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RESEARCH ARTICLE

Hassles with medication management perceived by caregivers of adults who have intellectual or developmental disabilities

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Abstract

Background Medication management is undertaken by caregivers of people who have intellectual or developmental disabilities. *Objective* The objectives were to measure the medication management hassles reported by caregivers of adults who have intellectual or developmental disabilities and to describe associations between characteristics of caregivers, medication regimens, and the person with intellectual or developmental disability and the scale score. *Setting* Web-based survey conducted in the United States. *Method* A newsletter announcement with a link to the survey was sent to members of a disability advocacy organization. Caregivers were age 18 years and older who manage medications for adults with intellectual or developmental disabilities. The survey questions were used to obtain characteristics of the caregiver, the medication regimen they managed, and the care-recipient. The study was approved by the Institutional Review Board of Michigan Medicine (HUM00091002). *Main outcome measure* The Family Caregiver Medication Administration Hassles Scale (caregiver scale). *Results* Forty-two caregivers responded, with 41 being female with a mean age of 56.7 years. The mean caregiver scale score was 28.9 (possible range 0–120). Highest scores (greatest hassles) were significantly associated with a greater level of support required by the care-recipient, stronger caregiver beliefs of the necessity of medication and concern about using medications, lack of previous caregiver health-care training, and being an employed caregiver rather than family member. *Conclusion* Medication management can contribute to caregiver stress. Pharmacists should ensure that caregivers are counseled about medication that they manage, be accessible for questions, and examine medication regimens to reduce polypharmacy and complexity of regimens.

Keywords Caregiver · Challenges · Health literacy · Intellectual developmental disability · Medication beliefs · Medication complexity · Medication use process

Impacts on practice

- Pharmacists should make an effort to know the caregivers who manage the medications for patients with intellectual or developmental disabilities. The caregivers often consider managing medications as a stressful and concerning activity.
- Pharmacists should serve as information resources for caregivers, counseling them on new prescriptions and ensuring that caregivers understand the medication regimens they are responsible for managing.
- Pharmacists may be able to reduce the burden of medication management for caregivers by ensuring the medication regimens are manageable and to be available for questions from caregivers about medications.

Introduction

The medication use process can be complex. Patients with intellectual or developmental disabilities (IDD) are at risk for not being able to competently engage in some or all of the tasks associated with the medication use process, often relying on other people for assistance. Developmental disabilities are severe chronic disabilities that can be cognitive or physical or both. The disabilities appear before the age of 22 and are likely to be lifelong [1]. Some developmental disabilities are largely physical issues, such as cerebral palsy

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or epilepsy. Some individuals may have a condition that includes a physical and intellectual disability, for example Down syndrome or fetal alcohol syndrome. Intellectual disability is a disability characterized by significant limitations in both intellectual functioning and in adaptive behavior, which covers many everyday social and practical skills [2]. In 2012 it was estimated that 1.5–2.5% of the US population is living with some form of IDD [3]. Patients with IDD often rely on caregivers to navigate the medication use process on their behalf. With a predicted increase in the prevalence of IDD as well as the fact that more people with IDD are living longer and acquire age-related chronic conditions, the demand for formal and informal caregivers will increase [3]. Medication regimens of people with IDD are almost twice as complex as the regimens of patients without IDD, and often include 5 or more medications [4]. This poses a risk for caregiver stress and concern. Several studies have reported the challenges to medication management experienced by caregivers of older adults, but no research has been conducted on the challenges faced by caregivers of patients with IDD [5–9].

Aim of the study

The aims of the study were to identify the medication management hassles perceived by caregivers of adults who have intellectual or developmental disabilities and to describe associations between characteristics of caregivers, medication regimens, and the person with intellectual or developmental disability and the scale score.

Ethics approval

All procedures performed in this study involving human participants were in accordance with the ethical standards of the institutional research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards. The study was approved by the Institutional Review Board (IRB) of Michigan Medicine (HUM00091002).

Methods

Study design

This was a cross-sectional study using an internet-based survey of caregivers of adults who have IDD.

Subjects

Caregivers were defined as family, friends, or employed support staff residing in the United States. For this study, subjects had to be age 18 years or over and had to provide care and medication management assistance to an adult person who has a condition associated with IDD were included. Caregivers were recruited from the membership of the Arc, an advocacy organization whose membership includes individuals with disabilities, family and friends, care-workers, and advocates. The method of recruitment was through the Arc's newsletter, sent to approximately 700 in mid-January 2015. The newsletter contained a summary of the study and a link to the survey website. Data collection was designed to be anonymous.

Survey components/measures

Caregiver and care-recipient characteristics

Demographic information of the caregiver as well as the care-recipient that were collected included age, gender, race, and general education. Education was categorized as high school graduate or equivalent training or some college, college graduate, graduate of a post-high school training program. Data on how many hours per day, on average, the care-recipient required personal assistance. This value was used as a proxy measure of severity of impairment of the care-recipient. Hours per day needing assistance has been found to correlate with level of impairment in people with dementia [10, 11].

Other characteristics that were collected included the relationship to the care-recipient, the length of time working with the care-recipient, and prior work experience as a caregiver. The caregiver was asked the frequency (do not perform, some of the time, most of the time, all of the time) of performing health-related tasks that were medication-centered (obtaining medications from the pharmacy, reminding the care-recipient to take medications, administering doses of medications, reviewing and documenting health-related tasks of the care-recipient) and physician-centered (scheduling appointments, transporting to appointments, and seeing physicians with the care-recipient). To determine caregiver's personal experience with medication, they were asked if they had taken or currently take prescription medication on a regular basis. To determine whether the caregiver had training in either health care or in medication management (medication pass training) they were asked if they had a degree or training in health care and whether they had participated in a medication administration training program.

Health literacy

A three-item health literacy screening scale was used to assess health literacy of the caregivers [12]. The scale, when created, was found to be effective in detecting inadequate health literacy as defined by the STOHFLA (Short Test of Functional Health Literacy in Adults), a commonly used health literacy assessment tool. Questions include "How often do you have problems learning about your medical condition because of difficulty understanding written information?", "How confident are you filling out medial forms by yourself?", and "How often do you have someone help you read instructions, pamphlets, or other written materials from your doctor or pharmacy?" [13, 14] A 5-point Likert scale is used for each question. The potential scale score ranges from 1 to 5, with higher scores indicating higher health literacy.

Beliefs about medicines questionnaire

The caregivers completed the beliefs about medicines questionnaire (BMQ) to determine beliefs and attitudes toward prescription medication utilization [15]. The BMQ consisted of 10 items that generated two scales scores: Specific-Necessity (SN) and Specific-Concerns (SC). For the present study, Necessity and Concerns belief will be used to designate each scale. Each BMQ item uses a five point Likert scale (from 1 = strongly disagree to 5 = strongly agree). Each scale score is derived from the mean of the scale items, with a possible score range from 1 to 5. Higher BMQ-scale scores indicated stronger agreement with the belief scale. Wording was modified to reflect the thoughts of the caregiver toward the medication therapy taken by the care-recipient. For example, The original BMQ question "My health, at present, depends on medicines" was changed to "The care-recipient's health, at present, depends on medicines."

Medication complexity

An additional set of questions were asked to determine the complexity of the medication regimens. People who have IDD are at risk for having complex medication regimens [4]. One measure of medication regimen complexity is the Medications Regimen Complexity Index (MRCI) [16]. The subscales of the MRCI include the frequency of doses taken per day, the route of administration, and special instructions for using the medication. For the present study, we included the concepts from the MRCI of frequency of doses taken per day and route of administration. We did not include a special instructions question. Also included was a question asking for the total number of medications the person with IDD takes per day.

Family Caregiver Medication Administration Hassles Scale

The Family Caregiver Medication Administration Hassles Scale (FCMAHS) was used to measure the caregiver's perceived hassles or concerns with medication management [17, 18]. The FCMAHS was developed to measure the hassles perceived by caregivers who administer medications to older people. The issues and concerns associated with administration of medications were reported to be a construct of daily hassles found in the caregiver literature [17, 18] Hassles are considered to be minor irritants of daily living that may represent a threat to a caregiver's health and well-being [9]. The instrument includes 24 items that have 6 response options (0 = not a hassle to 5 = one of the worst of all hassles). Four subscales include information seeking/information sharing (scale range 0–45); scheduling logistics (0–35); safety issues (0–25); and polypharmacy (0–15). A summary score is then calculated, ranging from 0 to 120 (or the sum of all items). Higher values on the subscales and the summary scale indicated greater hassles.

The survey was built and administered using Qualtrics survey software. Respondents were able to move freely throughout the survey as they completed it. Should a respondent not complete all the questions for a particular scale, then that scale was not calculated. Only one respondent did not complete all questions for several scales.

Analysis

Data are presented as means with standard deviation for continuous variables and frequencies with percentage for categorical variables. Internal consistency for each scale used in the study was assessed using Cronbach's alpha. A Cronbach's alpha of 0.7 or higher is desired. Bivariate associations between caregiver, care-recipient, and medication regimen characteristics with the score of the FCMAHS were explored by generating FCMAHS scores into quartiles, then conducting either one-way ANOVA or Chi square tests for each of the caregiver, care-recipient, and medication regimen characteristics. Creating FCMAHS quartiles provided a sense of the breadth of the variation between levels of hassle and the individual characteristics of the caregiver, care-recipient, and medication regimen. SPSS version 24 was the software used for analysis.

Results

Description of sample

Forty-three individuals started the on-line survey. One did not complete the survey. Another respondent completed almost all of the survey, with missing data in "Caregiver Involvement in Overall Medication Use Process" set of questions. The remaining forty-one respondents completed all questions. Refer to Table 1 for a description of the respondents. The mean age was 56.7 years and all but one were female. Over 80% of respondents had formal education of some college or college graduate. Fifty-seven percent indicated that they were employed outside the home. Sixty-nine percent of respondents were the parent of the care-recipient, 7.2% were family members, while 23.8% were employed direct support staff. The caregivers had, in general, a long-term caregiving relationship with the care-recipient. Less than half of respondents had prior experience as a caregiver, and almost half said they provide care for multiple care-recipients. Thirty-six percent indicated they had received training in health care. Just over 76% of the caregivers indicated that they currently take medication, and 38% had received training focused on medication administration. Care-recipients had an average age of 33 years and 58.5% were male. The care-recipient required supervision an average of 16 h per day.

Health literacy and beliefs about medicines

Caregivers had a high level of health literacy, with a mean scale score of almost 4. The Cronbach's alpha for this scale was 0.34, which is below the desired threshold of 0.7. As for beliefs about medications as measured by the belief about medication questionnaire, the mean score for the Necessity scale was 4.0, where 5 is the highest agreement that medications are necessary. This indicates a strong belief in the necessity of medication taken by the care-recipient. The Cronbach's alpha for this scale was 0.76, which is above the desired threshold of 0.7. As for the Concern scale, the mean score was 2.7 out of 5, indicating a moderate level of the concern about medication taking (safety, long term effects). The Cronbach's alpha for this scale was 0.77.

Medication complexity

The measures of medication regimen complexity included the total number of medications in the regimen, the number of times per day medication was taken, and a sum of the different routes of administration for medications in the regimen. The mean number of medications taken per day by the care-recipient was 8.3, the mean number of times per day medication was taken was 2.6, and the mean of the sum of different routes of administration was 2.6. The most common route of administration was oral (93%), followed by creams and ointments (48.8%), eye/ear drops (18.6%), injections (16%), suppositories (14%), patches (7%), gastric-tubes (7%), and intravenous infusions (4.7%).

Medication-management activities

Over 80% of caregivers indicated that either most of the time or all of the time they scheduled appointments with doctors (88.3%), transported the care-recipient to the doctor (86.0%), were present during the visit to the doctor (86.1%), and obtained the medication from the pharmacy (83.8%). Refer to Table 2. Between 70 and 80% of caregivers indicated that they would remind the care-recipient when to take medication or would administer it (74.4%), document medication-related information to share with the doctor (75.7%), and oversee or plan the medication administration schedule (79.1%). Just over 60% indicated that they make decisions on whether to give a medicine or increase or decrease a dose, or discontinue a medicine (60.4%). Actually administering the medication to the care-recipient was performed by 55.8% of respondents. Only 18.6% perform testing (point-of-care testing or take blood pressure). This is most likely reflective of low prevalence of diabetes or hypertension in the study sample.

Family Caregiver Medication Administration Hassles Scale (FCMAHS) results

The mean overall medication hassles scale score was 28.8, with a possible score range from 0 to 120. Refer to Table 3. The mean subscale scores included information seeking mean of 11.5 (possible range 0–45), scheduling/logistics mean of 7.6 (possible range 0–35), safety mean of 5.5 (possible range 0–25), and polypharmacy with a mean of 4.3 (possible range of 0–15). The Cronbach's alpha was 0.90 for the overall scale, 0.91 for the information seeking/sharing subscale, 0.79 for the scheduling/logistics subscale, 0.83 for the safety issues subscale, and 0.76 for the polypharmacy subscale. Analysis of the individual questions from within the four subscales provide a more refined assessment of the concerns or hassles. Within the information seeking/information sharing subscale, respondents indicated the greatest hassle was knowing why a medication was being given and if it was having a desired effect (25.6%), having someone available to answer questions (35.7%), getting information within a reasonable time frame (26.2%), and feeling comfortable about making medication decisions (30.2%). Within the scheduling logistics subscale, respondents found the most hassles when scheduling multiple medications throughout the day

Table 1 Description of study sample (N = 42)

Variables	Mean (SD) or frequency (%)
Caregivers	
Age in years	56.7 (9.5)
Gender	
Male	1 (2.4)
Female	41 (97.6)
Formal education	
High school graduate or equivalent training	7 (16.7)
Some college, college graduate, graduate of a post-high school training program	35 (83.3)
Employment outside home	
Yes	24 (57.1)
No	18 (42.9)
Relationship to care-recipient	
Family member/parent	29 (69.0)
Family member/brother, sister, aunt, uncle	2 (4.8)
Family member/child	1 (2.4)
Employed by an agency	8 (19.0)
Employed directly by care-recipient's family or designated guardian	2 (4.8)
Duration of care in years	22.9 (12.1)
Prior experience as a caregiver	
Yes	18 (43.9)
No	23 (56.1)
Care for multiple care-recipients	
Yes	17 (41.5)
No	24 (58.5)
Degree/training in health care area	
Yes	15 (36.6)
No	26 (63.4)
Regular medication use	
Yes	32 (76.2)
No	10 (23.8)
Participation in medication administration training	
Yes	16 (38.1)
No	26 (61.9)
Health literacy	4.5 (0.2)
Range	2.7–5.0
BMQ Necessity scale	4.0 (1.0)
Range	1–5
BMQ Concerns scale	2.7 (0.9)
Range	1–4.4
Care-recipients	
Age in years	33.5 (15.7)
Gender	
Male	24 (58.5)
Female	17 (41.5)
Average hours of care needed on a daily basis	16.9 (9.1)
Number of medications in regimen	8.3 (6.3)
Range	1–24
Number of times per day care-recipient takes medication	2.6 (1.6)
Range	1–7
Sum of the different routes of administration for medications in the daily regimen	2.6 (1.6)

Table 1 (continued)

Variables	Mean (SD) or frequency (%)
Range	1–7
Specific routes of administration	
Oral	40 (93)
Topical (creams, ointments)	21 (48.8)
Eye/ear drops	8 (18.6)
Injections	7 (16.0)
Suppositories	6 (14.0)
Topical patches	3 (7.0)
Gastric-tube liquids	3 (7.0)
Intravenous infusions	2 (4.7)

Table 2 Caregiver involvement in the overall medication use process (n = 41)

Question	Do not perform (%)	Some of the time (%)	Most of the time (%)	All of the time (%)
Obtain prescription or non-prescription medicines (from the pharmacy, store, etc.)	2 (4.7)	5 (11.6)	2 (4.7)	34 (79.1)
Remind the care-recipient to take medications	5 (11.6)	6 (14.0)	7 (16.3)	25 (58.1)
Hand the care-recipient medications when it's time to take them	8 (18.6)	4 (9.3)	6 (14.0)	25 (58.1)
Schedule doctor appointments for the care-recipient	3 (7.0)	2 (4.7)	1 (2.3)	37 (86.0)
Transport the care-recipient to doctor appointments	3 (7.0)	3 (7.0)	1 (2.3)	36 (83.7)
See the doctor with the care-recipient, including providing health information	3 (7.0)	3 (7.0)	2 (4.7)	35 (81.4)
Perform testing such as poking the care-recipient's finger for blood sugar or taking a blood pressure	29 (67.4)	6 (14.0)	1 (2.3)	7 (16.3)
Write down any health-related information to share with the physician or nurse	5 (12.2)	5 (12.2)	9 (22.0)	22 (53.7)
Oversee or plan the medication administration schedule	3 (7.0)	6 (14.0)	4 (9.3)	30 (69.8)
Make decisions to give, hold, increase, or decrease a dose or discontinue a medication	13 (30.2)	4 (9.3)	5 (11.6)	21 (48.8)
Actually administer the medication to the care-recipient, by mouth, injection, or other route of administration	16 (37.2)	3 (7.0)	7 (16.3)	17 (39.5)

Table 3 Summary of the Family Caregiver Medication Administration Hassles Scale (FCMAHS) scores (n = 42)

FCMAHS domain	Minimum	Maximum	Possible range	Mean	SD
Info/seeking info subscale	0	31	0–45	11.5	9.7
Scheduling logistics subscale	0	27	0–35	7.6	6.5
Safety subscale	0	24	0–25	5.5	5.6
Polypharmacy subscale	0	12	0–15	4.3	3.9
Overall scale score	0	72	0–120	28.9	19.4

(23.3%) and sharing the responsibility for keeping medication schedules (23.3%). Within the safety issues subscale, the most hassles experienced were related to recognizing adverse or bad side effects (30.3%). The distribution within the polypharmacy subscale was broader, with highest level of hassles in managing medication prescriptions written by multiple physicians (34.9%).

Association between caregiver, care-recipient, medication regimen characteristics and the overall FCMAHS scale score

Grouping the overall FCMAHS scores into quartiles resulted in the lowest quartile FCMAHS scores ranging from 0 to 10.0 with a mean of 3.2 ± 3.7 (n = 9); the second quartile

Table 4 Association between family caregiver medication hassles scale overall score and individual caregiver, care-recipient, and medication regimen variables

Variable	Quartile 1 FCMAHS score less than 11 (mean ± SD or frequency and percent)	Quartile 2 FCMAHS score 11–28.9 (mean ± SD or frequency and percent)	Quartile 3 FCMAHS score 29–40.9 (mean ± SD or frequency and percent)	Quartile 4 FCMAHS score 41 and greater (mean ± SD or frequency and percent)	*P* value
Age of caregiver	60 (11.6)	56.2 (6.9)	59.1 (9.2)	52.4 (10.0)	0.27
Age of care-recipient	44.7 (12.8)	29.4 (6.4)	26.6 (7.3)	37.2 (24.3)	0.06
Gender of caregiver—female	8 (100)	11 (100)	10 (90.0)	12 (100)	0.9
Gender of the care-recipient—female	3 (37.5)	5 (45.5)	5 (45.5)	4 (36.4)	0.96
Number of medications taken by the care recipient	6.5 (6.3)	8.3 (5.7)	9.6 (7.4)	8.4 (6.3)	0.8
Number of times per day the care recipient takes medications	1.6 (1.1)	2.6 (1.4)	3.3 (2.1)	2.7 (1.2)	0.16
Number of different routes of administration of medication	2.1 (2.1)	2.6 (1.5)	2.7 (1.6)	2.8 (1.3)	0.8
Number of hours per day the care recipient requires supervision	7.1 (7.8)	18.8 (7.9)	15.5 (10.3)	22.6 (2.8)	0.002
Caregiver health literacy	4.3 (0.6)	4.7 (0.4)	4.6 (0.4)	4.3 (0.9)	0.21
Caregiver belief of necessity of medication	2.8 (1.0)	4.3 (0.8)	4.4 (0.8)	4.1 (0.6)	< 0.001
Caregiver belief about concern using medications	2.0 (1.0)	2.5 (0.6)	2.9 (0.8)	3.1 (0.8)	0.02
Caregiver provides support for other people—yes	3 (37.5)	4 (36.4)	3 (30.0)	7 (58.3)	0.55
Caregiver education–some college of more	5 (62.5)	10 (90.9)	10 (90.9)	10 (83.3)	0.33
Caregiver health care training—yes	6 (75.0)	5 (45.5)	1 (9.1)	3 (27.3)	0.02
Caregiver takes medication regularly—yes	7 (87.5)	9 (81.8)	6 (54.5)	10 (83.3)	0.27
Caregiver participate in medication administration program	2 (25.0)	3 (27.3)	5 (45.5)	6 (50.0)	0.6
Caregiver affiliation with care recipient—family	4 (50.0)	11 (100.0)	10 (90.9)	7 (58.3)	0.02
Caregiver employed outside the home—yes	5 (20.8)	6 (25.0)	7 (29.2)	6 (25.0)	0.91
Family caregiver medication hassles scale overall score	3.1 (3.7)	18.5 (5.1)	34.7 (3.5)	52.3 (10.5)	< 0.001

One-way ANOVA for continuous variables, Chi squared for categorical variables

ranging from 11 to 28.9 with a mean of 18.5 ± 5.1 (n = 11); the third quartile ranging from 29 to 40.9 with a mean of 34.7 ± 3.5 (n = 11); and the highest quartile ranging from 41 to 72 with a mean of 52.3 ± 10.5 (n = 12). Table 4 provides the data for the bivariate analyses between the overall FCMAHS score and the individual caregiver, care-recipient, and medication regimen variables. There were significant differences in FCMAHS scores based on BMQ Necessity score, BMQ Concern score, the number of hours of supervision that the care-recipient required per day, whether the caregiver had formal training as a health care professional, and the type of caregiver. Greater caregiver belief of the necessity of medication and greater belief of concern about medication were associated with greater sense of medication management hassles (higher FCMAHS scores). Likewise, the greater the number of hours per day the care-recipient required supervision was associated with greater perceived hassles. Caregivers with prior training in a health care related field perceived lower levels of hassles. Family caregivers perceived lower levels of hassles compared to the higher levels of hassle perceived by direct support professionals. All other bivariate comparisons were statistically non-significant.

Discussion

Generally, caregivers who responded to the survey had a modest level of hassles associated with medication management, as determined by the overall FCMAHS score. The FCMAHS scores from the present study are similar to scores found in the original study describing the development of the instrument. When the instrument was initially developed by Travis et al., construct validity was measured by assessing the correlation of the total and subscale scores of the FCMAHS with the complexity of medication regimens and a modified Caregiver Strain Index, a measure of the burden of caregiving on the caregiver [18]. They found that medication complexity and caregiver strain were both significantly correlated with the FCMAHS total scale and all four subscale scores. This may be translated to the present study in that the FCMAHS scores were very similar, and therefore one may assume that the caregivers who had higher scores would have similar caregiver strain as that found in the original study by Travis.

Examination of individual items from the subscales of the FCMAHS provided a bit more clarity on the issues related to medication management hassles. Items within the information seeking subscale with greater than 20% of respondents score with the higher hassles scores included knowing why a medication was being given and if it was having a desired effect, having someone available to answer questions, getting information within a reasonable time frame, and feeling comfortable about making medication decisions. Having useful and appropriate information about medications is vital to ensure safe and effective use of medications. Having difficulty finding information, interpreting information, and using information can lead to increased anxiety and caregiver strain [18]. This notion is supported by the findings of this study. The subscales of safety issues and polypharmacy had over 30% of respondents reporting high levels of hassles, with recognizing adverse effects as well as managing medications prescribed by multiple physicians being commonly endorsed. Lastly, scheduling logistics items of scheduling multiple medications throughout the day and sharing responsibility of scheduling medications to be of highest hassle score in just over 20% of respondents. Taken all-together, one may hypothesize that pharmacists may be of great assistance to caregivers. For example, pharmacists may review a patient's medication profile, looking for ways to reduce the number of medications and the complexity of medication regimens, which should help reduce the hassles perceived by caregivers. Pharmacists should counsel caregivers about the medication regimens that they manage in an effort to maximize safe management of therapy. A recent study found that informal caregivers who have high knowledge hassles, or the daily stressors experienced while dealing with tasks which require knowledge about safety and effectiveness of care-recipients' medications, are more likely to perceive that a Home Medicines Review would be helpful [19].

Caregivers in this study were very involved in every step of the medication management process. This is but one of many forms of assistance that caregivers provide to individuals with IDD. Our study found that the caregivers of care-recipients who required more daily supervision had higher FCMAHS scores. In the long-term, hassles or stress associated with managing medications, coupled with the stress of other caregiving activities, may have a negative effect on both the caregiver as well as the care-recipient [20].

Individual factors associated with FCMAHS score

The complexity of the medication regimen in the present study, measured by three different variables representing different aspects of medication regimens (number of medications taken, number of times per day doses taken, and number of different routes of administration) was not significantly associated with medication hassles. Previous studies examined caregiver stress related to medication management for older patients, which often included descriptions of complexity of medication regimen being associated with stress [5–9]. The medication regimens of patients with IDD can be complex, and in fact as complex as the regimens of elderly patients [4]. In their review of the literature, Gillespie et al. found that the role of the informal caregiver in managing medication for older patients with dementia is complex and is often made more difficult because of increasing medication regimen complexities, aspects of the relationship between the caregiver and the care recipient, healthcare system practices and a lack of information and/or training available to the informal caregiver, especially when caring for people living with dementia [7]. A previous study using the FCMAHS administered to caregivers of older patients found that medication regimen complexity was associated with more intense hassles using the FCMAHS [9]. That study used a medication complexity scale that incorporated number of medications, the number of doses taken per day, the route of administration, and any special instructions. The present study used a similar approach to measure complexity of the regimen, but we intentionally left off the special instructions question. We felt that respondents may not always provide accurate information for this question which may have influence on the scale score. We elected to analyze the FCMAHS score by each of the other components of regimen complexity separately. We found the associations to be not significant, but there was a trend where as the number of doses taken per day increase, there was generally greater FCMAHS scores.

Caregiver beliefs about medication were significantly associated with the FCMAHS score. Respondents with greater belief of the necessity of the medications taken by the care recipient had more intense hassles scores. This may be due to anxiety-provoked feelings that medications must be managed well even when attending to other caregiving tasks or tasks in their own lives. Caregiver concern about medication was also significantly associated with the FCMAHS score. Stronger concern about medication taken by the care-recipient was associated with greater medication management hassles. A review of the literature found no studies assessing the association between medication beliefs and hassles associated with managing medication. Beliefs about medication and hassles associated with medication use are often identified as reasons why or why not patients engaging in appropriate health behaviors. Understanding the interaction between the two concepts is crucial when examining predictors of complex behaviors such as taking medication. More in-depth assessment is needed to determine why caregivers with higher levels of perceived hassles also have higher concerns about medicines and higher feelings of necessity for medications, and the impact the associations may have on their likelihood to encourage adherent behavior in the care-recipient.

Other variables that were not significantly associated with the FCMAHS scale included caregiver and care-recipient age and gender, caregiver health literacy, caregiver providing care for more than one care-recipient, caregiver formal education, caregiver having taken a medication management training program, caregiver taking medication themselves, or caregiver being employed outside the home.

One of the only other caregiver variables associated with the FCMAHS was whether they had previous health care training. Respondents with prior health care training had significantly lower levels of perceived hassles. It is assumed that their familiarity with the medication management process through their training would give them higher self-confidence and less concern with the tasks associated with managing medication.

Limitations

The primary limitation of this study is the small sample size (42 responses) which was composed of predominantly female caregivers. Because of the small sample size, we view the results to be more descriptive. We do provide bivariate analyses, examining individual characteristics of the caregiver, care-recipient, and medication regimen with the FCMAHS score, more to give the reader a sense of potential relationship that requires further research. In light of the small sample size and the fact that we conducted only bivariate analyses to explore the associations between variables, we view this as a hypothesis generating study. Another limitation was the method used to recruit subjects. The survey was internet-based, which may preclude individuals without access to computers or who may have lower health literacy. Study participants were members of an advocacy agency, tended to be well educated both in formal education as well as having themselves had experience with managing their own medications or health-care related training, had a long term caregiver relationship with the care-recipient, and were family members, all of which may be associated with the individual being more engaged in the care for people with IDD. Further research is needed to create a larger, more diverse sample of caregivers to increase the power for detecting significant differences on factors that affect caregiver strain and burden related to medication management. Another limitation is that the health literacy scale used for this study had a low Cronbach's alpha score, which indicates a low level of internal reliability. This scale is good at screening for health literacy problems, but may not be adequate for more robust measurement of health literacy. For example, The original BMQ question "My health, at present, depends on medicines" was changed to "The care-recipient's health, at present, depends on medicines." This change was not validated for this study, which is a limitation to the interpretation of the beliefs data. The internal reliability of the two scales was high, but construct validity was not tested.

Conclusion

Medication management is a commonly undertaken activity by people who provide care for individuals who have intellectual and developmental disabilities. These activities have the potential to contribute to stress in caregivers' lives. Pharmacists could intervene by ensuring caregivers are counseled about medication that they manage, as well as be accessible for questions as they arise, and to carefully scrutinize medication regimens to attempt to reduce polypharmacy and complexity of regimens.

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References

1. American Association on Intellectual and Developmental Disabilities. https://aaidd.org/intellectual-disability/definition/faqs-on-intellectual-disability. Accessed 30 Oct 2018.
2. American Association on Intellectual and Developmental Disabilities. https://aaidd.org/intellectual-disability/definition. Accessed 30 Oct 2018.
3. Bethesda Institute. How prevalent are intellectual and developmental disabilities in the United States? http://flroof.org/publication/view/how-prevalent-are-intellectual-and-developmental-disabilities-in-the-united-states/. Accessed 30 Oct 2018.
4. Erickson SR, Nicaj D, Barron S. Complexity of medication regimens of people with intellectual and developmental disabilities. J Intellect Dev Disabil. 2018;43:351–61.
5. Kaasalainen S, Dolovich L, Papaioannou A, Holbrook A, Lau E, Ploeg J, et al. The process of medication management for older adults with dementia. J Nurs Healthc Chronic Illn. 2011;3:407–18.
6. Cotrell V, Wild K, Bader T. Medication management and adherence among cognitively impaired older adults. J Gerontol Soc Work. 2006;47:31–46.
7. Gillespie R, Mullan J, Harrison L. Managing medications: the role of informal caretakers of older adults and people living with dementia. A review of the literature. J Clin Nurs. 2014;23:3296–308.
8. Gillespie RJ, Harrison L, Mullan J. Medication management concerns of ethnic minority family caregivers of people with dementia. Dementia. 2015;14:47–62.
9. Travis SS, McAuley WJ, Dmochowski J, Bernard MA, Kao HFS, Greene R. Factors associated with medication hassles experienced by family caregivers of older adults. Patient Educ Couns. 2007;66:51–7.
10. Langa KM, Chernew ME, Kabeto MU, Herzog AR, Ofstedal MB, Willis RJ, et al. Natinal estimates of the quantity and cost of informal caregiving in the elderly with demential. J Gen Intern Med. 2001;16:770–8.
11. Okura T, Langa KM. Caregiver burden and neuropsychotiatric symptoms in older adults with cognitive impairment: the aging, demographis, and memory study (ADAMS). Alzheimer Dis Assoc Disord. 2011;25:116–21. https://doi.org/10.1097/WAD.0b013e318203f208.
12. Chew LD, Bradley KA, Boyko EJ. Brief questions to identify patients with inadequate health literacy. Fam Med. 2004;36:588–94.
13. Schwartz KL, Bartoces M, Campbell-Voytal K, West P, Monsur J, Sartor A, et al. Estimating health literacy in family medicine clinics in metropolitan Detroit: a MetroNet study. J Am Board Fam Med. 2013;26:566–70.
14. Bauer AM, Schillinger D, Parker MM, Katon W, Adler N, Adams AS, et al. Health literacy and antidepressant medication adherence among adults with diabetes: the Diabetes Study of Northern California (DISTANCE). J Gen Intern Med. 2013;28:1181–7.
15. Horne R, Weinman J, Hankins M. The beliefs about medicines questionnaire: the development and evaluation of a new method for assessing the cognitive representation of medication. Psychol Health. 1999;14:1–24.
16. George J, Phun Y-T, Bailey MJ, Kong DCM, Stewart K. Development and validation of the Medication Regimen Complexity Index. Ann Pharmacother. 2004;38:1369–76. https://doi.org/10.1345/aph.1D479.
17. Travis SS, Bethea LS, Winn P. Medication administration hassles reported by family caregivers of dependent elderly persons. J Gerontol A Biol Sci Med Sci. 2000;55:M412–7.
18. Travis SS, Bernard MA, McAuley WJ, Thornton M, Kole T. Development of the Family Caregiver Medication Administration Hassles Scale. Gerontologist. 2003;43:360–8.
19. Carter SR, Moles R, White L, Chen TF. The willingness of informal caregives to assist their care-recipient to use Home Medicines Review. Health Expect. 2016;19:527–42.
20. DeLongis A, Coyne J, Dakof G, Folkman S, Lazarus R. Relationships of daily hassles, uplifts, and major life events on health status. Health Psychol. 1982;1:119–36.