ICAN3 SURVEY: LIFE OF A SANDWICH GENERATION CAREGIVER

Prepared for The Alzheimer's Foundation of America (AFA) and sponsored by Forest Pharmaceuticals, Inc.

Presented by

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Public Relations Research Team

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Background & Objectives

- **The Alzheimer's Foundation of America (AFA) and sponsored by Forest Pharmaceuticals, Inc. commissioned Harris Interactive to conduct a survey among 599 U.S. adults ages 18+ who**
  - Are the parent or legal guardian of a child/children under the age of 21 who are currently living in the same household or have lived in the same household in the past year; and,
  - Are also somewhat or very involved in the care and the treatment decisions of a patient with Alzheimer’s disease.
- **Key objectives of this study were to:**
  - Examine caregiver attitudes and perceptions toward their responsibilities;
  - Determine the level of difficulty in caring for both a patient with Alzheimer's disease and the children in their household;
  - Assess the amount of support caregivers receive;
  - Measure the impact that care giving has had on their lives; and,
  - Examine reasons for a delay in diagnosis.
- **Results from this study are intended for public release.**

Sample & Methodology

- **The national sample consists of 559 U.S. adults ages 18+ who**
  - Are the parent or legal guardian of a child/children under the age of 21 who are currently living in the same household or have lived in the same household in past year; and,
  - Are also somewhat or very involved in the care and the treatment decisions of a patient with Alzheimer's disease.
- **Data are weighted to be representative of this population of adults.**
- **The study was conducted online from December 12-27, 2007.**

Report Structure

- **In reviewing this report, please note that:**
  - Percentages may not add up to 100% due to rounding, the acceptance of multiple responses, or the exclusion of any “not sure” or “decline to answer” responses.
  - An asterisk (*) signifies a value of less than one-half percent. A dash (-) represents a value of zero.
  - Throughout the report,
    - The term “sandwich caregiver” or “caregiver” is used to refer to the national sample of adults who are caring for an Alzheimer’s patient and children in their household.
    - The term “pre-teens” is used to refer to the children of caregivers ages 8 – 12.
    - The term “teens” is used to refer to the children of caregivers ages 13 – 17.
    - The term “young adults” is used to refer to the children of caregivers ages 18 – 21.

Executive Summary

Executive Summary: Caregiver Pride

Most Caregivers Are Proud of Their Role And See Some Benefits In It

- Most caregivers have positive and self-affirming attitudes about their responsibilities. A majority derive a sense of accomplishment from their duties and over half have even grown from the experience. Most also rate themselves highly with regard to caring for their children, the patient, and balancing the care they provide to both. Moreover, most sandwich caregivers know their families are grateful for what they do.
  - More than 4 in 5 caregivers (84%) are proud of themselves for caring for two generations of loved ones.
  - Most give themselves good grades for the level of care they provide
    - ✓ The children in their household – A*;
    - ✓ The patient with Alzheimer's disease – B*; and,
    - ✓ Their ability to balance the care of both the patient and the children – B*.
  - About 3 in 5 caregivers (61%) say their family members often express gratitude for the care they provide.
  - A large majority of caregivers (94%) say there have been some positive results arising from their duties, including:
    - ✓ Knowing the patient they care for is receiving the best care possible (58%),
    - ✓ Being a stronger person (55%); and,
    - ✓ Having a better appreciation for their family (55%).
  - When it comes to the level of care sandwich caregivers provide…
    - ✓ 93% say they do an *excellent* (63%) or *good* (29%) job of taking care of their children.
    - ✓ 79% say they do an *excellent* (34%) or *good* (45%) job of caring for the patient.
    - ✓ 74% say they do an *excellent* (23%) or *good* (51%) job of balancing caring for both the children in their household and the patient with Alzheimer's disease.

** Caregivers were asked to rate the care they provide to the patient, the children and how they balance the care for both by giving themselves a letter grade of "A Excellent" to "F Terrible". Each grade from A through F was assigned a number – A=5, B=4, C=3, D=2, F=1 – from which we calculated a mean and then converted into a letter grade.*

Executive Summary: Importance of Support Network

Most Caregivers Say Family Support Helps Them Provide High Quality Care

- Although most sandwich caregivers think they are doing a good job, most have some form of help or support. Much of this assistance comes from their family. The caregiver's spouse or significant other as well as the spouse or significant other of the patient with Alzheimer's disease in particular, have provided a good deal of help. About one-third of caregivers also say that even more support from their family would ease the burden of caregiving.
  - Of the majority of caregivers (74%) who *highly* rate their ability to care for the patient and their children, most (82%) attribute their success to support they receive from their family.
    - ✓ 50% credit their spouse or significant other;
    - ✓ 55% credit the support of other family members (not including spouse/significant other);
    - ✓ 36% credit the support of their children; and,
    - ✓ 24% credit the support of the spouse or significant other of the patient.
  - Most caregivers with a spouse or significant other who is not the patient say their partner
    - ✓ Has taken on more responsibility for household tasks (56%), with 29% taking on *a lot* more responsibility.
    - ✓ Is involved in the care of the patient (77%), with a quarter (26%) being *very* involved.
  - Of caregivers with a spouse or significant other, nearly all (96%) say their partner is involved in caring for the children with nearly two-thirds (62%) being *very* involved.
  - Also, most caregivers who care for a patient with a spouse or significant other say the patient's spouse is…
    - ✓ Involved in the care of the children (66%), with a quarter (22%) being *very* involved.
    - ✓ Involved in the care of the patient (92%), with a quarter (59%) being *very* involved.
  - About one-third of caregivers (35%) say that more support from their family would make it easier for them to care for both the patient with Alzheimer's disease and the children in their household. Other items that would help are:
    - ✓ More money (51%); and,
    - ✓ More time (47%).

Executive Summary: Role Of Children In Caregiving

Many Children Play A Role In Caring For The Alzheimer's Patient

- Many caregivers also report assistance from their children. Not only do about half of caregivers say their children have taken on at least some more responsibility for household tasks, most say their children are also at least somewhat involved in caring for the patient – most often by visiting and entertaining them. However, among children who are involved in patient care, a number of teens and young adults may be taking on more significant tasks.
  - About half of caregivers say their children have assumed more responsibility for household tasks:
    - ✓ 52% of young adults have assumed *a lot* more (16%) or *a little* more responsibility (36%).
    - ✓ 46% of teens have assumed *a lot* more (20%) or *a little* more responsibility (26%).
    - ✓ 49% of pre-teens have assumed *a lot* more (4%) or *a little* more responsibility (45%).
  - Additionally, more than 3 in 5 caregivers say their children are involved in caring for the patient:
    - ✓ 59% of young adults are *very* involved (5%) or *somewhat* involved (54%).
    - ✓ 59% of teens are *very* involved (11%) or *somewhat* involved (48%).
    - ✓ 63% of pre-teens are *very* involved (12%) or *somewhat* involved (50%).
  - Among caregivers whose children are somewhat more involved in the patient's care, say young adults and teens:
    - ✓ Assist with the patient's doctors visits (32% among young adults, 8% among teens, 4% among pre-teens*)
    - ✓ Manage the patient's daily needs (29% among young adults, 21% among teens, 11% among pre-teens*)
    - ✓ Assist with transporting the patient (42% among young adults, 18% among teens, 5% among pre-teens*)
  - But most caregivers whose children are involved in the patient's care say their children are:
    - ✓ Visiting the patient (71% among young adults, 83% among teens, 88% among pre-teens*); and,
    - ✓ Entertaining the patient (63% among young adults, 72% among teens, 87% among pre-teens*).

** Please use caution when interpreting results due to small base size.*
Base: Pre-teens who are involved in patient's care (n= 80)

Executive Summary: Challenges In Caregiving

More Caregivers Say It Is Hard To Care For The Needs Of The Patient Than For The Needs Of Their Children

- Despite the assistance many caregivers receive from their partner and their children, most say that caring for both their children and a patient with Alzheimer's disease has been one of the hardest things they have ever had to do. Upon closer examination, it becomes apparent that the level of difficulty in caring for a patient with Alzheimer's disease and caring for children differs greatly. Caregivers are more likely to find the physical, emotional, and financial needs of the Alzheimer's patient more draining than the comparable needs for their children.
    - Most sandwich caregivers (68%) agree that caring for both a patient with Alzheimer's disease and for their children has been the biggest challenge they have faced in their life.
    - Overall, more caregivers say it is difficult to care for the patient with Alzheimer's disease than their children in terms of…
        - ✓ Providing for their physical needs: Patient (73%), Child(ren) (21%);
        - ✓ Providing for their emotional needs: Patient (78%), Child(ren) (41%);
        - ✓ Getting others to help with needs: Patient (73%), Child(ren) (37%); and,
        - ✓ Managing financial aspect of caring: Patient (72%), Child(ren) (56%).
    - Moreover, a majority of caregivers (70%) say they would like more help caring for the Alzheimer's patient, as opposed to only a minority (33%) who want more help caring for their children.

Executive Summary: Negative Emotional Impact Of Caregiving

Responsibilities Negatively Impact Many Caregivers' Emotional Health

- Most caregivers also experience a negative emotional toll as a result of their responsibilities. In addition to feeling at least a fair amount of stress, most caregivers have at some point felt frustrated, guilty, angry or emotionally drained. This may explain why they feel some resentment toward their family members and even the patient with Alzheimer's disease.
    - Most caregivers typically feel at least a fair amount of stress each day (55%) and 15% experience *a lot* of stress on a daily basis.
    - Moreover, 70% agree that other people have no idea the amount of stress they are under.
    - Due to their sandwich caregiving responsibilities, many caregivers feel frustrated (65%), guilty (32%) or angry (31%).
    - Many caregivers feel resentment toward other family members (41%), their spouse/significant other (16%) and even the patient with Alzheimer's disease for whom they care (22%).
    - Most caregivers agree that they are emotionally (70%) and physically (62%) exhausted from the experience.
        - ✓ Over half (58%) of caregivers say they are *both* emotionally and physically exhausted from their care giving tasks.
    - The majority of caregivers (75%) agree that they feel they are being pulled in many different directions.

Executive Summary: Negative Impact On Caregiver's Daily Life

Caregiving Duties Have Negatively Affected The Personal, Social, and Professional Lives of Many Caregivers

- The daily lives of many caregivers have also been negatively affected, due to their caregiving responsibilities. Most say their professional lives have been adversely affected in some way, and some caregivers may even be making personal sacrifices in their social and personal lives.
  - Due to their sandwich caregiving responsibilities, in the past year caregivers have had to:
    - ✓ Skip a social obligation (47%);
    - ✓ Skip going to the gym or doing physical exercise (38%); and,
    - ✓ Cancel a vacation or trip (29%).
  - In the past year, about one-third (33%) have even been less physically intimate with their spouse or significant other.
  - About two-thirds of employed caregivers (64%) also say their work life has been negatively affected in some way:
    - ✓ About one-third (35%) have had to take time/days off from work;
    - ✓ About one-quarter (24%) say they have difficulty concentrating on tasks; and,
    - ✓ About one-fifth (17%) have reduced their hours or switched to flextime.

Executive Summary: Delay in Diagnosis

Lack of Knowledge and Experience May Have Led to Delayed Diagnosis

- Though a substantial number of caregivers played a role that led to the patient's diagnosis, most caregivers say the patient with Alzheimer's disease experienced a delay in diagnosis. Among those who experienced a delay, about half attribute this delay to lack of familiarity with symptoms and insufficient knowledge about Alzheimer's disease.
  - Typically, caregivers say that the patient for whom they care experienced symptoms for 2 years before being diagnosed.
  - About 4 in 5 patients (81%) say the diagnosis of Alzheimer's was delayed for a year or more.
    - ✓ About one-quarter (28%) said diagnosis was delayed for more than 4 years.
  - Caregivers who say that the patient for whom they care was exhibiting symptoms for a year or more before diagnosis attribute the delay to:
    - ✓ Thinking the symptoms were just a natural part of getting older (48%);
    - ✓ Not wanting to face the possibility that something could be wrong (46%); and,
    - ✓ Not knowing enough about Alzheimer's disease (43%).
  - About 2 in 5 caregivers (38%) say the patient was diagnosed after the caregiver noticed symptoms and brought them to the physician.
  - Caregivers who brought the patient to see a physician and seek help were prompted to do so because the patient was exhibiting symptoms such as:
    - ✓ Forgetfulness or memory loss (83%);
    - ✓ Disorientation to time/place, wandering (63%); and,
    - ✓ Misplacing things (59%).

Detailed Findings

- **Caregiver Pride**
- Importance of Support Networks
- Role of Children in Caregiving
- Challenges In Caregiving
- Negative Emotional Impact Of Caregiving
- Negative Impact On Caregiver’s Daily Life
- Delay in Diagnosis
- Medication

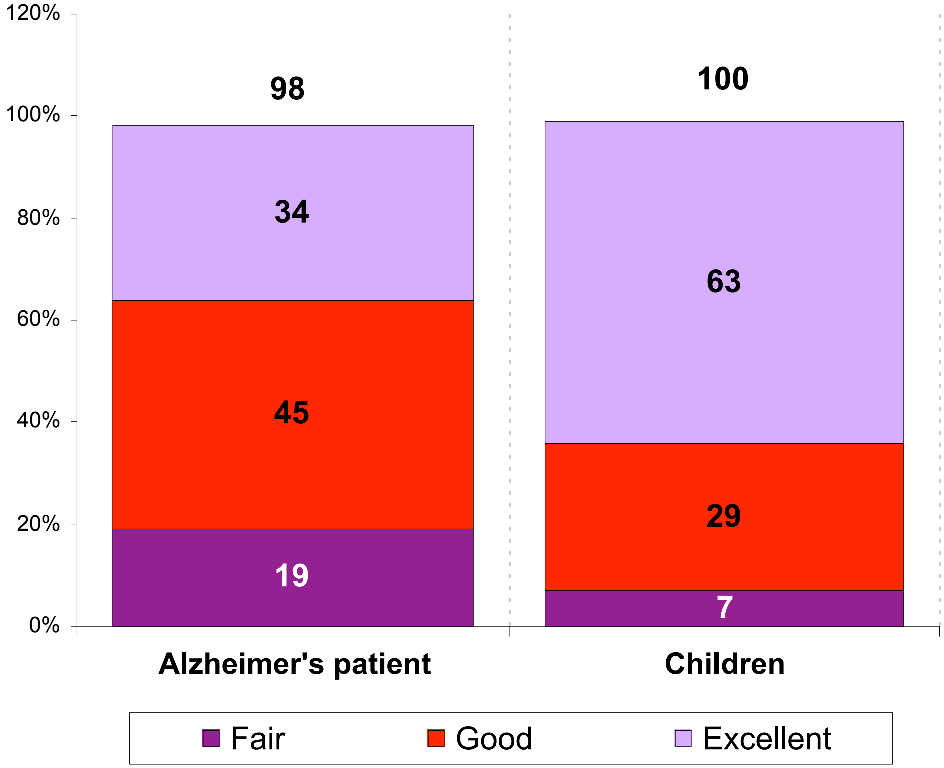
The vast majority of caregivers positively rate their ability to care for the patient with Alzheimer's disease and their ability to care for the children in their household.

How Caregivers Rate Their Caregiving Abilities

Report Card

B Care of Patient

A Care of Children



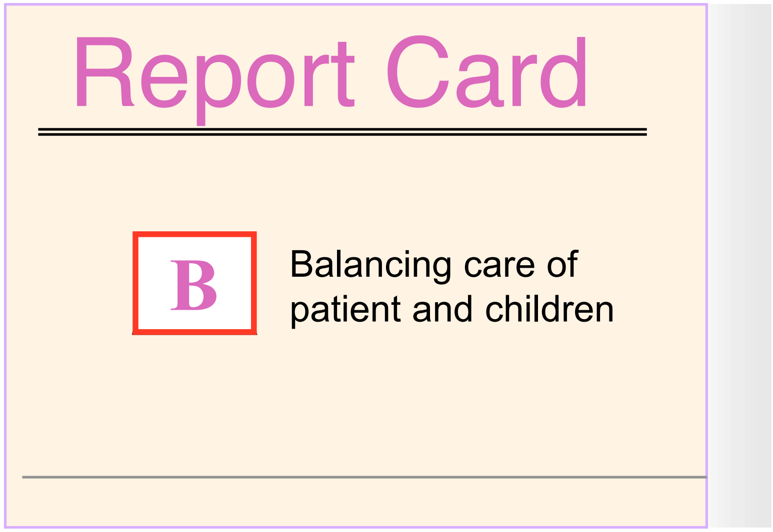
Q800: Overall, how would you rate the care you provide to each of the following?

Base: All respondents (n=559)

** Caregivers were asked to rate the care they provide to the patient, the children and how they balance the care for both by giving themselves a letter grade of "A Excellent" to "F Terrible". Each grade from A through F was assigned a number – A=5, B=4, C=3, D=2, F=1 – from which we calculated a mean and then converted into a letter grade.*

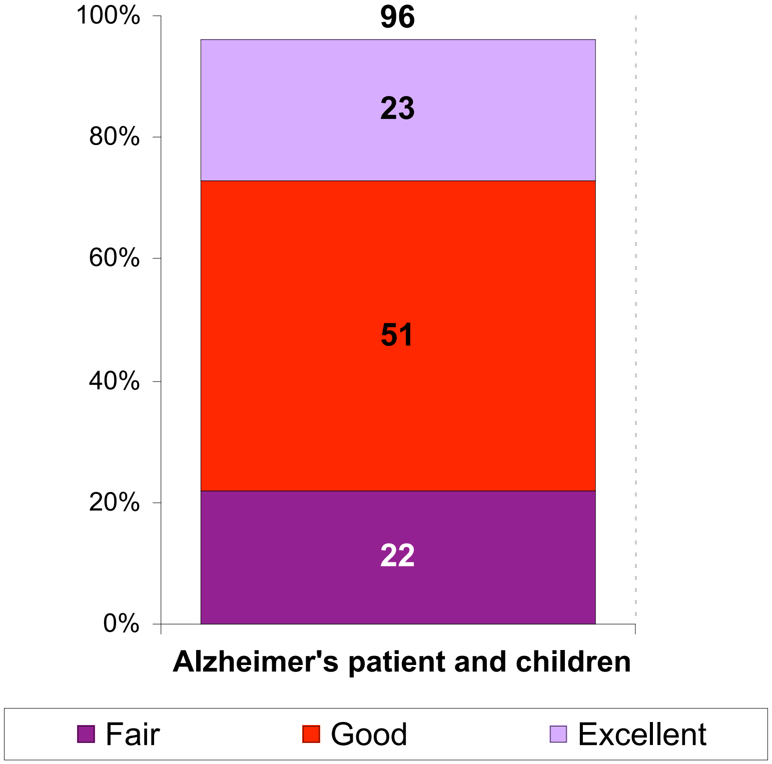
Nearly all caregivers positively rate their ability to balance the care they provide for the patient with Alzheimer's disease and the children in their household.

How Caregivers Rate Their Caregiving Abilities



Report Card

B Balancing care of patient and children



Q802: Overall, how would you rate your ability to balance providing care for both the patient with Alzheimer's disease and the child(ren) in your household?

Base: All respondents (n=559)

** Caregivers were asked to rate the care they provide to the patient, the children and how they balance the care for both by giving themselves a letter grade of "A Excellent" to "F Terrible". Each grade from A through F was assigned a number – A=5, B=4, C=3, D=2, F=1 – from which we calculated a mean and then converted into a letter grade.*

The majority of caregivers feel a sense of pride in what they do and know they have their family's gratitude.

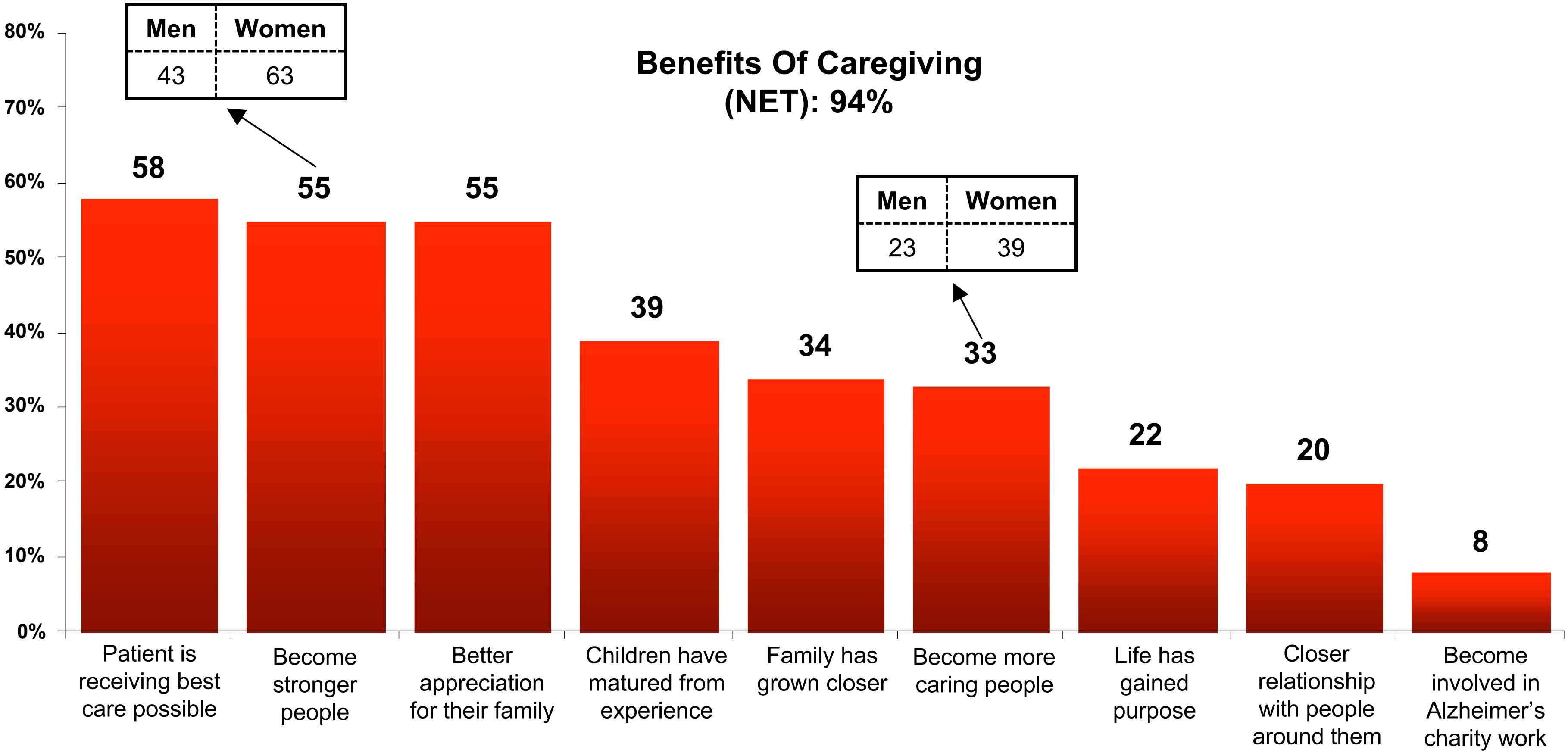
Benefits Of Sandwich Caregiving

Q836: Please tell us how much you agree or disagree with each of the following statements as they relate to caring for both the person with Alzheimer's disease and your children?

Base: All respondents (n=559)

Nearly all sandwich caregivers think there are benefits to what they do – the top benefits include knowing the patient is receiving the best care possible, becoming a stronger person, and having a better appreciation for their family.

Positive Aspects Of Sandwich Caregiving



Q1035: What, if any, have been the benefits or positive results of caring for both the person with Alzheimer's disease and your children? Please select all that apply.
Base: All respondents (n=559)

** Percentages not shown: Other: 6%, None 6%*

Detailed Findings

- Caregiver Pride
- **Importance of Support Networks**
- Role of Children in Caregiving
- Challenges In Caregiving
- Negative Emotional Impact Of Caregiving
- Negative Impact On Caregiver's Daily Life
- Delay in Diagnosis
- Medication

The majority of caregivers who say they do a good job of sandwich caregiving, say it is the support from their family that has helped them succeed.

Forms Of Help And/Or Support For Caregivers

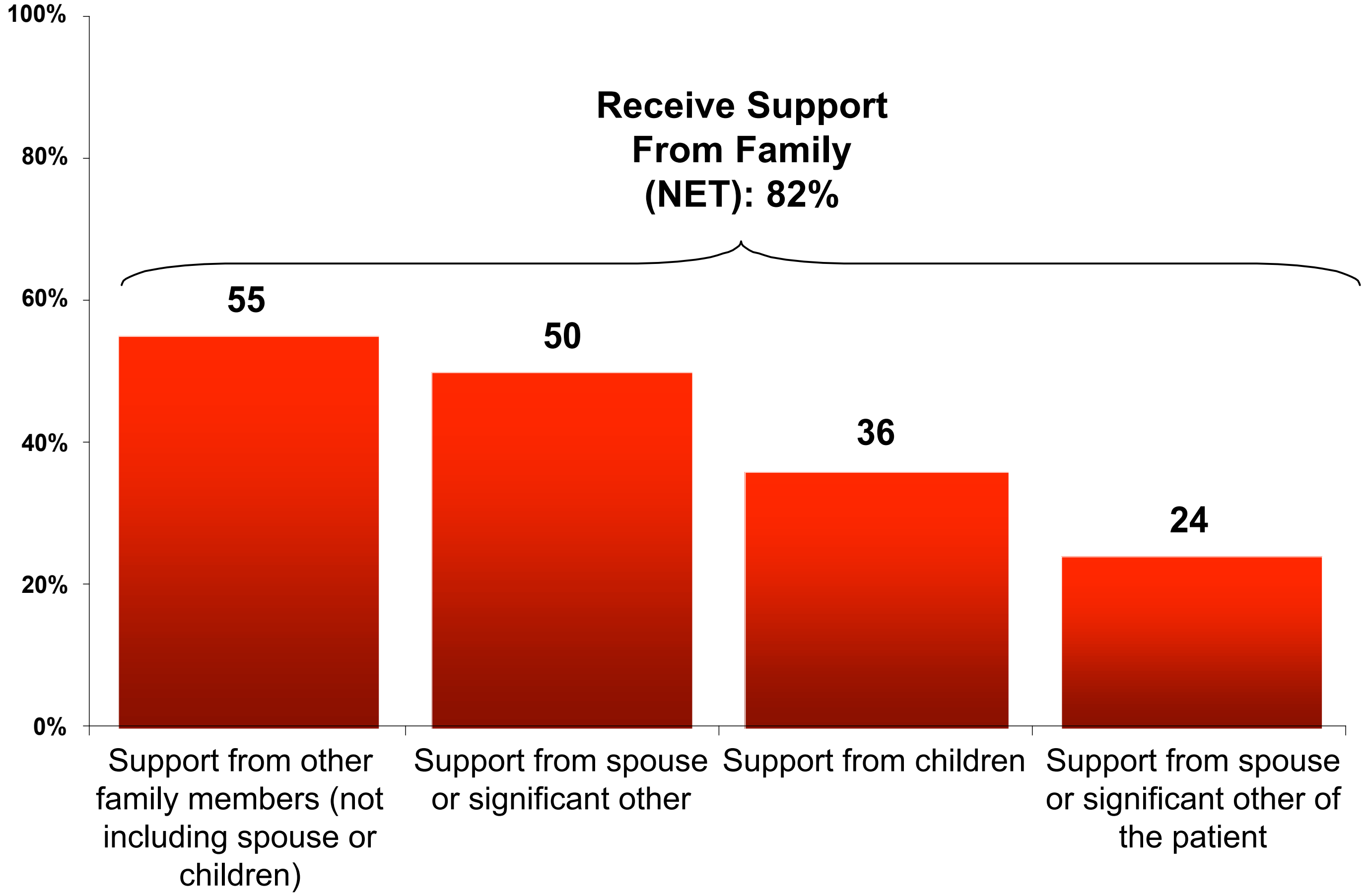
	Caregivers Who Do An Excellent/ Good Job Of Caring For Alzheimer's Patient And Child
Support From Family (NET)	82
Support from other family members (not including spouse or children)	55
Support from spouse or significant other	50
Support from children	36
Support from spouse or significant other of the patient	24
A good relationship with the patient with Alzheimer's disease	54
Being well-informed about Alzheimer's disease	47
Support from doctor or other healthcare professional	39
Support from friends	34
Having sufficient time	32
Having enough money	32
Easy access to transportation	19
Support from neighbors	16

	Caregivers Who Do An Excellent/Good Job Of Caring For Alzheimer's Patient And Child
Few demands from work	13
Support from co-workers/employer	13
Support from clergy or faith-based group	13
Previous experience in care giving for a patient with Alzheimer's disease	13
In home help (babysitter or home health aide)	11
Help From Support Groups (NET)	11
Help from support groups specifically for caregivers of two generations	8
Help from a support group for my children	4
Having information tailored to my needs as a caregiver of two generations	10
Support from an Alzheimer's agency	9
Support from children's school	4
Other	4
Nothing has helped me-I rely solely on myself	*

Q805: What has helped you do an excellent/a good job of balancing the care of the patient with Alzheimer's disease and the care of the children in your household? *Base: Respondents who are doing an excellent/good job of balancing the care of both the patient with Alzheimer's disease and children in household (n=396)*

Half of the support that caregivers get from their family comes from their spouse.

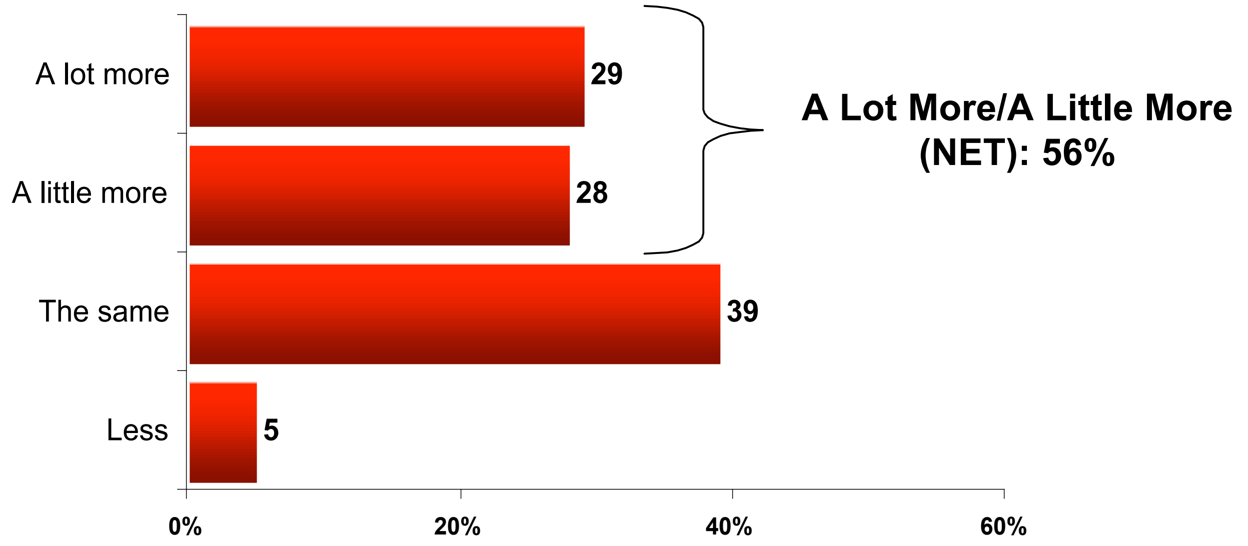
Sources Of Family Help And/Or Support For Caregivers



Q805: What has helped you do an excellent/a good job of balancing the care of the patient with Alzheimer's disease and the care of the children in your household? *Base: Respondents who are doing an excellent/good job of balancing the care of both the patient with Alzheimer's disease and children in household (n=396)*

Most caregivers say that their spouse or significant other has taken on at least a little more responsibility for household tasks since they have become a sandwich caregiver.

Amount Of Responsibility Caregiver's Spouse Has Taken On For Household Tasks



A Lot More/A Little More (NET): 56%

Q901: Since starting to care for the patient with Alzheimer's disease, did the following people assume less, the same , a little more or a lot more responsibility for household tasks?
Base: Respondents whose spouse or significant other is not an Alzheimer's patient (n=459)

The Alzheimer's patient's spouse or significant other is more involved in caring for the Alzheimer's patient, while the caregiver's spouse or significant other is more involved in caring for the children.

Level of Involvement In Caring For Child And Patient – Patient's Spouse vs. Caregiver's Spouse

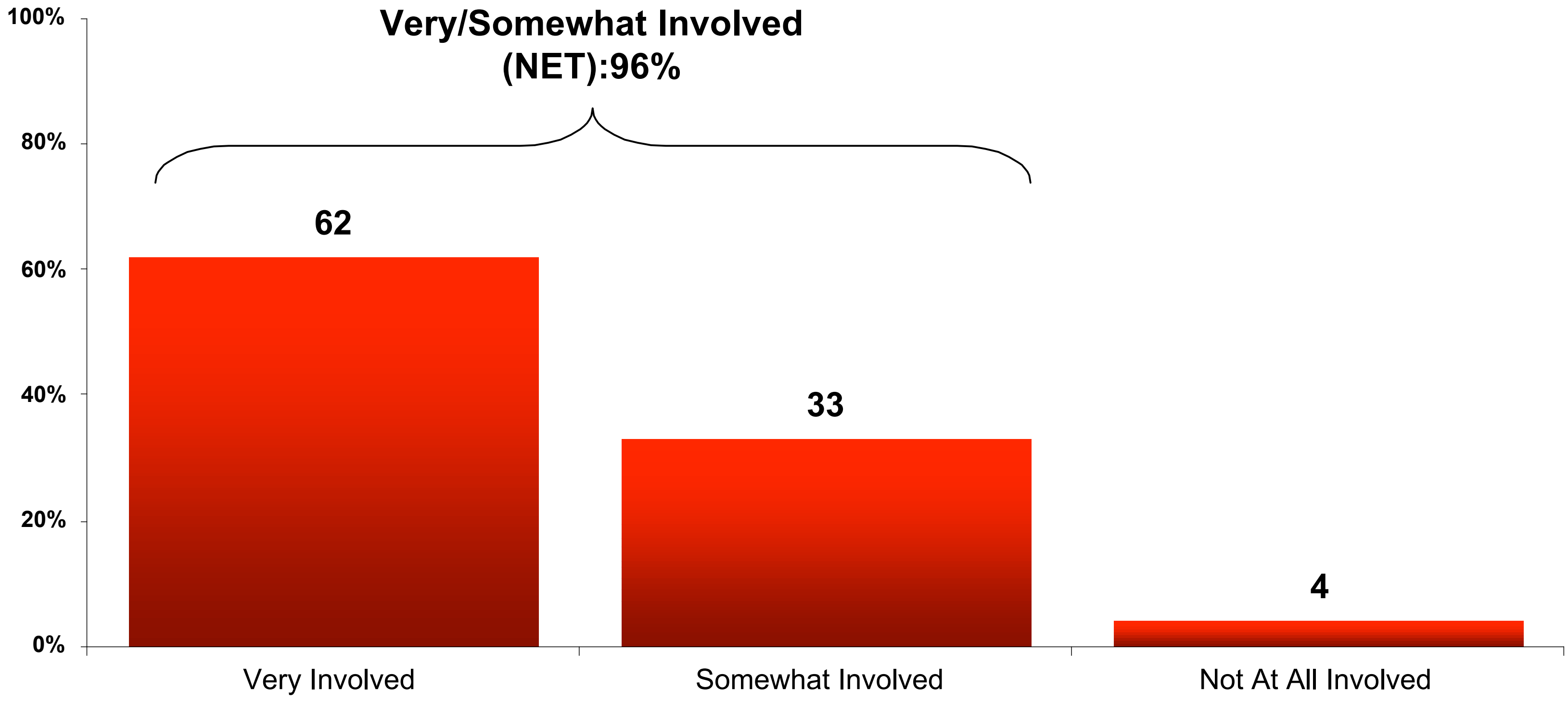
Report Card

CARE OF CHILD	Caregiver's Spouse	Patient's Spouse
Very/Somewhat Involved (NET) %	96	66
Very involved	62	22
Somewhat Involved	33	44
Not at all involved	4	34
CARE OF PATIENT	**Caregiver's Spouse**	**Patient's Spouse**
Very/Somewhat Involved (NET) %	77	92
Very involved	26	59
Somewhat Involved	51	34
Not at all involved	23	8

Q905: How involved are each of the following in caring for the children in your household?
Base: Respondents with spouse or significant other (n=466)
Base: Respondents whose Alzheimer's patient has a spouse or significant other (n=248)
Q910: How involved are each of the following in caring for the patient with Alzheimer's disease?
Base: Respondents whose spouse or significant other is not the Alzheimer patient (n=459)
Base: Respondents whose Alzheimer's patient has a spouse or significant other (n=248)

The majority of caregivers say their spouse or significant other is very involved in the care of the children.

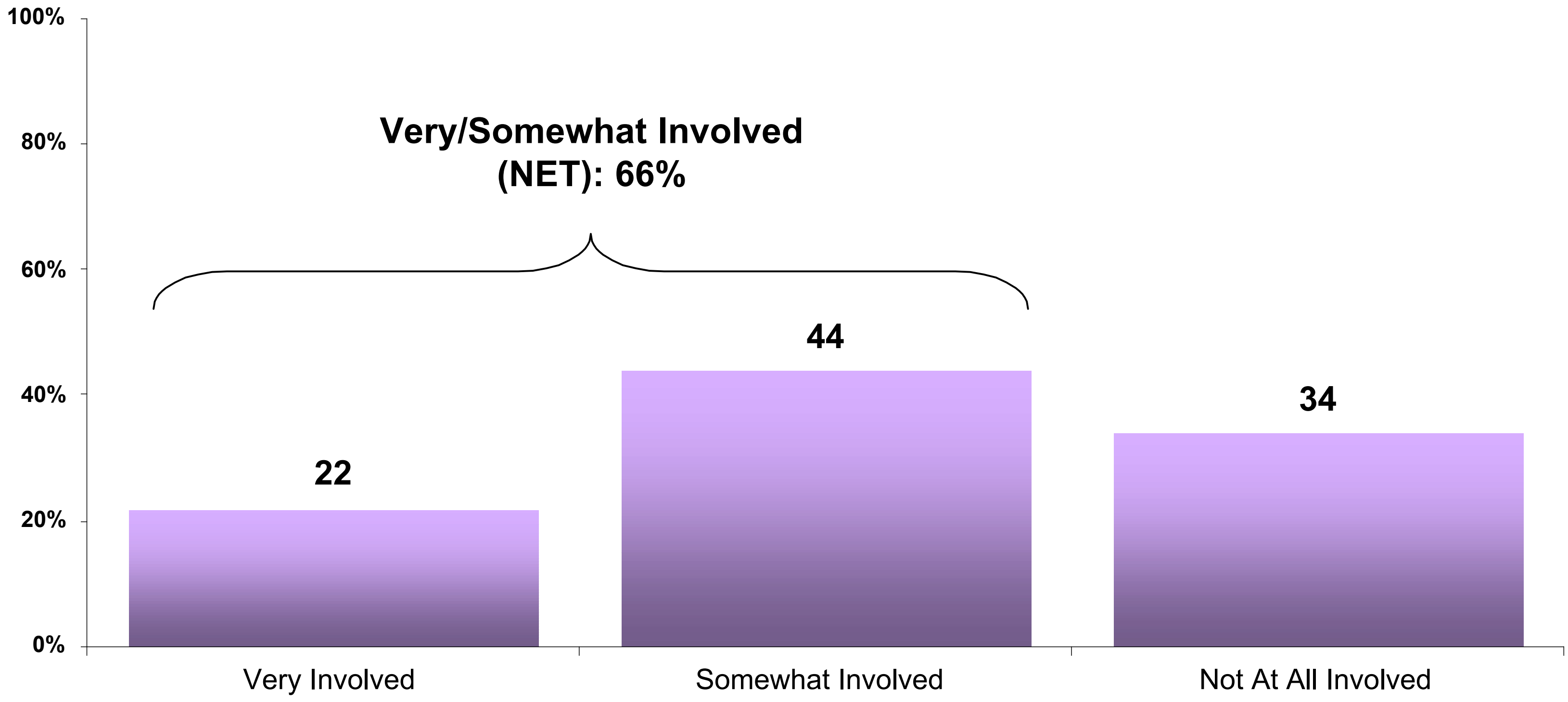
Involvement Of Caregiver's Spouse Or Significant Other In Care Of Children



Q905: How involved are each of the following in caring for the child(ren) in your household?
Base: Respondents with a spouse or significant other (n=466)

While most of the spouses or significant others of the Alzheimer's patients are involved in caring for the children, a large number are only somewhat involved in the care.

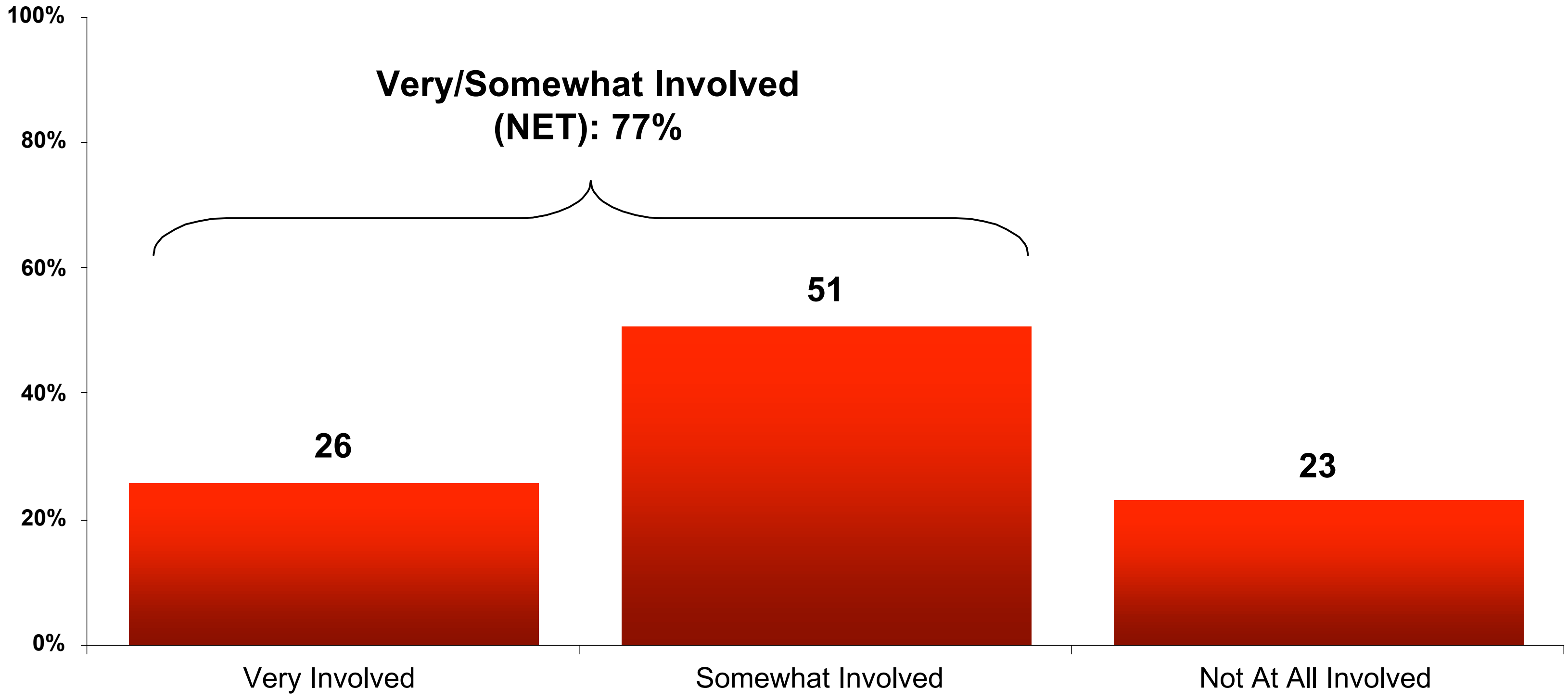
Involvement Of Alzheimer's Patient Spouse Or Significant Other In Care Of Children



Q905: How involved are each of the following in caring for the child(ren) in your household?
Base: Respondents whose Alzheimer's patient has a spouse or significant other (n=248)

While most of the spouses or significant others of caregivers are involved in caring for the Alzheimer's patient, most are only somewhat involved in the care.

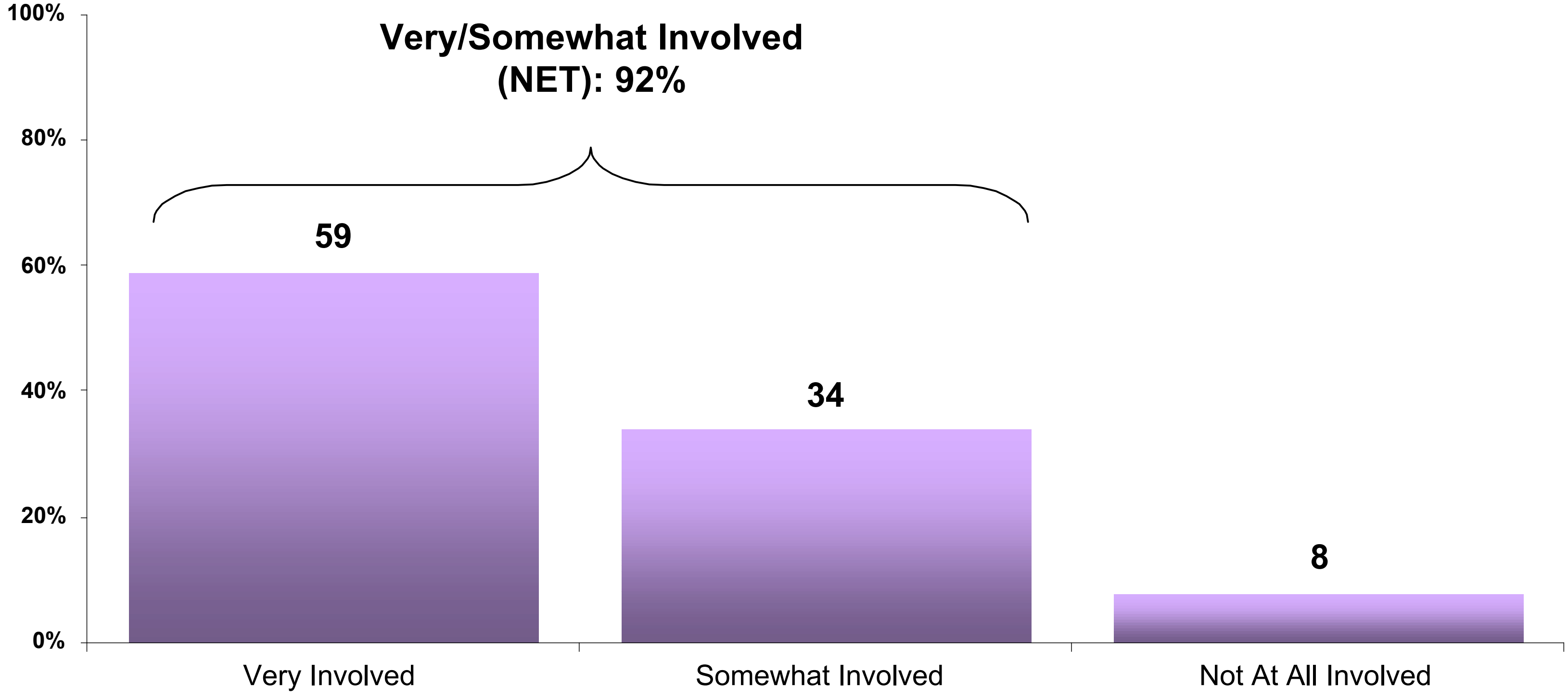
Involvement Of Caregiver's Spouse Or Significant Other In Care Of Patient



Q910: How involved are each of the following in caring for the Alzheimer's patient?
Base: Respondents whose spouse or significant other is not the Alzheimer's patient (n=459)

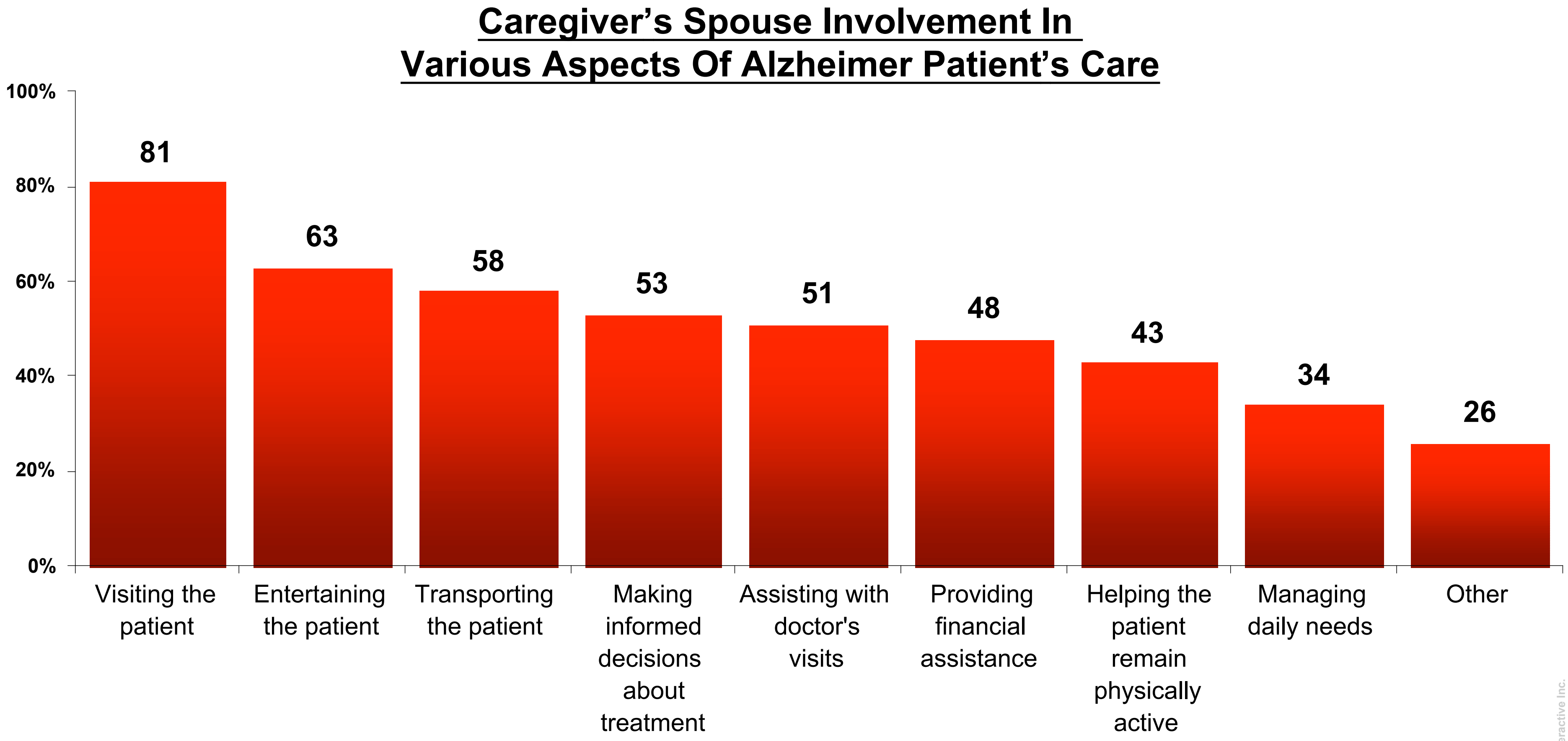
The vast majority of spouses or significant others of the Alzheimer's patient are involved in their care, and of those, most are very involved.

Involvement Of Alzheimer's Patient Spouse Or Significant Other In Care Of Patient



Q911: How involved are each of the following in caring for the Alzheimer's patient?
Base: Respondents whose Alzheimer's patient has a spouse or significant other (n=248)

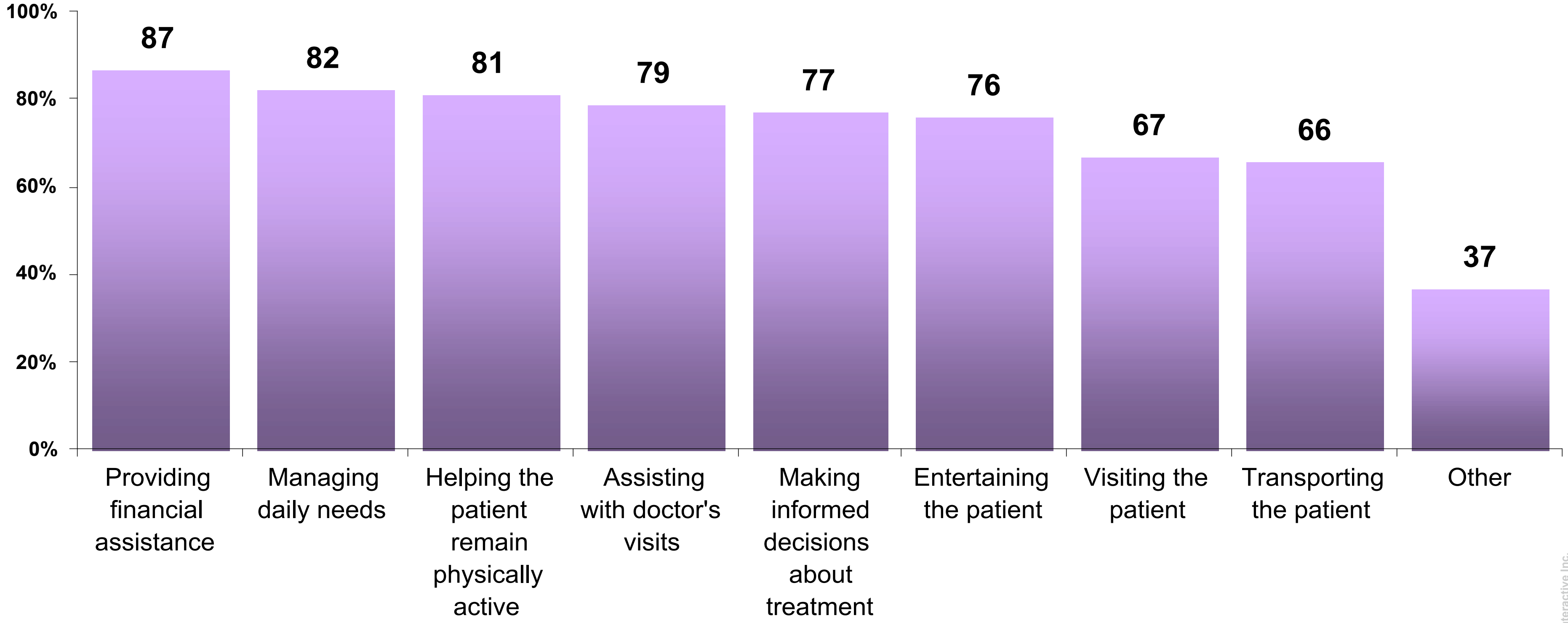
Among caregivers whose spouse or significant other is involved in the Alzheimer's patient's care, about half say their spouse is involved in treatment decisions and one-third say he/she helps with managing the patient's daily needs.



Q926: You indicated that the following people are involved in the care for the patient with Alzheimer's disease. Please indicate which aspects of care they are involved in?
Base: Respondents whose spouse or significant other is involved in Alzheimer patient's care (n=351)

Among patient’s whose spouse or significant other is involved in their care, most say that the patient’s spouse is involved in key aspects of care such as providing financial assistance and managing daily needs.

Alzheimer’s Patient’s Spouse Involvement In Various Aspects Of Alzheimer Patient’s Care



Q926: You indicated that the following people are involved in the care for the patient with Alzheimer’s disease. Please indicate which aspects of care they are involved in?

Base: Respondents whose Alzheimer patient’s spouse or significant other is involved in Alzheimer patient’s care (n=224)

About one-third of caregivers say more support from their family would ease their caregiving responsibilities.

Ways To Lessen The Burden Of Care Giving

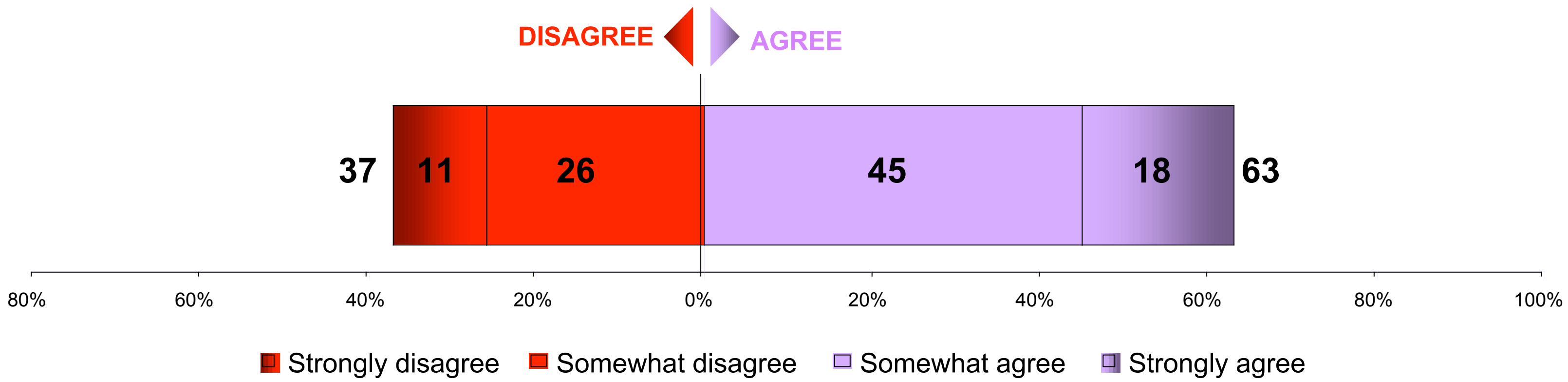
	Total %
More money	51
More time	47
More Support From Family (NET)	35
More support from other family members (not including spouse or children)	26
More support from my spouse/significant other	9
More support from my child(ren)	6
More support from the spouse or significant other of the patient	4
More experience in caring for a patient with Alzheimer's disease	24
Becoming well informed about Alzheimer's disease	22
In-home help (baby sitter for children, home health aide for patient)	21
Fewer demands from work	21
More support from doctor or healthcare professional	20
More information tailored to my needs as a caregiver of two generations	13

	Total %
More support from Alzheimer's agency (such as AFA or local group)	12
More Help From Support Groups (NET)	11
More help from support groups specifically for caregivers of two generations	9
More help from a support group for my child(ren)	3
Better access to transportation (public or otherwise)	7
A better relationship with the patient with Alzheimer's disease	5
More support from my child(ren)'s school	5
More support from friends	5
More support from clergy or faith-based group	3
More support from my co-workers/employer	2
More support from neighbors	2
Other	6
Nothing would make it easier for me	9

Q815: What would make it easier for you to care for both the patient with Alzheimer's disease and the child(ren)?
Base: All respondents (n=559)

Nearly two-thirds of sandwich caregivers would like more information on helping children cope when a family member or friend is diagnosed with Alzheimer's disease.

"I would like more information about how to help children cope when a family member or friend is diagnosed with Alzheimer's disease."



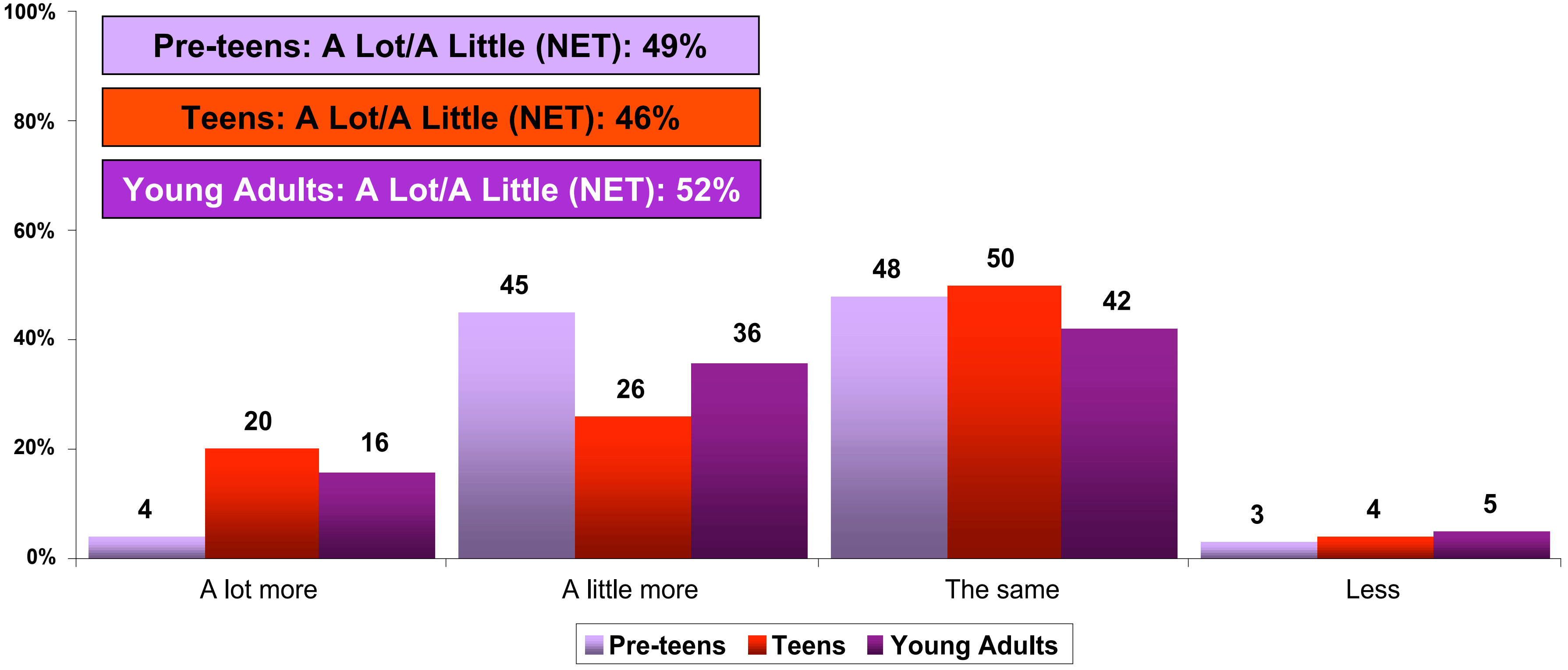
Q836: Please tell us how much you agree or disagree with each of the following statements as they relate to caring for both the person with Alzheimer's disease and your children?
Base: All respondents (n=559)

Detailed Findings

- Caregiver Pride
- Importance of Support Networks
- **Role of Children in Caregiving**
- Challenges In Caregiving
- Negative Emotional Impact Of Caregiving
- Negative Impact On Caregiver's Daily Life
- Delay in Diagnosis
- Medication

Among caregivers with children, about half say their children have taken on at least some more responsibility for household tasks, though slightly more so for teens and young adults.

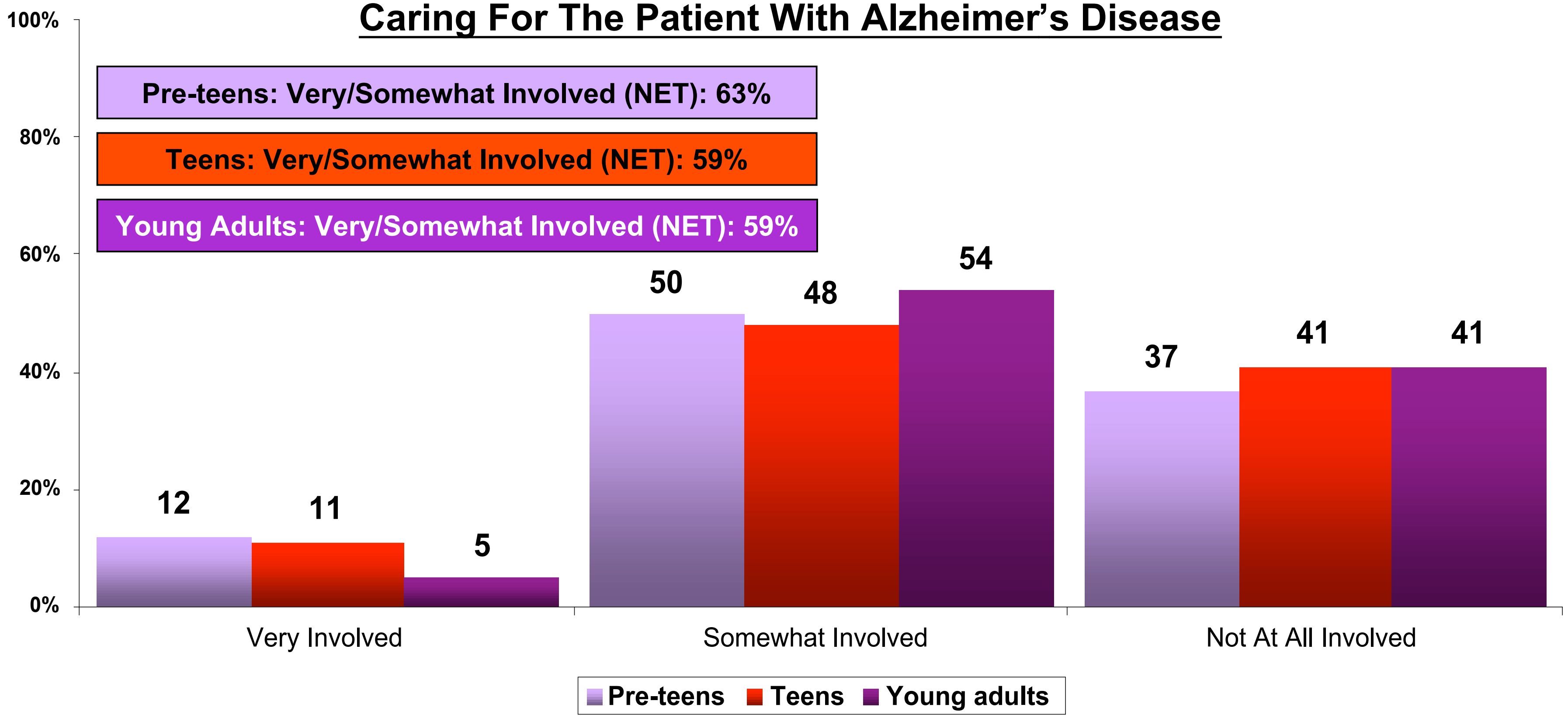
Children Have Taken On More Responsibility For Household Tasks



Q901: Since starting to care for the patient with Alzheimer's disease, did the following people assume less, the same , a little more or a lot more responsibility for household tasks?
Base: Respondents with children 8-12 (n=156), Respondents with children 13-17 (n=218), Respondents with children 18-21 (n=210)

Most caregivers with children say their children are at least somewhat involved in the Alzheimer's patient care, though few are very involved.

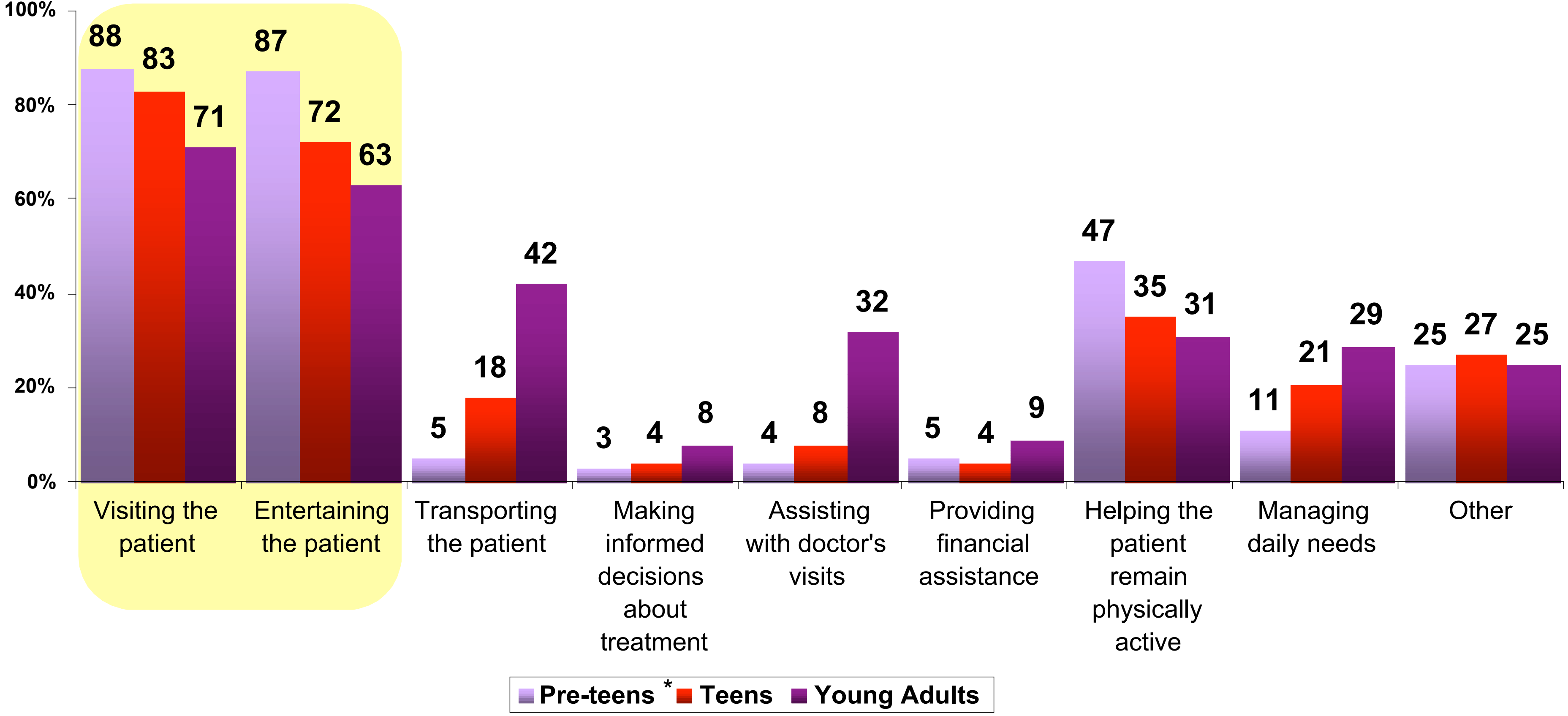
Children Are Involved In Caring For The Patient With Alzheimer's Disease



Q911: How involved are each of the following in caring for the patient with Alzheimer's disease?
Base: Respondents with children 8-12 (n=156), Respondents with children 13-17 (n=218), Respondents with children 18-21 (n=210)

Among caregivers with children who are involved in patient care, most say their children visit and entertain the patient.

Aspects Of Alzheimer's Patient's Care That Children Are Involved In

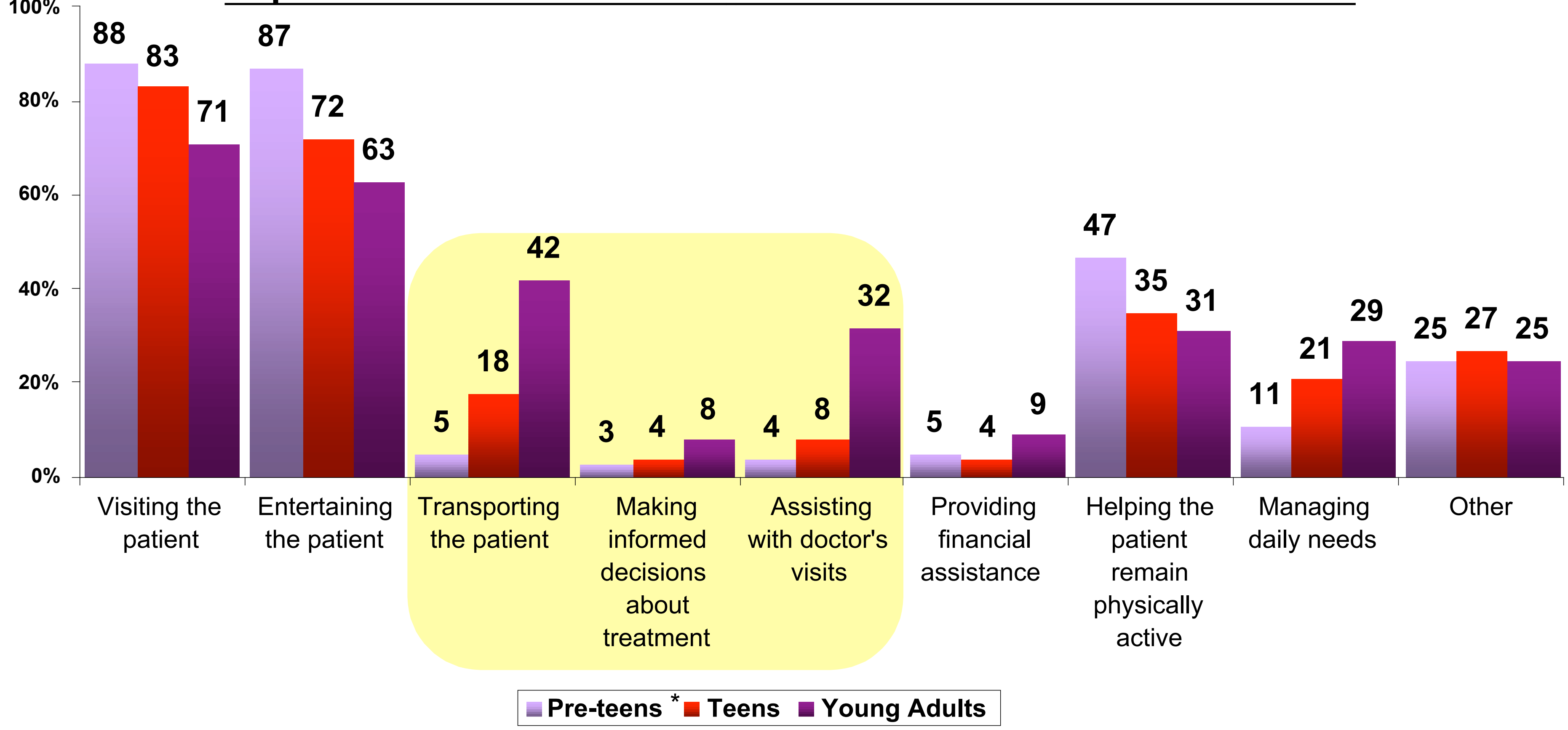


Q926: You indicated that the following people are involved in the care for the patient with Alzheimer's disease. Please indicate which aspects of care they are involved in?

Base: Respondents with children 8-12 who are involved in the care of the Alzheimer's patient (n=80), Respondents with children 13-17 who are involved in the care of the Alzheimer's patient (n=107), Respondents with children 18-21 who are involved in the care of the Alzheimer's patient (n=119)*

** Please use caution when interpreting results due to small base size.*

Among caregivers with children who are involved in patient care, about 2 in 5 say young adults help to transport the patient, while about one-third say they assist with doctor's visits – far fewer report pre-teens and teens doing so.



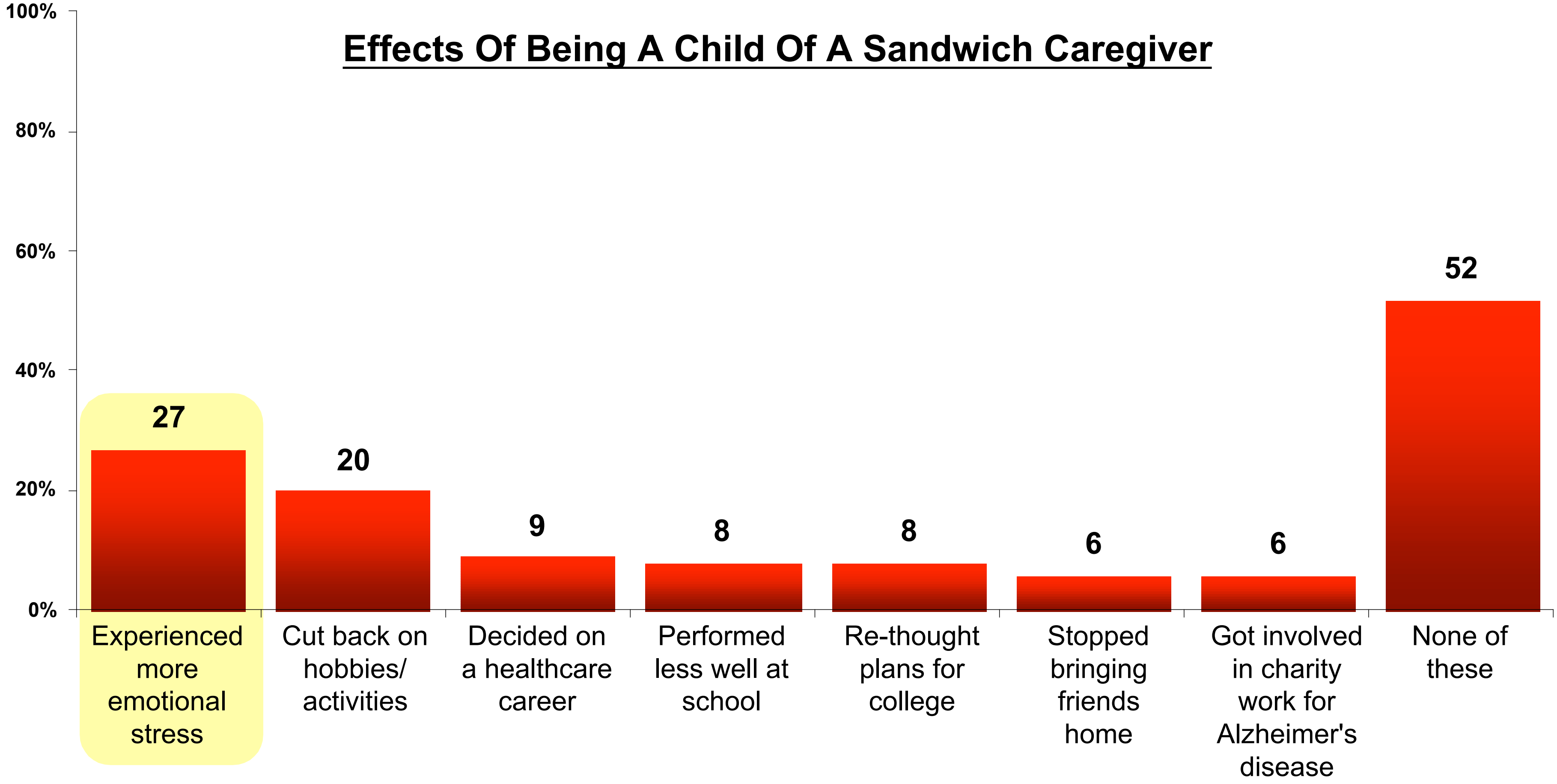
Aspects Of Alzheimer Patient's Care That Children Are Involved In

Q926: You indicated that the following people are involved in the care for the patient with Alzheimer's disease. Please indicate which aspects of care they are involved in?

Base: Respondents with children 8-12 who are involved in the care of the Alzheimer's patient (n=80), Respondents with children 13-17 who are involved in the care of the Alzheimer's patient (n=107), Respondents with children 18-21 who are involved in the care of the Alzheimer's patient (n=119)*

** Please use caution when interpreting results due to small base size.*

About one-quarter of caregivers say their child has experienced more emotional stress, due to being part of a household that is caring for a patient with Alzheimer's disease.



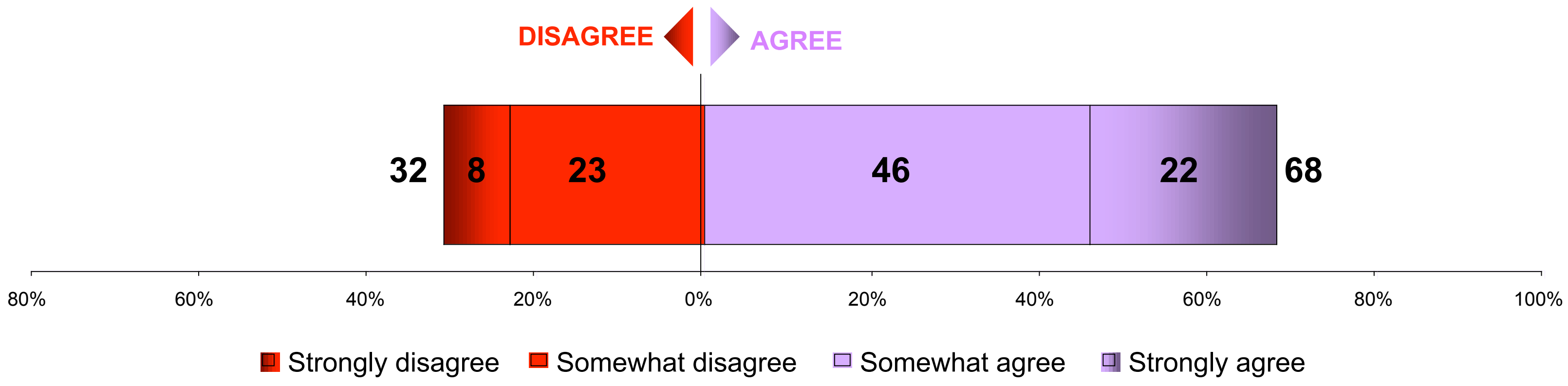
Q927: Have your child(ren) done any of the following as a result of being part of a household that is caring fora patient with Alzheimer's disease?
Base: All respondents (n=559)

Detailed Findings

- Caregiver Pride
- Importance of Support Networks
- Role of Children in Caregiving
- **Challenges In Caregiving**
- Negative Emotional Impact Of Caregiving
- Negative Impact On Caregiver’s Daily Life
- Delay in Diagnosis
- Medication

A majority of caregivers say that caring for a patient with Alzheimer's disease and their children has been one of the hardest things they've ever had to do.

"Caring for a patient with Alzheimer's disease and for children has been the biggest challenge I have ever faced in my life."



Q836: Please tell us how much you agree or disagree with each of the following statements as they relate to caring for both the person with Alzheimer's disease and your children?
Base: All respondents (n=559)

More caregivers find it difficult to care for the Alzheimer's patient than to care for their children.

Difficulty In Providing Care
For Patient vs. Child

Care of Patient

Very/Somewhat Difficult To:	Total %
Care for *emotional* needs	78
Care for *physical* needs	73
Get others to help with needs	73
Manage financial cost	72

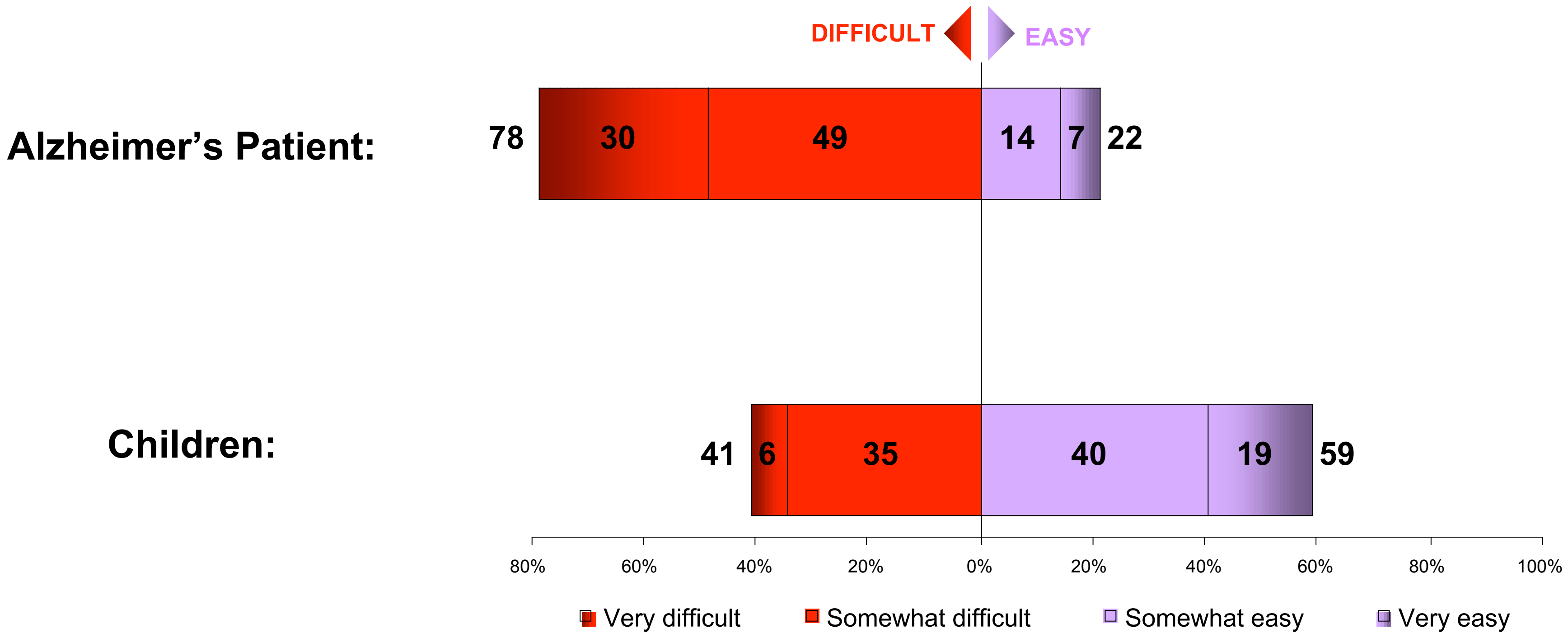
Care of Child

Very/Somewhat Difficult To:	Total %
Care for *emotional* needs	41
Care for *physical* needs	21
Get others to help with needs	37
Manage financial cost	56

Q821: How easy or difficult do you find each of the following?
Base: All respondents (n=559)

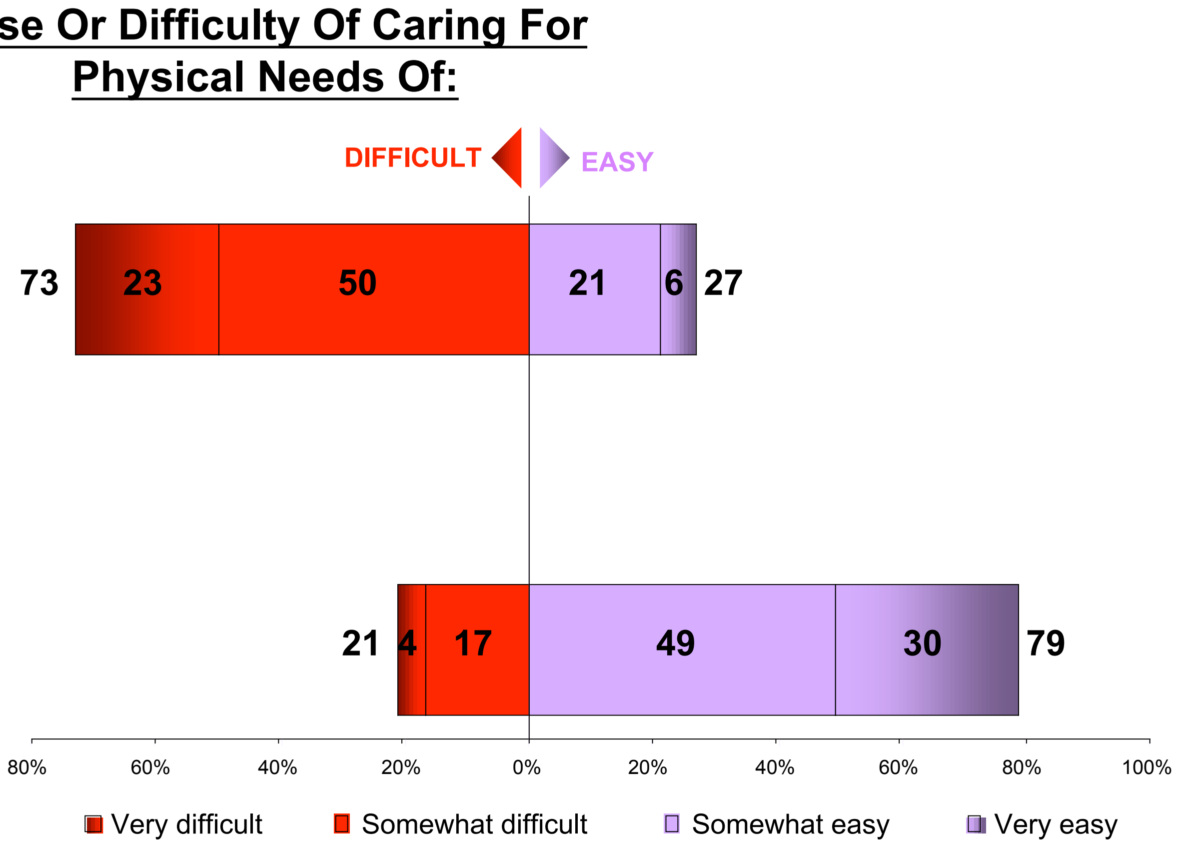
A majority of caregivers find it hard to care for the patient's emotional needs as opposed to only 2 in 5 who find it hard to care for the children's.

Ease Or Difficulty Of Caring For Emotional Needs Of:



Q821: How easy or difficult do you find each of the following?
Base: All respondents (n=559)

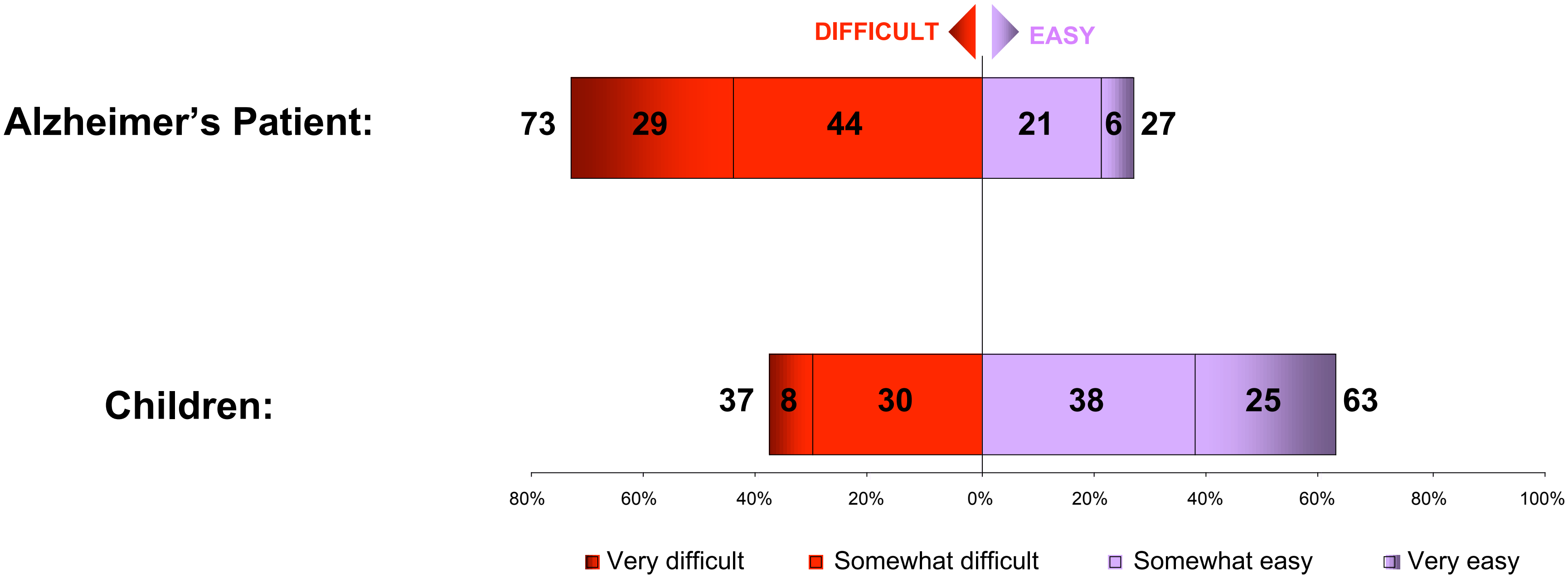
A much larger proportion of caregivers find it difficult to care for the patient's physical needs than to care for the children's.



Q821: How easy or difficult do you find each of the following?
Base: All respondents (n=559)

About three-quarters find it difficult to get help to care for the Alzheimer's patient, while less than 2 in 5 find it hard to do so for their children.

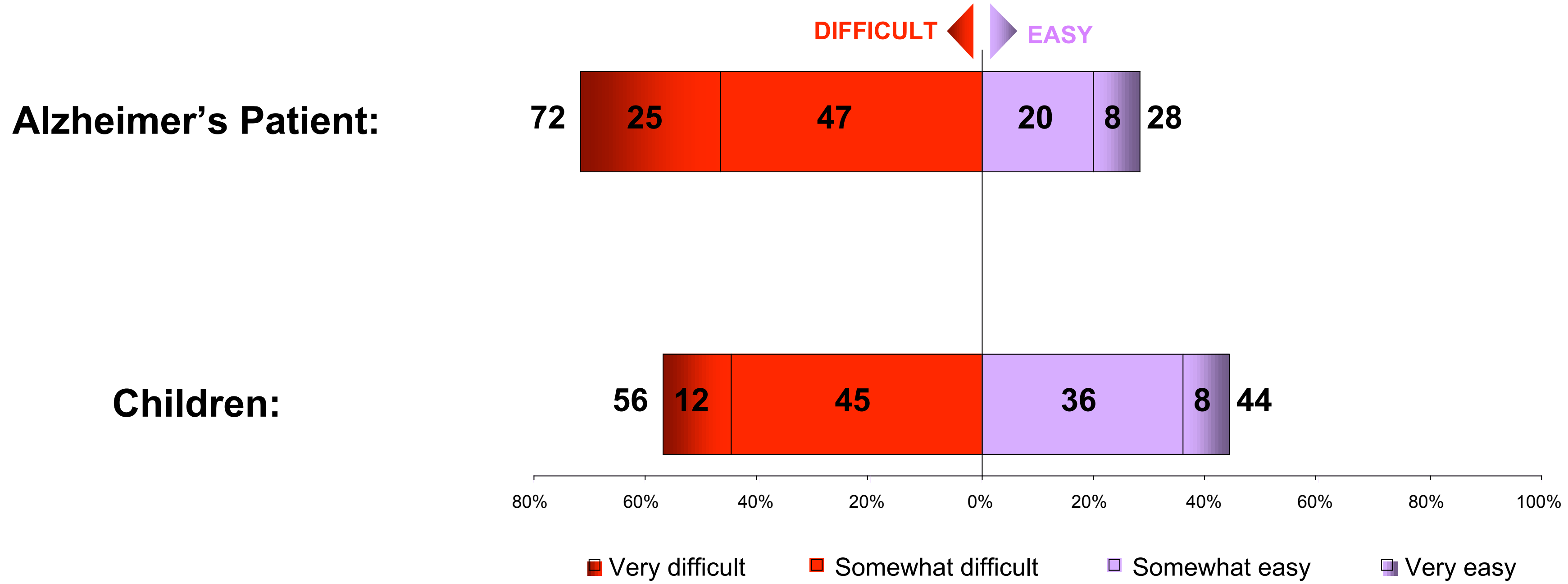
Ease Or Difficulty In Getting Other's To Help With Needs Of:



Q820: How easy or difficult do you find each of the following?
Base: All respondents (n=559)

Most caregivers find it difficult to manage the financial aspect of patient and child care, but more so when it comes to the patient.

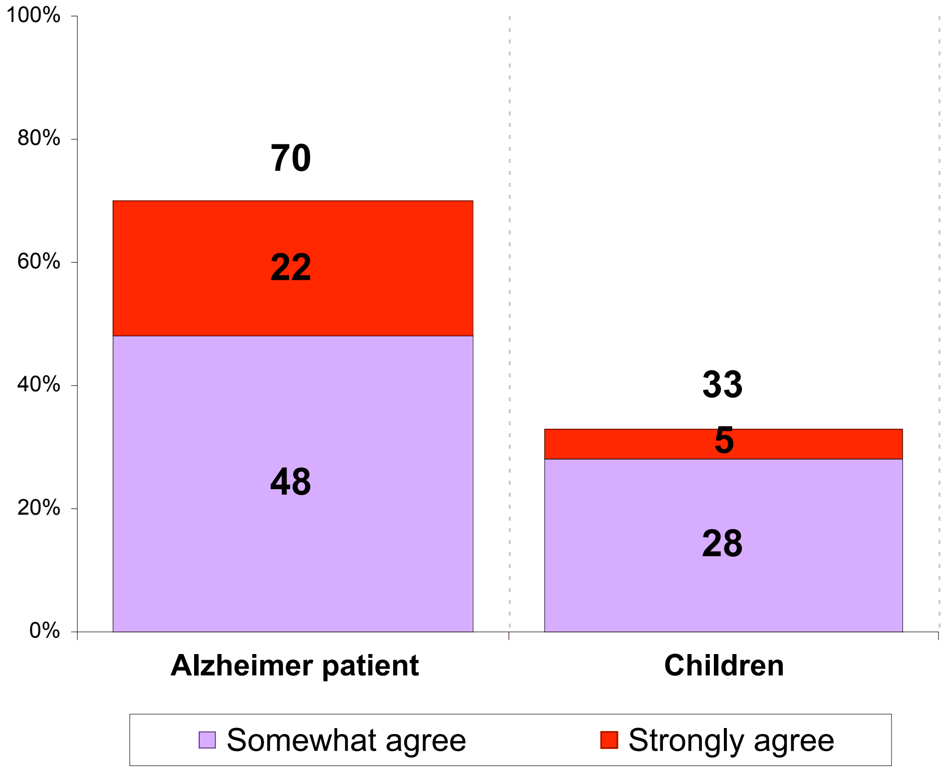
Ease Or Difficulty Of Managing Cost Of Caring For:



Q821: How easy or difficult do you find each of the following?
Base: All respondents (n=559)

Most caregivers would like more help caring for the Alzheimer's patient, as opposed to a minority who would want more help caring for their children.

Caregivers Who Agree They Would Like More Help Caring For The Alzheimer's Patient And The Children

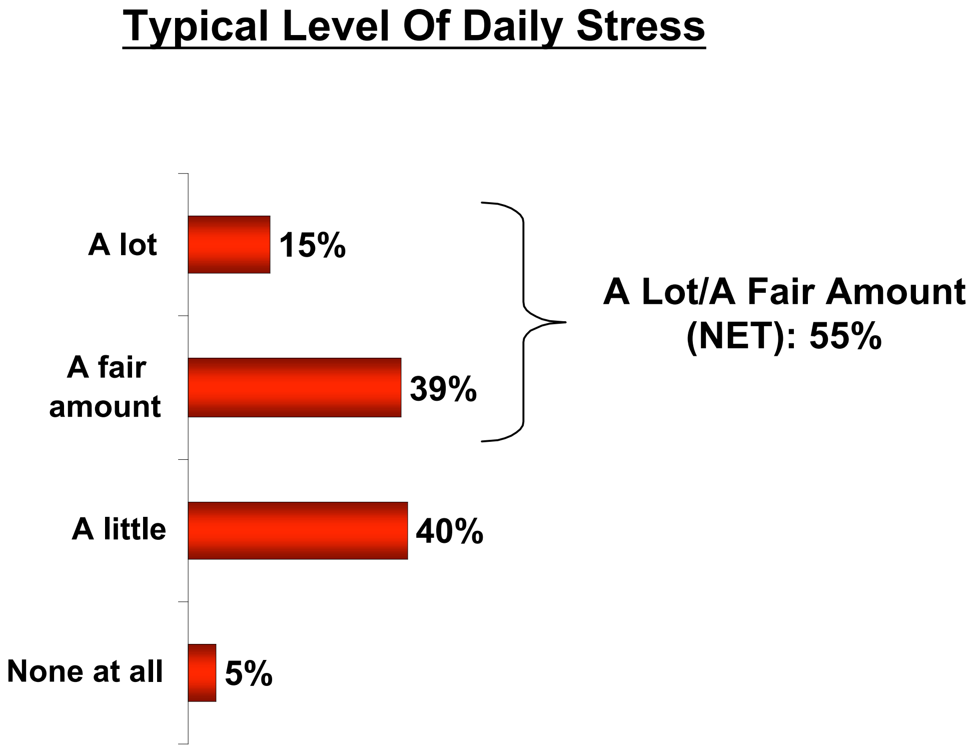


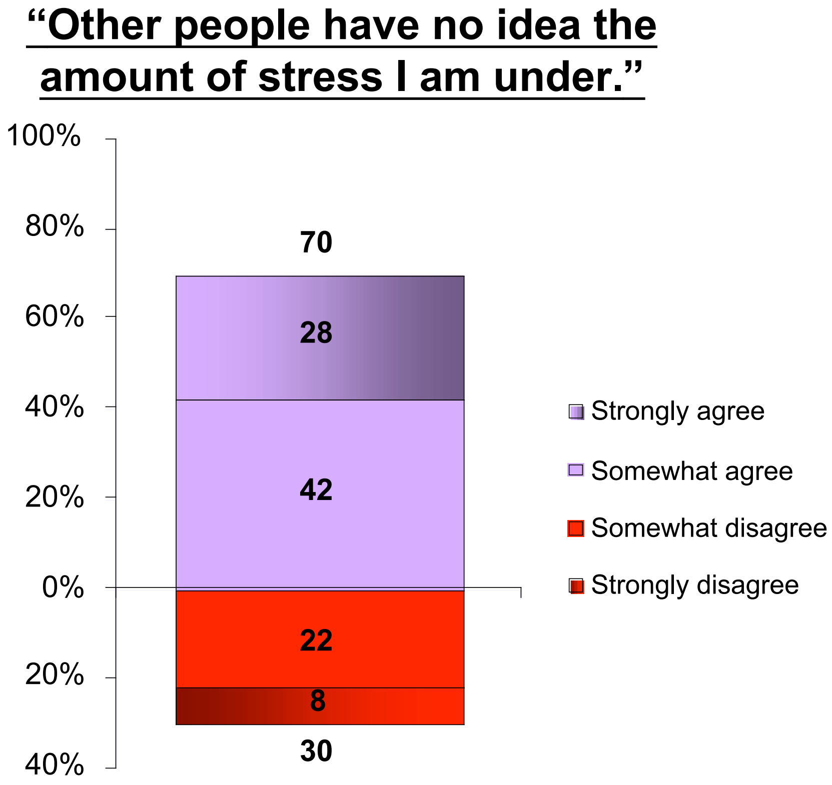
Q836: Please tell us how much you agree or disagree with the following statements as caring for both the person with Alzheimer's disease and your children
Base: All respondents (n=559)

Detailed Findings

- Caregiver Pride
- Importance of Support Networks
- Role of Children in Caregiving
- Challenges In Caregiving
- **Negative Emotional Impact Of Caregiving**
- Negative Impact On Caregiver’s Daily Life
- Delay in Diagnosis
- Medication

Three-quarters of caregivers think people don't recognize how much stress they face and about half are at least somewhat stressed everyday, due to their responsibilities.

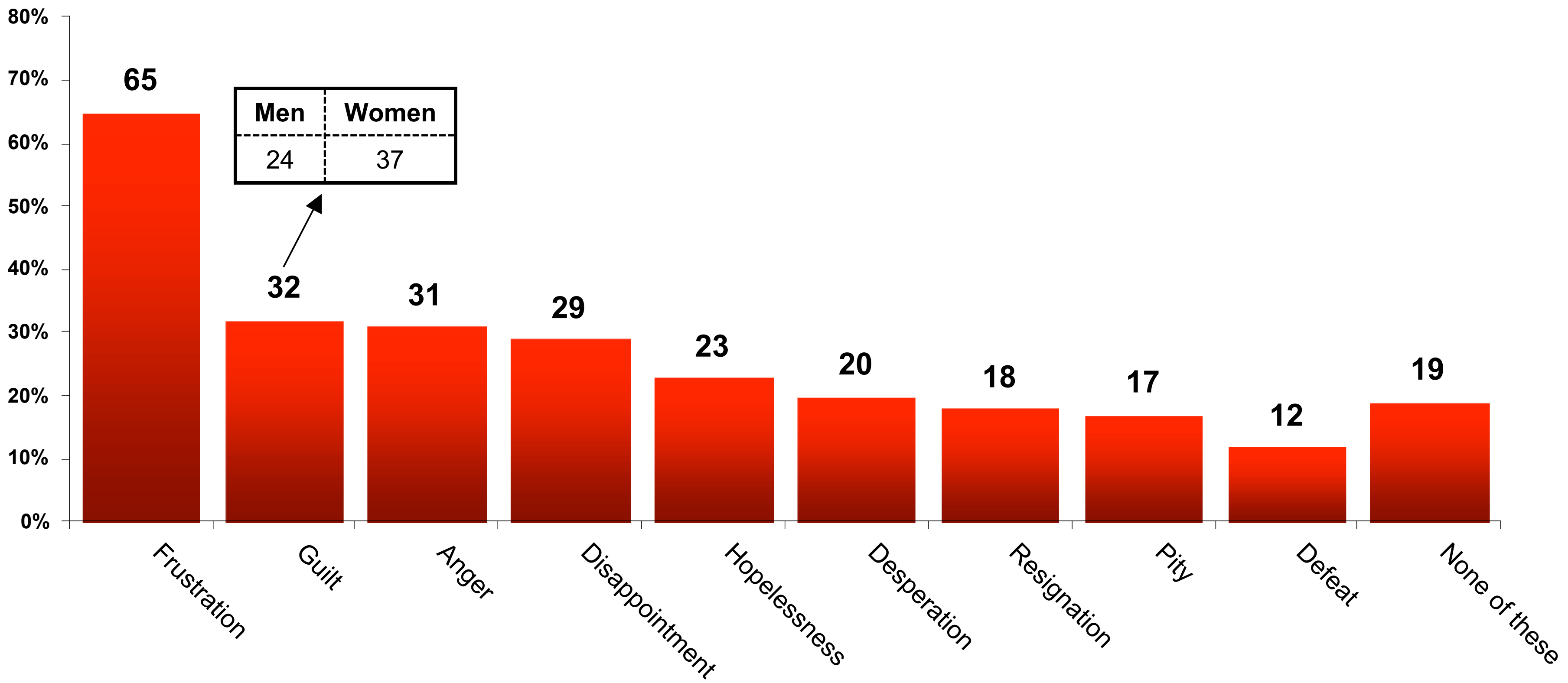




Q836: Please tell us how much you agree or disagree with each of the following statements as they relate to caring for both the person with Alzheimer's disease and your children?
Q1000: How much care giving related stress do you typically experience each day?
Base: All respondents (n=559)

About two-thirds of caregivers have felt frustrated and about one-third have felt guilty, due to their care giving responsibilities. Women are more likely than men to feel guilty.

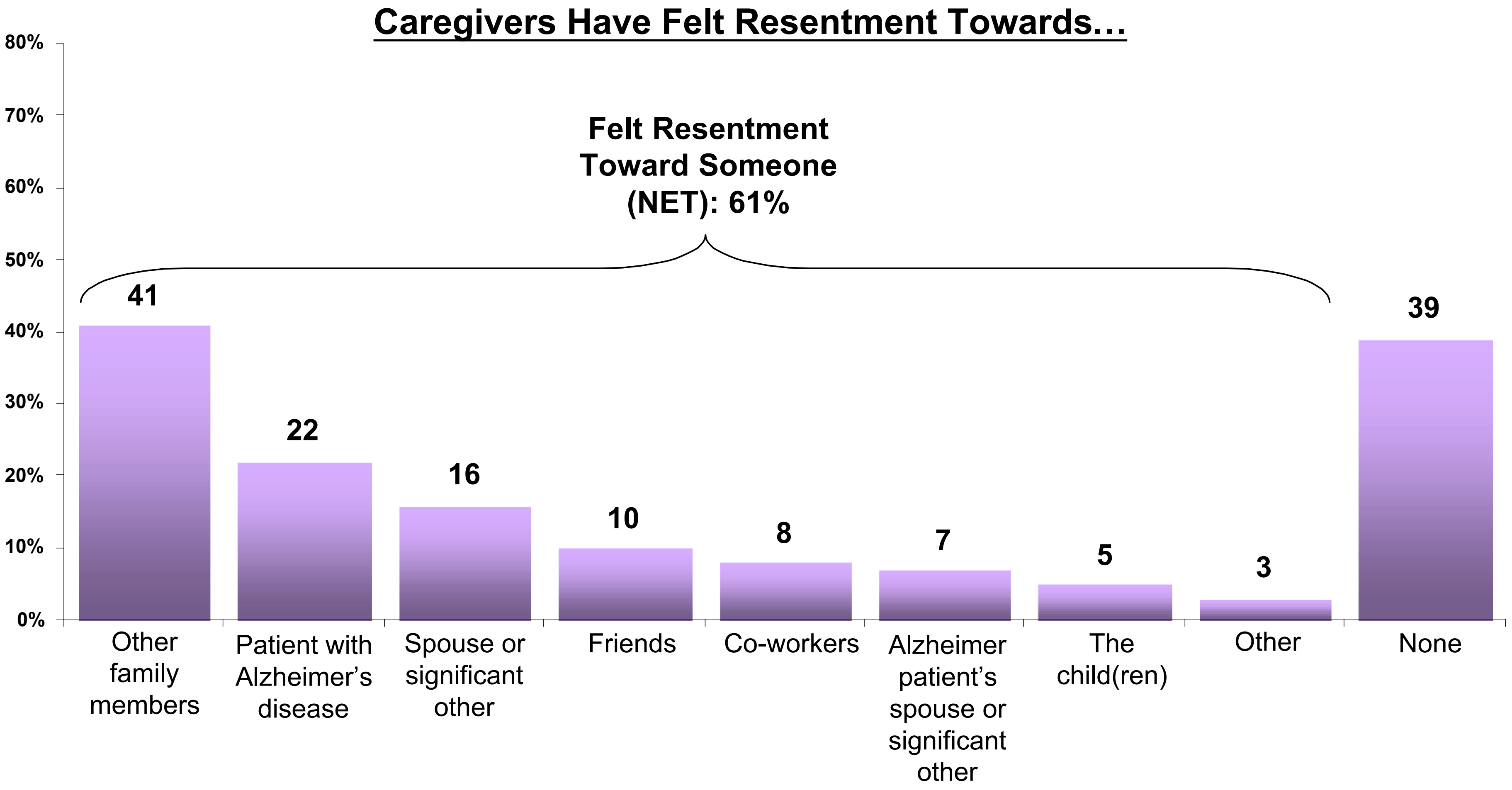
Negative Emotions Caregivers Experience Due To Responsibilities



Men	Women
24	37

Q1005: Do you experience any of the following negative emotions due to your responsibilities in caring for the patient with Alzheimer's disease and the child(ren) in your household?
Base: All respondents (n=559)

Most caregivers have felt resentful of others since shouldering their caregiving responsibilities, most commonly toward other family members and nearly a quarter toward the patient with Alzheimer's disease.

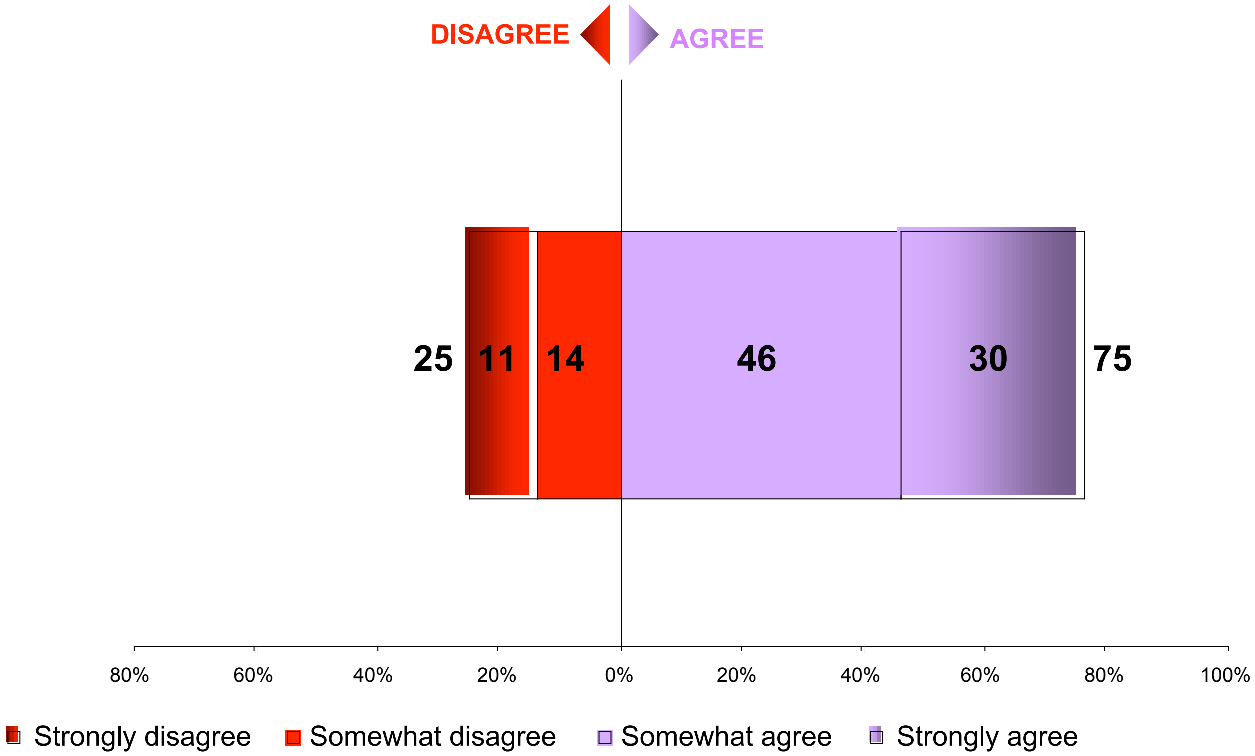


Q930: During the time you have been a caregiver for both the patient with Alzheimer's disease and children in your household, have you ever felt resentment toward any of the following?

Base: All respondents (n=559)

A majority of caregivers feel they are being pulled in many directions.

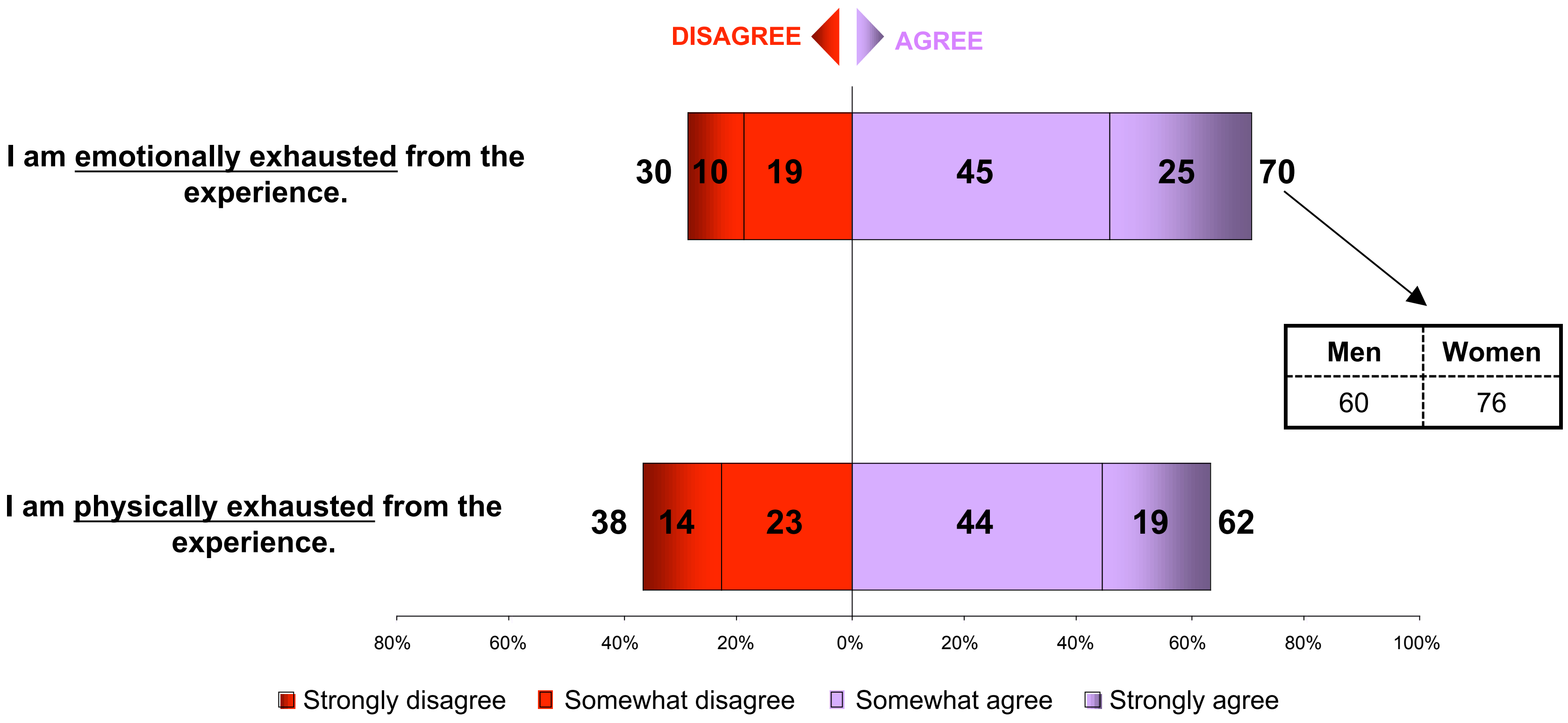
“I feel I am being pulled in many different directions.”



Q836: Please tell us how much you agree or disagree with each of the following statements as they relate to caring for both the person with Alzheimer’s disease and your children?
Base: All respondents (n=559)

A majority of caregivers report either physical or emotional exhaustion from their caregiving duties. Women are especially likely to feel emotionally exhausted.

Impact Of Caregiving



Men	Women
60	76

Q836: Please tell us how much you agree or disagree with each of the following statements as they relate to caring for both the person with Alzheimer's disease and your children?
Base: All respondents (n=559)

And nearly 3 in 5 caregivers say they are *both* emotionally and physically exhausted from their caregiving duties.

Impact Of Care Giving

Emotionally Exhausted
from the experience –
Strongly/Somewhat Agree

70%

Both Emotionally And Physically Exhausted
from the experience –
Strongly/Somewhat Agree

58%

Physically Exhausted
from the experience –
Strongly/Somewhat Agree

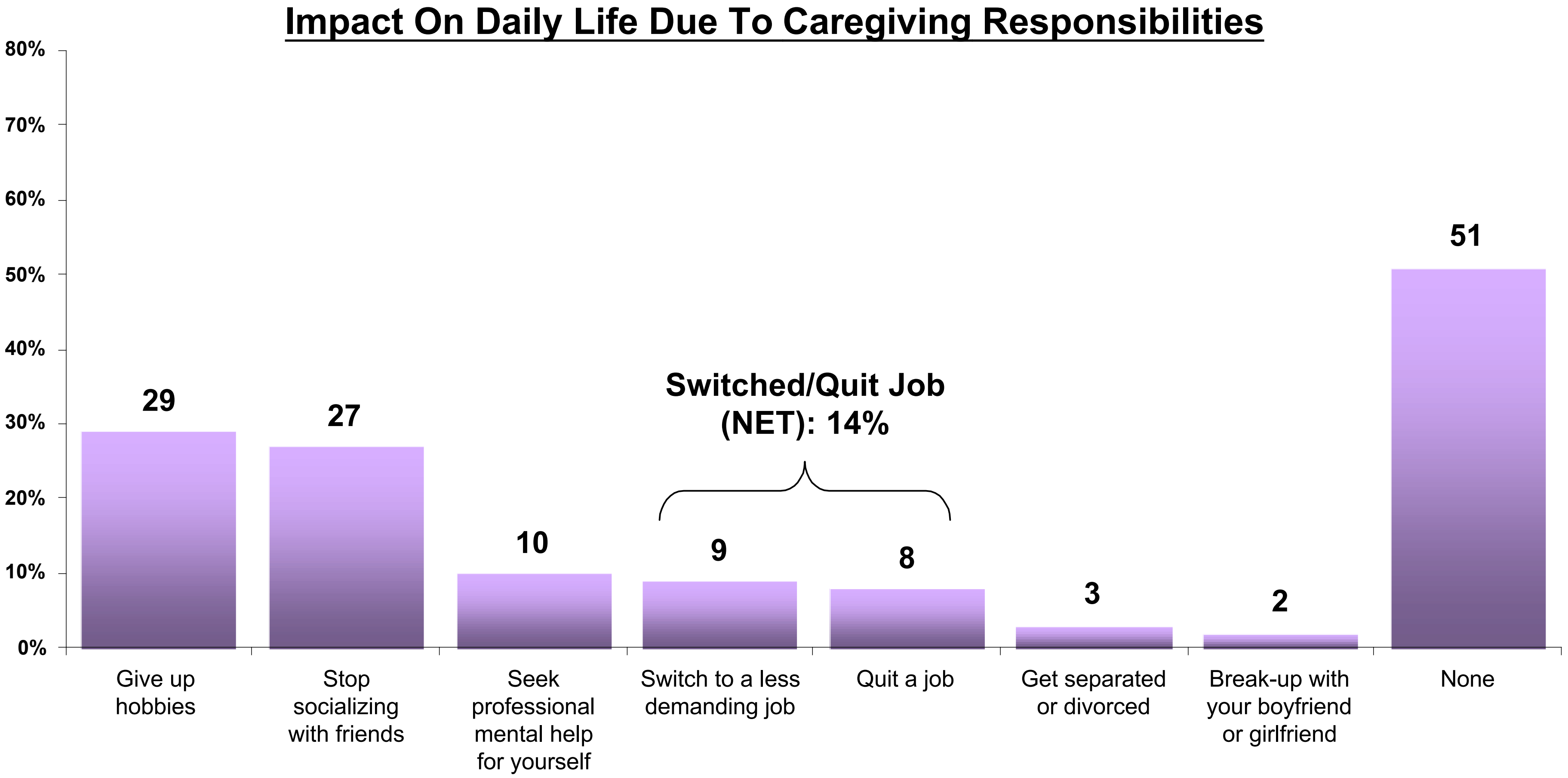
62%

Q836: Please tell us how much you agree or disagree with each of the following statements as they relate to caring for both the person with Alzheimer's disease and your children?
Base: All respondents (n=559)

Detailed Findings

- Caregiver Pride
- Importance of Support Networks
- Role of Children in Caregiving
- Challenges In Caregiving
- Negative Emotional Impact Of Caregiving
- **Negative Impact On Caregiver’s Daily Life**
- Delay in Diagnosis
- Medication

Nearly 3 in 10 caregivers have given up hobbies and a similar number have stopped socializing with friends due to their caregiving duties.



Q1020: Have you ever had to do any of the following due to your responsibilities in caring for the patient with Alzheimer’s disease and child(ren) in your household?

Base: All respondents (n=559)

Caregiving duties have had some impact on various domains of a caregiver's life in the past year - about one-third of caregivers are less intimate with their spouse or significant other and over a quarter have given up hobbies.

Things Caregivers Have Done Within The Past Year Due To Responsibilities

Social/Romance	Total %
Skip a social obligation	47
Be less intimate with spouse/significant other	33
Miss a romantic date or night out	24

Personal	Total %
Skip going to the gym or other physical exercise	38
Cancel a vacation or trip	29
Give up hobbies	29
Cancel a doctor's appointment for themselves	23

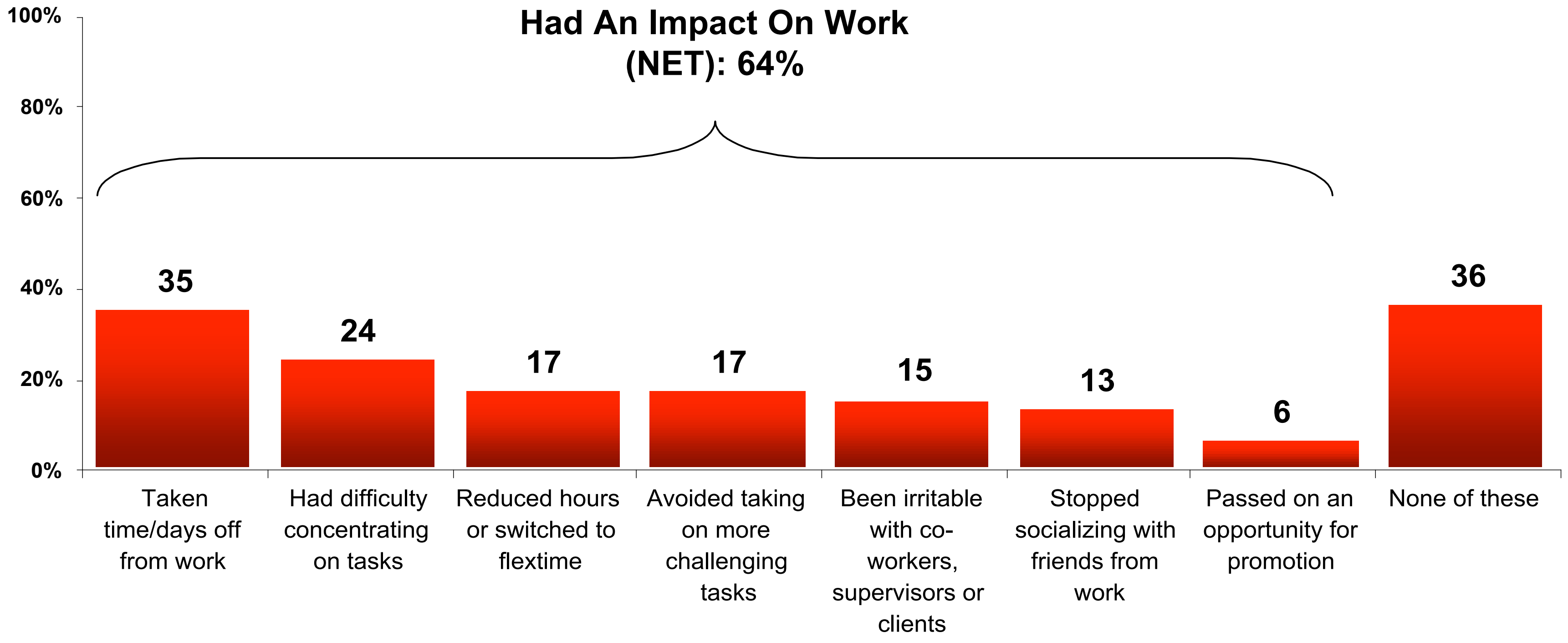
Work	Total %
Stay home from work	29

Family	Total %
Skip a family event	27
Miss out on the children's activities	22
Cancel a child's leisure activity	13
Cancel a doctor's appointment for the patient	12
Decline to help child with homework	9
Cancel a child's doctor appointment	7

Q1010: In the past year, have you had to do any of the following due to your responsibilities in caring for the patient with Alzheimer's disease and child(ren) in your household?
Base: All respondents (n=559)

Among employed caregivers, about one-third have taken days off from work and about one-quarter find it hard to focus on their work due to their responsibilities.

Impact On Work Life Due To Caregiving Responsibilities



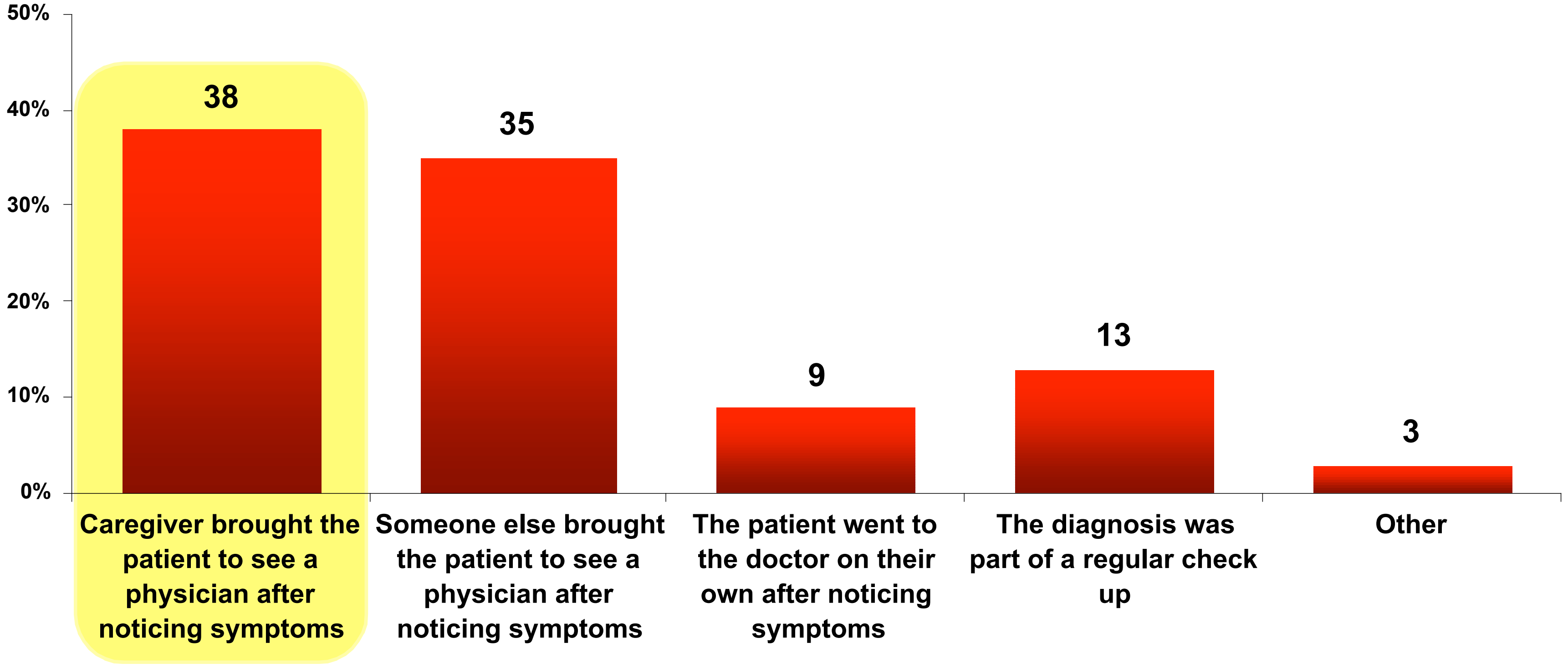
Q1030: Due to having to care for the patient with Alzheimer's disease and the children in your household, has your working life been adversely affected in any of the following ways?
Base: Respondents who are employed full time, part time or self employed (n=450)

Detailed Findings

- Caregiver Pride
- Importance of Support Networks
- Role of Children in Caregiving
- Challenges In Caregiving
- Negative Emotional Impact Of Caregiving
- Negative Impact On Caregiver's Daily Life
- **Delay in Diagnosis**
- Medication

Nearly 2 in 5 caregivers say the patient was diagnosed with Alzheimer's disease, because they noticed symptoms and took the patient to a doctor.

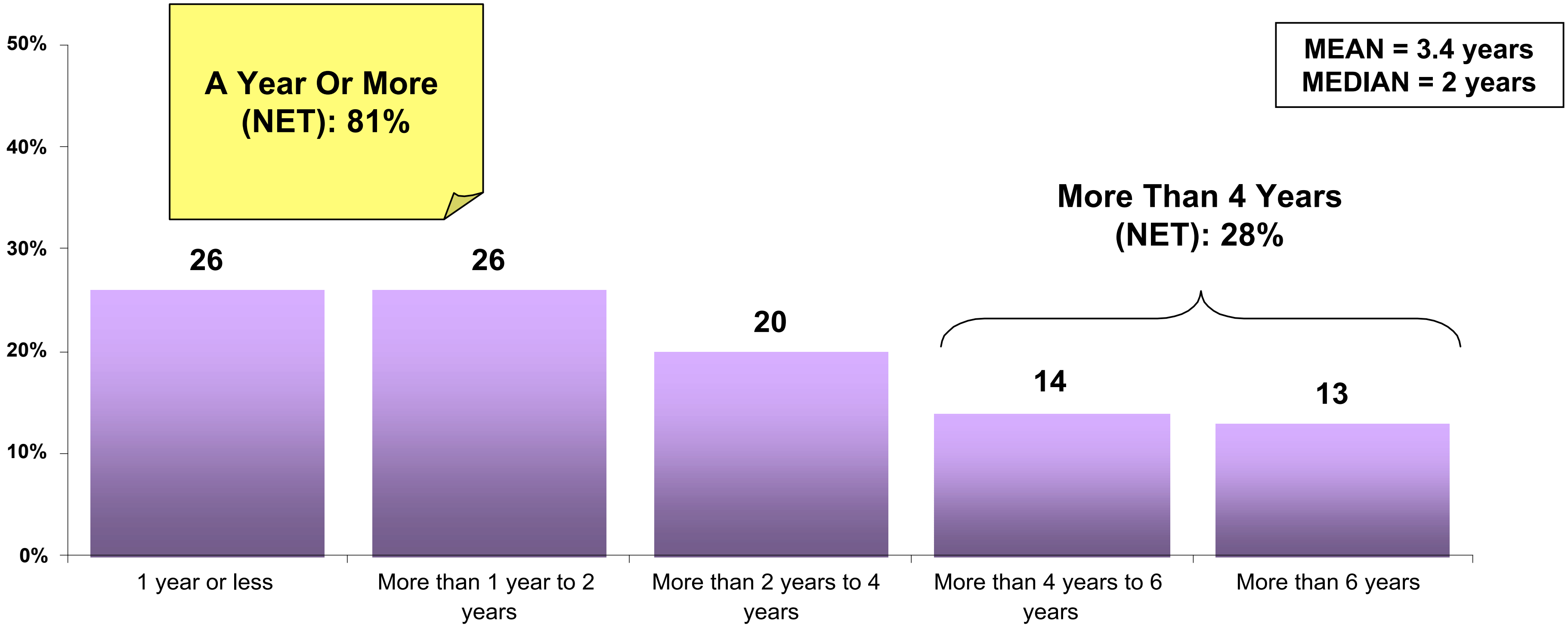
How Alzheimer's Patient Was Diagnosed



Q731: Which of the following best describes how the patient you care for with Alzheimer's disease was diagnosed?
Base: *All respondents (n=559)*

On average, caregivers say that diagnosis of Alzheimer’s disease was delayed for two years.

Length Of Time From When Symptoms Occurred To When Disease Was Diagnosed



A Year Or More (NET): 81%

MEAN = 3.4 years
MEDIAN = 2 years

More Than 4 Years (NET): 28%

Q729: How long ago was the patient you care for with Alzheimer’s disease experiencing symptoms before he/she was diagnosed?
Base: *All respondents (n=559)*

Nearly half of caregivers whose patient’s diagnosis of Alzheimer’s disease was delayed for a year or more thought that the symptoms were just signs of normal aging.

Reasons Alzheimer’s Diagnosis May Have Been Delayed

	% May Have Delayed
I thought the symptoms were just a natural part of getting older	48
Not Wanting To Face Possibility That Something Could Be Wrong (NET)	46
The patient did not want to face the possibility that something could be wrong	41
I did not want to face the possibility that something could be wrong	13
Insufficient Knowledge About Alzheimer’s Disease (NET)	43
I did not know enough about Alzheimer’s disease	28
The patient did not know enough about Alzheimer’s disease	25
Doctor Related (NET)	40
The doctor discussed the patient’s dementia symptoms, but seemed reluctant to provide an assessment and/or diagnosis of the patient’s condition	33
When we raised memory concerns, the doctor did not discuss Alzheimer’s as a possible diagnosis	18

	% May Have Delayed
Concerned About Stigma (NET)	24
The patient was concerned about the potential stigma of a diagnosis of Alzheimer’s disease	18
I was concerned about the potential stigma of a diagnosis of Alzheimer’s disease	9
The patient with Alzheimer’s disease that I care for did not want to visit the doctor	22
I was afraid I would be the caregiver should there be a diagnosis of Alzheimer’s disease	4
Little Access To Healthcare Professionals (NET)	2
The patient had little access to healthcare professionals	2
I had little access to healthcare professionals	1
I did not have time to take the patient with Alzheimer’s disease to the doctor due to my responsibility for caring for the child(ren)	2
Other	4
None of these	5

Q735: Which of the following, if any, may have delayed the Alzheimer’s diagnosis?
Base: *Respondents who say patient with Alzheimer’s disease was exhibiting symptoms for one year or more before diagnosis (n=500)*

Caregivers who brought their loved one to see a doctor after noticing symptoms, most often cite forgetfulness or memory loss as the symptom that prompted them to do so.

Symptoms That Led To Diagnosis

Forgetfulness or memory loss	83
Misplacing things	59
Personality changes (such as aggression, confusion or agitation)	57
Disorientation to time	51
Disorientation to place	48
Difficulty in performance of daily tasks	47
Showing unusually poor judgment when making decisions	40
Changes in personal hygiene	35
Less interest in hobbies or socializing	31
Acting in appropriately	28
Difficulty in communication or language	25
Difficulty in dressing	24
Wandering	20
Other	3

Disorientation/ Wandering (NET): 63%

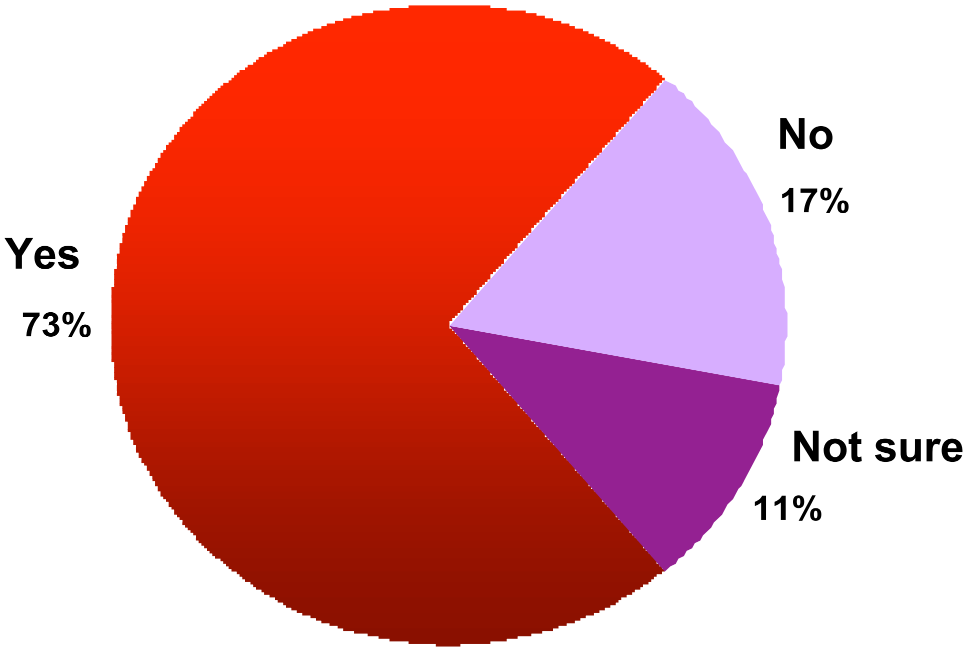
Q733: What symptoms caused you to first take the patient with Alzheimer's disease to see a physician and seek help?
Base: *Respondents who brought the patient to see a physician after noticing symptoms (n=191)*

Detailed Findings

- Caregiver Pride
- Importance of Support Networks
- Role of Children in Caregiving
- Challenges In Caregiving
- Negative Emotional Impact Of Caregiving
- Negative Impact On Caregiver’s Daily Life
- Delay in Diagnosis
- **Medication**

Most caregivers say the patient is taking a prescription medication for Alzheimer’s disease.

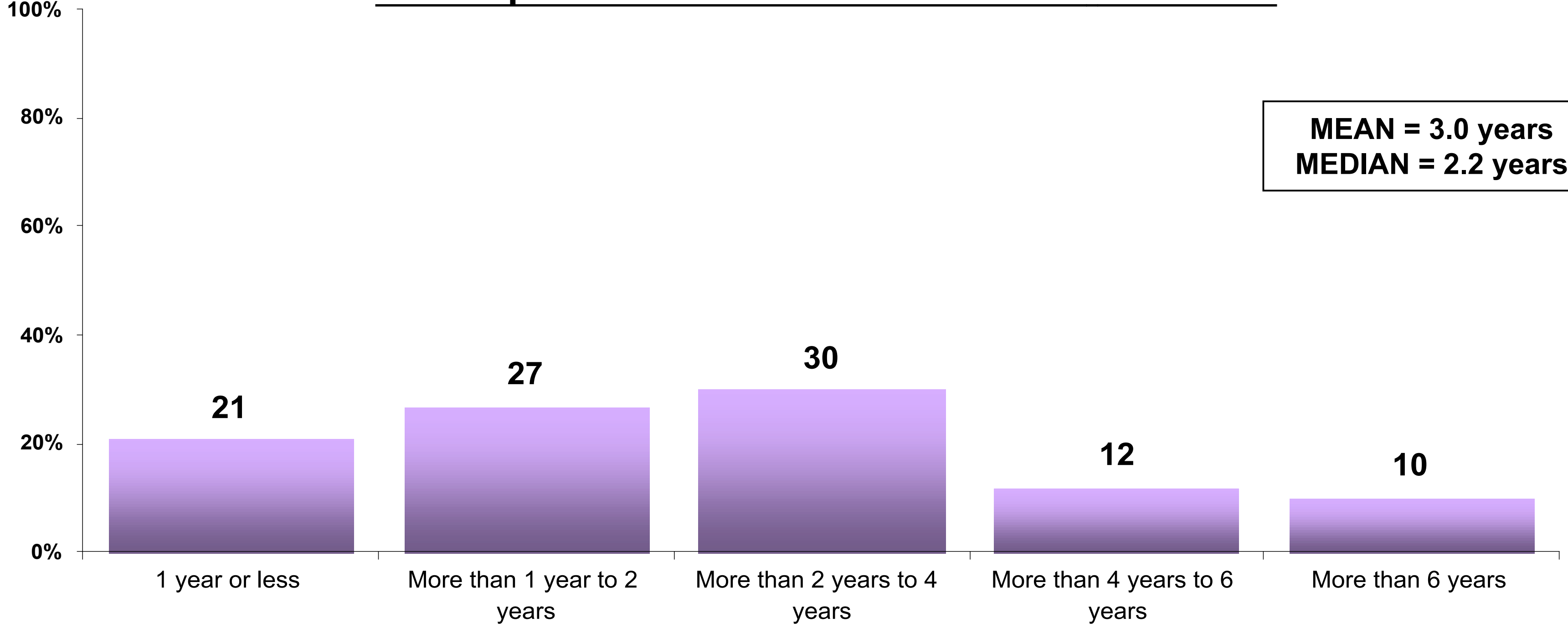
Whether Alzheimer’s Patients Take Prescription Medication



Q1105: Does the patient with Alzheimer’s disease currently take prescription medication for Alzheimer’s disease?
Base: All respondents (n=559)

Caregivers whose patients are taking prescription medication say the patient has been taking the medication for three years on average.

Length Of Time Alzheimer's Patient Has Taken Prescription Medication For Alzheimer's Disease

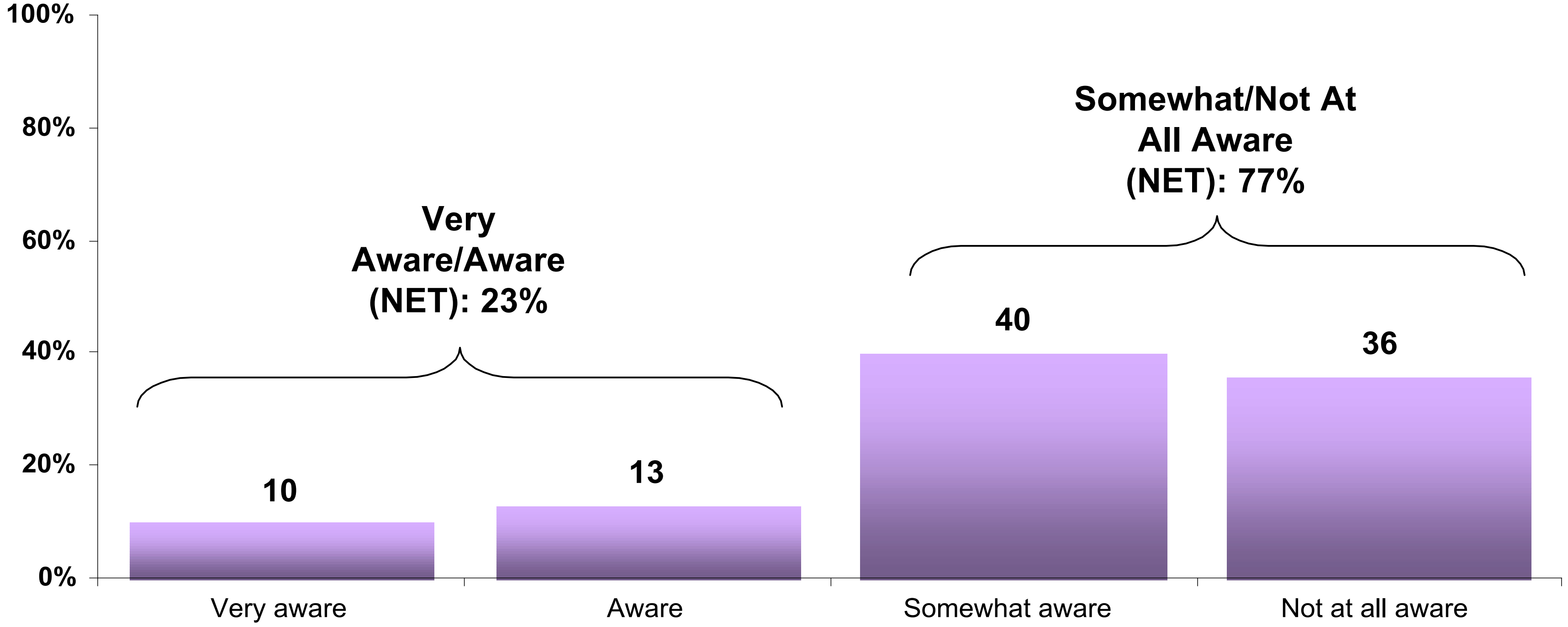


MEAN = 3.0 years
MEDIAN = 2.2 years

Q1110: How long has the patient with Alzheimer's disease been taking prescription medication for Alzheimer's disease?
Base*: Respondents whose Alzheimer's patient takes prescription medication (n=421)*

Less than one-quarter of caregivers are aware of an opportunity for two medications to be used in conjunction to treat Alzheimer's disease.

Awareness Of The Opportunity For Two Medications To Be Used Together To Treat Alzheimer's Disease



Q1120: How aware are you of the opportunity for two medications (that work in different ways) to be used together to treat Alzheimer's disease?
Base*: All respondents (n= 559)*

Demographic Profile

Respondent Profile – Gender, Age, Region

	Total
Gender	**%**
Male	37
Female	63

	Total
Region	**%**
East	22
Midwest	22
South	39
West	17

	Total
Age	**%**
18-19	*
20-24	2
25-29	8
30-34	8
35-39	11
40-44	14
45-49	20
50-54	18
55-59	11
60-64	3
65+	6

Respondent Profile – Education, Employment Status, Income

	Total
Education	**%**
High school or less (NET)	19
Less than high school	*
Completed some high school	1
High school graduate or equivalent	17
Some College (NET)	42
Completed some college, but no degree	34
Associate's degree	8
College or more (NET)	40
College	20
Completed some graduate school, but no degree	4
Graduate school	15

	Total
Employment Status	**%**
Employed (NET)	79
Employed full time	61
Employed part time	12
Self-employed	10
Not employed (NET)	2
Not employed, but looking for work	2
Not employed and not looking for work	1
Retired	9
Homemaker	15
Student	5

	Total
Income	**%**
Less than $35,000 (NET)	11
$35,000 to less than $75,000 (NET)	30
$75,000 or more (NET)	41
Decline to answer	18

Respondent Profile – Race/Ethnicity, Adults and Children in Household

	Total
Race/Ethnicity	**%**
White	67
Black/African American (NET)	11
Black	6
African American	5
Hispanic	13
Asian or Pacific Islander	3
Native American or Alaskan native	*
Mixed racial background	*
Other race	1
Decline to answer	5

	Total
Children under 21 in Household	**%**
1	50
2	35
3+	15
Mean	1.7

	Total
Adults in Household	**%**
1	10
2	46
3	30
4	12
5+	2
Mean	2.5

Respondent Profile – Children's Age and Gender, Marital Status, Other Household Members

	Total
Age group of child 21 years old and younger	**%**
0-4	19
5-7	15
8-12	25
13-17	41
18-12	40

	Total
Gender of each child under 21 in Household	**%**
Boy	71
Girl	59

	Total
Marital Status	**%**
Married/Have significant other (NET)	78
Married	70
Have significant other	8
Divorced/Separated/Widowed (NET)	13
Divorced	9
Widowed	2
Separated	1
Single, never married	9

	Total
Family members besides children and spouse or significant other living in household	**%**
Yes	25
No	75

Respondent Profile – Age, Gender and Marital Status of Alzheimer's Patient

	Total
Age of patient with Alzheimer's disease	**%**
50 or younger	1
51-70	13
71-80	33
81-90	47
91-100	6
Mean	79.2

	Total
Gender of patient with Alzheimer's disease	**%**
Male	33
Female	67

	Total
Patients with Alzheimer's disease with spouse or significant other	**%**
Yes	45
No	55