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# Family Members' Experiences Supporting Adults with Chronic Illness: A National Survey

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## Abstract

**Background—**Family and friends often help chronically ill adults manage their conditions. Information about specific ways supporters help with disease management, and their experiences with and concerns about helping are lacking.

**Objectives—**Describe key roles and concerns of family members who support the health management of adults with chronic illness, and compare experiences of health supporters living in and outside of support recipients' homes.

**Methods—**Data were obtained from a national internet survey of 1722 adults selected to represent the U.S. population. Detailed survey questions were completed by 703 respondents who reported providing regular disease-management help to at least one functionally-independent family member or friend with at least one of five chronic conditions (diabetes, heart failure, chronic lung disease, arthritis, depression).

**Results—**Current supporters assisted 834 chronically ill adults: 257 receiving in-home support and 577 receiving out-of-home support. Current supporters spent 2.1 hours/week on average helping their support recipient with health care, and 21.2% attended their recipient's health care appointments. Many recipients discussed crucial concerns about medication side effects (47%) and trouble paying for medications (32%) with supporters. However, 41% of supporters reported insufficient information about recipients' health conditions and regimen to be helpful. In-home supporters reported arguing more often with support recipients, but also received more information from recipients' health care providers than out-of-home supporters.

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**Conclusions—**Family and friends have significant potential to influence patients' chronic illness self-management. Programs to engage chronically ill patients' families to support self-management could provide information and skills targeting needs identified by supporters.

**Keywords**

Social support; chronic disease; self-management; family; informal caregivers

## Introduction

Optimal management of chronic health conditions, such as diabetes, heart disease, and chronic lung disease, involves multifaceted daily self-management routines and often complex interactions with health care professionals (Bayliss et al., 2007; Clark, 2003). To manage their chronic health conditions, most patients could benefit from an array of professional services (e.g., self-management classes, health education, professional consultation) and sustained informal support (e.g., support groups). However, these formal sources of support are often not available or accessible on a day-to-day basis, and may not be able to provide enough support over the long-term to meet patient needs.

Many patients with chronic health conditions find that involving family and friends in their care provides a crucial source of day-to-day support. In previous studies, over 60% of adults with diabetes or heart failure report that their family members and friends are regularly involved in their chronic illness self-management (Connell, 1991; Rosland, Heisler, Choi, Silveira, & Piette, 2010; Sayers, Riegel, Pawlowski, Coyne, & Samaha, 2008; Silliman, Bhatti, Khan, Dukes, & Sullivan, 1996). A nationally representative study found that 44% of U.S. adults reported helping a chronically ill adult family member or friend manage their health (Rosland et al., 2013). Importantly, family members and friends of chronically ill but functionally independent adults differ from caregivers of adults with severe functional limitations in the level and type of support they provide. Informal caregivers of adults with severe functional limitations often directly perform health related tasks for their family members or friends. In contrast, informal supporters of chronically ill but functionally independent adults typically assist their support recipients in providing their own self-management (Rosland et al., 2010). For example, health supporters may assist with day-to-day decisions about medication and routine symptom management, help coordinate health care among multiple providers, and facilitate healthy behavior changes such as improvements in diet or self-monitoring.

Social support from family and friends has great potential to help people with chronic illnesses better manage their conditions (DiMatteo, 2004; Gallant, 2003). Importantly, positive social support from family and friends has been linked with increased patient self-efficacy, better self-management behavior, better patient-doctor communication, and better health outcomes (Dunbar, Clark, Quinn, Gary, & Kaslow, 2008; Luttik, Jaarsma, Moser, Sanderman, & van Veldhuisen, 2005; Rosland, Heisler, & Piette, 2012; Strom & Egede, 2012; Wolff & Roter, 2011). Many adults are willing to help their chronically ill family and friends with health management (Rosland et al., 2013; Rosland, Piette, Choi, & Heisler, 2011; Wolff & Roter, 2008; Wolff, Spillman, Freedman, & Kasper, 2016). Programs to engage family members (defined here as any family member or friend providing unpaid support for health care) in chronic disease management programs, have potential to improve and sustain effective patient self-management (Rosland & Piette, 2010). A better understanding of the current roles of family members in providing disease-management support is necessary to optimize the effectiveness of such interventions.

To fully address the needs of older adults with chronic health conditions and their network of supporters, programs may need to extend beyond the patient's own household. Older adults in the United States frequently live apart from members of their social networks and U.S. adults frequently provide health support for individuals with chronic health conditions who do not live with them (Piette, Rosland, Silveira, Kabeto, & Langa, 2010; Rosland et al., 2013; Zulman et al., 2011). Supporters living outside their support recipient's home may be less aware of a patient's symptoms and self-management behaviors and may find it more difficult to provide more intensive support for disease management compared to in-home supporters. In contrast, in-home supporters may encounter more conflict when trying to help their chronically ill support recipient with health care. However, no studies of which we are aware, have directly compared experiences communicating with patients and patients' health care providers between health supporters living in and outside of patients' homes.

The purpose of this descriptive study was to inform the development of interventions aiming to help family members and friends living in or outside of their support recipients' homes be more effective in their roles as health and disease management supporters. We surveyed adults who provide disease management support for chronically ill adults about the extent of their involvement in the health care of support recipients and their experiences and concerns when communicating with support recipients and support recipients' health care providers about chronic disease management. When comparing in home and out of home supporters, we hypothesized that out of home health supporters would spend less time directly helping with health care and experience more barriers in communicating with patients' health care providers.

## Methods

We analyzed data from a subset of respondents to a nationally-representative internet survey of 1,722 Caucasian, African-American, and Latino U.S. adults age 18 years old and older (53% response rate; Rosland et al., 2013). Participants were recruited from Knowledge Networks, a research firm that maintains a large, representative survey panel of American adults. Panelist are randomly selected from US Postal Service Delivery Sequence File (Dennis, 2010). Knowledge Networks provides panelists with a computer and internet access to help ensure all invited individuals have an equal probability of panel membership. The Knowledge Networks panel closely reflects the general population of the United States in terms of race, ethnicity, age, sex, education, and income (Chang & Krosnick, 2009; Dennis, 2010). For the original survey, Latinos and African Americans were oversampled so that each group would represent 25% of respondents.

Respondents were prompted to list names of contacts who corresponded to each of twenty-five specific family relations (e.g., spouse, father, sister, mother-in-law) and up to five additional relatives or friends. Then, respondents were asked to identify those individuals among these listed contacts who had been "diagnosed by a doctor or health care provider" with one or more of the following common chronic illnesses: diabetes (or "high sugar"), heart disease ("such as heart attack or heart valve problem"), chronic lung disease ("such as asthma, emphysema, or COPD"), arthritis, or depression. From this group, respondents indicated the subset of people with whom they were in contact at least once a month, and who did not need assistance with Basic Activities of Daily Living (BADLs) including eating, dressing, toileting. Most survey respondents ($n$ = 1,108, 64.3%) reported having contact with one or more chronically ill but BADL-independent adults meeting these criteria.

The current study focuses on those respondents who reported that they provided current health support to one or more of their family or friends as identified above. "Health supporters" were defined as respondents who reported regularly helping one of their listed chronically ill contacts with health-related tasks according to at least one of five criteria: 1) the respondent identified themselves as "the *main* person who helps the contact with health related tasks like managing medicines, cooking healthy food, and keeping track of doctor's appointments," 2) the respondent helped their contact with health related tasks "like filling prescriptions and managing medicines, arranging medical appointments, filling out medical forms, or making decisions about health care" at least one day in the last three months, 3) the respondent regularly discussed the contact's health with the contact, 4) the respondent regularly went with their contact into the exam room for medical appointments, or 5) the respondent talked to their contact's health care provider once per year or more. Using these inclusion criteria, 703 (63.6%) respondents were designated as current health supporters.

Current disease management supporters rated each current support recipient on a Likert-type scale from 1 (not at all close) to 10 (extremely close). If a supporter had more than one in-home or out-of-home support recipient, the supporter was asked for detailed information on their health support for the recipient with the highest closeness rating in each category. Therefore, a respondent may have given information on one in-home recipient only, one out-of-home recipient only, or both one in-home and one out-of-home recipient. To make data collection feasible we were only able to ask detailed information about a maximum of two support recipients most likely to be receiving the most intensive help. Survey items assessed supporter and support recipient sociodemographic characteristics as well as supporter time spent assisting with recipients' health care (i.e., filling prescriptions and managing medicines, arranging medical appointments, filling out medical forms, or making decisions about health care). Respondents who reported discussing health issues with their support recipient were surveyed about their experiences with these conversations (Supplemental Table 1). Similarly, respondents who reported that they accompanied their support recipient into the health care exam room or communicated with their support recipient's health care providers via telephone one or more times/year were asked about their experiences communicating with their support recipients' health care provider (Supplemental Table 2). All study methods were approved by a local Human Subjects Research IRB.

### Data Analysis

Pearson's chi-square test and one-way ANOVA were used to compare supporter characteristics across location (i.e., in-home, out-of-home, or both in and out-of-home). Support recipients were clustered within respondents (i.e., supporters) for analyses comparing in-home and out-of-home support recipients. Chi-square and $t$-tests were used to compare characteristics of in-home and out-of-home supporter-recipient relationships at the level of support recipient. Significant omnibus chi-square tests comparing proportions of recipients' relationship to their supporter (e.g., parent or sibling) were followed by Bonferroni corrected $z$-tests comparing column proportions (i.e., in-home supporters vs. out-of-home supporters). Missing data were treated using pair-wise exclusion. Analyses were performed using Stata version 14.0 (StataCorp, 2015). All tests of statistical significance were two-tailed with alpha equal to .05.

## Results

### Supporter Characteristics

The final sample included 703 respondents who provided health support for 834 adults with one or more chronic diseases (Table 1a). Of these supporters, 17.9% provided only in-home support, 63.4% provided only out-of-home support, and 18.6% reported providing both in and out-of-home support. Supporters had an average age of 50 years. Most supporters were female, White, and had at least some college education. Supporters providing only out-of-home support were significantly more often female compared to supporters providing only in-home support ($p < .001$).

### Support Recipient Characteristics

Out-of-home support recipients were significantly more likely to be a parent, sibling, or other non-spouse relative/friend of their supporter, and over 50 years of age, compared to in-home support recipients (Table 1b). Among out-of-home support recipients, nearly half lived within 20 miles of the disease management supporter; however, more than one-third lived more than 100 miles away. Supporters were most commonly helping family and friends with arthritis followed by diabetes, depression, heart disease, and lung disease.

### Specific Ways Supporters Assisted in Disease Management

A significantly greater proportion of in-home support recipients received assistance with health-related tasks, such as managing prescriptions and medical appointments, compared to out-of-home support recipients, during the previous three months (Table 2). In-home support recipients were given assistance with health-related tasks on significantly more days per month than out-of-home support recipients. However, average hours spent helping with health care per day did not differ significantly between in-home and out-of-home support recipients. In-home support recipients were four times more likely to be accompanied into the exam room during medical appointments by their supporters than out-of-home support recipients. Similarly, the supporters of in-home support recipients were more than twice as likely to speak with the support recipient's health care provider on the telephone than supporters of out-of-home support recipients.

### Support Recipient Health Concerns Shared with Supporters

When supporters talk with support recipients about their health, most support recipients report that the topics of those conversations include bothersome symptoms and the desire to do more to stay healthy on a regular basis (Table 3). Almost half of support recipients regularly communicate concerns about medication side effects to their supporters. Approximately one-third of recipients regularly discuss confusion about their health care providers' instructions and trouble paying for medications or health care. In-home support recipients more frequently express to their supporter a desire to do more to stay healthy, concerns about medication side-effects, and feeling as though they are not getting support with health problems, compared to out-of-home support recipients.

### Supporter Concerns When Discussing Health with Support Recipients

When talking with their support recipients about health, supporters frequently report feeling that recipients downplay their health problems (Table 4). Over a third of health supporters report being confused about what is happening with their support recipients' health, and feeling that they don't know enough about their recipients' health problems to be helpful. A smaller, but considerable, proportion of supporters report feeling that support recipients often exaggerate their health problems. Supporters reported feeling that in-home recipients are less frequently receptive to their advice than out-of-home support recipients. Further, supporters indicate that they more frequently felt overwhelmed and were more likely to argue about health management when discussing health with support recipients living in the home compared to those living out-of-home.

### Supporters' Experiences Talking with Recipients' Health Care Providers

A large proportion of supporters accompany their support recipient into the exam room during medical appointments or communicate with their support recipient's health care providers via telephone at least once per year. Overall, these supporters reported more positive than negative interactions with health care providers (Table 5). Specifically, most supporters indicated that health care providers answer their questions on at least some occasions and approximately one-half of supporters reported that health care providers involve them in decisions or suggest ways that they could help with the support recipient's health care at least some of time. However, a large minority of supporters report experiencing occasions where health care providers were not willing to share patient information or did not listen to their input. Out-of-home supporters report a significantly lower frequency of both having their questions answered by recipients' health care providers and of being involved in health care decisions compared to in-home supporters.

## Discussion

This national survey highlights key roles and experiences of family members and friends who support the health management of adults with chronic illness. Family members and friends of adults with chronic health conditions frequently help their support recipients with health care and routinely discuss health issues that can substantively affect support recipients' health outcomes. Notably, thirty to forty percent of respondents reported challenges to providing support to their support recipients including: lack of knowledge, confusion about information provided by health care providers, and disagreements with their support recipient about strategies and practices for optimal health management. Similar proportions of health supporters indicated that their support recipients' health care providers did not share information or involve them in treatment decisions. Nearly twenty percent of supporters indicated that their support recipient's health care provider did not listen to their input. Consistent with our hypothesis, out of home supporters spent significantly less time directly helping with health care and were significantly less likely to interact or communicate with their support recipients' health care providers via telephone compared to in-home supporters. Yet, a considerable proportion of out of home supporters reported that they assisted with health care, accompanied patients to medical appointments, and communicated with health care providers. The present findings build on research documenting the experiences of informal caregivers experiences providing care to patients with severe functional impairment (Langa et al., 2001; Langa, Valenstein, Fendrick, Kabeto, & Vijan, 2004; Langa et al., 2002; Wolff, Spillman, et al., 2016).

Findings from this study highlight the significant potential for family members and friends to influence the health and health management of adults with chronic illness. Both in and out-of-home supporters spend an average of approximately two hours helping with health care on days that they provide help. Time spent providing support to family and friends with chronic health conditions might be leveraged to improve disease self-management and health outcomes. These supporters are frequently privy to patient concerns about their health conditions and health care that could directly impact patients' health and safety, such as bothersome symptoms, medication side effects and confusion about health care provider instructions. Future research could examine whether supporters can use strategies to help recipients solve problems in ways that could improve their health and encourage recipients to effectively communicate these concerns to their providers.

Many supporters reported difficulties communicating with support recipients about their health including arguments, support recipients discounting advice, or concerns about support recipients' minimization or exaggeration their health problems. This finding mirrors results from other studies of adults with chronic disease, in which a significant minority report that their family pester or criticize them about their self-management, or downplay their concerns (Mayberry & Osborn, 2014; Mayberry, Rothman, & Osborn, 2014; Rosland et al., 2010). These types of negative communication are associated with worse self-management of chronic conditions (Mayberry, Egede, Wagner, & Osborn, 2015; Rosland & Piette, 2010; Tang, Brown, Funnell, & Anderson, 2008). Supporters experiencing negative conversations with support recipients might benefit from training in positive communication techniques. When used by health care providers, autonomy supportive communication techniques increase support recipients' motivation and self-directed problem-solving to improve health behaviors (Ng et al., 2012; Patrick & Williams, 2012). Autonomy supportive communication skills include empathy, support for patient agency, and collaborative goal setting (Ryan, Patrick, Deci, & Williams, 2008). Future studies could test whether teaching informal supporters autonomy supportive communication skills helps functionally independent adults manage chronic disease (Dunbar et al., 2008).

Out-of-home supporters reported less disagreement and resistance, and feeling less overwhelmed when communicating with support recipients about health; however, these supporters were less likely to hear about key support recipient health concerns. Additionally, out-of-home supporters interacted less frequently with support recipients' health care providers, had more difficulty having their questions answered, and felt less involved in decisions compared to in-home supporters. While all health supporters may benefit from training in effective approaches (e.g., use of open-ended and probing questions) to ask support recipients about their chronic disease self-management, health related concerns, and plans made with health care providers, this type of communication training may prove to be particularly useful for supporters living outside their support recipients' home who reported more difficulties with communication.

Overall, disease management supporters reported frequent and positive communication with health care providers. Future interventions could draw on this existing contact between supporters and health care providers to attempt to improve patient-provider communication. For example, providing health supporters with enhanced mechanisms for directly relaying information to and from patients' providers may help ensure that important patient issues are addressed in a timely manner. Additional research is needed to better understand supporters' perspectives and preferences for communicating with patients' health care providers. For example, supporters could be provided with guidance in helping support recipients prepare questions or agendas for doctors' visits, or in how supporters themselves can interact effectively with health care providers (Wolff et al., 2014). Sharing access to patients' personal health records with health supporters may be a promising method to enhance supporter-provider communication. Existing research indicates that shared patient-supporter access to patients' personal health records is an underused, but acceptable, and effective method for improving patient-provider communication and patients' confidence in their care (Sarkar & Bates, 2014; Wolff, Darer, et al., 2016; Zulman et al., 2011).

The findings from our study should be interpreted in the context of several methodological limitations. First, this study used health supporters' self-report of support recipient health conditions rather than health care provider diagnoses. Second, this study relied on supporters' recall of discussions with support recipients and recipients' health care providers. Third, in-home supporters, by nature, have more extensive contact with their support recipient and may therefore be more aware of support recipients' health diagnoses and functional limitations, thus affecting the recipients' likelihood of being included or excluded from this study. Fourth, this study used survey items with set response options. Subsequent research studies could use open-ended questions to elicit more detailed information about key health supporter experiences and preferences identified in this study. Fifth, the study sample included larger proportions of African American and Latino adults compared to the general population of the United States. Therefore, findings reported is study may over represent the experiences of health supporters from these minority groups. Sixth, while Knowledge Networks employs several strategies to ensure the participation of panelists who do not have access to computers or the internet (Chang & Krosnick, 2009; Dennis, 2010), the respondents to this web-based survey may have had higher internet literacy than the average population. Seventh, we collected detailed data on a maximum of two potential support recipients most likely to be receiving support. Consequently, this study does not represent respondent experiences helping more than two support recipients. Finally, while we asked about several of the most common chronic health conditions among adults, respondents may have provided support to adults with chronic health conditions not included in this study.

### Conclusions

Family members and friends of adults with chronic illnesses spend a substantial amount of time providing health related support, and engage in critical discussions about health with support recipients. These supporters express difficulties communicating with their support recipients as well as a need for more information about their support recipients' health conditions and current health care. Future interventions could test whether programs targeting supporters' needs increase their effectiveness in supporting patients.

## Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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## Table 1

Chronic disease management supporter characteristics

***a***

| | Total | In-home support only | Out-of-home support only | In and out-of-home support | |
|---|---|---|---|---|---|
| | ***N* = 703** | ***n* = 126** | ***n* = 446** | ***n* = 131** | $p^{a}$ |
| Female | 59.3% | 42.9%$^{b}$ | 62.8%$^{c}$ | 63.4% | <.001 |
| Age in years (*SD*) | 50.00 (16.00) | 49.02 (16.94) | 49.62 (15.31) | 52.23 (17.24) | .196 |
| Race/ethnicity | | | | | .361 |
| White | 57.6% | 57.4% | 56.5% | 61.8% | |
| African-American | 21.9% | 22.2% | 23.8% | 15.3% | |
| Latino | 20.5% | 20.6% | 19.7% | 22.9% | |
| Education | | | | | .038 |
| <HS Degree | 11.5% | 15.1% | 10.5% | 11.5% | |
| HS Degree | 27.5% | 35.7% | 24.9% | 28.2% | |
| Some College | 30.2% | 25.4% | 30.0% | 35.1% | |
| ≥Bachelors Degree | 30.9% | 23.8% | 34.5% | 25.2% | |

***b***

| | Total | In-home recipient | Out-of- home recipient | |
|---|---|---|---|---|
| | ***N* = 834** | ***n* = 257** | ***n* = 577** | $p^{a}$ |
| Age ≥ 50 years | 73.4% | 65.5% | 76.9% | <.001 |
| Relation to supporter | | | | <.001 |
| Parent | 28.7% | 15.2% | 34.7% | <.001$^{b}$ |
| Sibling | 23.1% | 4.7% | 31.4% | <.001$^{b}$ |
| Spouse/partner | 21.2% | 66.2% | 1.2% | <.001$^{b}$ |
| Other relative/friend | 20.3% | 8.9% | 25.3% | <.001$^{b}$ |
| Adult child | 6.7% | 5.1% | 7.5% | .203$^{b}$ |

***b***

| | **Total** | **In-home recipient** | **Out-of- home recipient** | |
|---|---|---|---|---|
| | ***N* = 834** | ***n* = 257** | ***n* = 577** | $p^a$ |
| Distance from supporter | NA | NA | *n* = 570 | NA |
| <9 miles | | | 36.0% | |
| 10–20 miles | | | 13.0% | |
| 21–100 miles | | | 15.3% | |
| >100 miles | | | 35.8% | |
| Chronic illness | | | | |
| Arthritis | 40.7% | 44.4% | 39.0% | .130 |
| Diabetes | 34.5% | 30.4% | 36.4% | .089 |
| Depression | 26.3% | 30.0% | 24.6% | .092 |
| Heart Disease | 20.3% | 17.1% | 21.7% | .135 |
| Lung Disease | 13.7% | 16.7% | 12.3% | .088 |

Note: HS = High School.

[a] Significance for omnibus $\chi^2$ and *F*-tests comparing characteristics of in-home, out-of-home, and both in and out-of-home supporters. Different superscripts indicate significant differences column proportions.

[a] Significance of the chi-square tests comparing in-home and out-of-home supporters unless otherwise noted.

[b] Significance of the post-hoc *z*-tests comparing column proportions for in-home and out-of-home supporters.

## Table 2

Extent of supporters' involvement with support recipients' care

| | **Total** | **In-home recipient** | **Out-of-Home recipient** | |
|---|---|---|---|---|
| | ***N* = 834** | ***n* = 257** | ***n* = 577** | ***p***[a] |
| Time helping with healthcare | | | | |
| Any days/last 3 months[b] | 32.0% | 56.7% | 20.9% | <.001 |
| Average days/month[c] (*SD*) | 1.31 (0.16) | 3.48 (0.46) | 0.35 (0.06) | <.001 |
| Average hours/day[c] (*SD*) | 2.10 (0.16) | 2.22 (0.27) | 1.94 (0.14) | .383 |
| Accompany into exam room[d] | 21.2% | 45.0% | 11.2% | <.001 |
| Speak with provider via telephone[d] | 21.8% | 37.6% | 15.0% | <.001 |

Note: IADLs = Independent Activities of Daily Living.

[a] Significance of the chi-square or *t*-test comparing in-home and out-of-home supporter recipients.

[b] Any days vs. no days during the last three months.

[c] Item only asked of respondents who indicated that they spent any days helping their recipients during the last three months.

[d] Ever vs. never.

## Table 3

Support recipient health concerns shared with supporters

| **When you talk about health, your support recipient mentions:** | **Total** | **In-home recipient** | **Out-of-home recipient** | |
|---|---|---|---|---|
| | ***N* = 811[a]** | ***n* = 247** | ***n* = 564** | ***p*[b]** |
| Pain or bothersome symptoms | 74.8% | 78.1% | 73.3% | .139 |
| Feeling the need to do more to stay healthy | 56.3% | 64.8% | 52.6% | .001 |
| Concerns about medication side effects | 47.2% | 53.9% | 44.3% | .010 |
| Trouble paying for medications/healthcare | 31.8% | 31.7% | 31.9% | .967 |
| Not getting support with health problems | 31.1% | 37.3% | 28.3% | .015 |
| Confusion about healthcare provider instructions | 29.0% | 34.6% | 26.6% | .022 |

Note: All responses dichotomized as “some of the time, most of the time, or every time” vs. “rarely or never”.

[a] Items only asked of supporters who reported having discussed health issues with their health support recipient.

[b] Significance of chi-square tests comparing in-home and out-of-home support recipients.

## Table 4

Supporter experiences with health-related conversations with support recipients

| **When we [support recipient and I] talk about my support recipients' health:** | **Total** | **In-home recipient** | **Out-of-home recipient** | |
|---|---|---|---|---|
| | ***N* = 811**[a] | ***n* = 247** | ***n* = 564** | ***p***[b] |
| They minimize their health problems | 60.5% | 63.1% | 59.4% | .302 |
| I feel like I don't know enough about their health condition to be helpful | 40.5% | 40.7% | 40.4% | .935 |
| They don't seem to want my advice | 40.1% | 45.3% | 37.8% | .040 |
| I get confused about what's really going on with their health | 37.5% | 38.0% | 37.3% | .863 |
| I feel overwhelmed | 25.3% | 30.8% | 22.8% | .010 |
| They seem to exaggerate their health problems | 20.4% | 23.1% | 19.3% | .205 |
| We end up arguing about what they should do for their health | 18.3% | 30.8% | 12.8% | <.001 |
| I worry that I'm getting too involved | 12.6% | 12.7% | 12.5% | .949 |

Note: Responses dichotomized as "some of the time, most of the time, or every time" vs. "rarely or never".

[a] Items only asked of supporters who reported having discussed health issues with their health support recipient.

[b] Significance of chi-square tests comparing in-home and out-of-home support recipients.

### Table 5

Supporter experiences talking with support recipients' health care providers

| When you talk with your support recipient's healthcare provider he/she: | Total | In-home recipient | Out-of-home recipient | |
|---|---|---|---|---|
| | $N = 321^{a}$ | $n = 167$ | $n = 154$ | $p^{b}$ |
| Answered your questions | 69.2% | 76.1% | 61.7% | .006 |
| Involved you in decisions | 48.6% | 55.2% | 41.5% | .014 |
| Suggested ways you could help | 48.1% | 50.6% | 45.5% | .366 |
| Was not willing to share information about your recipients' healthcare | 29.0% | 26.7% | 31.6% | .314 |
| Did not listen to you | 18.8% | 16.8% | 20.9% | .211 |

Note: Responses dichotomized as "some of the time," "most of the time," or "every time" vs. "rarely" or "never".

[a] Items only asked of supporters who reported accompanying their support recipient into the healthcare exam room or communicating with their support recipient's health care providers via telephone.

[b] Significance of chi-square tests comparing in-home and out-of-home support recipients.