Family involvement in the care of healthy medical outpatients

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**Background.** Although the involvement of patients’ family members in office visits has been examined extensively, less is known about the involvement of family members in supporting patients’ medical care outside of office visits.

**Objective.** This study examines two questions: What types of family involvement do family members have in the medical care of relatively healthy older outpatients, and does self-rated health moderate patients’ reactions to this family involvement?

**Methods.** Patients from a large sample of medical practice outpatients ($N=1572$) were assessed to determine perceived emotional support, involvement of family members in their medical care, as well as the presence of depressive symptoms.

**Results.** Approximately 50% of patients had some family involvement in their medical care (e.g. taking part in medical decisions, reminding the patient to take medication). Marital status was a stronger predictor of family involvement than self-ratings of poor physical health. Additionally, there was no evidence that older patients who report good health have less favourable reactions to family involvement in their medical care.

**Conclusion.** Family involvement in medical care occurs routinely and is most likely to involve a spouse, and is consistent with family interaction patterns among older adults. These findings also suggest that when providers invite family members to support treatment outside the office visit, these invitations are appropriate for older adult patients across a continuum of good to poor health.

**Keywords.** Emotional support, family involvement, medical care, older adults.

**Introduction**

An important characteristic of family practice is the involvement of family members in the care of patients, although family physicians vary in the degree to which their practice is family-oriented.\textsuperscript{1,2} A variety of effective systematic family-based interventions for chronic diseases such as diabetes, heart disease or renal disease have been established.\textsuperscript{3–6} But the family practice and intervention literatures have focused much more on in-office care and less on naturally occurring family involvement in medical and self-care. Information about the role of family members outside of the physician’s office with such tasks as promoting medication adherence or making decisions about medical treatment can be crucial in developing feasible and effective family-based interventions. It is important to determine the characteristics of the family in an effort to predict who is likely to perform these roles (i.e. spouses, adult children). Patient characteristics such as age and current level of patient health are also likely to moderate the degree to which the family is involved in a patient’s medical care. These factors are key when planning and developing potential family-based interventions for medical illnesses.

Despite evidence that supportive relationships can increase adherence to treatment\textsuperscript{7} and improve medical outcomes\textsuperscript{3} the impact of close relationships are likely dependent on the degree to which the patient perceives a need for family involvement. Reminders to take medication, for example, may not always be perceived by the patient as supportive, but instead as ‘miscarried...
Patients who are in relatively better health may not feel that involvement is necessary or welcome. Attempts to influence the patients’ health-related behaviours have been shown in samples of older patients to engender greater psychological distress. The vast majority of research on family involvement in the care of older adults has focused on the role of family caregivers and the burdens experienced when caring for older adults with diabetes and other chronic conditions. Other research has focused on family members’ role in personal activities of daily living (e.g. bathing, dressing) and instrumental activities of daily living (e.g. shopping, housework). With some exceptions, the caregiver literature has focused more on the well being of the caregiver and with little consideration of the impact of caregiving on the patient. Furthermore, little research has focused on family involvement with patients who consider themselves to be in favourable health. If one can extrapolate to a relatively healthy sample, we might expect spouses to be the family members most involved, that marriage would create a natural environment for greater family involvement in medical care, and that poorer self-rated health would be associated with greater involvement on the part of family members.

The purpose of this study was to estimate the degree to which patients’ family members were naturally involved in several aspects of outpatient medical care for relatively healthy older adults and to estimate the ways in which each type of family member was involved. First, we tested the hypothesis that increased age, poor health and being married was associated with greater involvement on the part of family members in patients’ medical care. Second, we hypothesized that self-rated health would moderate the perceived supportiveness of greater involvement of family members. Specifically, we hypothesized that the association between family involvement and perceived emotional support would be greater among patients with poor health. We also anticipated that patients’ self-rated health would moderate the association between family member involvement and psychological distress. Thus, we hypothesized that among relatively healthy patients there would be a positive association between family involvement and psychological distress (i.e. miscarried helping), whereas patients with poorer self-rated health would report a negative association between family involvement and distress (i.e. more family involvement—lower distress).

Methods

Overview
Participants consisted of older patients (age 65+) screened for possible inclusion in a disease management trial focused on treating behavioural health conditions in outpatient settings. All patients who were reached by telephone and agreed to screening were assessed. Patients were recruited from geriatric, primary, cardiology and rheumatology outpatient practices affiliated with the University of Pennsylvania (PennCare). Thus, the sample is broadly representative of older patients in these outpatient settings. These patients were drawn from the Philadelphia sites of the PRISM-E project which is a multisite study, involving adults ages 65 and older. The data for the current study were obtained at only two of the sites (the PVAC and PennCare), and this sample should not be considered necessarily representative of the patients in the multisite trial.

Each potential participant was sent a letter from the provider and study investigators describing the study. Patients were selected based on a random sampling of outpatient visits scheduled for one of the participating clinics in the larger study (PRISM-E). Each patient was called by research staff, screened for mental health conditions and other clinical characteristics and then assessed using the measures below for possible inclusion in the disease management study. Thus, all assessments for this study were completed by telephone, except in rare cases in which the patient wanted to complete the assessments in person.

Participants
Across the sample of appointments (N = 3162), 8.8% of patients were not reachable due to not answering or incorrect telephone number, 15.5% were ineligible because they were in long-term care, had severe cognitive impairment, had died or had a medical care provider who was not participating in the disease management trials. Of the 2394 patients who were reached and eligible, 34.3% refused the clinical screening, resulting in 1572 (65.7%) patients who were screened and entered into the database for this study. There were no differences in age or gender among those who consented to telephone screening and those who did not. Due to the provisions of the human subjects committee, we were limited in the amount of information we could collect and utilize about patients who refused involvement in the study. Of interviewed patients, 48.5% came from the appointments of the PVAC outpatient care providers and 51.5% from the appointments of University affiliated practices.

Measures

Depression. The General Health Questionnaire (GHQ) was used to screen participants over the telephone for depression in the PRISM-E trial. The measure is widely used and has been validated for use in an older population and assessment of mental health by telephone is supported in the literature.

Medical care questionnaire (MCQ). Questions on the MCQ were developed for the current study and
concerned the degree to which family members were involved in patients’ overall medical and self-care regarding their health. A stem question asked the patient to indicate whether family members had regular involvement in patients’ care in the following ways: ‘schedule doctor’s appointments’, ‘go with you to doctors’ appointments’, ‘pick up prescriptions’, ‘help you to remember to take medication’ and ‘participate in making decisions about medical care’. Patients were prompted to indicate which family members provide assistance in any of these ways. An index of the sum of positive responses to each of these questions ranged from 0 to 5 (i.e. a ‘yes’ = 1 for involvement by any family member for each question), and was used in the analyses to indicate the degree of family involvement patients’ care.

Existing data on the psychometric properties of the MCQ suggests that patients can respond reliably to the questions, and initial findings support the validity of the overall index of family involvement. In a separate sample of outpatients with congestive heart failure,\textsuperscript{19} the test–retest coefficient of the overall degree of family involvement, using the Spearman rank-order correlation, was \( r = 0.63, P < 0.0001, n = 63 \). The mean test–retest length in days was \( M = 34.4, SD = 27.1 \). The total number of areas of family involvement was positively correlated with an index of total support from the Multidimensional Scale of Perceived Social Support (MSPSS),\textsuperscript{19} \( r = 0.25, P < 0.01, N = 114 \); the index of ‘significant other’ support from the MSPSS correlated most highly with the index of family involvement, \( r = 0.36, P < 0.0001, \) followed by social support from other family members, \( r = 0.18, P < 0.05 \). As expected, support from friends was not correlated with the index of family involvement in medical care, \( r = 0.08, P > 0.05 \).

**Self-rated health.** One question was used to assess self-rated health (ranging from Excellent to Poor), with higher values indicating poorer health. Patients were also asked whether they were currently being treated for a mental health or alcohol abuse problem.

**Demographic characteristics.** Demographics questions included gender, age, race, marital status, and whether the patient lived alone, with one other person or more than one other person. Additional information about family constellation was not available due to the desire to keep the respondent burden low.

**Emotional support.** Emotional support was assessed with a single item. Each participant was asked, ‘On the whole, how much do your friends and relatives make you feel loved and cared for?’ Response options ranged from ‘not at all’ to ‘a great deal.’ This item was developed from a group of highly intercorrelated items from Lawton et al.’s\textsuperscript{20} research on the emotional experience of older adults and quality of contact with family and friends. This single item was selected for use as part of the screening battery to reduce respondent burden. In the current sample, this emotional support question was positively correlated with the index of family involvement, \( r = 0.10, P < 0.0001, n = 1542 \).

**Statistical analysis**

Statistical analyses were performed with the Statistical Analysis System.\textsuperscript{21} Categorical responses were presented with 95% CI where possible. PROC CORR was used to conduct correlational analyses. PROC LOGISTIC was used to perform ordinal logistic regression (proportional odds model) using a range of predictors of the degree of family involvement in the patients’ medical care, including demographic factors, participation in mental treatment and depressive symptoms. The predictors of emotional support were also modelled using ordinal logistic regression. PROC REG was used to test the hypotheses regarding predictors of depressive symptoms in a linear regression model. The moderating role of self-reported health was tested using the interaction between the health and the family involvement index. PROC LOGISTIC was used to obtain odds ratios to assist in the interpretation of the significant findings from the linear regression model predicting depression level. We accomplished this by dichotomizing both the significant predictors of depression, and the dependent measure for depression itself, and estimating the odds ratios using PROC LOGISTIC.

In the logistic and standard regression models, demographic and clinical covariates were entered into the model first. The omnibus models were tested using the Wald chi-square test (ordinal logistic regression) or omnibus \( F \)-test (linear regression) at alpha \( P < 0.05 \).

**Results**

**Patient characteristics**

As shown in Table 1, most of the patients were white, male, older, and about half were married or had a live-in partner. The average reported levels of depressive symptoms was similar to other primary care samples assessed in person, \( M = 24.7 \), and by telephone, \( M = 25.0, N = 98 \).\textsuperscript{18} A small minority was currently receiving mental health or alcohol abuse treatment, and about two-thirds of the patients reported that their health was ‘good’, ‘very good’ or ‘excellent’.

**Zero-order relationships among key variables**

Patients with higher levels of emotional support reported better health and lower levels of depression. Patients with poorer self-rated health reported higher levels of depressive symptoms (Table 2).
Rates and types of family involvement in medical care

Frequency and types of involvement. For just over half of the patients (51.4%; 95% CI = 48.9–53.9%) family members were involved in the patients' medical care in one or more ways. Living situation and marital status were significant factors in the degree of involvement. Among patients who live alone, 26.74% (95% CI = 22.76–30.72%) of the patients had family members involved in one or more ways. Among those who lived with one or more people, 62.08% (95% CI = 59.21–64.95%) of the patients had family members involved in one or more ways. Similarly, among those with a spouse, 67.08% (95% CI = 64.00–70.16%) had family members involved in their care, compared with 30.81% (95% CI = 27.33–34.3%) of those without a spouse. An estimated 19.6% of patients who lived with one or more people were living with non-spouses.

Among those patients who reported any involvement of family members in their medical care, family members of patients were involved primarily by going with the patient to the doctor, being involved in medical decisions, and supporting medication use (Fig. 1).

Relationship of family members involved in medical care. For each type of involvement or help with getting medical care, we examined the relationship of the family member involved. Thus, for each type of family involvement, the percentage of involvement for each type of family member was determined (i.e. percentages for each type of involvement sum to 100%). Spouses/partners were by far named as the most frequently involved in the medical care of the patient, ranging from 60% among the family members who pick up prescriptions to 84.5% for those who remind the patient to take their medication. The ‘other’ category involved the full range of family relationships (siblings, nieces, etc.). Each type of ‘other’ family relationship was reported by <12% of respondents who reported some family involvement in their care. For simplicity of presentation, we collapsed the results into spouse/partner, sons/daughters, or others (Fig. 2).

Predictors of involvement in patients’ medical care

The final model shown in Table 3 was significant. Wald $\chi^2 = 274.73$, $P < 0.0001$. Several variables predicted higher degrees of family involvement in patients’ medical care. Most dramatically, patients with spouses were over five times more likely to have family members involved in their care for each additional form of involvement (i.e. accompany to an appointment, remind to take medications). Patients who were involved in mental health treatment were also more likely to have family involvement in greater degrees, and poorer

### Table 1

<table>
<thead>
<tr>
<th>Gender (% male)</th>
<th>68</th>
</tr>
</thead>
<tbody>
<tr>
<td>Race</td>
<td></td>
</tr>
<tr>
<td>Caucasian</td>
<td>70.9</td>
</tr>
<tr>
<td>Black/African American</td>
<td>26.4</td>
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<tr>
<td>Other</td>
<td>2.7</td>
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<tr>
<td>Married/partnered</td>
<td>43.1</td>
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<tr>
<td>In mental health treatment</td>
<td>4.2</td>
</tr>
<tr>
<td>In treatment for alcohol problems</td>
<td>0.2</td>
</tr>
<tr>
<td>Health</td>
<td></td>
</tr>
<tr>
<td>Excellent</td>
<td>10.3</td>
</tr>
<tr>
<td>Very good</td>
<td>22.6</td>
</tr>
<tr>
<td>Good</td>
<td>35.6</td>
</tr>
<tr>
<td>Fair</td>
<td>26.2</td>
</tr>
<tr>
<td>Poor</td>
<td>5.4</td>
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</table>

### Table 2

Interrelationships among key variables

<table>
<thead>
<tr>
<th>Poor health</th>
<th>Family involvement</th>
<th>Depression</th>
<th>Age</th>
</tr>
</thead>
<tbody>
<tr>
<td>Emotional support</td>
<td>-0.20**</td>
<td>0.10**</td>
<td>-0.28**</td>
</tr>
<tr>
<td>Poor health</td>
<td>0.12**</td>
<td>0.41**</td>
<td>-0.12**</td>
</tr>
<tr>
<td>Family involvement</td>
<td>0.10**</td>
<td>0.10**</td>
<td></td>
</tr>
<tr>
<td>Depression</td>
<td>0.07*</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*P < 0.01, **P < 0.0001. N = 1527 or greater for each coefficient.
health and greater age conferred small but significant increases in odds of having family members involved in their care. Although poor health was a statistically significant factor in increased family involvement in the medical care of patients, 48.8% of patients with good, very good or excellent self-rated health still reported some involvement of family members in their medical care. This compared with 56.8% of patients with fair or poor health who had some involvement of family members in their care.

The role of self-rated health in perceived emotional support and depressive symptoms

The final model for emotional support shown in Table 4 was significant, Wald $\chi^2 = 87.53, P < 0.0001$. Consistent with the concept of social support, the availability of a spouse and the involvement of family members in the patients’ medical care conferred increased odds that patients perceived higher levels of emotional support. Poorer perceived health was associated
with decreased odds of perceiving higher levels of emotional support. Contrary to our hypotheses, self-rated health did not affect the statistical relationship between family involvement and perceived emotional support.

The final regression model shown in Table 5 accounted for 23% of the variance of the depression scores, $F(8,1496) = 55.94, P < 0.0001$. Poorer health and receiving mental health treatment were associated with higher levels of depression, whereas having a spouse and reporting higher levels of emotional support were associated with lower levels of depression. Contrary to our expectations, there was a small but significant association between increased family member involvement in medical care and higher levels of depressive symptoms. The association between family involvement and depressive symptoms was not moderated by the patients’ self-reported health.

We dichotomized the significant ordinal or continuous variables from Table 5 as follows in order to obtain odds ratio estimates for these findings: Patients with Excellent/Very Good/Good Health (0) versus Fair/Poor health (1); No family involvement (0) versus family involved in one or more ways (1); Emotional support—Feel loved by friends and family—not at all/a little/some (0) versus a quite a bit/great deal (1); and total GHQ score ≤21 (median) (0) versus >21 (1). The odds, with 95% CIs, of having levels of depression above the median for each significant factor are presented in Table 5.

**Table 5 Predictors of depressive symptoms**

<table>
<thead>
<tr>
<th>Predictor</th>
<th>N = 1505</th>
<th>Partial $r$</th>
<th>OR (95% CI)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender (1 = female, 0 = male)</td>
<td>0.08</td>
<td>–</td>
<td>–</td>
</tr>
<tr>
<td>Race (1 = non-white, 0 = white)</td>
<td>0.08</td>
<td>–</td>
<td>–</td>
</tr>
<tr>
<td>Age</td>
<td>0.05</td>
<td>–</td>
<td>–</td>
</tr>
<tr>
<td>Poorer health</td>
<td>0.40****</td>
<td>2.88 (2.29–3.62)</td>
<td>–</td>
</tr>
<tr>
<td>Current mental health treatment</td>
<td>0.17****</td>
<td>2.84 (1.56–5.18)</td>
<td>–</td>
</tr>
<tr>
<td>Married/partnered</td>
<td>–0.11**</td>
<td>0.62 (0.49–0.78)</td>
<td>–</td>
</tr>
<tr>
<td>Family involvement</td>
<td>0.07***</td>
<td>1.39 (1.11–1.75)</td>
<td>–</td>
</tr>
<tr>
<td>Emotional support</td>
<td>–0.20****</td>
<td>0.57 (0.43–0.77)</td>
<td>–</td>
</tr>
<tr>
<td>X poorer health</td>
<td>0.04</td>
<td>–</td>
<td>–</td>
</tr>
</tbody>
</table>

* $P < 0.05$, ** $P < 0.01$, *** $P < 0.005$, **** $P < 0.001$.

Depressive Symptoms = GHQ score. The partial $r$ estimate for the effects of poorer health and emotional support were obtained from a model that did not contain the interaction effect of these two effects. The effective $N$ for each sample was lower than the total number of respondents due to missing data. The odds ratios (OR) were estimated from a logistic regression model with the variables dichotomized as described in the text.

**Discussion**

A significant proportion of older medical outpatients have family members, usually a spouse or adult child, involved in their medical care in one or more ways—typically in the form of accompanying the patient to appointments, making decisions about medical care, or supporting the patients’ use of prescribed medications. However, reminding the patient to take medication appears to be the role that is primarily occupied by marital partners.

The focus of this study was on ambulatory older adults, who for the most part, considered their health to be good, very good or excellent. This is in contrast to prior research regarding chronic illness in which the involvement of a family caregiver is often essential. Findings from the present study are consistent with previous research, indicating that patients with higher levels of self-rated health also have significant levels of family involvement in their medical care. In this sample of older adult patients the availability of a close family member, rather than need, appears to be the most important predictor of having a family member involved in medical care.

Contrary to expectations, the effect of family involvement on perceived supportiveness and depressive symptoms was not affected by the self-rated health of patients. We found no clear evidence of ‘miscarried helping’ among patients with better perceived health. We anticipated that the ‘miscarried helping’ effect would result in greater distress or lower perceptions of support among healthier patients. Consistent with previous research on social support in health, across the board, patients who perceived that they were cared for were more likely to report lower depressive symptoms.

It is important to note that the present study found that having family members involved in medical care was associated with slightly higher levels of depression. This finding has at least two interpretations. First, patients who are depressed or are in poorer health just may be more likely to have family members who attempt to meet their medical care needs. Alternatively, due to personal or family characteristics some patients may be slightly more distressed when family members become involved in their care, regardless of their health. This effect would likely be mitigated were the involvement seen as supportive, as the findings reported above suggest.

The findings from the present study are consistent with previous research indicating that family members are involved in the medical care of older adult patients and this involvement is welcomed and desired. For instance, patients have expressed a desire to have family members present for such things as conferences with the physician regarding serious medical problems. The results support and encourage the development of family interventions to improve outcomes of
medical patients. In light of a recent meta-analysis examining the positive role of social support on medication adherence, further examination of family involvement in medical care can be a fruitful direction for the development of systematic family-based interventions. A family-based intervention that encourages patient autonomy but still integrates support of family as needed may be particularly suited for this context.

**Strengths and limitations of the study**

Despite the interest in developing family interventions for medical problems, there has been minimal examination of naturally occurring family involvement in medical care or its correlates. One strength of the present study is that it examines these issues in a large, random sample of relatively healthy, older adult outpatients. The current study extends previous research in indicating that family involvement in medical care for relatively healthy patients is common and often extends beyond conferences with medical providers. However, the study was limited by its cross-sectional design and a moderately high refusal rate that was potentially caused by patients being informed in the introduction letter that they were being screened for mental health problems. In an effort to reduce participant burden, some of the study measures were limited to single-item instruments or were developed specifically for use in the present study.

The goals for future research may include the following. First, it may be important to test directly whether family involvement in the medical care of healthier older adult patients produces resentment. Second, an assessment of the attempts of family members to influence health behaviors of the patient was beyond the scope of the present study, but is nevertheless an important step in understanding the role of family members in the health of the patient. Third, there are important moderators that may influence the availability of family members to be involved in the medical care of older adults, including income, social status and the distances of the patient to medical care associated with rural versus urban living area.

In summary, it is reasonable to conclude that family members are naturally involved in the medical care of patients. Many patients have family members who may be available to be involved in the care of relatively healthy older adults. Natural treatment targets for future research on family involvement in medical care might include improved emotional support, medical decision-making and medication adherence as vehicles for improving health care outcomes.

**Acknowledgements**

The authors acknowledge the generous support of the VISN 4 Mental Illness Research, Education, and Clinical Center, and the Philadelphia Veterans Affairs Medical Center that made this project possible, as well as the PRISM-E study group for the use of the data obtained as part of that project.

**Declaration**

The project was reviewed and approved by appropriate Institutional Review Boards at the University of Pennsylvania and the PVAMC. Patients provided verbal consent for the research use of their responses.

The study was supported by SAMHSA grant no. 1UDISUM53033, National Institute of Mental Health grant no. 1K08 MH01599 and American Heart Association grant no. 0265447U. None of the authors have potential, perceived or real conflicts of interest associated with this project. Portions of the present results were presented at the Annual Meeting of the Association for the Advancement of Behavior Therapy, November, 2001, Philadelphia, PA, the Annual Meeting of the American Psychological Association, August, 2002, Chicago, IL, and the Annual Meeting of the Society of Behavioral Medicine, Salt Lake City, Utah, March, 2003.

**References**


