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How Do Community Dwelling Non-English Speaking Patients and Caregivers Perceive their Medication Management?

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How Do Community Dwelling Non-English Speaking Patients and Caregivers Perceive their Medication Management?

Abstract

Non-English-speaking individuals face a linguistic and cultural barrier to managing prescribed medications in the community. Wilson et al. (2005) found that limited English proficient (LEP) patients reported more misunderstanding and negative drug reactions when taking prescribed medication compared to English-speaking patients. Not only is the inappropriate management of medication dangerous, but it is also a disparity in health care that is inequitable. The purpose of this literature review is to collect community-dwelling non-English-speaking patient and caregiver experiences with managing medication. These perspectives will highlight what is successful and what needs to be improved regarding non-English-speaking patient medication interactions. Literature suggests that language interpretation, method of medication education, patient cultural variation, and relationships with health care professionals all impact medication management for this population. Recommendations to improve non-English-speaking patient and caregiver experience with medication management include increased use of trained medical interpreters and the development of a standardized assessment tool to measure medication knowledge.

How do community-dwelling non-English-speaking patients and caregivers perceive their medication management?

Julia Cosner, Sarah Miner, Yvette Conyers

Abstract: *Non-English-speaking individuals face a linguistic and cultural barrier to managing prescribed medications in the community. Wilson et al. (2005) found that limited English proficient (LEP) patients reported more misunderstanding and negative drug reactions when taking prescribed medication compared to English-speaking patients. Not only is the inappropriate management of medication dangerous, but it is also a disparity in health care that is inequitable. The purpose of this literature review is to collect community-dwelling non-English-speaking patient and caregiver experiences with managing medication. These perspectives will highlight what is successful and what needs to be improved regarding non-English-speaking patient medication interactions. Literature suggests that language interpretation, method of medication education, patient cultural variation, and relationships with health care professionals all impact medication management for this population. Recommendations to improve non-English-speaking patient and caregiver experience with medication management include increased use of trained medical interpreters and the development of a standardized assessment tool to measure medication knowledge.*

Background

When a patient is prescribed a therapeutic drug for an acute or chronic illness, effective and safe medication management is necessary. Patients residing in the community taking new medications after hospital discharge or through a community-based service are required to self-manage medications or rely on the help of caregivers. A patient and/or caregiver must understand the indication, dose, frequency, and administration of the drug while monitoring for adverse effects and drug interactions.

The mismanagement of medication by a patient or caregiver can lead to negative health outcomes. Ho et al. (2006, 2008) found that the nonadherence to coronary artery disease and diabetes medication was correlated with increased hospitalizations and higher mortality rates. Furthermore, from 2013-2014, 4 in 1000 individuals visited the Emergency Department in the U.S. for adverse drug events that occurred

outpatient (Shehab et al., 2016). It is important to recognize that non-English-speaking individuals have an additional barrier to properly managing medications in the community.

According to U.S. Census data released for 2018, 67.3 million people living in the U.S. speak a language other than English at home and 38% of those respondents reported speaking English “less than very well” (Zeigler and Camarota, 2019). It was found that limited English proficient (LEP) patients were more likely to report misunderstanding of labels and bad reactions to prescription medicine compared to English-speaking patients (Wilson et al., 2005). This population disparity in medication management must be addressed and further researched. Non-English-speaking individuals deserve equitable and appropriate health education that contributes to successful management of medication in the community.

To increase health care quality for the nation, the Office of Minority Health of the U.S. Department of Health and Human Services developed culturally and linguistically appropriate services (CLAS) standards for health care organizations to practice (Office of Minority Health, 2001). The ‘Communication and Language Assistance’ standards are one of the many categories included in the blueprint for the delivery of equitable health care. These specific guidelines state that U.S. health care organizations should provide necessary language services to all patients at no cost (Office of Minority Health, 2001). Examples of these services include trained interpreters and language-concordant health care professionals. The implementation of the CLAS standards should improve medication management for non-English-speaking patients and their caregivers and support health care professionals’ cultural understanding of their patients. As CLAS standard guidance is implemented, its impact calls for evaluation as research suggests many disparities are still present in non-English-speaking patient care related to medication teaching.

The purpose of this literature review is to collect community-dwelling non-English-speaking patient and caregiver perspectives about their medication management. These perspectives will increase the understanding of current health care practices in preparing non-English-speaking patients and caregivers to manage medications in the community. Health care professionals and the organizations to which they belong can use these lived experiences to better serve the non-English-speaking population.

Method

This literature review was conducted using CINAHL and Pubmed databases. The searches included full text research articles and randomized control studies available in

English with publish year ranging from 2010 to 2020. Within CINAHL, the following search terms were used: *non-English-speaking patient, limited English proficiency, medication management, medication adherence, compliance, non adherence, noncompliance, home care, and community*. Within Pubmed, the following search terms were used: *limited English proficiency and drug therapy*.

Articles were included if they focused on non-English-speaking patient or caregiver perspective on medication experiences. This highlights the unique point of view of the patient/caregiver that cannot be conveyed by a health care professional. Research studies that took place during hospital discharge and other community-based health care services were included if they occurred in a primarily English-speaking setting (U.S. and international). Articles were excluded if they consisted of inpatient hospital admissions and English-speaking patients. If a research study included only health care professional perspectives or medication management interventions they were also excluded. 348 articles were screened using the inclusion and exclusion criteria and duplicates were excluded. Seven articles were selected from the databases and one article was selected upon reviewing references. This generated a total of eight articles to be included in the literature review.

Four research studies collected qualitative data, two studies collected quantitative data, and two studies used mixed methods. In addition, research was done to evaluate medication experiences in various settings such as outpatient offices, hospital discharge, clinics, and home care. Data collection in six of the research studies was done in countries outside of the U.S in outpatient services delivered in English—Australia (3), Canada (2), Sri Lanka (1)—while only two were completed in the U.S. Two research studies isolated caregiver

perspectives and four studies collected data on older patients. More information about the articles can be found in Table 1.

Results

Medication Knowledge and Satisfaction

Non-English-speaking patient and caregiver knowledge about prescribed medications can dictate their ability to manage medication in the community. To improve medication management, current consensus of the knowledge that non-English-speaking patients and caregivers have should be measured; however there was not a standardized way of doing so in the pertinent articles. Perera et al. (2012) used a knowledge assessment questionnaire that surveyed the individuals' ability to identify the name, dose, frequency, and indication of medications followed by a calculated knowledge score. Ens et al. (2014) concluded the participants' knowledge of prescribed medications via interviews about pill characteristics and drug indication. The interview questions changed based on participant response. Despite the different data collection methods, the studies concluded that non-English-speaking patients have mixed levels of medication knowledge (El Samman et al., 2013; Ens et al., 2014 Perera et al., 2012).

Patients and caregivers should be satisfied with their medication knowledge. Medication education non-English-speaking patients and caregivers received within the studies was delivered by various sources such as primary care providers and pharmacists. Despite receiving this information, non-English-speaking patients and caregivers still described difficulty understanding medications and reported dissatisfaction of their knowledge level (Masland et al., 2011; Miner et al., 2018; Gillespie et al., 2015; Perera et al., 2012). Perera et al. (2012) found that only 38.5% of

South Asian patients felt their knowledge about their medication was satisfactory, although all patients received verbal drug information by a pharmacist. The population gap in medication management is highlighted by Masland et al. (2011) as they found 25% of LEP individuals had difficulty understanding prescription bottle labels compared to 5% of English-proficient individuals.

It was apparent in the literature that non-English-speaking patients and caregivers need more medication education. In one study, access to more medication information was an important factor to satisfying Somali patient needs in understanding medication (Miner et al, 2018). Furthermore, more than 90% of LEP patients requested more information about name, dose, indication and side effects (Perera et al., 2012). Requests for written language-concordant medication information such as drug labels were also made (Blennerhassett & Hilbers, 2011; El Samman et al., 2013). Lastly, although written drug information was identified as crucial for non-English-speaking patients by El Samman et al (2013), some participants expressed they were not literate in their native language. If illiterate, information given in written form is not effective in teaching non-English-speaking patients about medications.

Successful and unsuccessful interventions to improve medication comprehension were identified by non-English-speaking patients. Home health care visits were described as helpful to learn about medications because the environment caused less anxiety for the patients (Miner et al., 2018). The internet was another resource for medication information; however, ethnic minority caregivers and family of culturally and linguistically diverse (CALD) patients were wary to trust the internet (Gillespie et al., 2015; Schaffler et al., 2019).

Caregivers and Family Interpret for Patients and Request More Medication Education

Non-English-speaking patients and caregivers reported their use of family to improve the management of their medication in the community. Ethnic minority caregivers and CALD patients discussed the importance of caregiver communication during health-care provider and patient interactions (Gillespie et al., 2015; Shaffler et al., 2019). Family members interpreted verbal medication information and translated written material received at appointments with general practitioners and at pharmacies (El Samman et al., 2013; Ens et al., 2014). Although caregivers felt their interpretation was vital, caregivers who were non-English-speaking expressed interpreting medication terminology for the patient as stressful and difficult because they could not understand it themselves (Gillespie et al., 2015; Miner et al., 2018; Shaffler et al., 2019). LEP caregivers attempted to interpret information at the doctor's office or pharmacy for the non-English-speaking patient, but additional help was needed from extended family or neighbors due to their level of English proficiency (Gillespie et al., 2015). Although caregiving was seen as communal, caregivers that also do not speak English adopt the risk of receiving inaccurate translated medical information about prescribed drugs from family or neighbors. Multiple studies support the need for more medication teaching and language-concordant written information for caregivers of non-English-speaking patients (El Samman et al., 2013; Gillespie et al., 2015; Miner et al., 2018; Shaffler et al., 2019). Family caregivers recognized their need and desire for more teaching on the administration, indications, and side effects of drugs their relatives were taking (Gillespie et al., 2015; Miner et al., 2018).

Lastly, caregivers provided suggestions for improving medication instruction for non-English-speaking patients and their families. Suggestions included increased access to practical information and the use of home health care nurses to increase medication literacy (Miner et al., 2018; Shaffler et al., 2019).

Language Concordant Health Care and Trusting Relationships

Non-English-speaking patients and caregivers identified a preference for language-concordant health professionals because of their integral role in improving self-management of medication (Blennerhassett & Hilbers, 2011; El Samman et al., 2013; Ens et al., 2014; Masland et al., 2011). In one study, 54% of LEP patients had a bilingual doctor, a factor that researchers found significantly reduced the difficulty in understanding drug labels (Masland et al., 2011). Additionally, caregivers were willing to travel farther and wait longer for appointments with language concordant doctors to avoid difficulty understanding medication education (El Samman et al., 2013; Gillespie et al., 2015). Non-English-speaking patients also described a sense of belonging when the community pharmacist spoke their native language because it created an ongoing relationship that allowed for long-term medication education (Ens et al., 2014).

Literature suggests that quality relationships between non-English-speaking patients/caregivers and health care professionals were greatly valued with or without language concordance. Doctors and home health care nurses that spent time to educate and answer questions about medications were preferred even if they did not speak the same language as the patient (Ens et al., 2014; Miner et al., 2018; Shaffler et al., 2019). Miner et al. (2018) found that LEP patients and their family caregivers

were more likely to ask questions about medications if their home health care nurse took time to build a relationship in which both sides learn from each other. Trusting relationships were also created when health care professionals were available for frequent office visits and they were non-judgmental about past medication nonadherence (El Samman et al., 2013; Ens et al., 2014; Shaffler et al., 2019). Furthermore, trust was maintained when cultural customs of non-English-speaking patients were understood by community pharmacists and home health care nurses because these circumstances invited patients to discuss barriers to effective medication management (Ens et al., 2014; Miner et al., 2018).

Cultural Influence on Medication Management

Review of the literature revealed that cultural variation affects non-English-speaking patient experiences when managing medications. Taking routine medication is challenging for some non-English-speaking patients due to their cultural view on being diagnosed with a chronic illness (El Samman et al., 2013; Miner et al., 2018). Miner et al. (2018) found that some older refugee patients viewed their health status and medications as short term, which ultimately led to mismanagement of medication and uncontrolled chronic disease symptoms. Furthermore, Arabic-speaking females with long-term medication regimens expressed less concern and knowledge about medications and believed they did not suffer from a chronic disease (El Samman et al., 2013).

Refugee status and limited time spent living in the United States were also identified as barriers to managing medications (Masland et al., 2011; Miner et al., 2018). Somali refugees reported having less access to

medications in the refugee camps, making it difficult to learn about medications and take them for the first time with limited teaching (Miner et al., 2018). Similarly, LEP patients living in the United States for less than five years had significant association with difficulty understanding prescription labels (Masland et al., 2011).

Non-English-speaking patients in the literature explained that their family and social groups impact their medication management. Family members living in a South Asian patient's native country blamed poor health on cold weather, discouraging the use of medications for chronic conditions when the patient visits warmer climates (Ens et al., 2014). Conversely, patients that previously lived in refugee camps regarded the social support they experienced before living in a U.S. community as a conduit of health that is equally important as taking therapeutic drugs (Miner et al., 2018). Finally, caregivers of ethnic minority patients suggested the benefit of support groups to provide additional information about medications they are administering to their loved ones (Gillespie et al., 2015).

Discussion

Understanding the experience of community dwelling non-English-speaking patients and their caregivers is integral in the improvement of their medication management. This literature review provides the effects of current English dominant outpatient and hospital discharge medication teaching on non-English-speaking populations. Recommendations in clinical, education, and research settings can be made.

The reported caregiver burden of interpreting medication information from health care professionals was prevalent in the literature. Instead of relying on family and caregivers, health care organizations

should offer interpretation services for employees to use so they can deliver quality care, which is a 'Communication and Language Assistance' CLAS standard recommendation. These services will alleviate stress on family and caregivers, and will accommodate caregivers who also have language barriers of their own. The research studies done in the U.S. reflect the failure to adopt or adhere to the 'Communication and Language Assistance' CLAS standards. Additionally, the research studies done outside of the U.S. in primarily English-speaking settings show gaps in educating non-English-speaking patients about medications.

Health care professionals should use language concordance and interpretation services as a stepping stone in medication education for non-English-speaking patients and caregivers, not as a complacent achievement. Based on the review of literature it is evident that interpretation of information is not enough to create adequate medication knowledge. Another recommendation for the clinical setting is the creation of trusting relationships by health care professionals because they were highly regarded in the literature by patients. Health care professionals should take time to create relationships with their non-English-speaking patients. Health care organizations should also support this in their policy. To positively influence medication management of non-English-speaking patients/caregivers, health care professionals must be familiar with patient culture, taking time to learn and make the patient feel heard.

In addition to establishing trust, medication education techniques taught in the medical and nursing curriculum should be enhanced. If we expect nurses, pharmacists, and providers to effectively teach non-English-speaking patients and caregivers how to manage medications in the community they need adequate training. Instruction on how

to use live or virtual medical interpreters should be highlighted within curriculum, describing different teaching methods to use during these times. Teaching interventions such as the teach back method where a patient reiterates the information a health care professional provides them with should be incorporated. Written information in the patient's native preferred language should always supplement verbal instruction. These interventions allow for the identification of barriers to medication management.

A final recommendation is further research into a tool that measures medication knowledge of patients. There was not a standardized way to measure the medication knowledge of patients in the studies. The ability to evaluate the medication knowledge that a non-English-speaking patient or caregiver possesses can ensure the successful self-management of medication in the community and hold health care organizations accountable for quality patient teaching. A standardized tool can be utilized routinely during hospital discharge and community-based services.

These recommendations encompass the health care industry at large to improve non-English patient and caregiver medication management experiences to explain drug information to their non-English-speaking patients and families. All of these interventions collaborate on a systematic level to deliver equitable health care that will refine non-English-speaking patient and caregiver medication management experiences in the community that are highlighted in the literature.

Table 1. Literature Matrix

Citation	Purpose	Sample	Method	Results	Discussion
Blennerhassett, J. & Hilbers, J. (2011).	Examine medication management for older patients with NESB ¹ after discharge from hospital in Australia	18 NESB patients (Russian Greek, Mandarin/Cantonese): ≥70 years old, discharged from hospital Pharmacists, community nurses, and junior medical officers	Qualitative interviews with NESB patients and carers Focus groups with hospital clinicians	Patients found it difficult adhering to changing medication routines. Interpreters were not used when taught about medications. Factors that helped better manage medications included language concordant practitioners/pharmacists, family members, and written information.	Hospital wide framework for medication management from admission to discharge should be implemented. Increase interpreter use to avoid inaccurate interpretation by family.
El Samman, F., Chaar, B. B., McLachlan, A. J., & Aslani, P. (2013).	Explore access, satisfaction, awareness, and needs for medication and disease information from older-Arabic speaking patients in Australia	29 participants from Lebanon and Egypt: ≥65 years old with chronic disease, taking at least one prescription, primarily Arabic speaking	Qualitative semi-structured interviews and focus groups	Arabic speaking health care is purposely sought out by patients when learning about medications. Trusting relationships between patients and general practitioners are possible with language concordance. Patients rely on children and family members to purchase and translate written information about medication and is viewed as inconvenient.	Pharmacists that speak another language in addition to English would be helpful at pharmacies. Written material and diagrams for illiterate could be beneficial in translating medicine label instructions to patients.
Ens, T. A., Seneviratne C. C., Jones, C., & King-Shier, K. M. (2014).	Explore factors associated with adherence to cardiac medications in South Asians located in Canada	8 South Asian patients: ≥40 years old with coronary artery disease diagnosis, speak English or Punjabi/Hindi	Quantitative Morisky Medication Adherence Scale Qualitative interviews in homes and office Ethnography	Patients scores reflected compliance with prescriptions when rated on the Morisky Medication Adherence Scale. Family members and positive relationships with clinicians were viewed to help medication compliance by patients. A sense of community was felt by patients when using language concordant care due to ability to communicate about concerns more honestly. Medication knowledge varied when assessed.	Relationships with health care providers should be built by frequent appointments to increase adherence and provide opportunity for education.
Gillespie, R. J., Harrison, L., & Mullan J. (2015).	Explore the medication management experiences of ethnic minority family caregivers of people living with dementia in Australia	22 ethnic minority caregivers (Italian, Macedonian, Portuguese), family of patient	Qualitative semi-structured interviews Focus group	Participants reported the challenge of cognitive and physical decline in managing medications for the patient. LEP ² caregivers had to rely on family translation and scarce language concordant practitioners for medication information. Long-term relationships with pharmacists were seen as beneficial in medication management. The internet was used for information collection for convenience, but some caregivers reported they did not trust information.	Written, verbal, and visual medication information that is language concordant should be provided in an understandable reading level. Caregivers that faced language barriers need access to interpreters or bilingual health care professionals.
Masland, M. C., Kang, S. H., & Ma, Y. (2011).	Assess association between limited English and other factors on understanding prescriptions in California	48,968 adults (Mexican, Central American, Chinese, Korean, Vietnamese): ≥18 years old, received prescription in past 12 months	Quantitative analysis Chi square analysis Multivariate logistic regression Data collected from California Health Interview Survey to find health status and socio-demographics	More LEP patients had difficulty understanding prescriptions than English-speaking counterparts. More LEP patients had bilingual doctors, which significantly reduced the odds of having difficulty understanding medication labels for entire sample. Greater portions of LEP patients lived 200% under the federal poverty line, lived in an urban area, and had less than a high school education. Recent immigration status and low education level were other significant risk factors in misunderstanding.	More bilingual and bicultural providers needed, as well as investment in training to communicate with culturally diverse patients. Accommodations should be made for persons with disabilities, low education levels, and recent immigration as this increases risk for misunderstanding medication labels.
Miner, S., McDonald, M. V., & Squires, A. (2018).	Explore medication literacy in Somali older adults and families located in Rochester, New York USA	13 families and patients: ≥ 50 years old, received HHC ³	15 interviews conducted in Somali and interpreted, 2 interview conducted in English	Participants reported difficulty understanding medications and requested more teaching. Chronic medication was new for some patients and HHC provided a comfortable environment to learn in. Nurses helped teach patients about medications and were favored when they established trust. Participants note less social support in the US than in refugee camps.	HHC should be used to improve medication management in the presence of chronic illness. Medication knowledge of patient should be evaluated.
Perera, T., Ranasinghe P., Perera, U., Perera, S., Adikari, M., Jayasinghe, S., & Constantine, G. R. (2012).	Evaluate knowledge of medication in cardiac patients in Sri Lanka	200 patients of outpatient clinic at Institute of Cardiology National Hospital in Sri Lanka, primarily Sinhala speaking	Quantitative statistical analysis of medication knowledge	Drugs issued by Dept. of Pharmacy at hospital are all handwritten in English by prescribing doctor and pharmacist despite Sinhala being the primary language of all but two participants. All patients are given drug info from pharmacist, 55% were able to read the dose and frequency. 54% of participants identified inability to read English as the reason they did not understand how to take medications. Only 38.5% of participants thought their knowledge was satisfactory and 70% thought they would benefit from more knowledge.	Special nurse educators or pharmacists are suggested in hospitals if doctors do not have enough time to consult and teach about medications. Health care personnel should take patient perception into account during medication consultation to control for factors influencing self-management of medication.
Shaffler, J. L., Tremblay, S., Laizner, A. M., & Lambert, S. (2019).	Explore perspective of caregivers of CALD ⁴ on managing chronic illness of their family members in Quebec, Canada	11 caregivers: non-English/French speaking patients born outside of Canada that are treated outpatient	Qualitative interviews in preferred language (9 English, 1 French, 1 Greek)	Caregivers care for patients with a family/community approach, playing an indispensable role in establishing communication between provider and CALD patient. Difficulty in translating medical terminology primarily provided by health care professionals causes some caregivers to seek information from sources such as the internet. More health information is requested, including drug treatment.	Basic health education strategies should be tailored to CALD population- appropriate reading level of health material that includes cultural and linguistic examples for patients.

¹ Non-English-speaking Background² Limited English Proficient³ Home Health Care⁴ Culturally and Linguistically Diverse

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