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# Factors Associated With Medication Hassles Experienced By Family Caregivers of Older Adults[1]

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## Abstract

**Objective—** We wished to identify potential factors associated with medication administration hassles, daily irritants, among informal caregivers who provide long-term medication assistance to persons aged 55 or older.

**Methods—**A sample of 156 informal caregivers were recruited from seven states and several types of settings. The dependent variable was scores on the Family Caregiver Medication Administration Hassles Scale (FCMAHS). Independent variables included in the analyses were medication complexity; caregiver's gender, ethnicity, relationship to recipient, length of time in caregiving, education, and employment outside the home; care recipient's physical capacity and mental capacity; and whether the caregiver and care recipient live together. After preliminary analysis to reduce the number of independent variables, the remaining variables were included in a linear model (GLM procedure). Possible interactions and residuals were considered.

**Results—**Whites and Hispanics experience greater medication administration hassles than other groups, and perceived hassle intensity increases with medication complexity. Medication administration hassle scores increase with increasing education levels up to a high school degree, after which they remain consistently high. Caregivers whose care recipients have moderate levels of cognitive functioning have higher medication administration hassles scores than those whose care recipients have very high or very low cognitive functioning.

**Conclusion—**The preliminary set of significant variables can be used to identify caregivers who may be at risk of experiencing medication administration hassles, increased stress, and potentially harmful events for their care recipients.

**Practice Implications**—Family caregivers are accepting complex caregiving responsibility for family members while receiving little or no support or assistance with caregiving hassles associated with this duty. The FCMAHS offers the means to monitor how caregivers are handling the daily irritants involved with medication administration so that educational interventions can be provided before hassles lead to more serious stress and strain.

## Keywords

family caregiving; caregiver strain; medication complexity

## 1. Introduction

With changes in the levels of acuity and lengths of time in caregiving, contemporary family caregivers are assuming greater responsibility for monitoring and managing an array of serious chronic medical conditions[1–2]. While others have noted the contributions that medication management makes to perceived stress among family caregivers, measurement of this multidimensional stressor was largely absent in the caregiving literature until the recent development of the Family Caregiver Medication Administration Hassles Scale (FCMAHS) [3]. The purpose of this paper is to report a set of variables that are associated with the intensity of medication administration hassles on the FCMAHS that are experienced by family caregivers who manage some or all aspects of the medication regimens for their care recipients over the long-term.

Hassles are minor irritants [4]. This type of stress is often of little consequence and is a common experience of daily living. However, when hassles are prolonged and allowed to accumulate over time, there are clear consequences to an individual's health and well being [5]. In the case of long-term caregivers, medication administration hassles have been shown to be very time consuming[1] and related to perceptions of enduring problems (strain) associated with the caregiving situation [6]. Thus, the presence of medication hassles can have significant effects on the ability of the caregiver to carry out his or her responsibility over the long term.

The FCMAHS is a multidimensional measure of the daily irritants associated with managing some or all aspects of another person's medication regimen [3]. The instrument consists of 24 items and four subscales: Information Seeking/Information Sharing (9 items, $\alpha = .92$), Safety Issues (5 items, $\alpha = .83$), Scheduling Logistics (7 items, $\alpha = .90$) and Polypharmacy (3 items, $\alpha = .80$). Information Seeking/Information Sharing items deal with the multiple communication aspects of the caregiving duty and includes such items as talking to the doctor, knowing what questions to ask the doctor, and understanding directions and information. The Scheduling Logistics subscale measures the intensity of hassles associated with incorporating medication administration into one's daily schedule and routine. Safety Issues include admitting that mistakes are made, recognizing side effects, and knowing what to do if dosage or administration adjustments are necessary. Finally, the Polypharmacy subscale includes items for keeping prescriptions filled, planning ahead for weekends and holidays, and managing prescriptions written by multiple physicians. Overall scale reliability is .95, and test-retest reliability at 2 weeks is .84. Items are scored from 0 (not a hassle) to 5 (one of the worst of all hassles). Thus, higher scores are associated with greater levels of perceived medication administration hassles. A full description of instrument development has been previously reported [3]. A test of construct validity has also been reported in which the FCMAHS was significantly correlated ($r = .44$, $p = .001$) with a measure of family caregiver strain [6].

Based on the preliminary work by Travis and colleagues and a review of a related study on medication administration duties [3, 7–8], three types of variables appear to exert a potentially strong influence on medication administration hassles experienced by family caregivers: (1)

caregiver and care recipient characteristics, (2) the caregiving arrangement, and (3) the complexity of the specific task of interest, in this case the administration of medications taken on a regular basis.

### 1.1. Caregiver and Care recipient Characteristics

This set of variables includes age of the caregiver and care recipient, gender of the caregiver, relationship to the care recipient, race/ethnicity of the caregiver, caregiver level of education, and caregiver employment outside the home. An important concept in caregiving research is cohort membership and the socialization of caregivers within different historical eras [7–9]. We use age as a way of including cohort membership in the analyses. Although there was no information in the literature about medication administration issues, in particular, there is ample evidence about differences in caregiving experiences, in general, to include gender and ethnicity in the analyses [10–14]. Because caregivers' levels of education and employment status are known to impact their levels of stress and strain [15–17], it seemed plausible that these variables might also impact the intensity of related medication administration hassles.

We focused on two care recipient characteristics--level of physical functioning and level of mental functioning. We also considered a variable for overall functioning in our preliminary analyses.

### 1.2. The Caregiving Arrangement

Length of time the caregiver had been providing care to the care recipient and the living arrangement of the caregiver and care recipient were included to represent the ways in which caregiving changes over time with maturation of the caregiver and the caregiving situation, and the nature of the caregiving arrangement [18–20].

### 1.3. Medication Regimen Complexity

Simply counting the number and frequency of medications conceals the potential complexity of administering various types of medication and following complex directions that are required to administer the medication properly. The Medication Complexity Index (MCI) developed by Conn and colleagues [21] measures differences in drug regimen complexities, even when the number of medications is the same. Scores are calculated by recording (a) the number of medications managed, (b) the number of doses given each day, (c) any additional directions that must be followed, and (d) the actions necessary to administer the medications. The MCI score is the sum of points recorded for each action and decision required over a 24 hours period.

## 2. Methodology

### 2.1. Sample

A multiphase project was completed for the purpose of developing a medication administration hassles scale (the FCMAHS). The sample generated for the third phase of the project, field testing the new instrument, is used in the analyses for this paper. This mixed convenience sample consisted of 156 (out of 158) informal caregivers who completed all parts of the data collection process for field testing (background information via initial telephone interview, mailed questionnaires and retest procedures for one-third of the sample. Caregivers were recruited from pre-selected adult day services programs in Oklahoma and North Carolina (n = 93) to represent both rural and urban, large and small, and ethnically diverse programs. Two case management services (one in Oklahoma and one in North Carolina) also participated in recruitment efforts (n = 33). All adult day programs and case management services that were

asked to assist with recruitment activities agreed to participate in the project. Finally, announcements at state conferences on aging and personal contacts by members of the research team with prospective family caregivers in five other states generated an additional 32 participants. Three of the personal contact sample members were also in case management and one was in assisted living. Table 1 provides information about recruitment sources and medication administration hassle scores for each group of respondents for the analyses.

A total of 860 invitations were distributed by participating agencies and to personal and professional contacts by members of the research team. Of that number, 158 individuals enrolled in the project and 156 participants (99%) completed all data collection procedures. The sample represented an enrollment rate of 88.2% of the 179 individuals who sent eligible contact forms to the research office. Other descriptions of the recruitment process have been previously reported [3, 6].

Sample characteristics are described in Table 2. We compared our sample characteristics with caregiver data from the 2004 National Caregiver Study [16]. As compared to national data our sample had slightly more women, somewhat older caregivers, and individuals who had been in caregiving roles for slightly longer duration.

Caregivers were eligible for participation in the study if they provided medication assistance to an individual aged 55 or older and whose assistance could be considered long-term. Although we did not define "long-term" the caregivers who were associated with adult day programs and case management services, as well as personal contacts of members of the research team, were all involved in the management of chronic conditions for which life long assistance was implied. The care recipient had to depend on the informal caregiver to carry out at least two of the following activities related to prescription drugs or physician-directed use of over-the-counter medications: (a) purchase, order, or pick up care recipient's medications; (b) oversee or plan the medication administration schedule; (c) administer the medications; or (d) make decisions to hold, increase, or decrease a dose or discontinue a medication all together. Caregivers who were themselves dependent on others for personal care and/or medication administration were not recruited for the study.

### 2.2. Measurement

The outcome variable in the analyses is the total FCMAHS score. The theoretical range of these scores across the 4 subscales is 0 to 120.

**Medication complexity—**Because the upper value of the Medication Complexity Index [21] depends upon the number of medications, there is no specific theoretical upper limit (Mean = 13.29, SD = 9.13).

**Gender—**Sex of the caregiver was a dummy variable (1 = male; 18.6%).

**Relationship—**The relationship between the caregiver and care recipient included categories for spouse (41.0%), adult child (41.7%), sibling (4.5%), niece/nephew (2.6%), child-in-law (4.5%), and other relative/friend (5.8%). These relationship categories were represented in the data as a series of five dummy variables, with other relative/friend serving as the referent category.

**Ethnicity—**The analytical sample consisted of 118 White respondents (75.3%), 5 Native American respondents (3.2%), 21 Black respondents (13.5%), and 5 Hispanic respondents (3.2%). In addition, 7 individuals identified themselves as mixed ethnicity (Black/American Indian (1.3%) or White/American Indian (3.2%)). Five categories for ethnicity (American

Indian or Alaskan Native, Black/non-Hispanic, White/non-Hispanic, Hispanic, and Black/ American Indian) were retained and included as a series of dummy variables in the analyses, with White and American Indian respondents serving as the referent group.

**Education**—Education was treated as an ordinal categorical variable in the analyses, with a theoretical range of 0 (less than high school) to 5 (graduate degree) (Mean = 3.02, SD = 1.18).

**Employment outside the home**—We operationalized employment as a dummy variable in which paid employment outside the home (full time or part time) was scored 1 (40.4%).

**Physical capacity of the care recipient**—Level of physical functioning capacity was created for the project using measures of eight items for walking, dressing, eating, toilet use, personal hygiene, bathing, bowel incontinence, and bladder incontinence. Six of the items had response categories of 0 (independent in the ability to perform the activity) to 4 (totally dependent on the assistance of others). The last two items, bowel and bladder incontinence, had response categories of 0 (continent) through 4 (multiple daily episode of bladder incontinence or bowel incontinence all or most of the time). The summative measure of physical capacity had an internal reliability coefficient of $\alpha = .89$ and a theoretical range of 0 to 32 (M = 10.92, SD = 8.79).

**Mental capacity of the care recipient**—Mental capacity was created for the analyses using data from three questions: (a) how well does your care recipient make decisions regarding tasks of daily life?; (b) how well does your care recipient make him/herself understood?; and (c) how well does your care recipient understand others? The responses ranged from 0 (independent decisions consistent/reasonable or understood) to 3 (severely impaired-never/ rarely makes decisions or rarely/never understands) for the first two items, with higher scores equaling increased impairment. The last item regarding understanding of others included a response range of 0 (understands) through 2 (rarely/never understands). The three-item summative measure had a theoretical range of 0 to 8 and an internal reliability coefficient of $\alpha = .80$ (M = 3.79, SD = 2.60).

**Length of time in caregiving**—Length of time in the caregiving role was recorded in months and treated as a continuous variable (M = 62.63, SD = 67.23).

**Living arrangement**—The dyad's living arrangement was operationalized as a dummy variable, with a score of 1 if the caregiver lived with the care recipient (87.8%).

### 2.3. Data Analysis

Analyses were completed using the SAS version 9.1 statistical package. We began with an examination of univariate associations in order to restrict the final number of variables under consideration. Associations with p values < 0.25 were selected. Age of the caregiver and age of the care recipient, living arrangement, length of time in caregiving, and the caregiver's relationship to the care recipient were eliminated from further consideration. Next, all of the remaining variables were used to build a linear model (SAS GLM Procedure), and only those with statistical significance of p < 0.05 were retained. No additional variables were eliminated in this step.

At this point, all combinations of three or more of the significant variables were compared using the Bayesian Information Criterion (BIC) [22], which penalizes for too large a number of variables in the model, while also taking into account sample size. The full model, consisting of all significant variables, resulted in the lowest BIC score. At this stage of analyses, diagnostic

plots were constructed to test the plausibility of the model assumptions. The resulting diagnostics of residuals (descriptives, histogram, boxplot, qqplot) indicated that the distribution of residuals was skewed. Therefore, a transformed logarithmic hassle score (0.5 added to each raw score to eliminate zero scores) was selected for analysis. Diagnostic plots of the residuals based upon the transformed hassles score indicated a curvilinear relationship for education and care recipient's mental capacity. These were added to the model.

## 3. Results

The final model (p < .0001) (see Table 3) indicated that higher scores (more intense hassles) are associated with the level of a caregiver's education (p = .0011) and ethnicity (p = .0083), medication complexity (p = .0026), and the mental functioning (p = .0005) of the care recipient. Together, these variables accounted for 32.4% of the variance in the medication administration hassle scores. White and Hispanic caregivers perceived higher hassle levels than the other ethnic groups. A positive linear association was observed between the medication administration hassle scores and medication complexity, indicating that greater medication complexity is associated with higher perceived hassles. Every increase by 10 points of medication complexity was associated with an increase of 0.34 on the logarithm of medication hassle scores. In other words, in terms of the original hassle scores, hassles were 34% more intense for every 10 point increase on the medication complexity index.

Non-linear (quadratic) associations were observed between the medication hassle scores and both caregiver education (p = .0077), and care recipients' mental capacity (p = .0034). We explored the nature of these associations by examining the unadjusted means of the logarithm of the medication hassles scale for all levels of caregiver education and care recipient's mental capacity. Specifically, the medication hassles scale increased for the first three levels of caregiver education (0 for no high school, 18.5, for some high school, and 21.7 for high school diploma) and leveled off after this point (26.1 for some college, 28.3 for college degree, and 29.2 for graduate degree).

People with a high school education or higher may be more likely to work outside the home and may therefore experience more hassles associated with medication administration, while those with lower education may not work outside the home and therefore be better able to manage the medication issues of the care recipient. We explored such a possibility by first examining the distribution of work by education. In our sample, no caregivers with less than a high school education worked outside the home. This led us to generate a new variable that combined work and education as follows: 1 = less than a high school degree, 2 = high school degree or higher and not employed, 3 = high school degree and employed. Examination of the BIC scores suggested that the model with this variable was an improvement over the model with the quadratic education (results not shown in table).

The effects of the care recipients' mental functioning on the unadjusted medication administration hassles score were complex. For the three lowest scores (highest levels of mental capacity), hassle scores where between 18.6 and 21.4, for three medium levels they were between 30.1 and 31.5 (the highest hassle levels) and for three highest scores (most highly mentally impaired care recipients) the hassles scores ranged between 21.3 and 25.9. Therefore, caregivers of persons in the mid-range of mental impairment experienced the most intense medication administration hassles, which accounts for the presence of a significant non-linear adjusted association between the FCMAHS and the care recipient's mental functioning.

# 4. Discussion and Conclusion

## 4.1. Discussion

Understanding the nature and level of specific medication administration hassles can be quite useful for health care providers who work with elders requiring medication administration assistance from their informal support network. In this analysis, we uncovered a relatively complex set of associations that include characteristics of caregivers and care recipients, as well as the complexity of the medication regimen. This preliminary set of variables can be used to identify caregivers who may be at risk of experiencing medication administration hassles, increased stress, and potentially harmful situations for their care recipients.

Adjusting for other variables, Whites and Hispanics perceive the highest medication administration hassle levels. While the number of Hispanic caregivers was small, the fact that the effect was significant is an important finding. These results may be due to greater sharing of medication administration responsibility among caregivers in other ethnic groups, because they are more accepting of their medication administration responsibilities, or because they may truly experience less intense medication administration hassles as caregivers. The underlying dynamics of the ethnic group/FCMAHS association are certainly worthy of additional research with larger involvement of Hispanic caregivers.

The non-linear association between education and FCMAHS scores after adjustments for other variables suggests that, up to a point (a high school degree) hassles scores increase, and they then remain high with more education. This result is intriguing, in that one would assume that greater levels of education would buffer caregivers against hassles through such mechanisms as increased organizational skills, greater capacity for understanding instructions and for budgeting, and improved ability to converse effectively with physicians and pharmacists, leading to a consistently positive linear association. Instead, it appears that caregivers with little formal education may not appreciate the complexity of long-term medication management and may be most protected against perceived hassles associated with this caregiving duty. On the other hand, distribution of our sample by education and work may also lead to the curvilinear association between education and the FCMAHS. However, larger samples will be needed to fully explore how caregiver education and the FCMAHS are associated. This type of analysis will be important as we begin to think about caregiver educational interventions to manage or reduce medication administration hassles.

The curvilinear association between FCMAHS and care recipient mental functioning is an especially interesting finding. One possibility for the fact that hassle scores are highest among caregivers of recipients with moderate levels of mental function is that conflict, or at least the need for continual negotiation, is greatest with these care recipients. Those with moderate mental functioning may need considerable medication administration support but resist receiving it or try to override the decisions of the caregiver. It is also possible that at this intermediate stage of decline establishing new roles and responsibilities with respect to medication administration increases the perceived hassles of caregivers. Among the care recipients with the lowest mental functioning, these ground rules may have been previously established and no longer detected as hassles. More research is needed to address these and other possible explanations of the nonlinear association between mental functioning of the care recipient and the FCMAHS scores. In addition, the number of individuals in some categories is very low. Exploring potential interactions among variables with larger samples will certainly be an important area for future research.

Caregiver health and well being are essential for carrying out the responsibility of long term caregiving. In the case of medication administration, hassled caregivers may also put the health

and well being of their care-recipients in jeopardy. For example, hassles items on the FCMAHS for knowing what to do when doses are missed, knowing how to adjust dosages, and knowing what to do in case of an emergency can be stressful for the caregiver and potentially lethal for the care recipient. It is important for providers who prescribe medications to pay attention to the complexity of medication administration regimens, because as we have demonstrated this variable has significant impact on overall hassle scores.

### 4.2. Conclusion

This paper is based on an analysis of a relatively small sample, and the number of individuals in some categories is very low. The sample does, however, include caregivers from several states and different long-term care settings. Notwithstanding the limitations, the FCMAHS is proving to be useful as a research and applied tool. Clearly, more work is needed to fully understand factors that are associated with medication administration hassles. Additional refinement of the FCMAHS is also important for future research [3]. At this time, permission has been granted to two research teams to use the instrument for studies of African American and Hispanic caregivers in order to test the psychometric properties with diverse groups. A Spanish version of the instrument is also part of these research efforts. We are confident that a conceptual framework that includes caregiver and care recipient characteristics and a measure of the complexity of the medication regimen is a good foundation on which to build this area of family caregiving research and best practices in geriatric long-term care.

### 4.3. Practice Implications

Individualized attention to a caregiver's medication administration hassles is time consuming and difficult to achieve in the timeframe of a typical office, home, or clinic visit. Opportunities to prepare caregivers for medication administration duties and ongoing support for long-term medication management are also woefully lacking. Yet, most would agree that diminishing caregiver stress, avoiding adverse medication events, and monitoring the health of caregivers are important goals in long-term care practice [23]. The FCMAHS offers the means to monitor how caregivers are handling this important duty and provides a springboard for discussions with patients and their family caregivers about specific medication administration duties that cause individual irritation. It is important to note that the FCMHS is not a measure of health literacy or of adherence to a medication regimen. It is the caregiver's perception of the level of irritation created by a set of tasks and actions associated with medication administration. Thus, other measures of literacy and adherence may be necessary to obtain a complete picture of the caregiving situation and to clarify the source of the reported hassles.

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**Table 1**

Recruitment Sources of Sample and Mean Family Caregiver Medication Administration Hassles Scale (n = 156)

| Recruitment Source | N (%) | FCMAHS Score Mean (Standard deviation) |
|---|---|---|
| Adult day care | 93 (59.6%) | 27.9 (18.4) |
| Case management services | 35 (22.4%) | 18.6 (16.1) |
| Recruited through other sources[a] | 28 (17.95%) | 22.4 (24.1) |

[a]Three of those in the group recruited through other sources were also in case management and one was in adult day care. These cases were omitted from the "recruited through other sources" group and included in the adult day care and case management services group for the purpose of calculating means and standard deviations

**Table 2**

Sample Characteristics (n = 156)

| Variable | N (%) | Mean (Standard deviation) |
|---|---|---|
| Caregiver Age | | 61.2 (12.3) |
| Care Recipient Age | | 77.8 (9.8) |
| Caregiver Sex (males) | 29 (18.6%) | |
| Relationship to Caregiver | | (Treated as dummy variables, with other relative/friend as the referent category) |
| Spouse | 64 (41.0%) | |
| Adult child | 65 (41.7%) | |
| Niece/nephew | 4 (2.6%) | |
| Sibling | 7 (4.5%) | |
| Child-in-law | 7 (4.5%) | |
| Other relative/friend | 9 (5.8%) | |
| Caregiver Ethnicity | | (Treated as dummy variables, with White/American Indian as the referent category) |
| American Indian/Alaskan Native | 5 (3.2%) | |
| Black, not Hispanic | 21 (13.5%) | |
| White, not Hisanic | 118 (75.6%) | |
| Hispanic | 5 (3.2%) | |
| African American/American Indian | 2 (1.3%) | |
| White/American Indian | 5 (3.2%) | |
| Caregiver Education | | (Treated as categorical variable 0–5 in analysis) |
| No HS (0) | 2 (1.3%) | |
| Some HS (1) | 11 (7.1%) | |
| HS (2) | 38 (24.4%) | |
| Some college (2) | 60 (38.5%) | |
| College (4) | 21 (13.5%) | |
| Graduate degree (4) | 24 (15.4%) | |
| Caregiver Employed Outside Home (1) | 63 (40.4%) | |
| Care Recipient Physical Functioning | | 10.92 (8.79) |
| Care Recipient Mental Capacity | | 3.79 (2.60) |
| Time of Care (months) | | 62.64 (67.23) |
| Live in Same Residence (1) | 137 (87.8%) | |
| Medication Complexity | | 13.29 (9.13) |
| Hassle Score | | 24.92 (19.37) |
| Ln(Hassle + 0.5) | | 2.71 (1.34) |

**Table 3**

Final GLM Model Results for the Logarithm of Family Caregiver Medication Administration Hassles Scale (n = 156)

| Variable | Estimate | 95% CI | Effect Size t(145) | p value |
|---|---|---|---|---|
| Caregiver Education (CE) | 1.19 | 0.46, 1.91 | 3.33 | .0011 |
| CE*CE | −0.15 | −0.27, −0.04 | −2.70 | .0077 |
| Caregiver Ethnicity | --[a] | -- | -- | .0083 |
| American Indian/Alaskan Native | .064 | −1.26, 1.86 | 0.09 | 0.9301 |
| Black, not Hispanic | −0.26 | −1.06, 1.49 | −0.04 | 0.9645 |
| White, not Hispanic | 0.86 | −0.10, 2.27 | 1.61 | 0.1086 |
| Hispanic | 0.66 | −0.67, 2.49 | 0.88 | 0.3783 |
| Black and American Indian | −0.58 | −2.43, 1.70 | −0.59 | 0.5569 |
| Medication Complexity | 0.03 | 0.01, 0.06 | 3.07 | .0026 |
| Care Recipient Mental Capacity (CRMC) | 0.45 | 0.18, 0.70 | 3.56 | .0005 |
| CRMC*CRMC | −0.47 | −0.08, −0.01 | −2.98 | .0034 |
| Intercept | −1.08 | −2.90, 0.25 | −1.47 | .1426 |

[a]Because Caregiver Ethnicity was measured using a set of dummy variables, there is no single estimate. The overall significance level for the five dummy variables representing ethnicity is presented, as are the estimates for the constituent dummy variables.