

Caregivers: Life Changes and Coping Strategies

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Caregivers: Life Changes and Coping Strategies

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About this research

The purpose of this research was to investigate the life changes caregivers between the ages of 40-60 years identify in their own lives and the ways they cope with these changes. We also wanted to understand how they feel about the way they cope. Finally, we want to know how they would spend extra time if they have it and how they think they might be able to carve out additional time for themselves.

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Executive Summary

Becoming a caregiver means many things. One of the most noteworthy is caregivers take on responsibility for assisting another person without getting additional time or resources. When they start caring for someone, most people manage to keep their own life going without major disruptions. But as the person they help needs more support, or has a health crisis, this can change in the blink of an eye. For example, a fall can be life-threatening. On the other hand, for some caregivers time seems to move like a glacier. Care recipients experiencing dementia or Alzheimer’s disease may have a long, slow decline. These are the types of things that can make caregiving unpredictable.

We estimate there are more than 42 million caregivers in the U.S.¹ If 20 per cent of them experience difficulty, this effects a large number of people - more than eight million. The results of this study show a complex picture of how caregivers are doing. While a majority rate nine out of thirteen aspects of their current life high, a substantial proportion rate some life dimensions low.

Life is Good	Life is Not so Good
More than three-fourths of caregivers rate their relationship with the person they assist high.	More than half rate their satisfaction with their weight and their exercise routine low.
Seven in ten caregivers rate their own health high.	One-third of caregivers rate their satisfaction with their work or job low.
Seven in ten caregivers rate their relationship with their friends high.	More than four in ten caregivers rate their satisfaction with their social life low, and one in five rate their relationship with their spouse or partner low.

Most caregivers report things have “stayed the same” for them on these items compared to the way their life was six months before becoming a caregiver. However, overall almost three in ten people (27%) say their life has changed with caregiving, some for better, some for worse. For example, while one in five say their relationship with the person they help has “gotten better,” approximately one in five caregivers say some aspect of their life has “gotten worse” including their:

- Happiness (20%)
- Satisfaction with social life (20%)
- Weight (22%) and,
- Exercise routine (22%).

¹ Caregiving in the U.S. 2004, 2009. National Alliance for Caregiving in collaboration with AARP. Washington, D.C.

The more caregiving a person does, the more likely they are to say their happiness, social life, weight and exercise routine have “gotten worse.”

Caregivers identify few sources of support. Just over half of caregivers say they cope with the difficulties of caregiving through prayer (51%) or seeking support from a partner (51%). Female caregivers are relationship-oriented often relying on an inner circle of friends, siblings, children and medical professionals for support.

In addition, caregivers often have mixed feelings about how they cope with their caregiving responsibilities. While most are “pleased they can help someone” (82%), they also “wish things were different” (68%). While many are “satisfied” (62%) and “proud” (52%) to be caregivers, they often “feel sorry for the person they help” (51%), are “afraid about what might happen” (44%) or “feel other people should help me more” (38%).

When asked to think about how they would spend an extra hour, roughly one-third of caregivers chose a solitary activity such as having;

- “Time alone”,
- “Reading”, and
- “Taking a walk or exercising”.

Relatively few caregivers identified things that would inspire them to achieve and maintain healthy ways of coping with caregiving responsibilities. Similarly, many caregivers had difficulty selecting ways they could find time for themselves from a list of options. It is important to help caregivers and their family members find free resources that are available to assist them through difficult times from organizations like AARP (AARP.org/caregiving), the National Alliance for Caregiving, and community groups.

Looking forward, this study raises many questions for future research. For example, the data suggest that several characteristics may influence how caregivers cope including:

- Ethnicity
- Socio-economic status, and
- Marital status.

Introduction

The purpose of this study is to better understand how caregiving changes the lives of caregivers, how they manage these changes and how they feel they are doing. To achieve these goals, we conducted an on-line survey using GfK Custom Research (Knowledge Networks Knowledge Panel) to obtain responses from 1,036 caregivers between the ages of 40 to 60 years of age between June 14-24, 2013. The margin of error is plus or minus 3.8 percent.

The sample is composed of women (58%) and men (42%) who assist someone age 50+ with at least one activity of daily living or instrumental activity of daily living. On average these caregivers are 51 years old. Most are married (62%), working (63%), Caucasian (68%), the head of their household (85%) and about one-third have completed college (33%). Given the methodology and age-restriction of the sample the demographics differ somewhat from our previous work. *Caregiving in the U.S., 2009* was based on a nationally random sample of 1,397 caregivers 18+ caring for someone age 50+ who completed telephone interviews. Based on this study, we know that nationally caregivers are far more likely to be women than men (67% vs. 33%). The average age of caregivers was 50 years. Most are married (59%), Caucasian (76%), the head of a household. Roughly one-quarter were college graduates (26%) and one in five completed graduate school (20%).

In the current study, we asked caregivers to:

- Rate various parts of their current life,
- Compare their life today with the way it was six months before becoming a caregiver,
- Identify how they cope with changes,
- Express how they feel about the ways they cope,
- Imagine what they would do with extra time (if they had it), and
- Identify how they could carve out additional time for themselves.

Detailed Findings

Most Caregivers Rate Their Lives highly but there are Exceptions

We asked caregivers to rate thirteen different parts of their life. The scale ranged from a score of one representing the “highest score or best score”, to a score of four representing “the lowest or worst score”. The results show that regardless of gender, half or more of the caregivers rate nine out of thirteen parts of their life high (a one or two on a four-point scale see Figure 1 on the next page).

These include the following items rated at the top:

- Their relationship with the person they assist which was rated at the top of the list with more than three-fourths (77%) rating their relationship high.
- Their own physical health with seven in ten (70%) rating it high.
- Their relationship with their friends with roughly seven in ten (69%) rating it high.
- Their happiness with two-thirds (67%) rating it high. This finding is consistent with the findings from a 2012 AARP study that reported 68% of middle-aged and older Americans are “Very Happy” (19%) or “Pretty Happy” (49%).²

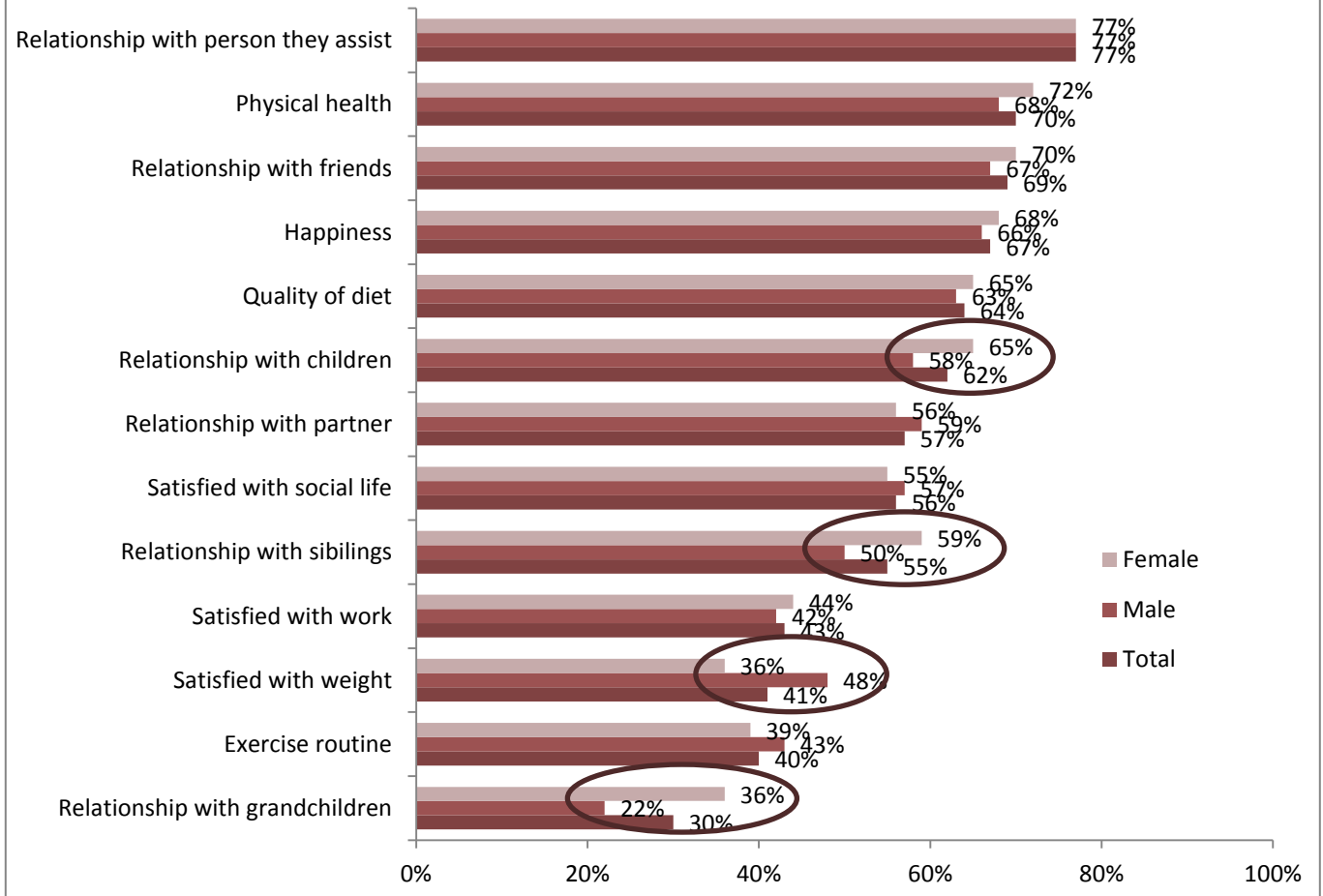
Despite this overall optimistic picture, when we dig into the data we find a substantial proportion of caregivers’ rate some life dimensions low (a 3 or 4 on a four point scale):

- More than half of the caregivers rate their satisfaction with their weight (58%) and their exercise routine (56%) low. Similarly, one-third (34%) rate the quality of their diet as low. This suggests an opportunity exists to help caregivers improve their physical health.
- More than four in ten caregivers rate their social life low (43%).
- One-third rate their satisfaction with their relationship with their siblings low (34%)
- Almost one-third (32%) rate their level of happiness low.

The last three items suggest there is a need to help caregivers with their interpersonal relationships.

² *Beyond Happiness: Thriving*, conducted by Heart + Mind Strategies for AARP in 2012.
Caregivers: Life Changes and Coping Strategies

Figure 1: Proportion of Caregivers who Rate Life Dimensions High (1 or 2 on a 4 point scale)



Source: Caregivers: Life Changes and Coping Strategies, AARP, November, 2013.

Q1: First we would like to know how you would currently rate a variety of parts of your life. Please rate each of the following parts from one to four where one is the highest rating (best) and four is the lowest rating (worst). N = all caregivers.

Figure 1, shows female caregivers are relationship oriented and sometimes hard on themselves.

- Female caregivers are more likely than male caregivers to rate their relationship with their children, siblings, and grandchildren high (circled items in Figure 1). When it comes to themselves, however, female caregivers are more likely than male caregivers to rate their satisfaction with their weight low.

Life Changes

More than half of caregivers say twelve out of thirteen parts of their life “have stayed the same” compared with the way it was six months before becoming a caregiver suggesting some stability.

Figure 2: Proportion of Caregivers who Say Their Life Has Changed

Part of Life	Current	Gotten Better	Stayed the Same	Gotten Worse
Satisfied with relationship to the person they assist	77%	21%	63%	12%
Physical health	70%	13%	68%	17%
Satisfied with relationship with friends	69%	9%	77%	10%
Happiness	67%	14%	63%	20%
Quality of diet	64%	18%	64%	15%
Satisfied with relationship with children (if any)	62%	13%	56%	6%
Satisfied with relationship with spouse/partner (if any)	57%	12%	54%	11%
Satisfied with social life	56%	8%	68%	20%
Satisfied with relationship with siblings	55%	13%	63%	13%
Satisfied with work or job	43%	9%	54%	12%
Satisfied with weight	41%	13%	62%	22%
Exercise routine	40%	16%	58%	22%
Satisfied with relationship with grandchildren (if any)	30%	8%	31%	2%

Source: Caregivers: Life Changes and Coping Strategies, AARP, November, 2013.

Q1: First we would like to know how you would currently rate a variety of parts of your life. Please rate each of the following parts from one to four where one is the highest rating (best) and four is the lowest rating (worst).

Q2: Next, we would like to know how you would compare each part of your life today with the way it was six months before you became a caregiver. Please indicate whether you think it has gotten better, worse, or stayed the same. N = all caregivers.

Most caregivers are satisfied with their relationship with the person they help and most say the relationship has stayed the same. This is the only area that shows relative improvement. About one in five (21%) caregivers’ report their satisfaction “with the relationship to the person they assist” has “gotten better.” They are typically:

- Younger (28% of those 40-49 years vs. 17% of those 50-60),
- Females (24% are female vs. 17% of males) and
- Unmarried (27% of these caregivers say they are widowed or divorced vs. 18% who are married or currently living with a significant other).

These characteristics suggest these caregivers may have more time to devote to caregiving than caregivers with other characteristics.

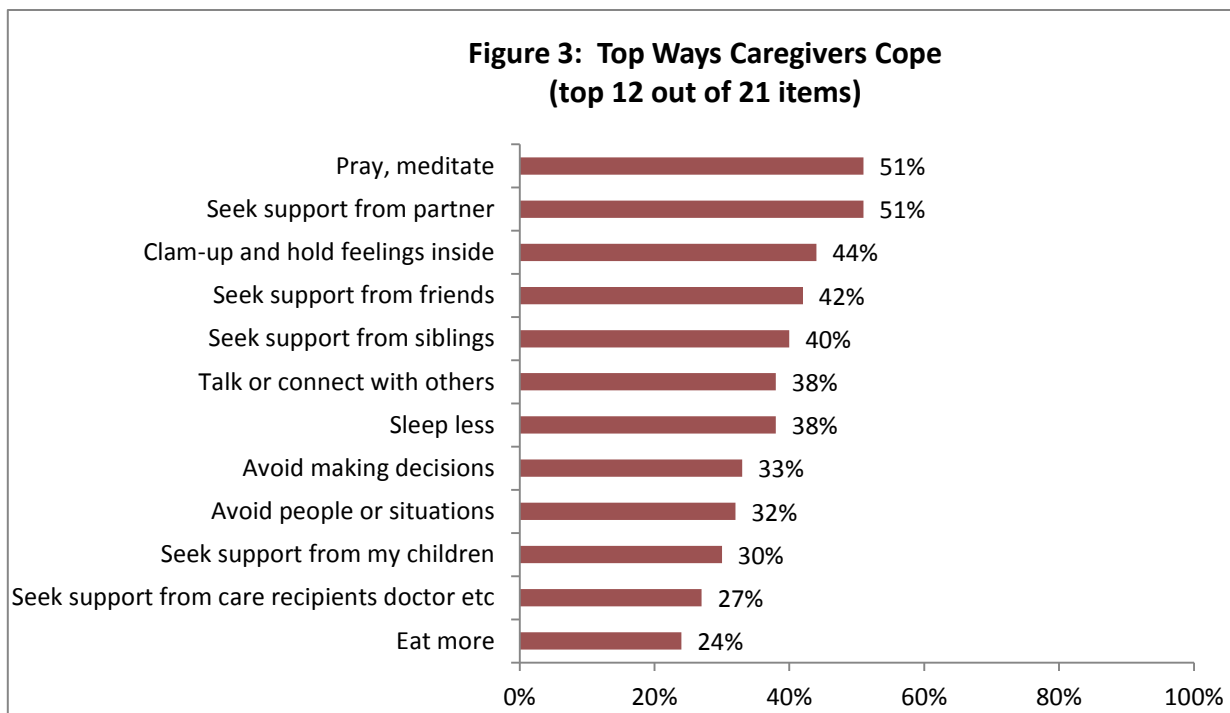
One in five caregivers say some part of their life has “gotten worse” (Figure 2). These are:

- Happiness (20%)
- Satisfaction with social life (20%)
- Weight (22%) and,
- Exercise routine (22%).

Coping with Difficult Caregiving Situations Varies

Slightly more than half of caregivers say they cope with their responsibilities through prayer, meditation (51%) or engaging in other spiritual practices (Figure 3 on the next page).

Roughly half (51%) of caregivers say they seek support from a partner or spouse and this increases to almost two-thirds (67%) among those who are married.

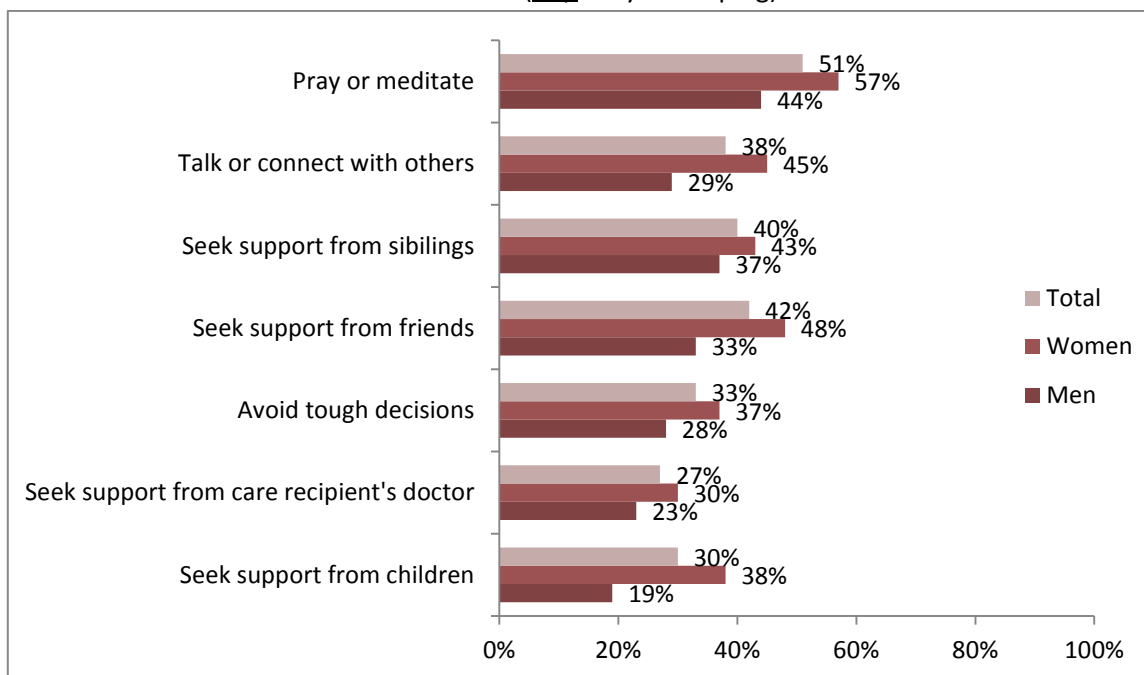


Source: Caregivers: Life Changes and Coping Strategies, AARP, November, 2013.

Q3. How do you cope with difficult caregiving situations when you feel frustrated with the way things are going? Do you? N = all caregivers

Not surprisingly, female caregivers (57%) are more likely than male caregivers (44%) to pray or meditate. Few caregivers wrote in additional options which included “write about my experiences”, “clean/yard work”, “take medication”, “listen to ambient music” and “empathy.”

Figure 4: Proportion of Men and women using Different Ways to Cope
(Top Ways of Coping)



Source: Caregivers: Life Changes and Coping Strategies, AARP, November, 2013.

Q3. How do you cope with difficult caregiving situations when you feel frustrated with the way things are going? Do you? N = all caregivers.

Female caregivers are relationship oriented (Figure 4). They are more likely than male caregivers to say they talk or connect with others (45% vs. 29%). Female caregivers are more likely than male caregivers to seek support from:

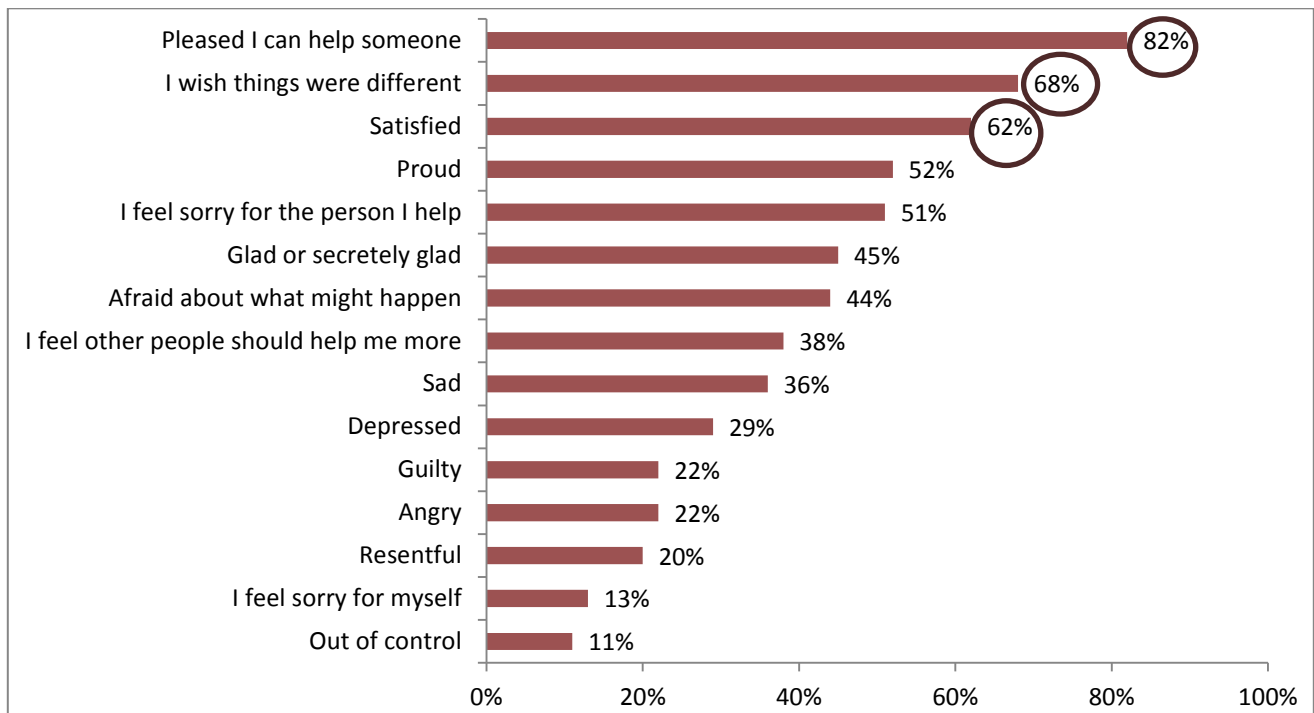
- Friends (48% vs. 33%),
- Siblings (43% vs. 37%),
- Their children (38% vs. 19%),
- Their own doctor (23% vs. 15%), and
- Their care recipients doctor (30% vs. 23%).

Female caregivers are also more likely than male caregivers to use some less productive coping mechanisms such as to “avoid making tough decisions by putting them off” (37% vs. 28%), and to say they smoke more (16%) than male caregivers (9%). Male caregivers (21%) are more likely than female caregivers (14%) to say they exercise more.

Caregivers Have Mixed Feelings about How They Cope

Caregivers have mixed feelings about how they cope with difficult caregiving situations (Figure 5). The vast majority are “pleased they can help someone”. However, two-thirds say they “wish things were different”. Six in ten say they are “satisfied”, yet more than half say “they feel sorry for the person (they) help”, and more than four in ten say they are “afraid about what might happen”. More than one-third report they “feel other people should help me more” or that they feel “sad”. Three in ten say they are “depressed” and about one in five say they feel “guilty”, “angry”, or “resentful”.

Figure 5: How Caregivers Feel About Coping



Source: Caregivers: Life Changes and Coping Strategies, AARP, November, 2013.

Q4. How do you feel about how you cope with difficult caregiving situations? N = all caregivers.

New caregivers are more likely to be pleased with role.

- More people (88%) who have become caregivers in the past year than caregivers who have provided two or more years of care (80%) say they are “pleased they can help someone”. Similarly, more caregivers who have provided care for a shorter period of time compared to those who have provided care longer say they are “satisfied” (68% of those providing 1 to 2 years compared to those 58% of those who provide care for more than two years).

Q4. How do you feel about how you cope with difficult caregiving situations? Verbatim comments.

“A mix of feelings at different times”

“All (feelings listed) apply at times”

“Torn in multiple directions”

“Wish it never had to happen”

“Wishing I never started this!”

“Wonder why me?”

“Empty”

“Blessed”

“Very short-tempered”

“Helpless”

“prayerful”

“Family duty”

“Very proud”

“I would like other family members to visit more and offer assistance”

“I would like to figure out how to have siblings cooperate in caring for parents”

“I realize we will all be there one day”

“do my best”

I do my best, what more can I do?
Therefore I have peace.”

“trustful”

“I wish he would stop being so nasty and hateful”

“20+ years of experience”

“I am not really very involved with much of the caregiving very often; she is in a nursing home. It would be taken care of if I didn't do it.”

Tight finances can affect how caregivers feel about their role.

➤ Lower income caregivers are more likely than caregivers with higher incomes to say they are:

➤ “Depressed” (38% of those with a household income of \$15,000-\$34,999 vs. 23% of those with \$75,000+).

➤ “Afraid of what might happen” (51% of those with \$15,000-\$34,999 vs. 44% of those with \$75,000+).

Caregivers' with more caregiving responsibility (78%) are more likely than caregivers' with less caregiving responsibility (62% and 65%) to say they “wish things were different”

Caregivers who have been in this role for 1-2 years are more likely than those who have been caregivers for 2+ years (58%) to say they are “satisfied” (68%).

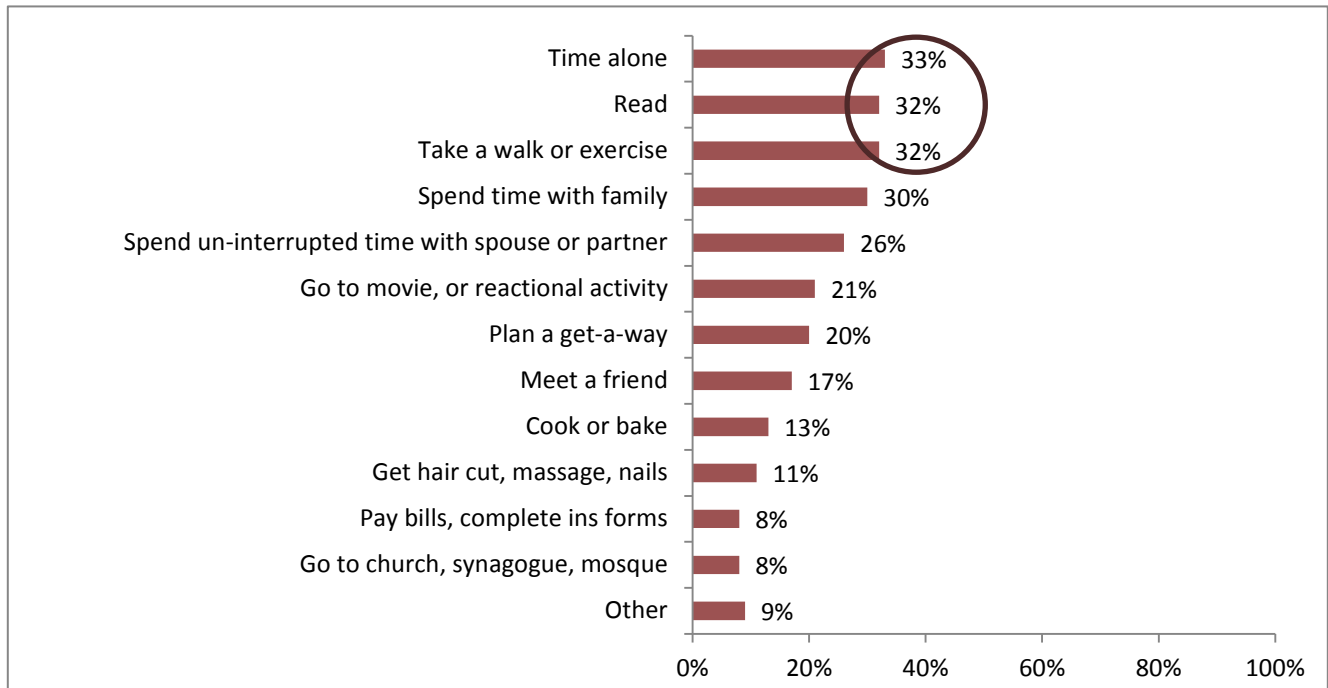
Female caregivers (27%) are more likely than male (16%) to feel “guilty”. Caregivers who have provided care for the longest periods of time are also more likely than relatively new caregivers to say they feel “guilty” (27% of those who have been caregivers for 2 year or more vs. 20% those who have been caregivers less than one year, and 14% who have been caregivers for 1-2 years).

Female caregivers (23%) are more likely than male caregivers (15%) to say they feel “resentful”. Caregivers who have a higher level of burden are also more likely than those with a lower level of burden to say they feel “resentful” (37% of those at level 5 vs. 14% at level 1 and 25% at level 2).

Caregivers Would Spend Extra Time in Solitary Pursuits

We asked caregivers how they would spend an extra hour if they had it, and asked them to choose their top three choices. Roughly one-third of caregivers chose a solitary activity such as spending time alone, reading, or taking a walk or exercising (Figure 6). Three in ten chose to spend time with their family, and approximately one-quarter would spend un-interrupted time with their spouse or partner. Roughly one in five would go to a movie or recreational activity, or plan a get-away trip.

Figure 6: Top Ways to Spend an Extra Hour



Source: Caregivers: Life Changes and Coping Strategies, AARP, November, 2013.

Q5. If you had an extra hour, what would you most like to do with that time (select three answers)? N = all caregivers.

Female caregivers were more likely than male caregivers to select the following activities:

- “Put my feet up and read the newspaper (book or magazine)” (38% vs. 23%).
- “Meet a friend” (19% vs. 14%).
- “Get my hair cut, have a massage, or have my nails done” (16% vs. 5%).
- “Cook or bake” (15% vs. 10%).

Male caregivers were more likely than female caregivers to select the following activities:

- Spend un-interrupted time with a spouse or partner (32% vs. 22%).
- Go to a movie, sporting event, or other recreational activity (26% vs. 18%).

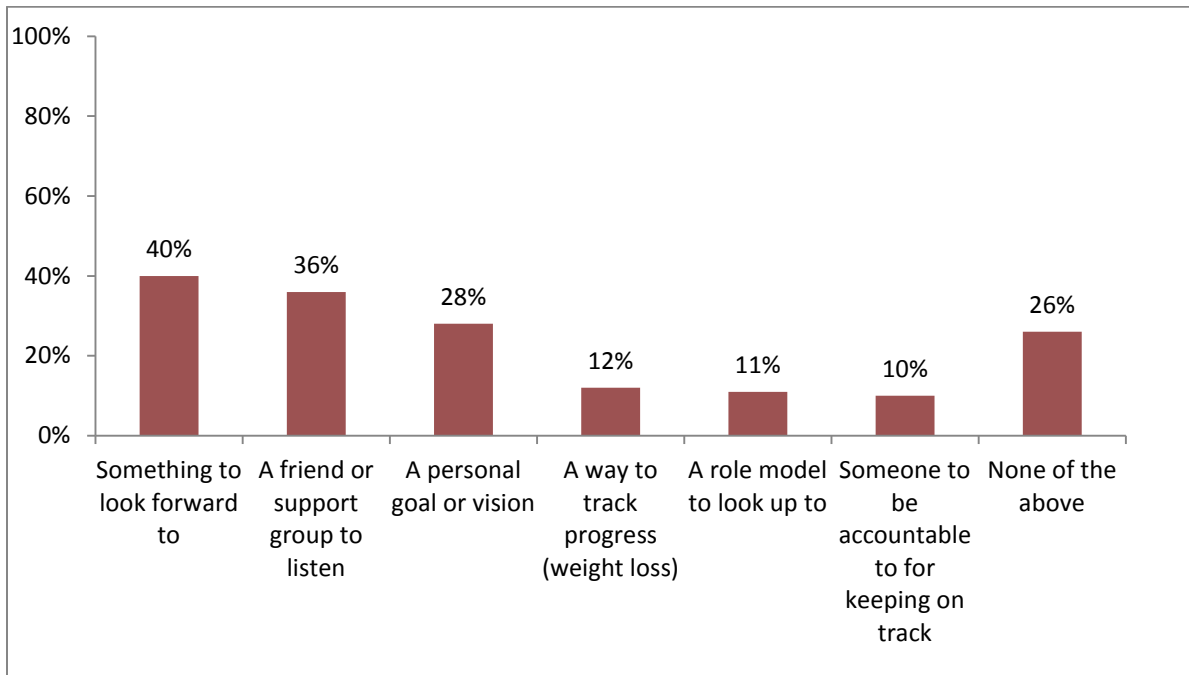
Marital Status influences favorite pastime:

- Married caregivers are more likely than single caregivers to say they would “spend time with family” (35% vs. 12%).

Few Caregivers Find Inspiration for Healthy Living

Relatively few caregivers identified things that would inspire them to achieve and maintain healthy ways of coping with caregiving responsibilities (Figure 7). Four in ten say having “something to look forward to” would help inspire them, more than one-third said having “a friend or support group to listen to them” would help inspire them, and more than one-quarter said having “a personal goal or vision” would inspire them. Few had other ideas and more than one-quarter said none of the above.

Figure 7: Finding Inspiration



Source: Caregivers: Life Changes and Coping Strategies, AARP, November, 2013.

Q6. What would inspire you to achieve and maintain healthy ways to cope with caregiving? (select all that apply). N = all caregivers.

Female caregivers (44%) are more likely than male caregivers (35%) to say they would be inspired to achieve and maintain healthy ways to cope with caregiving by “having something to look forward to such as a special occasion or celebration.”

**Q6. What would inspire you to achieve and maintain healthy ways to cope with caregiving?
Condensed and verbatim remarks.**

Getting more help or more time were frequent themes.

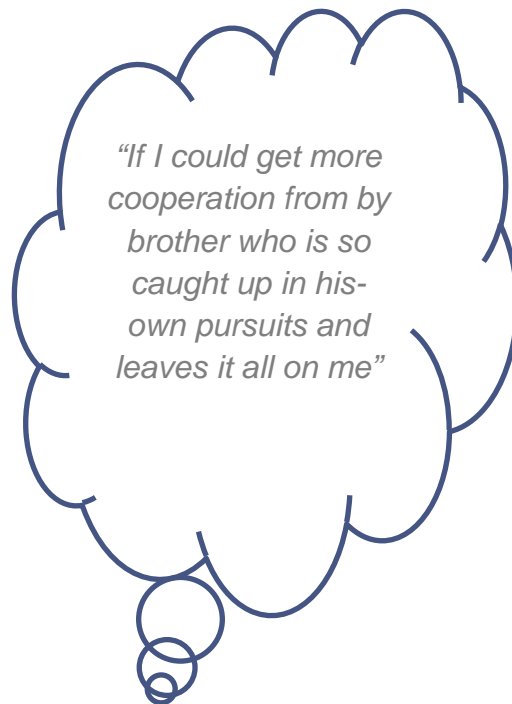
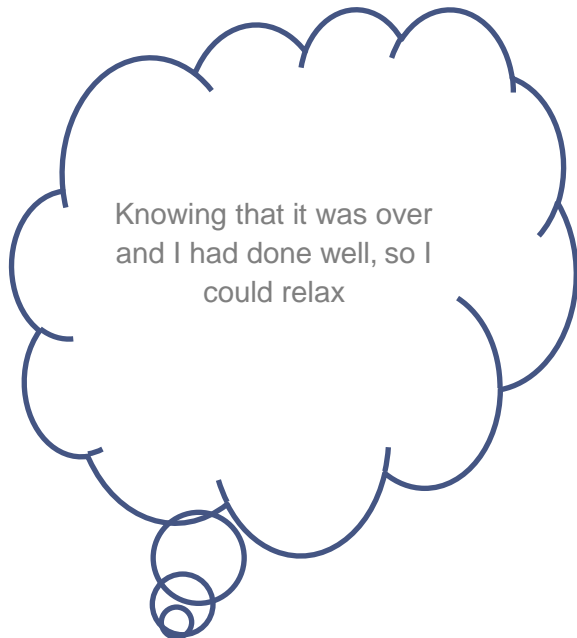
More help, support, interest in cooperating, or unity from other family members (especially from siblings) was mentioned often.

Information about how to help

Older caregivers (29% of those 50-60 years of age) are more likely than younger caregivers (20%) to say “none of the above items” would inspire them to achieve and maintain healthy ways to cope with caregiving.

➤ Caregivers who are widowed or divorced are more likely to be motivated by:

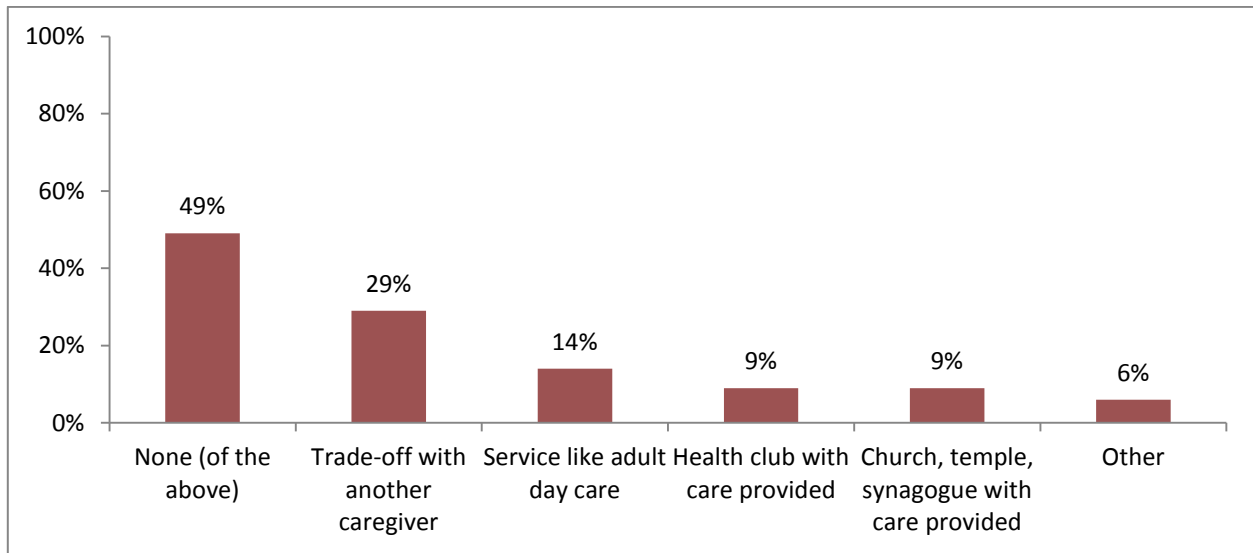
➤ “Someone to be accountable to for keeping on track (15% vs. 8% of those who are married or living with a partner).



Caregivers Have a Hard Time Identifying How to Find Time

Many caregivers have a hard time identifying actions that might help them find an extra hour or so for themselves (Figure 8). Almost half told us that none of the things we suggested would help them. Although, approximately three in ten said being able to “trade-off” caregiving responsibilities with another caregiver is something that could help them in this regard.

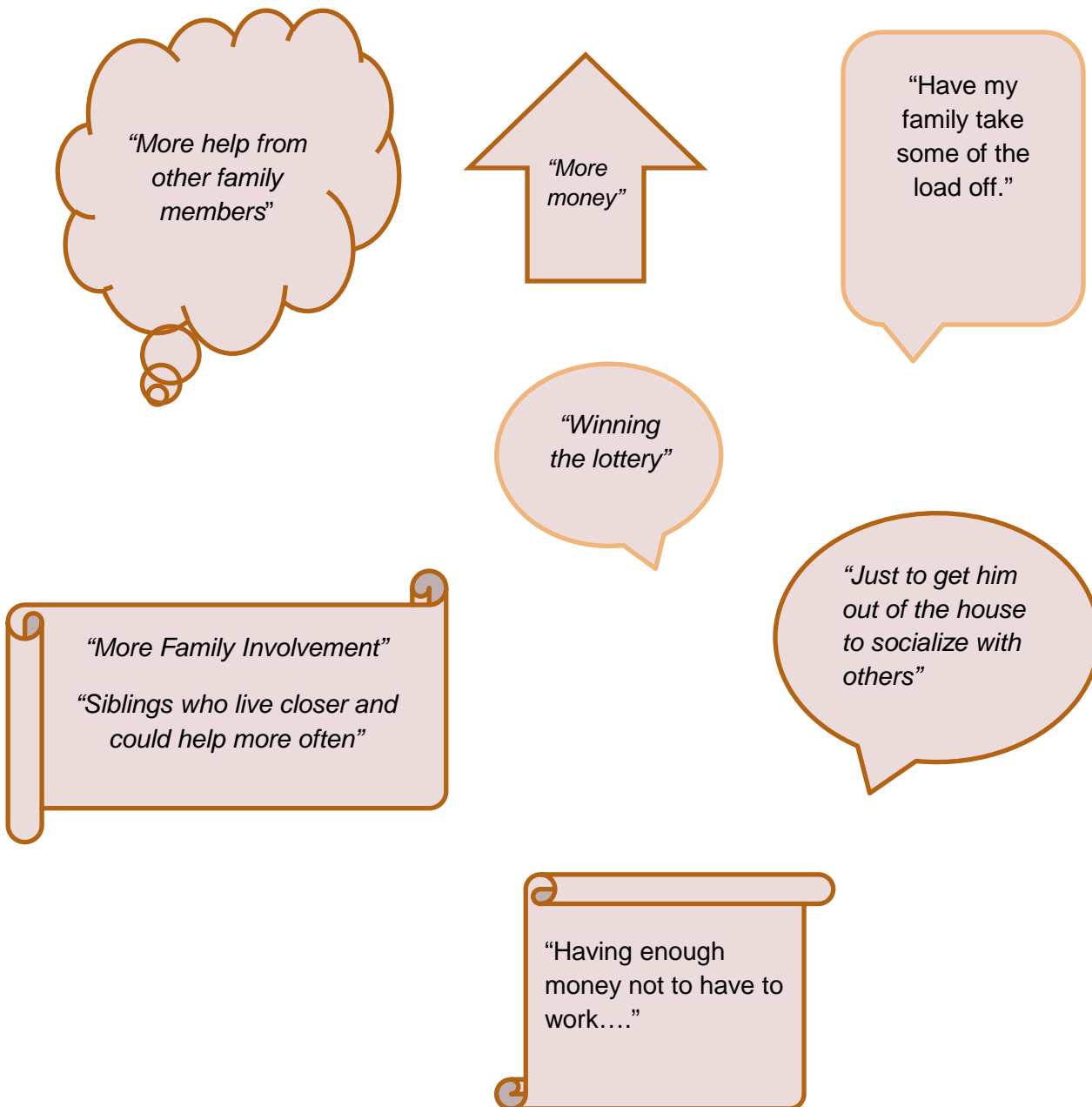
Figure 8: Finding Time for Myself



Source: Caregivers: Life Changes and Coping Strategies, AARP, November, 2013.

Q7. Which of the following would help you find more time for yourself (select all that apply)? N = all caregivers.

The following “thought bubbles” reflect the qualitative comments we received from caregivers in response to the question about how they could find more time for themselves.



Next Steps

Relatively few caregivers:

- Identified things that would inspire them to achieve and maintain healthy ways of coping with caregiving responsibilities, and
- Many caregivers had difficulty selecting ways they could find time for themselves from a list of options.

Consequently, it is important to help caregivers and their family members find free resources that are available to assist them through difficult times from organizations like AARP (AARP.org/caregiving), the National Alliance for Caregiving, and community groups.

In addition, future research should also attempt to boost the size of the ethnic and low-income samples because these factors are likely to influence caregiver coping. It would also be helpful to better understand the “career trajectory of a caregiver” and whether there are different trajectories depending on the care recipient’s needs.

Appendix 1: Gender and Level of Burden

Figure 9: Proportion of Caregivers by Gender and Level of Burden

Level of Burden	Male	Female	Total
1 or 2 (low)	67%	56%	61%
3	18%	16%	17%
4 or 5 (high)	15%	27%	22%
Total	100%	100%	100%

Source: Caregivers: Life Changes and Coping Strategies, AARP, November, 2013
 $\chi^2 = 23$, with 4 degrees of freedom, is significant at $p = .000$ (two sided).

Based on Caregiving in the U.S., 2009 by NAC in Collaboration with AARP, we know that among a representative sample of caregivers 18+ caring for those 50+ one-third (32%) have a high level of burden (9% at level 5 and 23% at level 4), one in five (20%) have a medium level of burden (level 3), and more than four in ten (45%) have a low level of burden (19% at level 2 and 27% at level 1).

Appendix 2: Caregivers Life Change Linked with Level of Burden

Caregiving responsibilities are measured by a level of burden index. This measure is a five-point scale ranging from a low of one to a high of five (Figure 4). It is based on the number of hours of care the caregiver reports providing in a typical week and the number of activities of daily living or instrumental activities of daily they tell us they perform. The level of burden is the characteristic that distinguishes caregivers from non-caregivers. As Figure 9 shows, most caregivers have a low level of burden (61% at level 1 and 2).

While we anticipated level of burden will help explain the changes caregivers report, we found level of burden is not equally distributed by gender. Female caregivers (27%) in this study are significantly more likely to have a high level of burden (4 or 5) than male caregivers (15%) and the reverse also holds showing male caregivers (67%) are more likely to have a low level of burden (1 or 2) than female caregivers (56%). The small proportion of caregivers at the highest level of burden (level 5) means we have few caregivers in this category indicating caution when interpreting the results for level 5 caregivers.

Change in Caregiver Happiness: Figure 10 shows that few caregivers with a *low level of burden* say their level of happiness “got worse” while more than one-third of caregivers with a *high level of burden* say their happiness changed for the worse. This table also shows that almost three-fourths caregivers with a *low level of burden* say their happiness “stayed the same”. Although a relatively small proportion of caregivers have a *high level of burden*, they are more likely to say their happiness “got worse” than caregivers with a low level of burden. Based on our analysis, we conclude that regardless of gender, caregiver level of burden and change in happiness are related.

Figure 10: Total Caregivers Change in Happiness by Level of Burden (n=1002)

Happiness Change	Low Burden (Levels 1+2)	Medium Burden (Level 3)	High Burden (Level 4+5)	Total
Got Worse % w/in newLOB	14% (n=82)	27% (n=48)	36% (n=81)	21% (n=211)
Stayed the Same % w/in newLOB	74% (n=446)	56% (n=98)	47% (n=106)	65% (n=650)
Got Better % w/in newLOB	12% (n=74)	17% (n=30)	17% (n=37)	14% (n=141)
Total % w/in newLOB % Total	100% (n=602)	100% (n=176)	100% (n=224)	100% (n=1002)

Source: Caregivers: Life Changes and Coping Strategies, AARP, November, 2013. $\chi^2=68$, 4df, $p=.000$.

In summary, having lighter caregiver responsibilities equates with being happy and satisfied with life.

- Caregivers with a low level of burden are more likely than caregivers with a high level of burden to say they are “happy” (74% of level one vs. 61% at level two, 60% at level three, 63% at level four, and 60% at level five). Caregivers with a low level of burden are also more likely than caregivers with a high level of burden to say they are “satisfied with their social life” (64% of level one vs. 54% of level three, 43% of level four, and only 40% of level five).

Change in Satisfaction with Social Life

Figure 11 shows that few caregivers with a *low level of burden* say their social life “got worse” while more than one-third of caregivers with a *high level of burden* say their social life “got worse”. This Figure also shows that more than three-fourths caregivers with a *low level of burden* say their social life “stayed the same”. Although a relatively small proportion of caregivers have a *high level of burden*, they are more likely to say their social life “got worse” than caregivers with a low level of burden. Based on our analysis, we conclude that regardless of gender, caregiver level of burden and change in social life are related.

Figure 11: Total Caregivers Change in Social Life by Level of Burden

(n=999)

Social Life Change	Low Burden (Levels 1+2)	Medium Burden (Level 3)	High Burden (Level 4+5)	Total
Got Worse % w/in newLOB	14% (84)	27% (46)	36% (n=80)	21% (n=210)
Stayed the Same % w/in newLOB	78% (n=471)	62% (n=108)	55% (n=122)	70% (701)
Got Better % w/in newLOB	8% (n=50)	11% (n=19)	9% (n=19)	9% (n=88)
Total % w/in newLOB % Total	100% (n=605)	100% (n=173)	100% (n=221)	100% (n=999)

Source: Caregivers: Life Changes and Coping Strategies, AARP, November, 2013. $\chi^2=56, 4df, p=.000$.

Change in Weight

Table 12 shows that few caregivers with a *low level of burden* say their weight “got worse” while one-third of *high level of burden* caregivers’ report their weight “got worse”. This table also shows that seven in ten caregivers with a *low level of burden* say their weight stayed the same. Although a relatively small proportion of caregivers have a *high level of burden*, they are more likely to say their weight got “worse” than caregivers with a low level of burden. Based on our analysis, we conclude that regardless of gender, caregiver level of burden and change in weight are related.

Figure 12: Total Caregivers Change in Weight by Level of Burden

(n=1006)

Weight Change	Low Burden (Levels 1+2)	Medium Burden (Level 3)	High Burden (Level 4+5)	Total
Got Worse % w/in newLOB	18% (n=110)	28% (n=48)	32% (n=72)	23% (n=230)
Stayed the Same % w/in newLOB	70% N=429	53% N=92	54% N=120	64% N=641
Got Better % w/in newLOB	12% (n=70)	20% (n=34)	14% (n=31)	13% (n=135)
Total % w/in newLOB % Total	100% (n=609)	100% (n=174)	100% (n=223)	100% (n=1006)

Source: Caregivers: Life Changes and Coping Strategies, AARP, November, 2013. $X^2=34$, 4df, $p=.000$.

Change in Exercise Routine

Table 13 shows that few caregivers with a *low level of burden* say their exercise routine “got worse” while one-third of high level of burden caregivers say their exercise routine “got worse”. This table also shows that three-fourths of caregivers with a low level of burden say their exercise routine “stayed the same”. Although a relatively small proportion of caregivers have a high level of burden, they are more likely to say their exercise routine “got worse” than caregivers with a low level of burden. Based on our analysis, we conclude that regardless of gender, caregiver level of burden and change in exercise routine are related.

Table 13: Total Caregivers Change in Exercise Routine by Level of Burden

(n=999)

Exercise Change	Low Burden (Levels 1+2)	Medium Burden (Level 3)	High Burden (Level 4+5)	Total
Got Worse % w/in newLOB	14% (n=84)	27% (n=46)	36% (n=80)	21% (n=210)
Stayed the Same % w/in newLOB	78% (n=471)	62% (n=108)	55% (n=122)	70% (n=701)
Got Better % w/in newLOB	8% (n=50)	11% (n=19)	9% (n=19)	9% (n=88)
Total % w/in newLOB % Total	100% (n=605)	100% (n=173)	100% (n=221)	100% (n=999)

Source: Caregivers: Life Changes and Coping Strategies, AARP, November, 2013. $X^2=56$, 4df, $p=.000$.

Caregivers who have a higher level of burden are more likely than caregivers with a low level of burden to be able to ways to find time for themselves. Caregivers with higher levels of burden are more likely to say the following four things would help them find time for themselves. These are:

- “Knowing another caregiver who is willing to trade-of watching both of the people we help so that we each have regular ‘free’ time to spend as we want” (39% of level 4 and 46% of level 5 vs. 24% of level 1, and 27% of level 2). This strategy is also more likely to be selected by younger caregivers (39% of those 40-49 years vs. 24% of those 50-60 years).
- “Having a health club or gym provide care for the person I help while I work out is a strategy that could help them find time for themselves (14% of level 4 and 16% of level 5 vs. 6% of level 1).

- “Having a church, temple, or synagogue that provides care for the person I help while I attend services (22% of level 5, 14% of level 4, and 15% of level 3 vs. 3% of level 1 and 10% of level 2).

Conversely, caregivers with a low level of burden are more likely than those with a high level of burden to say they none of the above options would help them (58% of level 1 caregivers, and 54% of level 2 caregivers vs. 31% of level 4 and 34% of level 5 caregivers).

Life Change and Level of Burden by Gender

Figure 14: Female Caregivers Change in Happiness by Level of Burden
(n=577)

Happiness Change	Low Burden (Levels 1+2)	Medium Burden (Level 3)	High Burden (Level 4+5)	Total
Got Worse % w/in newLOB	15% (n=49)	32% (n=31)	35% (n=56)	24% (n=136)
Stayed the Same % w/in newLOB	72% (n=232)	55% (n=53)	46% (n=73)	62% (n=358)
Got Better % w/in newLOB	13% (n=40)	13% (n=13)	19% (n=30)	14% (n=83)
Total % w/in newLOB % Total	100% (n=321)	100% (n=97)	100% (n=159)	100% (n=577)

Source: Caregivers: Life Changes and Coping Strategies, AARP, November, 2013. $\chi^2=34$, 4df, p=.000.

Figure 15: Male Caregivers Change in Happiness by Level of Burden
(n=425)

Happiness Change	Low Burden (Levels 1+2)	Medium Burden (Level 3)	High Burden (Level 4+5)	Total
Got Worse % w/in newLOB	12% (n=33)	22% (n=17)	39% (n=25)	18% (n=75)
Stayed the Same % w/in newLOB	76% (n=214)	57% (n=45)	51% (n=33)	69% (n=292)
Got Better % w/in newLOB	12% (n=34)	22% (n=17%)	11% (n=7)	14% (n=58)
<i>Total</i> % w/in newLOB % Total	100% (n=281)	100% (n=79)	100% (n=65)	100% (n=425)

Source: Caregivers: Life Changes and Coping Strategies, AARP, November, 2013. $\chi^2=37$, 4df, p=.000.

Figure 16: Female Caregivers Change in Social Life by Level of Burden
(n=580)

Social Life Change	Low Burden (Levels 1+2)	Medium Burden (Level 3)	High Burden (Level 4+5)	Total
Got Worse % w/in newLOB	14% (n=46)	31% (n=29)	33% (n=51)	22% (n=126)
Stayed the Same % w/in newLOB	78% (n=257)	59% (n=55)	59% (n=92)	70% (n=404)
Got Better % w/in newLOB	8% (n=26)	11% (n=10)	9% (14)	9% (50)
Total % w/in newLOB	100% (n=329)	100% (n=94)	100% (n=157)	100% (n=580)
% Total				

Source: Caregivers: Life Changes and Coping Strategies, AARP, November, 2013. $X^2=30$, 4df, $p=.000$.

Figure 17: Male Caregivers Change in Social Life by Level of Burden
(n=419)

Social Life Change	Low Burden (Levels 1+2)	Medium Burden (Level 3)	High Burden (Level 4+5)	Total
Got Worse % w/in newLOB	14% (n=38)	22% (n=17)	45% (n=29)	20% (n=84)
Stayed the Same % w/in newLOB	78% (n=214)	67% (n=53)	47% (n=30)	71% (n=297)
Got Better % w/in newLOB	9% (n=24)	11% (n=9)	8% (n=5)	9% (n=38)
Total % w/in newLOB	100% (n=276)	100% (n=79)	100% (n=64)	100% (n=419)
% Total				

Source: Caregivers: Life Changes and Coping Strategies, AARP, November, 2013. $X^2=34$, 4df, $p=.000$.

Figure 18: Female Caregivers Change in Weight by Level of Burden
(n=580)

Weight Change	Low Burden (Levels 1+2)	Medium Burden (Level 3)	High Burden (Level 4+5)	Total
Got Worse % w/in newLOB	21% (n=69)	39% (n=38)	32% (n=50)	27% (n=157)
Stayed the Same % w/in newLOB	69% (n=224)	43% (n=42)	55% (n=87)	61% (n=353)
Got Better % w/in newLOB	10% (n=32)	18% (n=17)	13% (n=21)	12% (n=70)
Total % w/in newLOB % Total	100% (n=325)	100% (n=97)	100% (n=158)	100% (n=580)

Source: Caregivers: Life Changes and Coping Strategies, AARP, November, 2013. $X^2=24$, 4df, $p=.000$.

Figure 19: Male Caregivers Change in Weight by Level of Burden
(n=426)

Weight change	Low Burden (Levels 1+2)	Medium Burden (Level 3)	High Burden (Level 4+5)	Total
Got Worse % w/in newLOB	14% (n=41)	13% (n=10)	34% (n=22)	17% (n=73)
Stayed the Same % w/in newLOB	72% (n=205)	65% (n=50)	51% (n=33)	68% (n=288)
Got Better % w/in newLOB	13% (n=38)	22% (n=17)	15% (n=10)	15% (n=65)
Total % w/in newLOB % Total	100% (n=284)	100% (n=77)	100% (n=65)	100% (n=426)

Source: Caregivers: Life Changes and Coping Strategies, AARP, November, 2013. $X^2=19$, 4df, $p=.001$.

Figure 20: Female Caregivers Change in Exercise Routine by Level of Burden
(n=580)

Exercise Routine Change	Low Burden (Levels 1+2)	Medium Burden (Level 3)	High Burden (Level 4+5)	Total
Got Worse % w/in newLOB	14% (n=46)	31% (n=29)	33% (n=51)	22% (n=126)
Stayed the Same % w/in newLOB	78% (n=257)	59% (n=55)	59% (n=92)	70% (n=404)
Got Better % w/in newLOB	8% (n=26)	11% (n=10)	9% (n=14)	9% (n=50)
Total % w/in newLOB % Total	100% (n=329)	100% (n=94)	100% (n=157)	100% (n=580)

Source: Caregivers: Life Changes and Coping Strategies, AARP, November, 2013. $X^2=30$, 4df, $p=.000$.

Figure 21: Male Caregivers Change in Exercise Routine by Level of Burden
(n=419)

Exercise Routine Change	Low Burden (Levels 1+2)	Medium Burden (Level 3)	High Burden (Level 4+5)	Total
Got Worse % w/in newLOB	14% (n=38)	22% (n=17)	45% (n=29)	20% (n=84)
Stayed the Same % w/in newLOB	78% (n=214)	67% (n=53)	47% (n=30)	71% (n=297)
Got Better % w/in newLOB	9% (n=24)	11% (n=9)	8% (n=5)	9% (n=38)
Total % w/in newLOB % Total	100% (n=276)	100% (n=79)	100% (n=64)	100% (n=419)

Source: Caregivers: Life Changes and Coping Strategies, AARP, November, 2013. $X^2=34$, 4df, $p=.000$.

Appendix 3: Annotated Questionnaire: Final Caregiver Coping Survey

Sample: 1,036 women and men between the ages of 40 to 60 who are caregivers

Screening Questions

At any time in the last 12 months, including now, have you provided unpaid care to a relative or friend 50 years or older to help them take care of themselves?

Caregiving may include help with personal needs or household chores. It might be managing a person's finances, arranging for outside services, or visiting regularly to see how they are doing. This person does not need to live with you.

- a. Yes
- b. No → terminate

S1. The following list of shows kinds of help, which might be provided to a person, if the person cannot do this by him or herself. For each, just check if you provide this kind of help.

- a. Get in and out of beds and chairs
- b. Get dressed
- c. Get to and from the toilet
- d. Bathe or shower
- e. By dealing with incontinence or diapers
- f. By feeding him or her
- g. None of these

S2. Do you provide any of the following types of help to the person you assist?

- a. By giving medicines, pills or injections for his/her condition
- b. With managing finances, such as paying bills, or filling out insurance claims
- c. With grocery shopping
- d. With housework, such as doing dishes, laundry, or straightening up
- e. With preparing meals
- f. With transportation, either by driving him/her, or helping them get transportation
- g. With arranging or supervising services from an agency such as nurses or aides
- h. None of these

Respondents who answer yes to at least one item in S1 or S2 qualify to continue.

If respondent says yes to at least one item in S1 or S2 ask:

S3. Thinking now of all the kinds of help you provide for the person you assist, about how many hours do you spend in an average week doing these things?

- a. Less than one hour per week
- b. One to eight hours
- c. Nine to twenty hours
- d. Twenty-one to forty hours
- e. Forty-one or more hours
- f. Don't know/Refused

Introduction

Based on what you have told us, we consider you to be an unpaid caregiver of someone age 50 or older. We are interested in knowing about how you deal with the various things that caregivers experience. There is no right or wrong answer to these questions. We appreciate your being as honest as you can with us. This survey is completely anonymous and no one will ever know who you are.

Questions

1. **First, we would like to know how you would currently rate a variety of parts of your life. Please rate each of the following parts from one to four where one is the highest rating (best) and four is the lowest rating (worst):**

	% 1 best	% 2	% 3	% 4 worst	% Does not apply
a. Your physical health	17	54	25	4	1
b. The quality of your diet	14	50	30	4	<1
c. Your exercise routine	10	30	37	19	2
d. How happy you are	25	43	24	8	<1
e. How satisfied you are with your <u>weight</u>	10	31	32	25	1
f. How satisfied you are with your <u>social life</u>	16	40	26	17	1
g. How satisfied you are with your relationship with your <u>spouse or partner</u>	30	27	13	8	22
h. How satisfied are you with your relationship with your <u>children</u> (if any)	34	27	12	3	23
i. How satisfied are you with your relationship with your <u>grandchildren</u> (if any)	20	10	5	2	62
j. How satisfied are you with your relationship with your <u>sibling(s)</u>	19	36	22	13	9
k. How satisfied are you with your relationship with your <u>friends</u>	24	44	22	6	2
l. How satisfied are you with your <u>work or job</u>	15	28	21	10	24
m. How satisfied are you with your relationship to the <u>person you assist</u>	35	42	17	4	2

2. Next, we would like to know how you would compare each part of your life today with the way it was six months before you became a caregiver. Please indicate whether you think it has gotten better, worse, or stayed the same:

	Gotten Better %	Gotten Worse %	Stayed the same %	Does not apply %
a. Your physical health	13	17	68	2
b. The quality of your diet	18	15	64	2
c. Your exercise routine	16	22	58	3
d. How happy you are	14	20	63	2
e. How satisfied you are with your <u>weight</u>	13	22	62	2
f. How satisfied you are with your <u>social life</u>	8	20	68	2
g. How satisfied you are with your relationship with your <u>spouse or partner</u>	12	11	54	22
h. How satisfied are you with your relationship with your <u>children</u> (if any)	13	6	56	24
i. How satisfied are you with your relationship with your <u>grandchildren</u> (if any)	8	2	31	57
j. How satisfied are you with your relationship with your <u>sibling(s)</u>	13	13	63	10
k. How satisfied are you with your relationship with your <u>friends</u>	9	10	77	3
l. How satisfied are you with your <u>work or job</u>	9	12	54	23
m. How satisfied are you with your relationship to the <u>person you assist</u>	21	12	63	3

3. How do you cope with difficult caregiving situations when you feel frustrated with the way things are going? Do you . . . ?

	% Yes	% No
a. Eat more	24	75
b. Drink more alcoholic beverages	14	84
c. Avoid people or situations	32	65
d. Avoid making tough decisions by putting them off and focusing on other things such as cleaning the house, spending time on-line, watching TV or movies, etc.	33	65
e. Clam-up and hold my feelings inside	44	54
f. Smoke more	13	85
g. Exercise more	17	80
h. Talk or connect with other people (in person, on the phone or on-line) about how I am feeling	38	60
i. Pray, meditate or engage in other spiritual practices more	51	47
j. Search on-line for help	21	77
k. Shop more	13	85
l. Get my hair done, have a massage, or have my nails done	12	87
m. Sleep more	22	77
n. Sleep less	38	60
o. Seek support from my spouse/partner	51	47
p. Seek support from my children	30	68
q. Seek support from my friends	42	57
r. Seek support from sibling(s)	40	58
s. Seek support from <u>my own</u> doctor, nurse, or counselor	19	79
t. Seek support from the doctor, nurse, or counselor who <u>helps the person I provide care</u>	27	72
u. Seek help from a spiritual advisor such as a minister, rabbi, etc.	20	79
v. Other (please specify – text box)	4	64

4. How do you feel about how you cope with situations like this?

	% Yes	% No
a. Glad or secretly glad	45	53
b. Sad	36	63
c. Angry	22	76
d. Afraid about what might happen	44	53
e. Depressed	29	68
f. Out of control	11	88
g. Guilty	22	76
h. Resentful	20	77
i. Proud	52	46
j. Satisfied	62	37
k. I feel sorry for myself	13	85
l. I feel sorry for the person I help	51	48
m. I feel other people should help me more	38	60
n. I wish things were different	68	30
o. Pleased I can help someone	82	16
p. Other (please specify in textbox)	3	56

5. If you had an extra hour, what would you most like to do with that time? (Select top 3)

a. Put my feet up and read the newspaper (book or magazine)	32%
b. Talk a walk or exercise	32
c. Cook or bake	13
d. Catch up on paying bills, completing insurance forms, etc.	8
e. Get my hair cut, have a massage, or have my nails done	11
f. Meet a friend	17
g. Go to a movie, sporting event, or other recreational activity	21
h. Go to church, synagogue, or mosque	6
i. Spend un-interrupted time with spouse or partner	26
j. Plan a get-away	20
k. Spend time with family	30
l. Spend time alone	33
m. Other (specify in text box)	9

6. What would inspire you to achieve and maintain healthy ways to cope with caregiving?

Having:

a. A friend or support group to listen or offer encouragement	36%
b. A role model to look up to	11
c. A personal goal or vision	28
d. Someone to be accountable to for keeping on track	10
e. A way to track my progress (for example tracking weight loss)	12
f. Something to look forward to such as a special occasion or celebration	40
g. Other (please specify in text box)	5
h. None of the above	26

7. Which of the following would help you find more time for yourself?

a. Knowing another caregiver who is willing to trade-off watching both of the people we help so that we each have regular “free” time to spend as we want	29%
b. Having a health club or gym provide care for the person I help while I work out	9
c. Having a church, temple, or synagogue that provides care for the person I help while I attend services	9
d. Use a service like adult day care	14
e. Other (please specify in text box)	6
f. None of the above	50

8. How long have you been helping the person you assist?

a. Less than one year	27%
b. One year to two years	20
c. More than two years	52