting, although recently more efforts are underway to address this area.

As Lang et. al. [1] point out, applying the notion of patient safety as conceptualized for the hospital sector (with a sole focus on error detection and adverse events) is too narrow and therefore, insufficient for home care. Safety in the home setting requires a broader definition to acknowledge the complexity of health conditions, residential settings and family dynamics and the unregulated and at times unpredictable process of health care delivery within the home. There are structural and procedural differences between the hospital and home setting that affect patient safety considerations. One example is the fact that home health staff often work alone in the field during a home visit with support resources available remotely (in contrast to clinical teams within the hospital that operate as teams of care physically co-located). Often, physicians rely to home care nurses to make assessments and communicate findings while they may have little or no direct contact with patients. Home health care nurses spend more time on documentation and addressing reimbursement issues than hospital nurses [2]. Additionally, patient autonomy is respected in both settings but overseeing the implementation of a behavioral or pharmaceutical or other intervention varies based on the opportunities for observation and reinforcement. Medication adherence is one such area where hospital-based care may be more effective in eliminating barriers. Patient variables such as reading skill, cognitive ability and financial resources have been found to affect patients' ability to safely manage medication regimens in the home [3] whereas these parameters are less instrumental in effective medication administration in the hospital setting. Finally, family members often play an essential role in the health care of a patient in the home and need to play an essential role in the discourse on patient safety [4]. As significant elements of the health care services delivered to patients become responsibilities of family or informal caregivers, challenges arise related to training, supervision, competencies and information flow during transitions of care that require coordination across multiple stakeholders and settings of care.

Efforts to address patient safety in the home include initiatives that target specific aspects of home care such as fall prevention [5], medication management [6], unplanned hospital admissions [7], functional outcomes [8], wound [9] and pressure ulcer management [10]. However, a more comprehensive conceptualization of patient safety in home care is needed in order to identify opportunities for tailored interventions. Lang has developed a model to outline four dimensions of safety in the home [11]: The physical dimension involves the physical attributes of the home care setting, including environmental hazards such as home layout and infrastructure, clutter, and unsanitary conditions. Key processes of care that affect home safety — medication management, infection control, nutrition, fall prevention, complex clinical care, and care coordination — are also included in this category. The emotional dimension of home care safety involves stress, trauma, and discomfort related to receiving and providing care. Finally, the social and functional dimensions of home care safety involve the community and the network of support, and the effects of health conditions on activities of daily living [12].

As with any health care process, delivery of care in the home setting involves information gathering and exchange among various stakeholders and between different systems of care. Home care patients and their families are called to manage personal health information generated from multiple sources and often between systems and across sites of care facing challenges of interoperability and threats to continuity of care. Personal health information management is critical to ensuring care coordination and high quality of care and affects all four dimensions of patient safety.

Personal health information management (PHIM), defined as the entire set of activities that "support consumers' access, integration, organization, and use of their personal health information" [13] is at the core of patient safety considerations in home care where care transitions, personal relationships, unsupervised caregiving work, and environmental attributes introduce unique challenges. The goal of this paper is to explore how PHIM can be a facilitator for patient safety in the home. We aim to discuss a comprehensive framework of patient safety in the home and identify the role of PHIM in facilitating patient safety based on a secondary data analysis of interview data with community dwelling older adults to highlight these considerations.

Methods

We conducted a qualitative analysis of interview data using the theoretical framework by Lang et. al. [11] to highlight the underlying elements of patient safety in the home. The qualitative data were generated as part of the SOARING study (soaringstudy.org), a five-year investigation of the personal health information needs and practices of adults 60 years and older living in a metropolitan area in the Pacific Northwest in the United States. The SOARING project focuses on information needs and personal health information management of older adults; patient safety in the home is not examined in that parent project but its large data set is used for a secondary analysis for the patient safety focus of the study presented here. Secondary data included interviews conducted over a three-year period with older adults and their friends and family members that were involved in their health and health information management [14]. Interviews focused on health, health information seeking, technology use and health information management. Purposive sampling ensured a diverse representation of gender, living situation, race, and income. Living situations included independent living, retirement communities, assisted living and homelessness. Inclusion criteria for participation included age 60 or over, ability to communicate in English, and lack of cognitive impairment. Additionally, interviews were conducted with health care providers who provide care to older adults. The interview protocol covered a broad range of topics including needs and preferences pertaining to personal health information management, and the personal stories of aiming to maintain independent aging. We analyzed the coded transcripts which were collected from in-depth in person interviews with 88 older adults (60 year and older) and phone interviews with 56 identified by older adults as friends and family who were involved in their health and health information management, and 27 clinicians (physicians, nurses, social workers). Older adult participants had an average age of 76 years, were predominantly female (69%), and white (72%). In terms of living arrangements, they lived in various settings: in independent private residences (25%), independent-shared dwellings (27%), retirement communities (27%), assisted living facilities (19%), and homeless (2%).

The content analysis was informed by the theoretical framework by Lang et. al. [11] in order to highlight the underlying elements of patient safety in the home. We reviewed transcripts for their pertinence to patient safety issues in particular along the dimensions of care (physical, emotional and social and functional). For each of these themes we described the role of information technology as a patient safety facilitator.

Results

Table 1 provides a summary of the dimensions of patient safety in the home with example quotes from our corpus of qualitative data generated by interviews with older adults and their families and providers demonstrating instances where a specific dimension may become a challenge for patient safety.

The use of the framework by Lang et. al. [11] enabled us to confirm its validity by identifying the underlying dimensions in our own data and also inform how PHIM may become a facilitator in that context. The physical dimension of patient safety in the home context includes multiple sub-themes. There are numerous key processes of care that may include safety risks when information flow or oversight are deficient. These processes include medication management, infection control, fall prevention, nutrition, complex clinical care coordination and transitions of care. Challenges associated with medication management and adherence have been well documented and are expected to intensify with aging as patients may experience cognitive or functional limitations [15]. The physical dimension also includes environmental hazards that pertain to aspects such as the home infrastructure and physical layout of the residential space as well as potential clutter.

The emotional dimension of patient safety includes concepts such as burden, stigma, self-view, confidence and resilience, all psychological constructs that affect self-efficacy, communication and coping, ultimately impact patient autonomy and safety.

The social dimension includes elements such as family and community support and social isolation and loneliness. As Lang notes, patients may face increased risk to their safety simply because of the desire to remain at home "at any cost." Illnesses bring about inherent limitations in daily functioning, which may multiply as an illness progresses. However, the extent to which safety risks increase, and for whom, is a function of the patient's social matrix.

Finally, the functional dimension of patient safety includes numerous potential limitations such as visual, hearing, mobility, and cognitive limitations that may affect one's ability to safely manage their health condition in the home and the degree to which assistance or additional tools may be necessary to safely execute health related procedures and tasks.

Discussion

Our findings validate the dimenions of patient safety in the home setting as outlined by Lang's framework [11] and demonstrate how information management may act as mediator for these patient safety attributes. Informatics can play a role in facilitating information flow and exchage among

stakeholders to address and maximize patient safety. Various informatics tools such as passive monitoring sensors, personal health records, wearables, symptom management tracking and reporting apps can support the physical, emotional, social and functional dimensions of patient safety. Patient and family characteristics, available resources and the participating entities in transitions of care and coordination of services have to be considered when designing strategies to safeguard patient safety in home health care. Additionally, our findings demonstrate that home care patients may often struggle with information management challenges while trying to cope with complex care needs. Educational initiatives to increase awareness of patient safety among clinicians, family members and patients themselves can be tailored to address the unique challenges and opportunities as outlined in this framework. System designers can integrate informatics elements into the system overall functionalities to promote safety and well-being of home care patients. Personal health records and other PHIM tools may benefit from incorporating a patient safety perspective in their design in order to improve processes of health care and meaningfully engage or even empower home care patients and their families.

Conclusions

The findings of this qualitative analysis demonstrate patient safety concerns and challenges as experienced by older adults, family members and health care providers. Patient safety in the home needs to be examined beyond previous work that has defined and measured safety solely in the hospital setting. This is to our knowledge the first comprehensive inquiry of patient safety as a broad concept in the home setting engaging multiple stakeholder groups and examining the potential of informatics tools to serve as safety facilitators. Personal health information management and informatics tools can be implemented to promote patient safety in an inclusive approach that covers the physical, functional, social, emotional and social dimensions of patient safety. Our findings can inform the design of tailored patient safety interventions in home health care.

Acknowledgements

References

[1] A. Lang, N. Edwards, and A. Fleiszer , Safety in home care: a broadened perspective of patient safety, *Int J Qual Health Care* **20** (2008), 130-135.

[2] A. Anthony, and P. Milone-Nuzzo, Factors attracting and keeping nurses in home health care, *Home Healthc Nurse* **23** (2005), 372-377.

[3] C.H. Ellenbecker , S.C. Frazier, and S. Verney, Nurses' observations and experiences of problems and adverse effects of medication management in home health care, *Geriatr Nurs* **25** (2004), 164-170.

[4] A. Harrison, and M. Verhoef, Understanding coordination of care from the consumer's perspective in a regional health system, *Health Services Research*, **37** (2002), 1031-1054.

[5] S. Sperling, K. Neal, and K. Hales. A quality improvement project to reduce falls and improve medication management, *Home Health Care Serv Q* **24** (2005), 13-28.

[6] S. Meredith, P. Feldman, and D. Frey, Improving medication use in newly admitted home health care patients: a randomized controlled trial, *J Am Geriatr Soc* **50** (2002), 1584-1491.

[7] R.H. Fortinsky, E.A. Madigan, and T.J. Sheehan, Risk factors for hospitalization among Medicare home care patients, *West J Nurs Res* **28** (2006), 902-917

[8] L.D. Scott, K. Setter-Kline, and A.S. Britton, The effects of nursing interventions to enhance mental health and quality of life among individuals with heart failure, *Applied Nurs Res* **17** (2004), 248-256.

[9] J. Fellows, and L. Crestodina, Home-prepared saline: a safe, cost-effective alternative for wound cleansing in home care, *J Wound Ostomy Continence Nurs* **33** (2006), 606-609.

[10] M.J. Strauss, J. Gong, and B.D. Gary, The cost of home air-fluidized therapy for pressure sores. A randomized controlled trial, *J Fam Pract* **33** (1991), 52-59.

[11] Lang A, Macdonald MT, Storch J, et al. Researching triads in home care: Perceptions of safety from home care clients, their caregivers, and providers. *Home Health Care Management & Practice.* 2014;26(2):59–71.

[12] D. Carpenter, T. Famolaro , S. Hassell, B. Kaeberle, S. Reefer, C. Robins, and S. Siegel, *Patient Safety in the Home: Assessment of Issues, Challenges, and Opportunities*. Cambridge, Massachusetts: Institute for Healthcare Improvement, 2017.

[13] A. Civan, M.M. Skeels, A. Stolyar, and W. Pratt, Personal health information management: consumers' perspectives. *AMIA Annu Symp Proc* (2006),156-60.

[14] A.M. Turner, K. Osterhage, A. Hartzler, J. Joe, L. Lin, N. Kanagat, G. Demiris. Use of Patient Portals for Personal Health Information Management: the Older Adult Perspective. *AMIA Annu Symp Proc* (2015), 1234-1241.

[15] E.P. Peron, S.L. Gray, J.T. Hanlon. Medication use and functional status decline in older adults: a narrative review. *Am J Geriatr Pharmacother* **9** (2011), 378-391.

Address for correspondence

Corresponding author:
George Demiris
University of Pennsylvania
Claire Fagin Hall, Room 324
418 Curie Blvd, Philadelphia 19104 PA, USA;
gdemiris@upenn.edu

Table 1– Dimensions of Patient Safety in the Home in the Context of Personal Health Information

Safety Dimension		Definition *Selected Participant Quotes* *OA-Older Adult Participant* *P-Provider* *FC-Family Member)*	Informatics tools as facilitators
Physical	Medication Management and Adherence	Challenges include risks for wrong dosage, missed dosage, wrong medication, side effects, administration of medication *So knowing what their* [patients'] *medicines are, is actually a huge barrier. I literally have to track down their mental health provider. Page, call, recall, receive faxes, take phone calls, just so that I can get a med list.* (P)	IT tools to provide: • Reminders • Automatic dispensing • Tracking of medication administration • Communication of adherence challenges • Notifications • Reporting of Side Effects
	Infection Control	Challenges to infection surveillance, prevention and control in the home setting can jeopardize patient safety and well-being. Tools are needed to measure and study the risks for home-care acquired infections (including valid definitions, measures and tools for surveillance). *Another thing I'm starting to do is infection control. I need to start tracking who has infections that mostly is communicable, like flu or pneumonia, or something like that.* (P)	IT tools that track: • Physiological variables associated with infection (e.g. temperature) • Photographic or video-assessment of wounds or other infection sites • Access to information • Symptom tracking and reporting
	Fall Prevention	Falls are a major risk for home care patients, especially frail elderly patients and those with rehabilitation needs after a major health event. *a fear of falling because I know that – I've – it's been several years since I fell, but I've fallen twice and the older I get, the less inclined I – I mean the more inclined I am to not want to fall anymore because – yeah. I mean your bones get more brittle and I don't want to break anything, let alone a hip. So yeah.* (OA)	IT tools to facilitate • Fall Prevention (e.g., motion sensors to detect mobility patterns, gait monitors to assess gait characteristics over time) • Fall Detection (e.g. sensors that detect weight and pressure, acoustic sensors that register fall, wearables that track falls)
	Nutrition	Nutritional needs may have a great level of complexity. Considerations include nutritional guidelines informed by the diagnosis or symptom management needs of the patient as well as potential challenges in accessing and preparing meals that adhere to specific dietary restrictions (including potential practical barriers to grocery shopping, transporting and storing food items, meal preparation and feeding). *If we plan to do something, we need to know when he needs to eat. Or we're always arranging any activities around the schedule of his insulin and his dietary needs also. We're aware of that, so if we're cooking or – we're all watching him because we know the signs now of when something's not right.* (FC)	IT tools that facilitate • Tracking of dietary choices • Access to information about nutritional values • Reminders

Table 1 (cont.)

	Care Coordination and Transition	Patients with complex care needs experience transitions from various care settings (e.g., discharge from hospital to a rehabilitation site to home health care) and challenges include barriers to information flow across settings. Missing or incomplete information and lack of coordination may introduce significant patient safety risks. *But it has happened several times that I'd come home and find him unconscious on the porch, ... he's had an incident with his insulin. And so, I've asked them to please give me the information or tell me what they want me to do or what we're supposed to do.* (FC)	IT tools that provide a platform for access, sharing and transferring of data sets across stakeholder groups and systems of care
	Environmental Hazards	Environmental hazards include elements of the home infrastructure and physical layout, challenges of clutter in the home and unsanitary conditions. The actual residential infrastructure may introduce risks to patient safety. Infrastructure elements may include attributes such as temperature, light and level of accessibility that may hinder or pose a risk as residents carry out activities of daily living. *I wish I had a bath tub instead of a shower so it's a sit-down shower and that's just hard for me.* (OA) *I mean, her apartment is such a mess. So, that's another thing that can interfere with people's ability to keep track. They absolutely don't know where anything is.* (P)	IT tools that facilitate environmental scanning and assessment to identify accessibility issues as well as ongoing monitoring of hazards or triggers for adverse events.
Emotional	Emotional Challenges	Emotional challenges such as lack of confidence and resilience, issues of self-view and perceived stigma of frailty or vulnerability may affect the ability of a patient to engage in effective disease management to maximize patient safety. *But I had this terrible night where I really wanted to die –my daughter is still kind of out there somewhere. She texts me, but I don't see her anymore and I really wanted to die.* (OA)	IT tools to promote assessment of mental health issues and psycho-social aspects of mental health and well-being
Social	Social Support	Social support includes family and friends and other community members who interact with a home care patient and can provide practical or emotional support. Lack of social support may lead to isolation and loneliness, both linked to disease trajectory and clinical outcomes and as such may affect overall patient safety. *It occurs to me that that's probably something if you can help the patient to understand how necessary it is that the people around them have a list of what to watch out for and what to do about it.* (FC)	IT tools that facilitate: • virtual connections and social interactions with friends and family • sharing of information, messaging, communication • assessment of ongoing social interactions, visits, calls and detection of trends of social isolation • tools to promote social inclusion in virtual and physical communities
Functional	Functional Limitations	Functional limitations (including visual, hearing, mobility and cognitive limitations) may affect patient safety as they can interfere with the ability to independently carry out activities of daily living and also engage in disease management and symptom control activities. *The fire alarm going off and me not being able to go up and down the stairs that well because you can't use the elevator.* (OA) *And I have come in here and the stove has been left on. That's very scary to me.* (FC)	Informatics solutions that provide audio-assistance such as voice-interfaces to process visual information, that facilitate hearing aids or provide alternative (such as visual) displays of information, and cognitive orthotics (reminders, voice-interfaces to provide contextual information for activities)