

THE STRAIN OF CAREGIVING

HOW CAREGIVER INVOLVEMENT REDUCES
DISTRESS AND CONFLICT



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Executive Summary

From October 2019 to May 2020, Mental Health America (MHA) conducted a survey designed for caregivers of a family member or friend living with a mental health condition. The following findings were drawn from the 817 responses received during that time:

- **Fewer than 6 in 10 caregivers feel involved in care.** While all of the respondents of the survey identified themselves as caregivers and 71 percent indicated that the person they cared for was living with them, only 58 percent reported that they felt involved in the mental health care of their loved one.
- **Despite reporting feeling involved in care, only 50-60 percent of caregivers reported that providers checked in with them about their loved one's care.** 62 percent of caregivers who were involved in care reported that providers asked them about how treatment was going for their loved one, including what was going well and what could be improved, and 53 percent answered that providers informed them about what was happening in their loved one's treatment. Only 43 percent reported being involved in the discussion of their loved one's treatment goals.
- **The strain of caregiving was a universal experience of caregivers.** Overall, 68 percent of caregivers reported that they always or often experienced distress about how to take care of all the things that needed to happen, and 51 percent of caregivers reported feeling frequent distress about being able to take care of their own physical and/or mental health needs.
- **Caregivers who were not involved in care experience more uncertainty and distress about their loved one's treatment.** Caregivers who were not involved in care were 22 percent more likely to feel frequent distress about their loved one refusing treatment, and 5 percent more likely to feel distress at least some of the time about their medications or treatment not working.
- **Conflicts regarding care were common, but the sources of those conflicts differed based on caregiver involvement.** Overall, the majority (63 percent) of caregivers reported that they got into arguments or conflicts with their loved one specifically related to their care. Caregivers who did not feel involved in care were 10 percent more likely to report not feeling involved in making care decisions as a source of conflict (31 percent compared to 22 percent). They were 9 percent more likely to report conflict about their loved one frequently missing appointments with their mental health provider (30 percent compared to 21 percent) than caregivers who felt involved in care. Caregivers who felt involved in care were 11 percent more likely to report their loved one's independence or lack of independence as a source of conflict than those who did not feel involved in care (60 percent compared to 49 percent).
- **Despite conflicts and distress, most caregivers expressed hope for their loved one's recovery.** 62 percent of caregivers agreed that they were hopeful that their family member would get better. Whether a caregiver felt involved in care did not significantly affect hope for recovery.

The Caregiver Survey

From October 2019-May 2020, Mental Health America (MHA) hosted a survey for family caregivers to investigate whether they felt involved in the care of their loved ones, if involvement had an effect on their levels of distress and conflict in providing care, and the hope they had for their loved one's recovery.

Measuring Needs Among Help-Seeking Population

This survey was available to the public through MHA's Screening 2 Supports website (www.mhascreening.org), and distributed through partner organizations whose audiences include family caregivers.

Most users of MHA's Screening 2 Supports website find the platform while searching for mental health resources and supports online. The sample collected by MHA's screening tools and surveys therefore weighs heavily toward users who are already experiencing mental health concerns. While respondents to this survey may have been accessing MHA's website for resources for their loved ones or may have been recruited through partner organizations, it is possible that the respondents found this survey while searching for resources to support their own mental health. This convenience sample allows MHA to understand the experiences of family caregivers who are experiencing higher levels of stress and mental health concerns, creating opportunities to respond to those with the highest need who are searching for resources and supports.

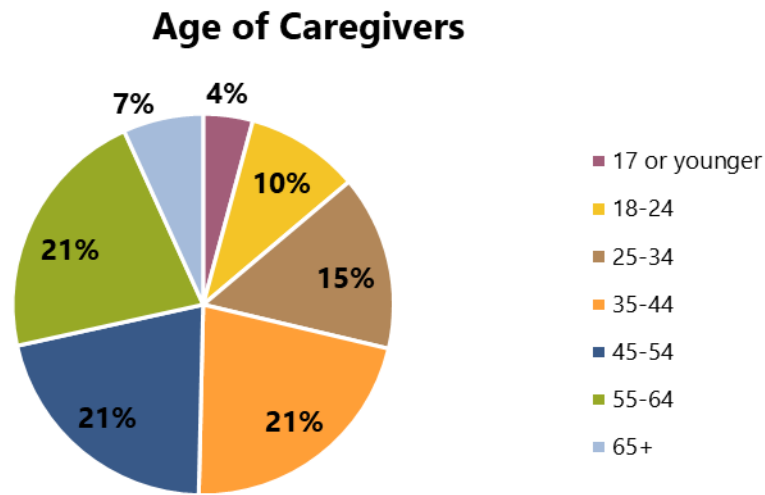
The following is an analysis of the responses of 817 caregivers of a family member or friend living with a mental health condition collected from October 2019 through May 2020.

Demographics

817 people responded to the Caregiver Survey and identified as a caregiver for a family member or friend with a mental illness.

Of these respondents, 82 percent identified as female, 17 percent identified as male, and 1 percent as another gender.

Most caregivers were adults ages 35-64 (64 percent). The proportions of adults ages 35-44, 45-54, and 55-64 were even, at 21 percent. 14 percent of caregivers were under the age of 24, and 7 percent were over the age of 65.



22 percent of caregivers reported household incomes less than \$20,000, and 56 percent reported a household income under \$60,000.

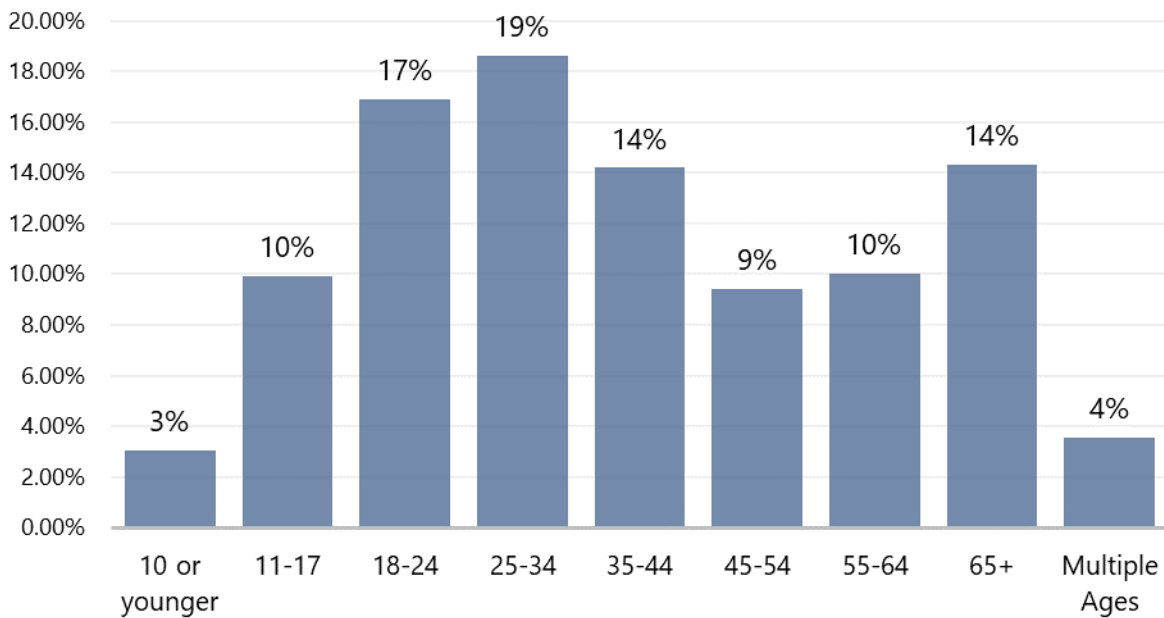
| Annual Household Income | Count | Percentage |
|-------------------------|------------|----------------|
| Less than \$20,000 | 172 | 21.72% |
| \$20,000-\$39,0999 | 148 | 18.69% |
| \$40,000-\$59,999 | 126 | 15.91% |
| \$60,000-\$79,999 | 88 | 11.11% |
| \$80,000-\$99,999 | 91 | 11.49% |
| \$100,000-\$149,999 | 99 | 12.50% |
| \$150,000+ | 68 | 8.59% |
| Grand Total | 792 | 100.00% |

When asked who they were caring for, most respondents were caring for family members, with 33 percent reporting they were caring for their child, 29 percent for a spouse or partner, 19 percent for a parent, and 11 percent for another relative. Most people who chose "Other" were caring for multiple people.

| Who are you caring for? | Count | Percentage |
|-----------------------------|------------|----------------|
| My child | 267 | 32.68% |
| My spouse or partner | 237 | 29.01% |
| My parent | 155 | 18.97% |
| Another relative | 90 | 11.02% |
| Friend | 29 | 3.55% |
| Other | 39 | 4.77% |
| Grand Total | 817 | 100.00% |

Half of people who were receiving care were adults between the ages of 18-44 (50 percent). Only 13 percent were children under the age of 18, and 14 percent were over age 65.

Age of the Person Receiving Care



Most caregivers surveyed were providing care to individuals living with depression (55 percent) or anxiety disorders (52 percent), followed by bipolar disorder (31 percent) and psychotic disorders (22 percent). 60 percent of caregivers reported the person they cared for lived with more than one mental health condition.

| Which mental health problem does your loved one have? (Check all that apply) | Count | Percentage |
|---|--------------|-------------------|
| Depression | 446 | 54.59% |
| Anxiety disorder (obsessive-compulsive, panic, PTSD) | 424 | 51.90% |
| Bipolar Disorder | 250 | 30.60% |
| Psychotic disorder (schizophrenia, schizoaffective) | 177 | 21.66% |
| Substance Use Disorder | 141 | 17.26% |
| Alzheimer's or Dementia | 54 | 6.61% |
| ADHD | 31 | 3.79% |
| Autism | 25 | 3.06% |
| Other | 120 | 14.69% |
| Total | 817 | |

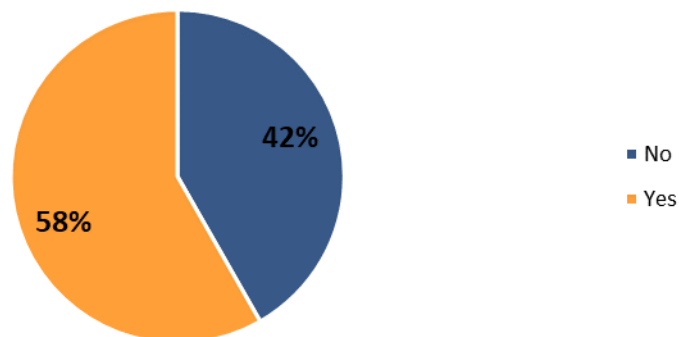
To gather more information about what kind of care they were providing, caregivers were asked, "Which statements are true about your caregiving situation? Check all that apply." The majority (71 percent) of caregivers reported that they were living with the person they were caring for. This was followed by 43 percent reporting that they provide emotional support to their loved one but were not involved in daily or functional tasks. One-third (33 percent) of caregivers reported that they were the primary caregiver and took care of all their loved one's needs.

| Which of the following statements are true about your caregiving situation? (Check all that apply) | Count | Percentage |
|---|--------------|-------------------|
| My loved one lives with me. | 579 | 70.87% |
| I provide emotional support but not really other daily or functional tasks (preparing meals, showering). | 355 | 43.45% |
| I take care of some things (like finances or some transportation). | 316 | 38.68% |
| I take care of my loved one's treatment needs (medications and appointments). | 299 | 36.60% |
| I am the primary caregiver and do everything for my loved one. | 269 | 32.93% |
| My loved one doesn't live with me. They live with another family member. | 99 | 12.12% |
| My loved one lives in a facility (hospital, nursing home, shelter, jail). | 46 | 5.63% |
| My loved one is homeless. | 25 | 3.06% |
| Grand Total | 817 | |

Caregiver Involvement

Overall, while all of the respondents of the survey identified themselves as caregivers and 71 percent indicated that the person they cared for was living with them, only 58 percent reported that they felt involved in the mental health care of their loved one. 42 percent reported that they did not feel involved.

Do you feel involved in your family member's mental health care?

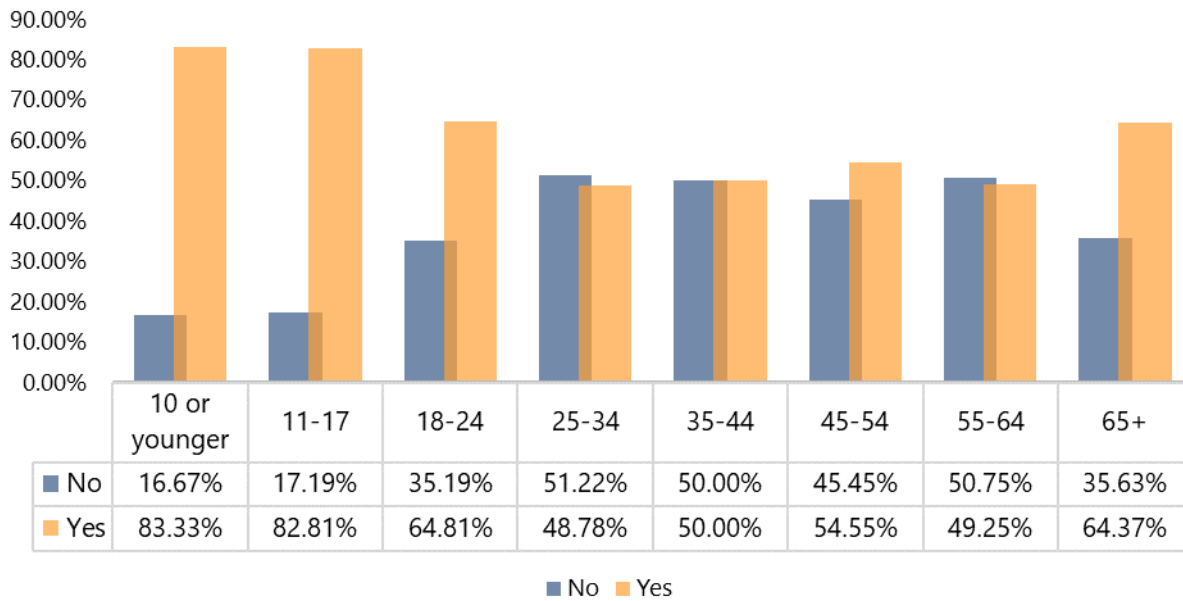


Fewer than half (47 percent) of caregivers of someone living with a substance use disorder reported that they felt involved in their loved one's care. Caregivers who felt most involved in care were those of people living with ADHD (81 percent), Alzheimer's or Dementia (76 percent), and psychotic disorders, including schizophrenia and schizoaffective disorder (63 percent).

| Do you feel involved in your family member's mental health care? | Percentage |
|--|--------------|
| Anxiety disorder (obsessive-compulsive, panic, PTSD) | N=424 |
| No, I do not feel involved in care. | 45.75% |
| Yes, I feel involved in care. | 54.25% |
| Bipolar disorder | N=250 |
| No, I do not feel involved in care. | 42.80% |
| Yes, I feel involved in care. | 57.20% |
| ADHD | N=31 |
| No, I do not feel involved in care. | 19.35% |
| Yes, I feel involved in care. | 80.65% |
| Alzheimer's or Dementia | N=54 |
| No, I do not feel involved in care. | 24.07% |
| Yes, I feel involved in care. | 75.93% |
| Depression | N=446 |
| No, I do not feel involved in care. | 43.95% |
| Yes, I feel involved in care. | 56.05% |
| Psychotic disorder (schizophrenia, schizoaffective) | N=177 |
| No, I do not feel involved in care. | 37.29% |
| Yes, I feel involved in care. | 62.71% |
| Substance Use Disorder | N=141 |
| No, I do not feel involved in care. | 53.19% |
| Yes, I feel involved in care. | 46.81% |

Across all conditions, caregivers were less likely to feel involved when the loved one they were caring for was a young adult, ages 25-34 (49 percent). Caregivers were most likely to report feeling involved in care if the person they were caring for was a minor, ages 10 or younger (83 percent) or 11-17 (83 percent).

Caregiver Involvement by Age of Person Receiving Care



Some of the variation in involvement by mental health condition may be explained by the overlap between those conditions and age of the individual receiving care. Individuals under age 18 were more likely to be living with ADHD than any other mental health condition (52 percent), and individuals over the age of 65 were more likely to be living with Alzheimer’s or dementia than any other mental health condition (88 percent).

| Age of Individual Receiving Care, by Mental Health Condition | ADHD | Anxiety disorder (obsessive compulsive, panic, PTSD) | Bipolar disorder | Alzheimer's or dementia | Depression | Psychotic disorders (schizophrenia, schizoaffective) | Substance Use disorder |
|--|-----------|--|------------------|-------------------------|------------|--|------------------------|
| 10 or younger | 29.03% | 3.61% | 0.41% | 0.00% | 1.83% | 0.58% | 0.00% |
| 11-17 | 22.58% | 11.81% | 8.68% | 0.00% | 12.10% | 5.23% | 4.32% |
| 18-24 | 9.68% | 19.04% | 21.49% | 0.00% | 19.41% | 19.77% | 16.55% |
| 25-34 | 22.58% | 20.96% | 21.90% | 0.00% | 17.58% | 27.91% | 28.06% |
| 35-44 | 6.45% | 16.14% | 20.25% | 0.00% | 15.30% | 15.12% | 14.39% |
| 45-54 | 3.23% | 8.92% | 8.68% | 5.00% | 9.82% | 10.47% | 8.63% |
| 55-64 | 6.45% | 9.40% | 9.50% | 7.50% | 11.42% | 12.21% | 15.11% |
| 65+ | 0.00% | 10.12% | 9.09% | 87.50% | 12.56% | 8.72% | 12.95% |
| Total Count | 31 | 415 | 242 | 40 | 438 | 172 | 139 |

How Caregivers are Involved in Care

Among caregivers who reported that they felt involved in their loved one's mental health care, 40 percent indicated that they interacted with their loved one's therapist and 39 percent with their loved one's psychiatrist. 24 percent were involved with a mental health care team.

40 percent of caregivers reported they interacted with others in their care. This includes primary care providers, case workers, and nurses, as well as peer support specialists, support groups, and other family members who assisted in providing care. Several caregivers also listed individuals outside of the health care sector, including teachers and religious figures, indicating both diversity in where individuals receive services, and who caregivers consider integral partners in the provision of their loved one's care.

| Who do you talk to? (Check all that apply) | Count | Percentage |
|--|------------|------------|
| Therapist | 191 | 40.13% |
| Psychiatrist | 185 | 38.87% |
| Mental Health Team | 112 | 23.53% |
| Other | 189 | 39.71% |
| Grand Total | 476 | |

Access to Team Based Care

The kinds of providers with whom a caregiver speaks highlights the challenge of poor access to comprehensive provider types rather than concerns regarding caregiver involvement. Many more individuals experiencing mental health conditions have access to therapists and psychiatrists than to mental health teams. Only a quarter of caregivers responded that they speak to their loved one's mental health team. This may not be because 76 percent of caregivers are not involved in their loved one's mental health team, but because 76 percent of individuals do not have access to a mental health team at all.

When asked how they were involved, 62 percent of caregivers reported that providers asked them about how treatment was going for their loved one, including what was going well and what could be improved. Despite reporting that they felt involved in their loved one's care, only 53 percent answered that providers informed them about what was happening in their loved one's treatment, and only 43 percent were involved in the discussion of their loved one's goals and how they could be involved in helping them meet these goals. Only one-quarter of respondents (24 percent) reported that they were asked about their own personal needs as the caregiver.

| How are you involved? (Check all that apply) – Among Caregivers who Felt Involved in Care | Count | Percentage |
|---|------------|------------|
| They ask me questions (what's going well or what could be improved). | 293 | 61.55% |
| They tell me about what is going on in treatment for my loved one. | 250 | 52.52% |
| They talk to me about goals and how I can be involved in helping my loved one meet their goals. | 206 | 43.28% |
| They ask me about my personal needs. | 112 | 23.53% |
| Other | 80 | 16.81% |
| Grand Total | 476 | |

How Caregivers Would Like to Be Involved in Care

Caregivers who reported that they did not feel involved in their loved one's mental health care were asked who they would want to speak to for greater involvement, and how they would like to be involved in care by those providers.

Among caregivers who did not feel involved in care, only 13 percent indicated that they would not want to be involved in their loved one's care. The majority (61 percent) reported that they would like to speak to their loved one's therapist and 52 percent reported wanting to speak to their loved one's psychiatrist. 52 percent also reported that they would like to be involved with a mental health team, over twice the percentage of caregivers who reported they were involved with a mental health team.

| Who would you want to talk to if you were involved in your loved one's mental health care? (check all that apply) | Count | Percentage |
|--|--------------|-------------------|
| Therapist | 209 | 61.29% |
| Mental Health Team | 179 | 52.49% |
| Psychiatrist | 178 | 52.20% |
| I do not want to be involved in my loved one's care. | 46 | 13.49% |
| Other | 28 | 8.21% |
| Grand Total | 341 | |

When asked how they would like to be involved, 74 percent of caregivers who currently did not feel involved in care reported that they wanted to be asked questions about their loved one's treatment, including what was going well and what could be improved. 72 percent reported that they would like to know about their loved one's goals in treatment, and how they could be involved in helping them achieve those goals. 63 percent reported that they wanted to know what was going on in treatment for their loved one and nearly half (47 percent) indicated that they wanted to be asked about their personal needs as caregivers.

| How would you like to be involved in your loved one's mental health care? (Check all that apply) | Count | Percentage |
|--|--------------|-------------------|
| They would ask me questions (what's going well or what could be improved). | 251 | 73.61% |
| They would talk to me about goals and how I can be involved in helping my loved one meet their goals. | 244 | 71.55% |
| They would tell me about what is going on in treatment for my loved one. | 216 | 63.34% |
| They would ask me about my personal needs. | 159 | 46.63% |
| I do not want to be involved in my loved one's care. | 33 | 9.68% |
| Other | 8 | 2.35% |
| Grand Total | 341 | |

Improving effective caregiver engagement

Our data indicate that only half of caregivers who are involved in their loved one's care are integrated in a meaningful way, but 3 out of 4 want to be more significantly involved. Provider check-ins with caregivers should include at minimum an exchange of information about what is happening at home and how treatment can be improved. To support a client's recovery, providers should increase their focus on engaging caregivers in understanding their loved one's goals, helping caregivers identify strategies to assist their loved ones in achieving those goals, and allowing a space for the caregiver to voice their own goals and needs.

Increasing positive social support between caregivers and their loved ones is an important and meaningful focus for recovery. Providers can improve family dynamics by inquiring about and exploring the needs and goals of both the person receiving care and their caregiver. Providers can mediate conversation when these goals are not aligned or where the care plan does not match with the personal needs of the caregiver.

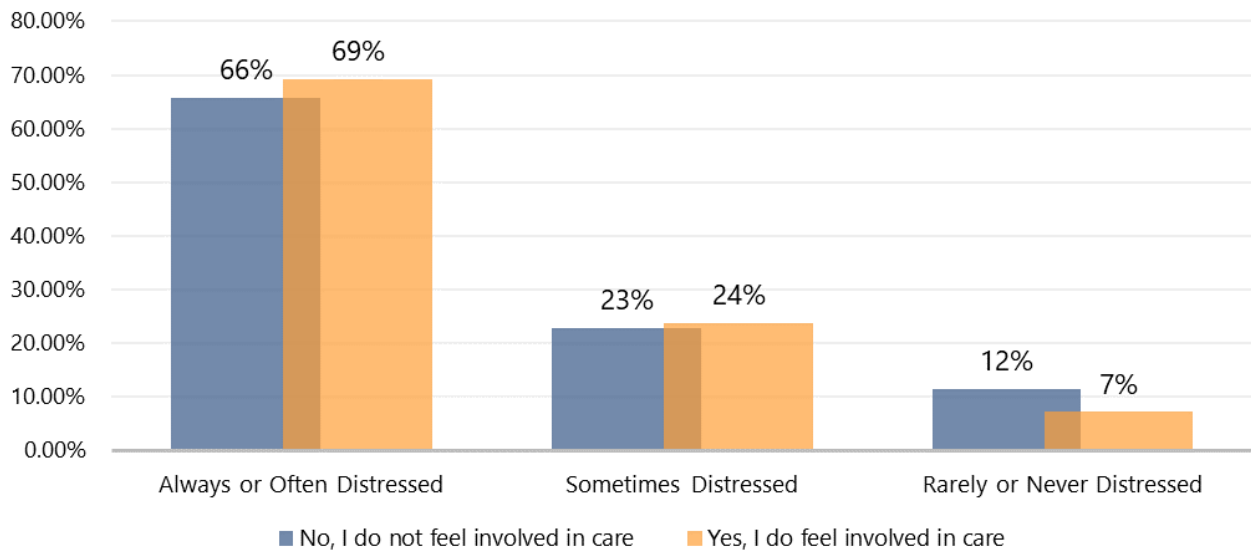
A more comprehensive and inclusive caregiver relationship among provider, client, and caregiver will result in whole family care. Increasing engagement toward whole family care can improve recovery, support continuity of care, reduce conflict, and reduce distress and uncertainty related to caregiving.

The Effect of Caregiver Involvement on Feelings of Distress

Both caregivers who felt involved in care and those who did not were asked to report how often they felt distressed about different challenges in caregiving.

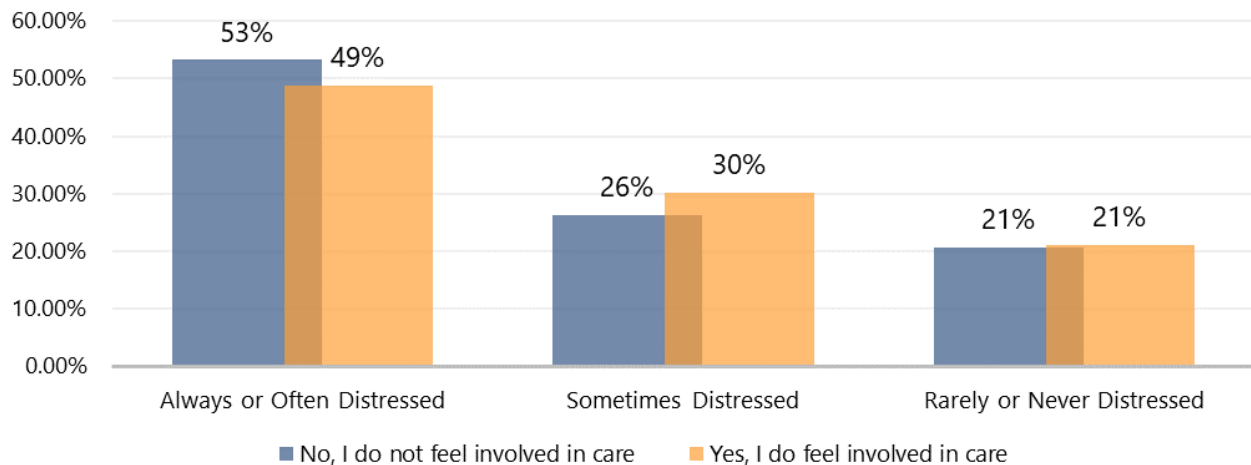
The strain of caregiving appeared to be a universal experience of caregivers in both categories. Overall, 68 percent of caregivers reported that they always or often experienced distress about how to take care of all the things that needed to happen. When separated by whether caregivers felt involved in care, 69 percent of those involved reported always or often feeling distress about taking care of things that needed to happen, compared to 66 percent of those who did not feel involved in care. This is consistent with findings from the [MHA Screening program](#), in which 43 percent of caregivers who take a mental health screen report that they are seeking resources and supports because of the stress of caregiving.

How Often Do You Feel Distress About: How to Take Care of All the Things That Need to Happen



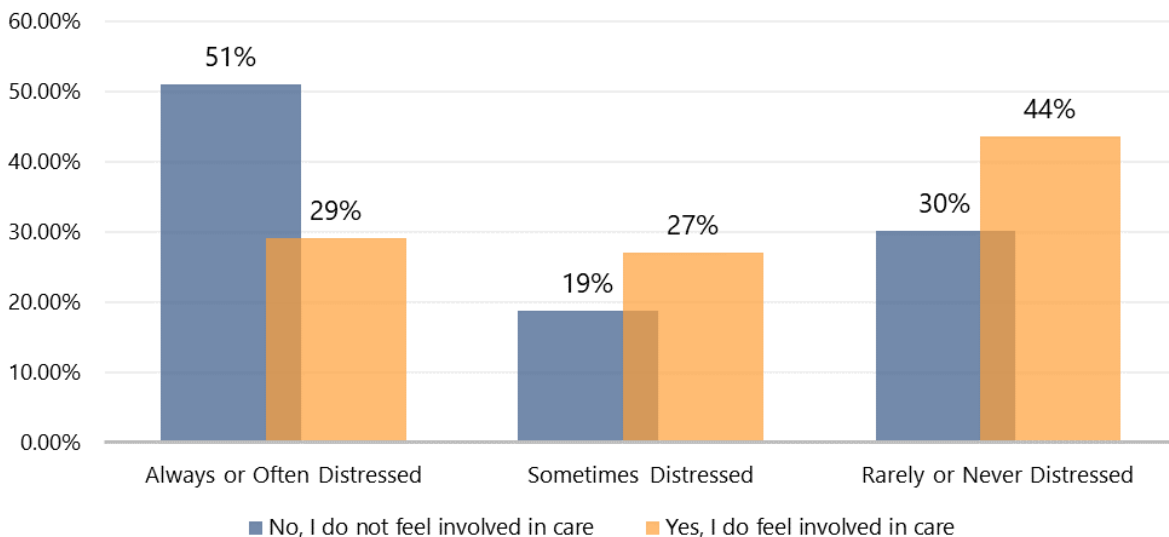
Over half (51 percent) of all caregivers also reported feeling frequent distress about being able to take care of their own physical and/or mental health needs, and 79 percent reported this distressed them at least some of the time. However, feeling distress about taking care of one's own needs was slightly higher among caregivers who reported that they did not feel involved in their loved one's care (53 percent) than those who did feel involved (49 percent).

How Often Do You Feel Distress About: Taking Care of Your Own Physical And/Or Mental Health Needs?



Caregivers who did not feel involved in their loved one's care were much more likely to report experiencing frequent distress that their loved one was refusing treatment. Over half (51 percent) of caregivers who were not involved in care reported always or often feeling distress about their loved one refusing treatment compared to only 29 percent of those who felt involved in care.

How Often Do You Feel Distress About: Your Family Member Refusing Treatment



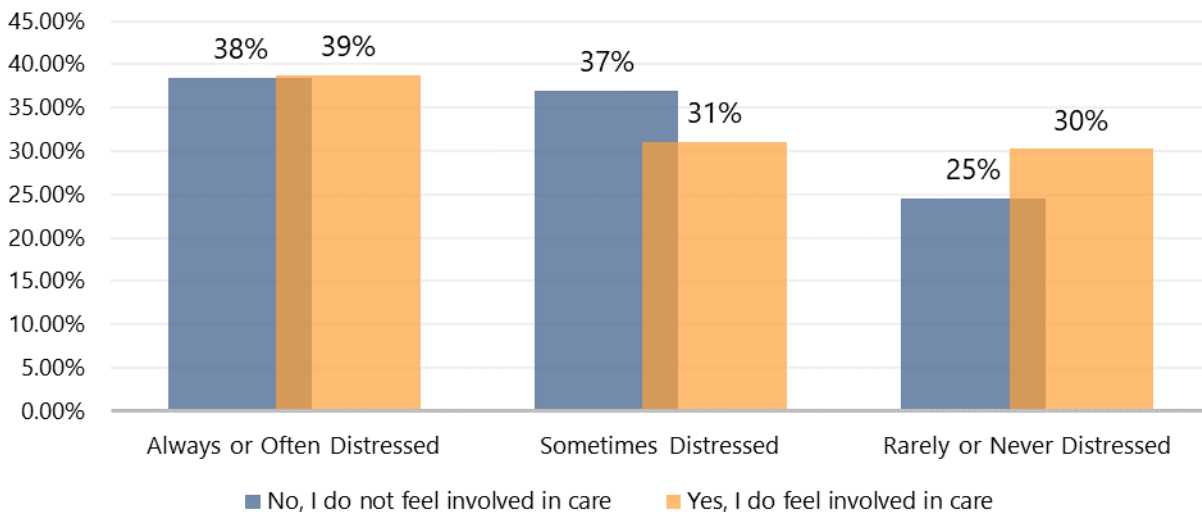
Distress related to uncertainty

Caregivers who are not involved in care are often not aware of what is happening in their loved one's treatment. This uncertainty increases stress and a sense of lost control, or a hopelessness related to their ability to provide help for their loved one's recovery.

For caregivers, one of the most challenging scenarios is the discontinuation of treatment. Discontinuation or interruption in care results in instability in the recovery process that might result in catastrophic outcomes, including homelessness or incarceration.

Overall, 39 percent of caregivers reported that they always or often felt distress about their loved one's medication or treatment not working, and 72 percent reported feeling distress about this at least some of the time. Rates of frequent distress did not differ significantly whether caregivers felt involved in care – 38 percent of caregivers who were not involved in care reported always or often feeling distressed that their loved one's treatment does not work, compared to 39 percent of caregivers who did feel involved in care. However, caregivers who were involved in care were 5 percent more likely to report rarely or never feeling distress about the effectiveness of their loved one's treatment.

How Often Do You Feel Distress About: Your Loved One's Medication or Treatment Does Not Work?



Treatment efficacy and caregiving

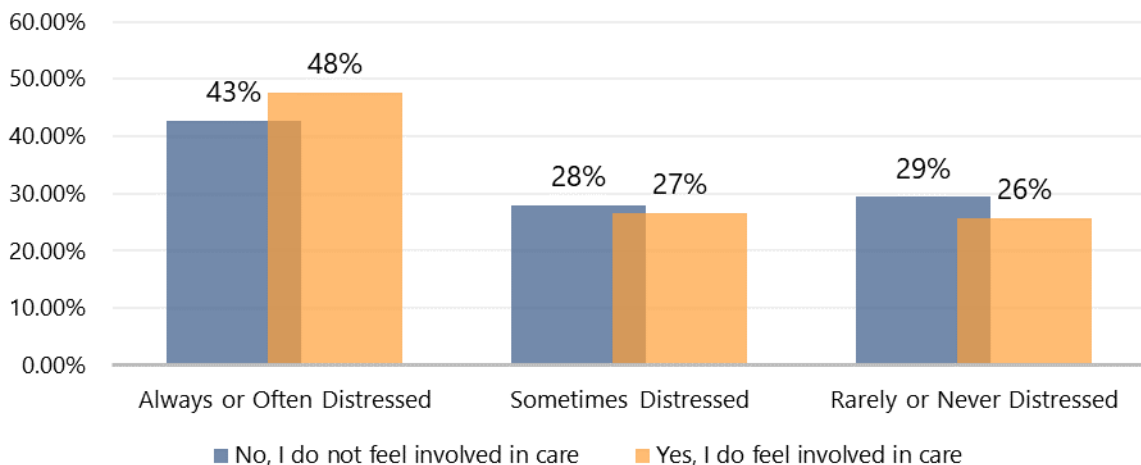
Regardless of whether caregivers are involved or not involved, nearly 40 percent of all caregivers were frequently distressed about medication and treatment efficacy. This speaks to the importance of having regular conversations with both caregivers and clients about whether medications and treatment are effective.

Caregivers may have a sense that medications are not working, and how this impacts recovery, or if changes in medication might provide improvements to support long term goals. Regularly scheduled discussions on medication efficacy and improvements are imperative to effective care.

Caregivers report wanting to be involved in treatment planning. Engagement on treatment planning with caregivers and clients will reduce caregiver distress related to ineffective or discontinued treatment while honoring the goals and needs of the individual receiving care.

Overall, nearly half of caregivers (46 percent) reported feeling frequent distress about the mental health system being complicated or difficult to navigate and 73 percent reported feeling distress about the mental health system at least some of the time. However, caregivers who reported they were involved in care were more likely to report distress about navigating the mental health system – 48 percent of caregivers who were involved in care were always or often distressed, compared to 43 percent of caregivers who were not involved.

How Often Do You Feel Distressed About: The Mental Health Care System is Complicated or Difficult to Navigate?



Navigating a complicated mental health system

Distress about navigating the mental health care system not only demonstrates the complication of federal, state, and local systems of care, but the challenges associated with navigating recovery as a caregiver as well. The mental health care system is disjointed and requires caregivers and those receiving care to carry the burden of consistently learning and responding to changes in policies, providers, or treatment costs. This distress is magnified across the lifetime when families experience multiple periods of instability due to changes in policies that impact the kinds of medications or treatments to which the family has access. These changes may include when an effective medication a person has been taken consistently is no longer covered by insurance or when a family moves to a different state and must navigate how to transfer their Medicaid benefits.

The case for a simpler healthcare option

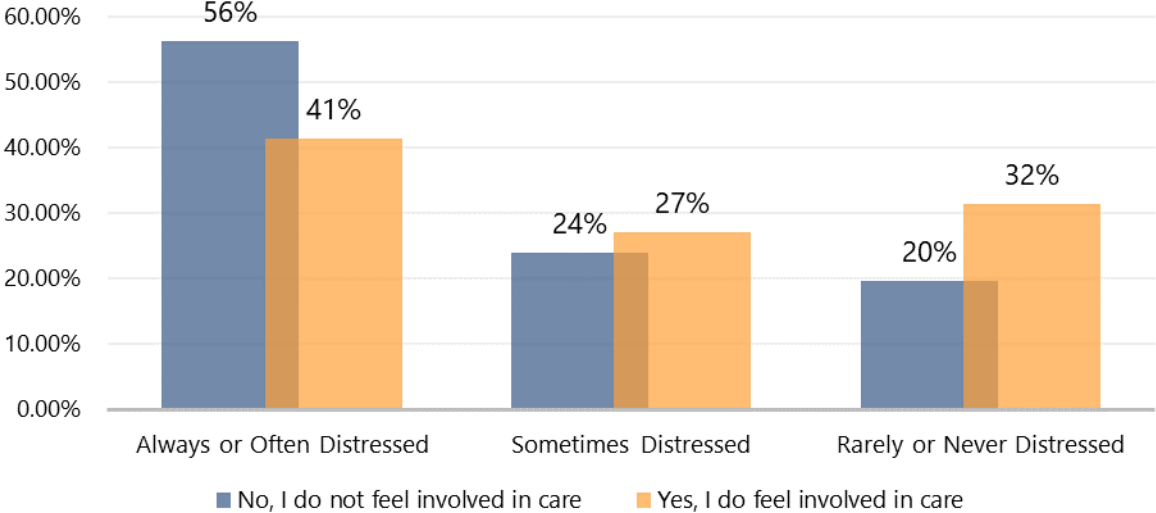
To reduce the uncertainty and distress of navigating the mental health care system, there must be broad systemic change that helps ensure continuity of care. The use of peers as care navigators is an example of a support that is effective in helping people link to proper care but is insufficient as a systemic approach.

One systemic change that would allow people to stay consistently involved in care is changing Medicaid. Medicaid provides coverage for millions of people in the U.S. with mental health conditions, and for many is the only source of funding for some behavioral health services. Currently, each state can control who is covered under Medicaid and which services are covered, creating a huge impediment to continuity of care. For example, if caregivers and their loved ones move from one state to the other, they must reapply to their new state's Medicaid system to continue receiving treatment. Some may lose eligibility, certain medications, or types of treatments that are not covered in their new states. Having a universal federal healthcare option would reduce discontinuation of treatment and could create a system that is easier to navigate.

Additionally, mental health care should be integrated into all systems, not just health care systems, to meet people where they are. While mental health care should be integrated into primary care to increase access and bridge gaps between the provision of physical and mental health care, mental health resources and supports should also be built into schools, workplaces, and other community settings. A community prevention and early intervention approach can save money by reducing life-long disability and risks of interactions with the criminal justice system.

Finally, caregivers who were not involved in their loved one’s care were much more likely to report experiencing distress about conflicts or fighting with their loved one. 56 percent of caregivers who were not involved in care reported always or often feeling distressed about conflicts with their loved one, compared to 41 percent of caregivers who were involved. This represented the largest difference in distress between groups.

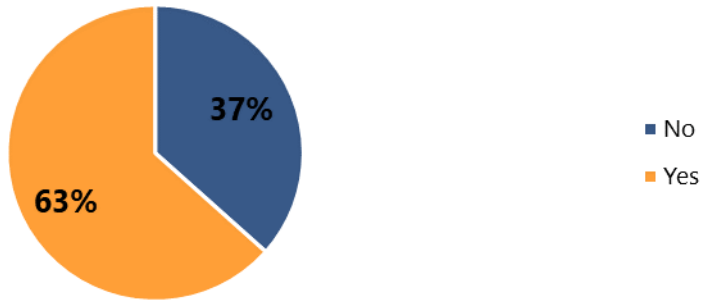
How Often Do You Feel Distressed About: Conflicts or Fighting With Your Loved One?



Sources of Conflict Between Caregivers and Those They Care For

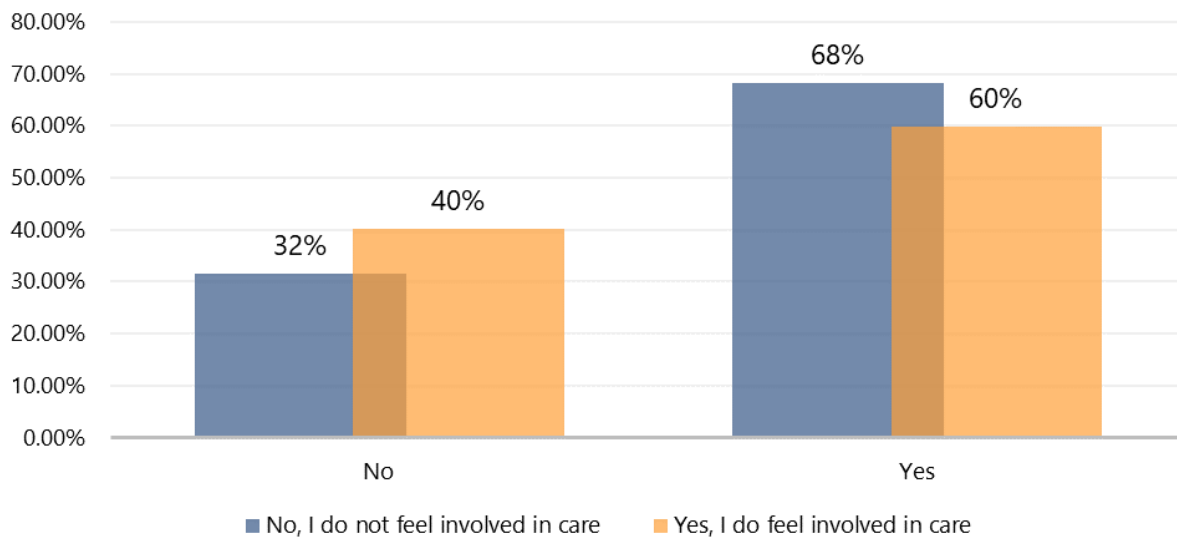
Overall, the majority (63 percent) of caregivers reported that they got into arguments or conflicts with their loved one specifically related to their care.

Do you and your loved one get in arguments or conflicts related to their care?



However, similar to the rates of caregivers experiencing distress about general conflict above, caregivers who were not involved in care were more likely to report experiencing arguments or conflict with their loved ones about their care than those who were involved (68 percent compared to 60 percent).

Do you and your loved one get in arguments or conflicts related to their care?



Both caregivers who reported they felt involved in care and those who did not feel involved were asked, "Which of the following has been a source of conflict for you? Check all that apply."

Caregivers who indicated they felt involved in their loved one's care reported the most conflict around their loved one's motivation to accomplish daily tasks (69 percent), followed by disagreements about how much care they need (65 percent) and their independence or lack of independence (60 percent).

Caregivers who indicated they did not feel involved in care reported the greatest amount of conflict around disagreements about the amount of care their loved one needed (62 percent), followed by their motivation to accomplish daily tasks (61 percent) and relationships with family or friends (58 percent).

| Caregivers Who Felt Involved in Care | | | Caregivers Who Did Not Feel Involved in Care | | |
|--|------------|------------|--|------------|------------|
| If so, which of the following has been a source of conflict for you? (Check all that apply) Ranked from Highest to Lowest | Count | Percentage | If so, which of the following has been a source of conflict for you? (Check all that apply) Ranked from Highest to Lowest | Count | Percentage |
| Their motivation to accomplish daily tasks (cleaning, hygiene, going to work or school, etc.) | 197 | 69.12% | Disagreements about how much care they need | 145 | 62.23% |
| Disagreements about how much care they need | 186 | 65.26% | Their motivation to accomplish daily tasks (cleaning, hygiene, going to work or school, etc.) | 142 | 60.94% |
| Their independence (or lack of independence) | 171 | 60.00% | Relationships with family or friends | 136 | 58.37% |
| Relationships with family or friends | 155 | 54.39% | Their independence (or lack of independence) | 114 | 48.93% |
| They don't adhere to their treatment as prescribed | 142 | 49.82% | They don't adhere to their treatment as prescribed | 97 | 41.63% |
| Disagreements about the care that I provide or my ability to provide care | 107 | 37.54% | Disagreements about the care that I provide or my ability to provide care | 93 | 39.91% |
| Medications they are taking (and/or the side effects of those medications) | 106 | 37.19% | Medications they are taking (and/or the side effects of those medications) | 80 | 34.33% |
| Money and/or financial responsibilities of their care | 93 | 32.63% | I don't feel like I am involved in making decisions about their treatment | 73 | 31.33% |
| I don't feel like I am involved in making decisions about their treatment | 62 | 21.75% | They frequently miss appointments with their mental health provider | 70 | 30.04% |
| They frequently miss appointments with their mental health provider | 61 | 21.40% | Money and/or financial responsibilities of their care | 68 | 29.18% |
| My loved one doesn't feel that they are involved in making decisions about their treatment | 42 | 14.74% | My loved one doesn't feel that they are involved in making decisions about their treatment | 20 | 8.58% |
| Total | 285 | | | 233 | |

Caregivers who did not feel involved in care were 10 percent more likely to report not feeling involved in making care decisions as a source of conflict (31 percent compared to 22 percent). They were 9 percent more likely to report conflict about their loved one frequently missing appointments with their mental health provider (30 percent compared to 21 percent) than caregivers who felt involved in care.

Caregivers who felt involved in care were 11 percent more likely to report their loved one's independence or lack of independence as a source of conflict than those who did not feel involved in care (60 percent compared to 49 percent).

The importance of supporting independence

Providers should discuss expectations and goals for independence as part of care. Providers can explore specific challenges the caregiver is experiencing in terms of independence, including whether the caregiver wants the person they care for to be more independent or whether they are concerned about what their loved one's independence may mean for their stability in recovery. Reducing conflicts in care increases social support between caregivers and their loved ones. Exploring and mediating challenges that serve as sources of conflict is a vital part of collaborative treatment among the provider, the caregiver, and the person receiving care.

Providers can explore what living independently looks like for the person receiving care, including their respective employment, housing, and intimate partner goals. Medication prescribers should explore whether medications interfere with functioning and independence goals, if medication side effects are a barrier to achieving goals, whether a new medication option is needed, or whether different treatment modalities such as prescribing long-acting injectables may reduce the burden of daily medications.

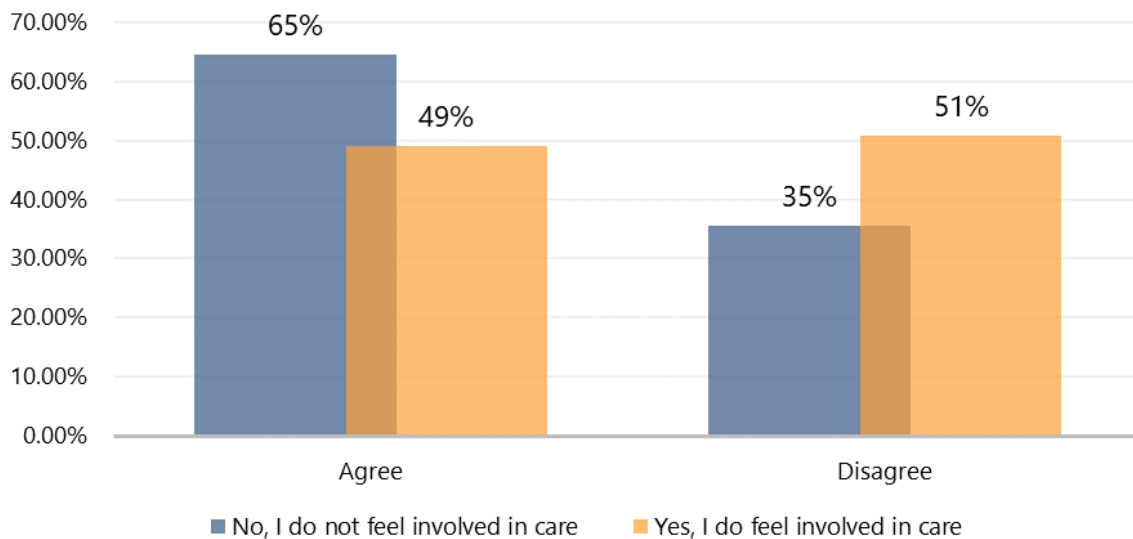
Caregiver Involvement and Hope for Recovery

All caregiver respondents to the survey were asked to what degree they agreed with the statements, "I feel hopeful that my family member can live independently," and "I feel hopeful that my family member will get better."

Over half (56 percent) of all caregiver respondents to the survey agreed that they felt hopeful that their loved one could live independently. However, the responses to this statement differed based on whether a caregiver reported that they felt involved in care. 64 percent of caregivers who did not feel involved in their loved one's care agreed that they were hopeful that their loved one could live independently, compared to 49 percent among caregivers who did feel they were involved in care.

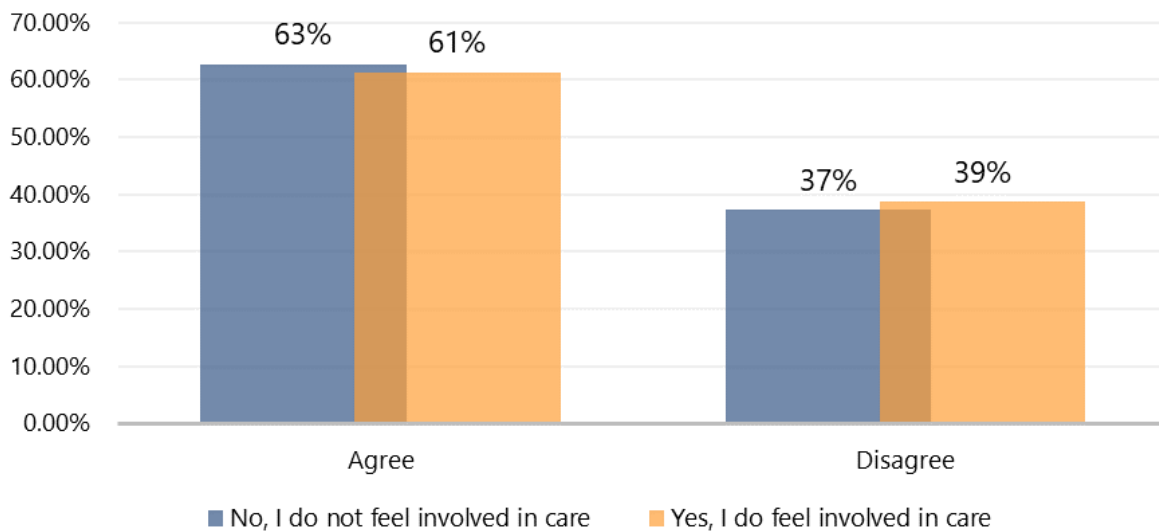
Caregivers who reported that they did not feel involved in care may have expressed more hope for their loved one living independently because their loved one may already be managing their care on their own.

I Feel Hopeful That My Family Member Can Live Independently



Finally, the majority (62 percent) of caregivers agreed that they were hopeful that their family member would get better. Whether a caregiver felt involved in care also did not significantly affect hope for recovery. 63 percent of caregivers who did not feel involved in care and 61 percent of those who did expressed hope that their family member would get better.

I Feel Hopeful That My Family Member Will Get Better



Despite conflict and distress reported by caregivers in providing care, and regardless of whether caregivers felt involved in their loved one's care, caregivers continued to feel hopeful for their loved one's recovery.

Effective caregiver engagement reduces conflicts and distress that contribute to the strain of caregiving. It improves recovery, continuity of care, and interpersonal dynamics between the caregiver and the person for whom they are caring. Building comprehensive and inclusive relationships among providers, clients, and caregivers will result in whole family care and improved treatment outcomes. Beyond improving engagement, systemic changes must be made to simplify health care systems and ensure greater continuity of care.

Caregiving can be incredibly difficult, and it is important for caregivers to take care of their own mental health as well. For more resources and supports for family caregivers and their loved ones, visit www.mhanational.org/caregivers.