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Medication understanding among patients living with multiple chronic conditions: implications for patient-reported measures of adherence

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Abstract

Background—Low health literacy is associated with poor medication adherence and poor health outcomes. Limited understanding of prescribed medications may decrease validity of patient-reported adherence measures.

Objectives—To assess knowledge of names and purposes of prescribed medications among patients with multiple chronic conditions.

Methods—Individual interviews were conducted with a convenience sample of patients from six U.S. primary care clinics. Participants (n=57) were English and/or Spanish-speaking patients prescribed 3+ medications for chronic conditions, for which non-adherence may lead to disability or death. In individual interviews, patients were asked to name their medications, explain the purpose of each, and to explain how they distinguish them from one another. Interviews were

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Conflict of interest

There are no conflicts of interest to report among the authors.

audio recorded, transcribed, and coded; coded content was quantified by 1) whether or not the patient could name medications; 2) method of categorizing medications; 3) whether or not the purpose of the medication was understood. Descriptive statistics were compiled using Fisher's exact test to determine the relationship between patient knowledge and medication characteristics.

Results—Thirty percent of patients could not name at least one of their medications; 19% did not know their purpose; 30% held misconceptions about the purpose of one or more medications. There was no significant difference in ability to name medications or state their medication's purpose between patients using medi-sets, pre-packaged rolls, or blister packs, and patients who stored pills in their original containers ($p=0.56$ and $p=0.73$, respectively), or across demographic groups ($p=0.085$ to 0.767)

Conclusions—Many patients demonstrated difficulty identifying the name and purpose of prescribed medications; this did not differ by demographic group or medication storage type. Patients may benefit from routine review of medications with their provider in order to improve health literacy, outcomes, and patient-reported adherence measurement.

Keywords

Medication literacy; health literacy; medication adherence; patient-reported outcomes; multiple chronic conditions

Introduction

Nearly one-third of all Americans, and 80% of Americans aged 65 and older, live with multiple chronic conditions (MCC).(1) The combination of an increasing population of older adults and longer life expectancy (2) suggests this proportion will increase, as will prescription medication use.(3) In fact, since 1988, the percentage of patients taking three or more prescription medications has increased across all age groups for both males and females.(4) The rates for all persons prescribed 3 or more medications increased from 11.8% to 20.8% in the period 1988–2010, and among persons 65 years and older from 35.3% to 66.6% in the same time period.(5) As the number of medications prescribed per patient increases, so may the potential for non-adherence; two meta-analyses that included patients with at least one chronic condition found less-than-adequate adherence, broadly defined across multiple studies, to be widespread at rates of 25–50%.(6, 7)

Patients prescribed multiple medications are expected to process and understand a large amount of health information. This expectation has led to increased interest in the relationship between medication adherence and health literacy.(8–10) Health literacy is defined as “the degree to which an individual has the capacity to obtain, communicate, process, and understand basic health information and services to make appropriate health decisions”.(11) Pharmacy health literacy focuses this definition to include medication information and pharmacy services.(12) Inadequate health literacy has been found in nearly half of the US population,(13) and has been associated with poorer health, medication non-adherence,(14–17) medication errors, higher medical expenses, and increased hospitalization. (15) Conversely, health literacy has been positively associated with adherence. (18) Several studies of patients using antiretroviral medications (ARVs) for HIV

indicate that patients with limited health literacy are less likely to be adherent to their medications (19–21) which leads to poor health outcomes.

Patients with low health literacy are less able to identify or distinguish their medications from each other (22–24) or to report how their medications work, (25) which may negatively impact medication adherence. Low health literacy and limited understanding of prescribed medications may also diminish the validity or usefulness of patients' reports of their own adherence, including the use of patient-reported outcome measures, also known as PROs or PROMs, defined as assessments of a patient's health and disability experiences elicited in a structured and standardized format directly from the patient.(26) Understanding of medication type and purpose was assessed among patients prescribed medications for MCC for which a high level of adherence is advisable to avert illness or death. This research aimed to understand to what extent patients in the study clinic populations could 1) name each medication, 2) identify its associated class (i.e., "antiretrovirals" for HIV medications), and 3) articulate the medication's intended purpose.

Methods

Study design

This was a qualitative study using structured individual interviews, a maximum of 45 minutes in duration, with a convenience sample of HIV-infected and uninfected patients across six U.S. primary care clinics.

Setting

Interviews were conducted on-site with patients of three clinics within the Centers for AIDS Research Network of Integrated Clinical Systems (CNICS), and four community health centers across the U.S. This ensured a mix of patients from diverse geographic regions and urban/suburban/rural areas. Institutional review board (IRB) approval was gained at the University of Washington, and at the local institutional level.

Participants

Participants were English and Spanish-speaking patients prescribed three or more medications from the following classes: ARVs, antihypertensives, lipid-lowering medications, diabetes medications, anticonvulsants, antidepressants, mood stabilizers, antipsychotics, medication for cardiovascular disease (CVD) (excluding aspirin), and/or osteoporosis medications. Patients with known cognitive impairment were excluded. From the CNICS sites, patients with both optimal and sub-optimal self-reported adherence were recruited, the latter defined as self-report of two or more missed doses of ARV medications in the past 7 days on a self-administered computerized assessment completed by patients on-site as part of routine clinical care prior to their same-day clinic visit.(27) Patient responses to the assessment triggered a research coordinator pager; the coordinator then reviewed the patient's medication list to determine study eligibility. If eligible, the patients were approached by the coordinator in a private room in clinic prior to their appointment to invite participation in the study, administering informed consent when there was interest. Non-CNICS (HIV-uninfected) patients were identified by research staff members at each site

prior to their clinic visit and were invited by phone on the day before their visit to participate. Those interested were administered informed consent on-site on the day of the appointment. Both CNICS and non-CNICS patients were interviewed either before or after their clinic visit, depending on their preference and timing of their arrival to clinic.

Measurement

An interview guide was developed based on existing measures of medication-related health literacy. Patients were asked to bring in all of their currently prescribed medications to the interview, and to name their prescribed medications from memory. Patients were then asked to place their medications outside of their containers on a surface in front of them, name each (either generic or brand names sufficed), and explain how they categorized each of them (i.e., “What ‘kind’ of medication is this?”). Finally, patients were asked the purpose of each medication.

Analyses

Digital audio recordings of the interviews were transcribed by an external transcription service. The transcribed interviews were coded for themes by a multi-site team of qualitative researchers; these included identification, categorization, and perceived purpose of medications. Secondary codes were independently created by three reviewers for each category; for example, secondary codes developed under “categorization” included “by time of day taken” and “by disease/condition.” Consensus on final coding categories was achieved by three reviewers. Interview content was independently coded by three qualitative team members; reviewers discussed and reconciled differences in interpretation on biweekly conference calls. Coded content was quantified by 1) whether or not the patient could name all of their medications; 2) self-described method of categorizing medications; and 3) whether or not the purpose of the medication was understood.

All coding of transcribed interviews and qualitative analyses was conducted using the Dedoose web-based platform.⁽²⁸⁾ Fisher’s exact test was used to evaluate differences in medication literacy by sex, interview language (Spanish vs. English), race, and packaging type, and t-tests were used to evaluate differences by age.

Results

The mean age of patients (n=57) was 53 (SD 9 years, range 35–74 years old). Table 1 shows patient demographics and medication use, by HIV status. Patients were prescribed a mean of 3.3 (SD 1.1) classes of medications for these conditions. Sixty-three percent stored medications in their vials; 31% used pill boxes parsed by day/time, 4% used blister packs (pills stored individually in a sheet within dome-shaped plastic barriers)⁽²⁹⁾, and 2% used medication packets, administrable by dispensable rolls.

Naming

Thirty percent of patients were unable to name all of their prescribed medications (Table 2). Within each medication category, the proportion of patients unable to name at least one medication prescribed for that condition ranged from 3% to 11% (Table 2). There was no

significant difference in ability to name medications between patients using medi-sets, pre-packaged rolls, or blister packs, and patients who stored pills in their original containers ($p=0.56$). No demographic group was significantly more or less likely to be able to name all of their medications ($p=.08$ to $p=.77$).

Categorization

Fifty-eight percent of patients categorized their medications by disease or condition, and typically did not refer to their medication by therapeutic class, instead using terms such as “HIV meds” or “cholesterol medications” rather than “integrase inhibitor” or “statin” (for example). Patients prescribed medication for cardiovascular disease and/or mood disorders classified these medications more broadly as “heart medications” or “psych medications.” Nineteen patients (33%) categorized their medications by time of day taken (i.e., “morning meds”). Ten patients (18%) categorized their medications both of these ways. Nine patients (16%) spoke of their medications in terms of function, using brief explanations of how each medication works (i.e., “these lower my blood sugar”). Most patients prescribed multiple medications within a class were able to distinguish between individual medications within that class. However, patients prescribed ARV medications were generally uncertain about which medications within that class were which, and simply identified them as “HIV meds”.

Perceived purpose: what do these medications treat?

Approximately one-fifth of patients did not know and could not guess the purpose of one or more of their medications, overall and by chronic condition (Table 2). There was no significant difference in ability to state medication purpose between patients using medi-sets, pre-packaged rolls, or blister packs and patients who stored pills in their original containers ($p=0.73$).

Thirty percent of patients had at least one misconception about the purpose of one or more of their medications; 24 misconceptions were identified. One-third of these misconceptions incorrectly attributed medication as being prescribed for “heart”, “blood pressure” or “cholesterol.” Thirteen percent reported diabetes medications as being prescribed for cholesterol or the heart; another 13% believed the reverse. Eight percent each reported cholesterol medications as being prescribed for blood pressure; HIV medication as being prescribed for diabetes; and non-mental health medications as being prescribed for mental health. No demographic group was significantly more or less likely to hold misconceptions about their medications ($p=0.45 - 1.00$).

Discussion

In assessing patients’ ability to name and classify their medications and to understand their function and purpose, insight was gained regarding 1) how such understanding might inform patients’ relationships with medications, 2) implications for adherence and clinical outcomes, and 3) implications for development and/or use of patient-reported adherence measures in clinical care.

Thirty percent of patients were unable to name all of their prescribed medications. This is concerning, as dependency on visual identification of medications alone has been associated

with worse adherence among patients with hypertension.(30) In addition, it raises concern that patients may be forced to rely on their own recollection of their medications, such as in the case of medical emergencies, separation from medications while traveling, or when establishing care at a new clinic. While the study findings demonstrated that medication storage type did not affect patients' ability to name their medications, more research is needed with larger sample sizes to substantiate this.

A large proportion of patients did not know, could not guess, and/or held misconceptions about their medications' purpose; again, this did not vary by medication storage type. Lack of knowledge of long-term benefits of medications has been negatively associated with adherence.(31) Among patients with MCC, not understanding the purpose of specific medications may result in a patient confusing medications with one another, potentially resulting in under-dosing, overdose, or toxic interactions with other medications and substances. In addition, lack of knowledge of medication purpose, in the absence of patient apathy or cognitive impairment, implies a remote relationship with one's health care; poor engagement in care has been negatively associated with poor health outcomes by way of suboptimal adherence among patients living with HIV.(32–34) Notably, no patient expressed a desire to improve their own understanding of medication names, classification, or purpose.

What are the implications of patients' understanding of medications for assessing patients' adherence with the use of self-report instruments? Patient-reported measures to assess medication adherence are unlikely to consistently yield accurate information when referencing medications by name, class, or purpose among MCC patients when high proportions do not know or recognize them. Patients' ability to distinguish between medications was unreliable. Misconceptions and errors surrounding cardiovascular medications were particularly prevalent, raising concerns that patients may, for example, confuse antihypertensive for lipid lowering medications. For patient-reported assessments of adherence or medication literacy to work well in this population, they must include clarifying detail, such as pictures of medications accompanying questions in order to increase the likelihood of an accurate response.

The study findings indicate an opportunity to improve medication literacy among patients living with MCC. The "patient-centeredness" essential to improvements in modern care consistent with the Chronic Care Model (35–38) highlights the need for patients' meaningful participation in care. Possessing a basic understanding of medication purpose is helpful in order for patients to fully participate and engage in their treatment and medication-related decisions. The limited medication-related understanding among patients with chronic co-morbidities prompts the recommendation for routine review during clinic visits of at least names and purposes of prescribed medicines, particularly those for cardiovascular disorders, with all medications present during the visit. The study findings render this especially important given that pharmacies periodically change generic manufacturers, resulting in changes to the colors and shapes of medications. For assessment of patient medication adherence to work, providers and patients must make certain they are talking about the same things.

Strengths

Patients interviewed represent a geographically and racially diverse sample and a balance of urban, suburban, and rural populations recruited from community health centers, as well as outpatient clinics based in public hospitals.

Limitations

The small sample size limits the generalizability of these findings. This study did not address other dimensions of pharmaceutical literacy such as perceived self-efficacy to refill medications, or ability to read dosage. Patients were not asked to identify the source of their knowledge about medications.

Conclusions

This study assessed the understanding of medication name, type, and purpose among patients prescribed medications for MCC. A large proportion of patients demonstrated difficulty stating the name of each medication, and articulating the purpose of the medication. Provider knowledge of how patients identify and differentiate between their medications, and how well patients understand each medication's purpose, may supplement patient-provider communication when assessing overall adherence. Patients may benefit from a review of each medication's purpose, which ideally would occur with the actual pills or their visual representations present.

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Table 1

Demographics and medication use by HIV status.

	HIV Negative (n=25)	HIV Positive (n=32)	Total (n=57)
Male	12 (48%)	24 (75%)	36 (63%)
Race/Ethnicity			
Black	11 (44%)	8 (25%)	19 (33%)
White	12 (48%)	11 (34%)	23 (40%)
Hawaiian/Pacific Islander	1 (4%)	0 (0%)	1 (2%)
Latino	1 (4%)	13 (41%)	14 (25%)
Interviewed in Spanish	0 (0%)	12 (38%)	12 (21%)
Age			
34–49	6 (24%)	15 (47%)	21 (37%)
50–59	7 (28%)	13 (41%)	20 (35%)
60–74	12 (48%)	4 (13%)	16 (28%)
Medications			
HIV	–	33 (100%)	33 (58%)
Diabetes	19 (76%)	16 (50%)	35 (61%)
CVD	5 (20%)	4 (13%)	9 (16%)
Hypertension	21 (84%)	22 (69%)	43 (75%)
Dyslipidemia	13 (52%)	21 (66%)	34 (60%)
Depression	14 (56%)	20 (63%)	34 (60%)

Table 2

Patient Understanding of Medications Overall, and for Specific Chronic Conditions

	Could Not Name All of Their Medication(s)	Did Not Know Purpose of Their Medications	N
Overall	17 (30%)	11 (19%)	57
By condition *			
Hypertension	2 (5%)	6 (14%)	43
Diabetes	3 (9%)	2 (6%)	35
Depression	1 (3%)	0 (0%)	34
Dyslipidemia	3 (9%)	4 (12%)	34
HIV	1 (3%)	0 (0%)	32
CVD	1 (11%)	0 (0%)	9

* Only for medications related to the specific condition