Family caregiving

Prevalence
A large portion of the population is involved in providing unpaid care for a family member with a short-term or long-term disability, medical conditions or issues related to aging.

Burden & strain
Many caregivers are also constantly struggling to find balance between work, family life, and their caregiving responsibilities. They are likely to have negative experiences, which entails physical and financial strain, emotional stress, social isolation, mismanagement of care, lack of access to support, and more.
Research agenda

Understanding caregivers
A comprehensive understanding of demographic, behavioral and experiential characteristics of caregivers themselves, and their associations with stress and burden, can help uncover opportunities for improving the caregiving experience.

Understanding caregiving tasks
Little is known about detailed caregiver jobs and related resources that affect caregiving experiences as well as care outcomes.
Need to understand details of caregiving to understand the types and frequency of different jobs, level of difficulty, and access to/use of necessary resources.

Finding ways to improve the caregiving experience
Identify “pain points” that may be improved with new solutions.
Develop ways to help caregivers stay well and organized, and save time and money.
Find insights for service providers to communicate with caregivers.

The MIT AgeLab Caregiving Study

Long-term data collection
Caregivers were surveyed over 12 weeks (4 weeks of detailed daily surveys and 8 weeks of topic-specific surveys). Phone interviews were conducted multiple times for assistance in participation and for collecting additional information.

Creating a caregiver journey map
Understanding experiential patterns among caregivers of various characteristics.
Developing personas and describing their experiences to illustrate the caregiver journey and to identify pain points.

Micro-mapping the caregiver experience
Describing details of caregiving tasks at a micro level – What specific things does each caregiving task entail? How much time do caregivers spend on different tasks? Where do they find resources? How much strain do they feel?
Symposium overview

1. Profile of employed caregivers
   Characteristics of caregivers who participated in the MIT AgeLab Caregiving Study.

2. A Day in the Life of an Employed Family Caregiver
   Descriptions of distinct caregiver personas.
   Walking through a typical day as each caregiver persona.

3. Caregiver Well-Being – Managing Burden and Stress
   Understanding the burden, stress and strain associated with caregiving.
   Reports of how caregivers manage their well-being and personal life.

4. Assisting with Various Needs
   Presentation on details of specific caregiving tasks – both basic and instrumental.
   Comparison between different caregiver characteristics.
Unpaid caregivers in the US

Providing unpaid care to a loved one

- An estimated 43.5 million adults in the US have provided unpaid care to an adult or child
- An estimated 39.8 million, or about 91% of the caregiving population, care for an adult
- The majority of participants provide care for a relative, with about half of them caring for a parent or parent-in-law
- The majority of caregivers are female (60%)
- Caregivers are 49 years old on average
- Six in ten are employed, most of them full-time
- Responses from 1,248 caregivers

The MIT AgeLab sample

Recruiting

A convenience sample of self-identified caregivers
Screening questionnaire to determine eligibility:

- Family caregivers
- Providing unpaid care
- Employed outside of caregiving

Sample size

A total of 30 caregivers initially enrolled in the study
29 of them completed the first part of study (4 weeks of daily surveys)
28 fully completed all parts of study (daily surveys & 8 weeks of weekly surveys)
Data collection

- Conducted prior to the first day of study
- Introduction to study and the overall procedure
- Questions covering detailed information about the caregiving situation, including characteristics of the caregivers and their care recipients
- Lasted about an hour on average

Initial phone interview

The caregivers

<table>
<thead>
<tr>
<th>Caregiver age &amp; gender</th>
<th>50% of participating caregivers were aged 48 to 57</th>
</tr>
</thead>
<tbody>
<tr>
<td>35</td>
<td>Youngest caregiver in study</td>
</tr>
<tr>
<td>47.75</td>
<td>1st quartile</td>
</tr>
<tr>
<td>53</td>
<td>Median age</td>
</tr>
<tr>
<td>57</td>
<td>3rd quartile</td>
</tr>
<tr>
<td>63</td>
<td>Oldest in study</td>
</tr>
<tr>
<td>90%</td>
<td>of participating caregivers were female</td>
</tr>
<tr>
<td>10%</td>
<td>Only 10% were male</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Income &amp; employment</th>
<th>13% were employed part-time</th>
</tr>
</thead>
<tbody>
<tr>
<td>Less than $50K</td>
<td>87% of caregivers in study were employed full-time</td>
</tr>
<tr>
<td>$50-75K</td>
<td></td>
</tr>
<tr>
<td>$75-100K</td>
<td></td>
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<tr>
<td>$100-150K</td>
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<tr>
<td>$150K or more</td>
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</table>

<table>
<thead>
<tr>
<th>Marital status &amp; household</th>
<th>7 caregivers are single, never married</th>
</tr>
</thead>
<tbody>
<tr>
<td>17 caregivers are married or living with partner</td>
<td>6 caregivers are divorced or separated</td>
</tr>
<tr>
<td>7 caregivers are married or living with partner</td>
<td>20% of caregivers live with kids</td>
</tr>
<tr>
<td>On average, caregivers live with 1.5 other people</td>
<td></td>
</tr>
</tbody>
</table>
The care recipients

- 33 youngest care recipient
- 83 median age
- 98 oldest in study

50% of care recipients were aged 75 to 88

- 63% of care recipients were female
- 37% were male

Long-term physical condition: 19
Memory problem: 23
Emotional/mental issue: 15
Behavioral issue: 8
Short-term physical condition: 3
Developmental/intellectual issue: 2

The majority of caregivers in this study were helping an older family with long-term physical conditions & memory issues.

The caregiving situation (1/2)

**Relationship & living arrangements**
- 26 caregivers provide care to their parent or parent-in-law
- Others care for an adult child, a grandparent, an aunt/uncle, and a spouse
- 15 caregivers live with the care recipient

**Time spent caregiving**
- 30.8 hours per week
- 2.8 hours per week
- Average time spent providing care directly
- Average time spent searching for resources & info

**Caregiving support**
- 3 caregivers are the only caregiver for their care recipient
- Others get help from family, friend, and/or service providers

- 22 help from family
- 3 help from friend(s)
- 1 medical professional
- 5 home health aide
- 7 other

- Only 4 are in a caregiver support group

4 live at a walking distance
8 live at a short driving distance
3 live at a far distance

The majority of caregivers in this study were helping an older family with long-term physical conditions & memory issues.
### Caregiving Jobs

<table>
<thead>
<tr>
<th>Task</th>
<th>Number of Caregivers</th>
</tr>
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<tbody>
<tr>
<td>1. Transportation, getting to places</td>
<td>27</td>
</tr>
<tr>
<td>2. Grocery and other shopping</td>
<td>27</td>
</tr>
<tr>
<td>3. Arranging services &amp; appointments</td>
<td>26</td>
</tr>
<tr>
<td>4. Seeking info &amp; resources</td>
<td>26</td>
</tr>
<tr>
<td>5. Social activities &amp; interactions</td>
<td>23</td>
</tr>
<tr>
<td>6. Preparing meals &amp; eating</td>
<td>23</td>
</tr>
<tr>
<td>7. Housework &amp; home management</td>
<td>22</td>
</tr>
<tr>
<td>8. Managing finances</td>
<td>18</td>
</tr>
<tr>
<td>9. Using technology</td>
<td>16</td>
</tr>
<tr>
<td>10. Personal hygiene, dressing</td>
<td>16</td>
</tr>
</tbody>
</table>

### Medication Management

- **All 30 care recipients** take prescribed medications daily.
- **Half of them** take 5 or more per day:
  - 1/day: 3
  - 2/day: 3
  - 3/day: 4
  - 4/day: 5
  - 5+/day: 15

- **All 30 caregivers** help their care recipient with medications.
- **25 caregivers** take prescribed medications daily themselves.
Data collection

- 4 weeks (28 days) of daily surveys
- Details of various caregiving tasks carried out each day
- Task type and sub-level activities
- Frequency of each task and time of day (including night time)
- Amount of time spent on each caregiving task
- Level of difficulty and degree of strain (physical, financial and emotional)
- Shared responsibilities, if any

Daily surveys

Caregiving tasks

- Getting in and out of beds and chairs
- Getting dressed
- Getting to and from the toilet
- Bathing or showering
- Dealing with incontinence or diapers
- Feeding and/or eating
- Giving or managing medicines
- Managing finances
- Grocery or other shopping
- Housework
- Managing or coordinating maintenance for thing in and around the home
- Preparing meals
- Transportation
- Arranging outside services
- Keeping him or her company
- Other (please specify)
Caregiving sub-tasks

**Getting dressed:**
- Selecting clothes
- Getting clothes from drawer and/or closet
- Putting on and/or removing clothes
- Putting on and/or removing shoes
- Fastening clothes
- Calling/texting to ask about getting dressed

**Feeding and/or eating:**
- Helping him/her move to dining location
- Putting food on plates
- Cutting food
- Encouraging him/her to eat
- Arranging utensil
- Feeding
- Wiping/cleaning food that falls
- Calling/texting to ask about eating

Caregiving tasks

**Follow up on each task:**
- Frequency of the task during the day
- Time of day (including the night time) when the task was carried out
- Duration of time spent on the task
- Preparedness - How prepared did you feel to help with the task?
- Challenging - How challenging was it for you to help with this task?
- Strain – physical, financial and emotional associated with task
- Details of any services, resources, or help used for each task
- Info on if anyone else shared the caregivers' responsibilities
Effects of caregiving on the day overall

- Overall, how challenging was it for you to help your care recipient today?

- Physical strain
- Financial strain
- Emotional strain

How much of a ___ strain was it for you to help your care recipient today?

- Effect of caregiving on caregiver’s own health, family life and work life

Finding caregiver personas

Collective segmentation
Identifying distinct caregiver groups based on a collection of different characteristics, rather than segmenting by a single condition

Cluster analysis
- An exploratory data mining technique where a set of objects is partitioned into a set of meaningful sub-classes
- Based on a statistical analysis of distances between data points (i.e., similarities and differences between items), cases are grouped into distinct sets
- In this study, degree of similarity between caregivers was analyzed by looking at various characteristics (e.g., age, years in caregiving, distance from care recipient, time spent providing care, care recipient conditions, etc.)
The caregiver profile: persona journey maps

A day in the life of a family caregiver “Dana”

Dana lives with her parent who has memory issues and long-term physical conditions, and sees a doctor about twice per month. Dana is employed full-time, and sometimes her family helps with caregiving. Dana has been a caregiver for over 5 years.
**DANA’S DAY**

- **7 AM** Dana wakes up and starts getting ready for work
- **8 AM** She helps her parent with showering, getting dressed, and toileting
- **9 AM** She calls home to ask her parent about eating breakfast
- **10 AM** She makes calls to set up medical appointments and to arrange services for her parent
- **NOON** Dana eats lunch
- **1 PM** She calls home to ask if her parent ate lunch and took medications
- **2 PM** She finds a bit of time to do finance-related caregiving tasks
- **3 PM**

**HER CAREGIVING ACTIVITIES**

- **7 AM** Dana wakes up her parent, and helps with transferring from bed
- **physical & emotional strain**
- **8 AM** She helps her parent with showering, getting dressed, and toileting
- **physical & emotional strain**
- **9 AM** She calls home to ask her parent about eating breakfast
- **emotional strain**
- **10 AM** She makes calls to set up medical appointments and to arrange services for her parent
- **emotional & financial strain**
- **NOON** Dana eats lunch
- **emotional strain**
- **1 PM** She calls home to ask if her parent ate lunch and took medications
- **emotional strain**
- **2 PM** She finds a bit of time to do finance-related caregiving tasks
- **emotional & financial strain**

**DANA’S DAY**

- **4 PM** She gets out early to drive her parent to medical appointment or other duties
- **physical & emotional strain**
- **5 PM** She shops for things her parent needs
- **physical, financial & emotional strain**
- **gets unpaid family help**
- **6 PM** She prepares meal for her parent
- **challenging**
- **Preparing ingredients, cooking, cleaning**
- **7 PM** She helps her parent with eating, sometimes her family helps too
- **emotional strain**
- **8 PM** She makes sure her parent takes medications at right time and context
- **emotional strain**
- **gets unpaid family help**
- **9 PM** She spends time with her parent throughout the evening, and helps with getting around the home
- **emotional strain**
- **10 PM**
- **11 PM**

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- **emotional strain**
- **gets unpaid family help**
- **9 PM** She spends time with her parent throughout the evening, and helps with getting around the home
- **emotional strain**
- **10 PM**
- **11 PM**
A day in the life of a family caregiver “Carley”

Carley has been caring for her parent for less than 5 years. She lives near her parent who has a long-term physical condition, and emotional/mental health issues. Carley is employed full time.
CARLEY'S DAY

7 AM
Carley wakes up and starts getting ready for work

8 AM
She calls her parent to chat, emotional strain
and to remind to eat breakfast
"If I go away for a few days, then it becomes a big problem
for me in terms of (my parent) getting a meal"

9 AM
Carley goes to work

10 AM
She calls her parent to remind and to ask about taking medications

11 AM

NOON
Carley eats lunch

1 PM
She helps with her parent's financial & emotional strain
home maintenance issues
Making note of things to be fixed, searching for info, making calls
"(I'm) really acting as intermediary between (my parent)
and various contractors that they're having issues with"

2 PM

3 PM

3 PM
CARLEY'S DAY

4 PM

5 PM
She shops for her parent physical strain
Carley prepares dinner for herself and her family

5 PM
She shops for her parent

6 PM
She keeps her parent company as she cooks

7 PM
She helps her parent with eating

8 PM
She helps her parent with housework
Cleaning, laundry, taking trash out
She helps her parent with paying bills challenging

9 PM

10 PM

11 PM

MIDNIGHT
MORE ABOUT CARLEY

Every week, Carley spends 11 hrs providing direct care & 2.4 hrs looking up related info

Carley doesn't help with transportation often, but spends a lot of time when she does

“One time I had to work on Sunday and had to get (my parent) transportation to church. That was a big thing, I had to call and make sure he was on the bus and stuff like that.”

She occasionally gets unpaid help from family

Carley needs help in the following areas:
- keeping her parent safe at home
- making end-of-life decisions

her parent is mostly independent, but sometimes needs help with instrumental ADLs

“(My parent) needs more help with cognitive things than physical things”

On weekends, she spends time with her parent in person and helps with arranging medications

Carley is highly experienced with using technology in general and is an early adopter

“Sam” and “Lisa” Personas:

A DAY IN THE LIFE OF A FAMILY CAREGIVER

“SAM”

Sam has been caring for her parent for over 5 years.
She lives with her parent who has memory issues and emotional/mental health conditions, and sees a doctor about once per month.
Sam is employed full-time.

A DAY IN THE LIFE OF A FAMILY CAREGIVER

“LISA”

Lisa has been caring for her parent for less than 5 years.
She lives with her parent who has a long-term physical condition, memory problems and behavioral issues.
Lisa used to work full-time, but changed to part-time to meet her caregiving responsibilities.
Caregiver Well-being

Employed family caregivers often must manage not only their caregiving responsibilities, but also work, family, interpersonal relationships, and their own health, well-being, and personal time.

In our study, caregivers answered in-depth questions about: the physical, emotional, and financial burdens related to caregiving; how they manage and cope with stress; and where they seek support.
Even though I make time for myself, there can always be intruding thoughts about what's next: worries, tasks, caregiver scheduling, etc. Some days the demands exceed the amount of time I have available.

By the time I'm done with caregivers duties it's time for bed.

Time limits on how long I can be away from home; constant worry that the phone will ring and it will be an emergency, no ability to take a vacation, loss of sleep, strict limits to what home health aides are allowed to do which leaves more work for me.

Everyone else can flake on caregiving arrangements and MY schedule has to change to accommodate the caregiving. It is just like the mom thing...you can't call in sick as a mom!

To what extent do you struggle to manage your well-being and personal time?
### Effects of Caregiving

**Caregiver's health**
- 37% of caregivers in study are showing signs of depression
- 47% of caregivers in study said caregiving had negative effects on their health

**Family life**
- Does caregiving have a negative effect on the caregiver's family life?
  - Only 7% of daily reports said that caregiving had a negative effect on family life
  - However, when thinking about caregiving overall, 57% reported that caregiving has negatively affected family life
- While caregiving doesn't negatively affect family life everyday, many caregivers are likely to experience negative effects at some point
  - Been unable to do/complete housework
  - Missed family events
  - Got involved in arguments with family
  - Fallen behind in managing own finances
  - Stayed out for several days or longer
  - Other (gave up vacations, strain on marriage, etc.)

**Work life**
- Does caregiving have a negative effect on the caregiver's work life?
  - Only 10.5% of daily reports said that caregiving had a negative effect on work life
  - However, throughout caregiving, 63% reported that caregiving has negatively affected work life
- While caregiving doesn't negatively affect work life everyday, many caregivers are likely to experience negative effects at some point
  - Went in late, left early or took time of duty day
  - Changed to part-time or cut back hours
  - Took a leave of absence
  - Turned down a promotion
  - Got warned about performance/attendance
  - Other (changed position to best avoid caregiving, took a leave of absence for caregiving, etc.)

### Strain and Difficulty

**Strain with caregiving**
- Overall, how much of a strain was it for you to help your care recipient today?
  - Physical strain
  - Financial strain
  - Emotional strain
  - Not a strain
  - Very much a strain

**Difficulty**
- Not challenging
- Very challenging

*Based on 834 daily reports, it is shown that after several years of caregiving, caregivers still find it challenging to help their care recipients, and find their responsibilities emotionally strenuous.*

**Stress**
- Stress level
  - 2.34 Average stress score among caregivers in study
  - 1.47-1.97 Average stress score among the general population

*Caregivers are significantly more stressed than the general population! (Measured in a 1-5 scale)*

**Help & support**
- Almost everyone (12 out of 20 caregivers) said they need help
  - Keeping care recipient safe at home
  - Managing caregiver’s emotional & physical stress
  - Making end-of-life decisions
  - Managing incontinence or toileting problems
  - Managing challenging behaviors
  - Other

*Finding resources, coordinating between doctors, understanding insurance terms, finding respite care, keeping care recipient engaged and cognitively active, finding available services, etc.*

**The Gerontological Society of America**
How would you rate your health and well-being?

To what degree do you feel your caregiving responsibilities limit your ability/availability to . . .
To what degree do you feel your caregiving responsibilities limit your ability/availability to . . .

<table>
<thead>
<tr>
<th>Activity</th>
<th>Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Eat healthy</td>
<td>1.5</td>
</tr>
<tr>
<td>Religious practice</td>
<td>2.0</td>
</tr>
<tr>
<td>Personal care</td>
<td>2.0</td>
</tr>
<tr>
<td>Get myself organized</td>
<td>2.5</td>
</tr>
<tr>
<td>Physical exercise</td>
<td>2.5</td>
</tr>
<tr>
<td>See family</td>
<td>2.5</td>
</tr>
<tr>
<td>Get enough sleep</td>
<td>2.5</td>
</tr>
<tr>
<td>Organize my time</td>
<td>2.5</td>
</tr>
<tr>
<td>See romantic partner</td>
<td>2.5</td>
</tr>
<tr>
<td>Do a hobby</td>
<td>3.0</td>
</tr>
<tr>
<td>See friends</td>
<td>3.0</td>
</tr>
</tbody>
</table>

Please describe how you typically manage your own well-being and find personal time as a caregiver.

I always take advantage of the 20 hours a week of respite time I have allotted to me by leaving the house, even if it is just to go off by myself for some quiet time.

It is not easy. I feel like I am on the go from the minute my feet hit the floor. There is always something to do, and there is always a fire to put out. I usually close myself off in my room, or use an iPod to block out my surroundings.

I don't usually get any personal time. Really the only time I get to myself is when I take a shower, or driving to and from work. . .

I have not managed my own time very well. I have been told that I am unreliable and always tired.
Which of the following activities do you do to reduce stress?

- Watching TV or movies: 75%
- Walking: 75%
- Physical exercise: 71%
- Spending time alone: 61%
- Reading: 61%
- Music (playing or listening): 54%
- Meditation: 43%
- Spending time with pets: 43%
- Praying or engaging in religious practice: 43%
- Spending time with family or friends: 40%
- Traveling: 40%

Caregivers are more likely to engage in activities that don’t involve social interactions to reduce stress.

When you have difficulties or stress as a caregiver, where do you go for support?

- Friend: 64%
- Romantic partner: 43%
- Family member: 29%
- Counselor or therapist: 25%
- In-person support group: 11%
- Colleague: 11%
- Medical professional: 11%
- Online community: 7%

Caregivers are more likely to seek social and emotional support compared to functional or informational support.
### Caregiving demands

Family caregivers often assist their care recipients with activities and tasks across different domains. 

<table>
<thead>
<tr>
<th>Basic ADLs</th>
<th>Instrumental ADLs</th>
</tr>
</thead>
<tbody>
<tr>
<td>Getting in and out of beds and chairs</td>
<td>Getting medications, pills, or injections</td>
</tr>
<tr>
<td>Getting dressed</td>
<td>43%</td>
</tr>
<tr>
<td>Getting to and from the toilet</td>
<td>76%</td>
</tr>
<tr>
<td>Bathing or showering</td>
<td></td>
</tr>
<tr>
<td>Feeding</td>
<td>27%</td>
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<tr>
<td>Dealing with incontinence or diapers</td>
<td>26%</td>
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<tr>
<td>16%</td>
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<td>32%</td>
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<td>16%</td>
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</table>
Caregiving demands: our sample

Family caregivers often assist their care recipients with activities and tasks across different domains.

Caregiving tasks range from
- assisting with personal care activities and fundamental functioning;
- instrumental activities for independent living; to
- interacting with providers and agencies, and acting on the care recipient’s behalf.

Data collection

Daily surveys
- Details of various caregiving tasks carried out each day
- Task type and sub-level activities
- Frequency of each task, and time of day (including night time)
- Amount of time spent on each caregiving task
- Level of difficulty, and degree of strain (physical, financial and emotional)
- Shared responsibilities, if any
Data collection

Weekly surveys
- Week 5. Transportation
- Week 6. Caregiver well-being
- Week 7. Technology
- Week 8. Social networks and communication
- Week 9. Information seeking
- Week 10. Time management
- Week 11. Medication management
- Week 12. Finances

Caregiving tasks

- Keeping company
- Preparing meals
- Transportation
- Arranging outside services
- Bathing/showering
- Dealing with incontinence or diapers
- Getting in/out of beds/chairs
- Getting dressed
- Giving or managing medication
- Managing finances
- Managing home maintenance
- Housework
- Grocery or other shopping

Low strain
High strain

Less frequent
More frequent
Task dashboards

Task details
• Visual representation of data to effectively communicate information
• Associations between activity and sub-activity types, scheduling, load and strain, and help and support

Comparing between different situations
• Looking into specific segments (e.g. caregivers living with their care recipient who has memory issues, married caregivers who are employed full-time, etc.)
• Exploring specific conditions (e.g. weekdays vs. weekends, early in study vs. last few days of study, etc.)

Let’s see some examples!
Helping with bathing or showering

Caregiver and care recipient live together

They live apart from each other

Helping with getting dressed and undressed

“Dana” Care recipient has memory issues and long-term physical conditions

“Sam” Care recipient has memory issues and emotional/mental conditions
Helping with getting dressed and undressed

“Dana” Care recipient has memory issues and long-term physical conditions

“Sam” Care recipient has memory issues and emotional/mental conditions

Helping with grocery and other shopping

Weekday

Weekend
Additional results

Understanding related issues
• Use of products, technologies and services to assist various tasks
• Getting help, support and information: emotional, social, functional and financial
• Organizing, managing and setting priorities among various demands

Understanding caregiver needs
• Ideas for improving the caregiving experience
• Ideas for new and better ways of doing things
• Finding experiences and situations that can be improved with new services or resources

Let’s see some examples!

Additional results – services

- Only a limited number of caregivers are using services and tools available to them
- Lack of awareness and knowledge
- Convenience and cost-related barriers
- Trust issues
Additional results – information

- Available sources are being under-utilized
- No central location for getting information and resources
- Doctors and pharmacists: possible sources or entry points for additional info

Additional results – associations

- Transportation and finances are closely associated with other tasks
- Support in these areas may have positive effects on other domains
Qualitative data describing issues and needs

“As my care recipient’s dementia has progressed, he has become less faithful about showering. I notate a calendar to help myself remember when he showered last. Without this system, he would go days without bathing.”

“She (care recipient) discusses what we should prepare, which ingredients to use, and often checks with me to confirm that the way she is preparing the food is correct. She has been having trouble remembering things and cooking is more difficult as a result.”

“I can’t quit my job every time he (care recipient) needs to be somewhere. I just felt really lost and frustrated. Even this week he had to miss an appointment because I couldn't get him there, and there wasn’t a volunteer to drive the van. And I don’t have enough extended family members close by to do it.”

“She (care recipient) kept saying that we were taking her money, but we were actually losing money because of taking care of her.”