

Diet Quality, Stress and Caregiver Burden Relationship in Long-Term Caregivers

Taylor L. Kennedy

University of Georgia

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## INTRODUCTION

Poor diet, lack of exercise, high stress and poor sleep quality are risk factors for developing chronic diseases and contribute to an overall reduction in quality of life (e.g., Linardakis et al., 2015; Ramsey et al., 2008). It is well known that maintaining a healthy diet and exercise regimen contributes to positive health outcomes, yet many people struggle to achieve these lifestyle goals. According to the National Health and Nutrition Examination Survey (NHANES), 35.8% of American men and 26.3% of American women are overweight (Fryar, Cheryl D., Carroll, Margaret D., and Ogden, 2018). Furthermore, chronic diseases like cancer, heart disease and stroke, which are more likely to occur in individuals with poor diet quality and lack of exercise, account for 86% of the annual \$2.7 trillion health expenditures in the United States (Buttorff, Ruder, & Bauman, 2017; Centers for Medicare & Medicaid Services, 2016).

### Caregivers

While diet, exercise and other lifestyle factors are implicated in chronic health conditions in the U.S. population at large, special populations, like caregivers, may be even more vulnerable to these lifestyle-related chronic conditions. As the number of caregivers continues to grow, the health and economic implications of lifestyle behaviors in this population becomes even more important. The term caregiver can be defined as “a person who gives care to people who need help taking care of themselves” (National Cancer Institute, 2018). Most commonly, caretakers provide care for individuals with chronic disease (National Cancer Institute, 2018). An informal caregiver is a non-professional individual who is not paid for their caregiving duties. For the purposes of this paper, caregiver is defined as an informal caregiver of someone with a chronic disease or illness, who has provided that care for at least one month. In 2015, there were an estimated 43.5 million informal, unpaid caregivers in the United States (Gibson Hunt et al.,

2014). Caregivers have become an integral part of the healthcare system in the United States, saving \$350 billion in healthcare costs (Bastawrous, 2013). The number of caregivers in the U.S. is expected to increase as the number of older adults aged 65 years and older proportionally increases to a projected 78 million people by the year 2035 (US Census Bureau, 2018).

### **Stress**

Although caregivers provide a vital health service, they face a number of health-related challenges while caring. For example, caregivers are likely to experience increased levels of psychosocial stress related to their caregiving duties, which, over the months and years of caregiving, can lead to chronic stress (e.g., Schulz & Sherwood, 2008). These psychosocial stressors can arise from primary sources such as cognitive status of the care recipient, activities of daily living (ADL) / instrumental activities of daily living (IADL) needs of the care recipient and amount of time spent providing care. Psychosocial stressors also arise from secondary sources such as caregiver employment, caregiver satisfaction with social life and family dynamics (Bastawrous, 2013). When all of these sources of stress are combined, it is not surprising to find that more than half of caregivers find their role to be moderately to highly emotionally stressful (Gibson Hunt et al., 2014).

### **Time**

Time spent providing care is a significant predictor of caregiver health. Caregivers who spend more hours providing care per week self-rate their health as poorer than those who care for less hours per week. According to the 2015 Caregiving in the U.S. Report, less than half of caregivers who provide more than 20 hours of care per week rate their health as excellent (Gibson Hunt et al., 2014). Lack of time combined with high psychosocial stress means that

caregivers often have poor self-care practices, negative health behaviors and higher levels of healthcare consumption (Son et al., 2007).

### **Risk Factors**

Negative health behaviors that may be adopted by caregivers include lack of exercise, lack of sleep and poor diet. These negative health outcomes place caregivers at risk of increased risk for cognitive decline, increased metabolic risk, anxiety and depression (Vitaliano et al., 2005). Furthermore, older age, lower socioeconomic status, and limited support also contribute to poorer health outcomes among caregivers (Schulz & Sherwood, 2008). Caregivers face a number of risk factors for developing chronic disease, making them a unique at-risk population. Given the fact that average diet quality in the U.S. is relatively poor *without* the extra time burden, financial strain and stress of caregiving, caregivers might be especially likely to have poor diet quality, and thus increased risk for future chronic disease, themselves.

### **Diet**

Poor diet is a key risk factor for developing a chronic disease. Dietary patterns have been independently linked to poor metabolic status and higher risk for cognitive decline (e.g., van de Rest, Berendsen, Haveman-Nies, & de Groot, 2015; Smith & Blumenthal, 2016). Diet quality is also known to be associated with chronic stress and anxiety, and can influence neurological health and function, independent of caregiving status (e.g., Ans et al., 2018; Baran et al., 2005). Current research suggests higher consumption of vegetables and fruits, and lower consumption of saturated and trans fats may help maintain cognitive function and contribute to overall well-being (e.g., Smith & Blumenthal, 2016). While a number of foods and nutrients have been identified as neuroprotective (e.g., McEvoy, Guyer, Langa, & Yaffe, 2017; Miquel et al., 2018),

a variety of factors including higher food prices and reduced income often limit the consumption of foods with these neuroprotective nutrients (Brinkman, de Pee, Sanogo, Subran, & Bloem, 2010). These barriers must be taken into consideration in the caregiver population, who is more likely to be facing job loss or reduced pay due to amount of time spent caregiving (Schulz et al., 2016), which can negatively impact their ability to buy these foods.

Additionally, diet can impact the mental health of individuals regardless of caregiver status. A study conducted by Australian researchers found an association between higher quality diets and the emotional health among women (Milte, Thorpe, Crawford, Ball, & McNaughton, 2015). Caregivers already face a higher risk for developing anxiety or depression and a poor diet can increase this risk, particularly for women who comprise 60% of caregiver population in the United States (Gibson Hunt et al., 2014).

Given the fact that caregiving is related to stress and greater risk for negative health outcomes, and that diet quality is also independently related to stress and risk for negative health outcomes, it is feasible that dietary interventions focused on neurological health and stress reduction could reduce these risks in caregivers. Little is known, however, about the dietary habits of caregivers, as very little research has been conducted on this particular risk factor in this unique population. Furthermore, it is unclear what a dietary intervention might look like for a group characterized by lack of time to devote to self-care. As a first step in understanding the relationships between diet quality, stress and caregiver burden, long-term caregivers (those providing care for longer than one month) were surveyed regarding psychosocial stress, caregiver burden and dietary quality. I hypothesize that when compared to the national average, the caregiver population will have an overall poorer diet quality in addition to higher levels of stress and negative health outcomes.

## METHODS

### Design and Participants

In order to test the hypothesis that caregivers will have poorer diet quality than the national average, this preliminary study was developed using a cross sectional design to survey the caregiving population about psychosocial stress, physical health, perceived burden and diet intake. A total of 39 individuals participated in the study. Participant eligibility criteria included being at least 18 years of age; currently serving as a non-professional caregiver for someone with a chronic disease; have been caregiving for at least one month and be in otherwise self-reported good health.

### Ethics

Prior to beginning data collection, the Institutional Review Board at the University of Georgia approved this study and the tenets of the Declaration of Helsinki were adhered to at all times while conducting the study. Upon opening the survey in the Qualtrics survey platform, all participants were provided a consent letter stating study eligibility criteria, potential risks, explanation of how data would be protected and contact information for the research team. Individuals who met the study criteria and who chose to participate were asked to enter the date as confirmation to participate in the study. Those who did not enter the date and therefore did not provide consent were unable to proceed with the survey.

### Materials and Procedure

This pilot survey was created using validated instruments that measured diet quality, mental health and physical health of participants. These evidence-based instruments are

presented in **Table 1** and include the Beck's Depression Inventory (BDI) (Beck, A. T.; Ward, C. H.; Mendelson, M.; Mock, J.; Erbaugh, 1961), Beck's Anxiety Inventory (BAI) (Beck, Epstein, Brown, & Steer, 1988), Caregiver Well-Being Tool (CWBT) (Bédard et al., 2001; Zarit, Reever, & Bach-Peterson, 1980), Scale for Positive Aspects of Caring Experience (PACE) (Tarlow et al., 2004), and General Nutrition Assessment Food Frequency Questionnaire (GNA FFQ) (Fred Hutchinson Cancer Research Center, 2018). Additional questions specific to caregiving were included, which inquired about changes in employment status, time spent caregiving, participant relation and location to care recipient.

**Table 1. Survey Instruments**

<b>Scale</b>	<b>Purpose</b>	<b>Scoring</b>
<b>Beck's Depression Inventory (BDI)</b>	Measures depressive symptomology in adults, experienced over one month	11-16 = mild mood disturbance 17-20 = borderline clinical depression 21-30 = moderate depression 31-40 = severe depression >40 = extreme depression
<b>Beck's Anxiety Inventory (BAI)</b>	Measures symptoms of anxiety in adults, experienced over one month	0-21 = low anxiety 22-35 = moderate anxiety ≥36 = potentially concerning levels of anxiety
<b>Caregiver Well-being Tool (CWBT)</b>	Quickly screens adults for stress due to caregiving	≥17 = high caregiver burden
<b>Positive Aspects of Caring (PACE)</b>	Measures the perceived positive aspects of caregivers of older adults	Range from 9-45, with the higher score reflecting a more positive experience
<b>General Nutrition Assessment Food Frequency Questionnaire (GNA FFQ)</b>	Measures frequency of consumption and portion size of food and beverages consumed over the course of one month	Number of times a specific food item was reported as being consumed within the specified timeframe

The Qualtrics survey platform was used to deliver the survey. A link to the survey was distributed to various organizations, institutions, and groups that may include caregivers. The survey was open from August to November of 2018 and distributed via social media, support groups, email listservs, flyers and word of mouth within the community. Participants completed



the survey with no supervision and in their own time. No incentive was provided for participation.

### **Statistical Analysis**

Data collected using the survey tool were downloaded and entered into SPSS, version 25. Data are reported as mean  $\pm$  standard deviation, unless otherwise indicated. To determine the relations between diet quality, feelings of depression and anxiety and caregiver wellbeing, correlations (or non-parametric alternatives when data are not normally distributed) were computed between composite scores on the BDI, BAI, CWBT and PACE, as well as total fruit and vegetable intake generated from the GNA FFQ (Cade, Burley, Warm, Thompson, & Margetts, 2004; Steinemann et al., 2017), before and after controlling for education, caregiver financial status, time spent caregiving, and months of caregiving burden. The CWBT was then used to divide caregivers into high burden ( $\geq 17$  on the CWBT) and low burden groups ( $< 17$  on the CWBT). Fruit and vegetable intake and scores on the PACE, BDI and BAI in high and low burden groups were then compared using a one-way ANOVA for normally distributed data, or a Mann-Whitney U Test for non-normal data. Because this study was exploratory in nature, and because sample size was relatively low,  $p \leq 0.07$  was used as the criterion for significance, and  $p < 0.10$  was considered trending. All tests were conducted in both tails of the distribution, despite the fact that the *a priori* hypotheses were directional in nature, because the study was exploratory.

## **RESULTS**

### **Demographics, Description of Caregiving Activities and Descriptive Data on the Sample**

### Demographics and Caregiving Activities

A total 39 participants accessed the survey and completed at least some of the content. Two participants opted to stop completing the survey after the initial demographics portion, and an additional participant opted to stop completing the survey after the psychosocial wellbeing portion of the survey. A total of 33 participants completed all survey items. Because multiple items contained an “opt out” feature, which allowed the participant to skip the item if he or she chose to do so, the sample size that responded to each item will be indicated in each subsequent result.

Participant demographics are presented in **Table 2**. The majority of the sample was aged 55-64 years (35.9%). Based on U.S. Census grouping guidelines, 54% of the sample was classified as older (55 years of age or older). The majority of the sample (71.8%) was White / non-Hispanic, and female (73.7%).

<b>Table 2. Participant Demographics</b>		
	<b>Number</b>	<b>%</b>
<b>Sample Size</b>	<b>n=39</b>	<b>100%</b>
<b>Age</b>	<b>n=39</b>	<b>100%</b>
18-24	2	5.13%
25-34	4	10.26%
35-44	8	20.51%
45-54	4	10.26%
55-64	14	35.90%
65-74	5	12.82%
75-84	2	5.13%
<b>Gender</b>	<b>n=38</b>	<b>97.43%</b>
Male	10	26.32%
Female	28	73.68%
<b>Race/ethnicity</b>	<b>n=39</b>	<b>100%</b>
Black/African American	10	25.64%
White non-Hispanic	28	71.79%
Other	1	2.56%
<b>Relationship status</b>	<b>n=39</b>	<b>100%</b>
Married	23	58.97%
Single	5	12.82%
Divorced	3	7.69%

Widowed	3	7.69%
Living together	3	7.69%
Partner	2	5.13%
<b>Annual household income</b>	<b>n=39</b>	<b>100%</b>
Under \$9,000	1	2.56%
\$20,000 - \$39,999	3	7.69%
\$40,000 - \$59,999	8	20.51%
\$60,000 - \$79,999	11	28.21%
\$80,000 - \$99,999	5	12.82%
\$100,000 or over	8	20.51%
Prefer not to answer	3	7.69%
<b>Highest level of education</b>	<b>n=38</b>	<b>97.43%</b>
Some high school	1	2.63%
High school graduate	1	2.63%
Some college	8	21.05%
College graduate	14	36.84%
Post-college degree	14	36.84%
<b>Current employment status</b>	<b>n=39</b>	<b>100%</b>
Full time (35 hours/week or more)	21	53.85%
Part time (less than 35 hours/week)	7	17.95%
Not employed	4	10.26%
Retired	7	17.95%

Descriptive information about caregiving is presented in **Table 3**. Participants were largely caretakers for domestic partners (41.0%) or children (35.9%). The majority of the sample lived with their care recipients (76.3%) and reported providing more than 40 hours per week of care (39.5%).

<b>Table 3. Caregiving</b>		
	<b>Number</b>	<b>%</b>
<b>Sample Size</b>	<b>n=39</b>	<b>100%</b>
<b>Hours per week providing care</b>	<b>n=38</b>	<b>97.43%</b>
1-5 hours	6	15.79%
6-10 hours	4	10.53%
11-15 hours	3	7.89%
16-20 hours	0	0%
21-25 hours	4	10.53%
26-30 hours	4	10.53%
31-35 hours	1	2.63%
36-40 hours	1	2.63%
More than 40 hours	15	39.47%
<b>Duration of time providing care</b>	<b>n=38</b>	<b>97.43%</b>
Less than 6 months	6	15.79%
6-11 months	8	21.05%
1-3 years	8	21.05%
3-5 years	2	5.26%
More than 5 years	14	36.84%
<b>Employment status change due to caregiving duties</b>	<b>n=39</b>	<b>100%</b>

Decreased hours	6	15.38%
No change	21	53.85%
Began working	1	2.56%
Family/medical leave	3	7.69%
Changed jobs	2	5.13%
Early retirement	1	2.56%
Quit job	2	5.13%
Other	3	7.69%
<b>Relationship to care recipient</b>	<b>n=39</b>	<b>100%</b>
Wife/partner	2	5.13%
Husband/partner	14	35.90%
Daughter/daughter-in-law	7	17.95%
Son/son-in-law	7	17.95%
Mother	2	5.13%
Father	3	7.69%
Sister	1	2.56%
Other	3	7.69%
<b>Live with care recipient</b>	<b>n=38</b>	<b>97.43%</b>
Yes	29	76.32%
No	9	23.68%

### Symptoms of Depression and Anxiety

A total of 37 participants completed the BDI portion of the survey. Participants who completed the survey scored an average of  $10.62 \pm 6.62$ , which is indicative of mild mood disturbance, based on standard scoring criteria. Given the high standard deviation, a median split was conducted to group individuals who scored below 10 ( $n = 17$ ) and those who scored 10 or higher ( $n = 20$ ). Participants who scored above 10 had an average BDI score of 16.21, which indicates the borderline possibility of clinical depression.

A total of 36 participants completed the BAI portion of the survey. These participants scored an average of  $11.94 \pm 9.86$ , indicating low levels of anxiety. Given the high standard deviation, a median split was conducted to group individuals who scored lower than 8.5. Participants who scored above 8.5 had an average BAI score of 19.44, which is still considered relatively low anxiety.

### Caregiver Burden and Strain

A total of 36 participants completed the CWBT. These participants scored an average of  $16.03 \pm 6.25$ , which is not indicative of an exceptionally high caregiver burden. Given the high standard deviation between participants, participants who scored below the high burden cutoff of 17 ( $n = 19$ ) were compared against people above or equal to 17 ( $n = 17$ ). The average CWBT score of those who indicated a significant caregiver burden was 21.87.

### Positive Affect Associated with Caregiving

A total of 37 participants completed the PACE portion of the survey, and one participant did not complete the entire PACE measure. Consequently, a total of 36 participants were analyzed. The PACE ranges from 9-45, with higher scores equaling more satisfaction with caregiving. The average PACE score for the 36 subjects analyzed was  $29.14 \pm 9.21$ .

### Diet Quality, Compared Against National Norms

As a measure of diet quality, total fruit and vegetable intakes (servings / day) were generated from the GNA FFQ. In the study sample, 32 participants completed the GNA FFQ portion of the survey. These participants consumed an average of  $0.63 \pm 0.27$  servings of fruit per day and  $0.74 \pm 0.29$  servings of vegetable per day. Comparisons between the study sample, normative data from the Behavioral Risk Factor Surveillance System (Lee-Kwan, Moore, Blanck, Harris, & Galuska, 2017) and recommended servings per day from the USDA (U.S. Department of Health and Human Services & U.S. Department of Agriculture, 2015) are presented in **Table 4**.

**Table 4.** *Caregiver diets, compared to normative data for the United States*

	USDA recommendation, servings / day*	Current sample, servings / day	Normative data, servings / day
Fruits	2.0	0.63	1.0
Vegetables	2.5	0.74	1.7

\* based on a 2,000 calorie diet

### **Relations Between Caregiver Burden, Wellbeing, Negative Affect and Diet Quality**

To determine whether parametric or non-parametric relations between these variables should be computed, data for each variable were plotted against a normal curve, and the Shapiro-Wilk test was completed. Neither the composite BAI score ( $W = 0.86, p < 0.001$ ) nor servings of fruits ( $W = 0.92, p = 0.021$ ) and vegetables ( $W = 0.93, p = 0.045$ ) per week were normally distributed. Consequently, Spearman's rho was computed to determine relations between these variables. Fruit consumption was inversely related to composite BDI score ( $r_s = -0.30, p < 0.1$ ) and caregiver burden ( $r_s = -0.31, p < 0.09$ ). Vegetable consumption was not significantly related to caregiver burden, positive aspects of caregiving, or feelings of depression and anxiety. Feelings of depression were significantly related to caregiver burden ( $r_s = 0.61, p < 0.001$ ) and feelings of anxiety ( $r_s = 0.74, p < 0.001$ ). Positive feelings of caregiving, and caregiver burden were inversely related ( $r_s = -0.47, p < 0.005$ ).

### **High Burden vs. Low Burden Caregivers**

Fruit and vegetable intakes were not significantly different between high burden ( $M = 5.13 \pm 2.22$  servings vegetables / week;  $4.19 \pm 1.91$  servings fruit / week) and low burden ( $M = 5.25 \pm 1.88$  servings vegetables / week;  $4.56 \pm 1.93$  servings fruit / week) caregivers ( $p > 0.10$ ). High burden caregivers had significantly higher ( $F [1,35] = 8.98, p < 0.005$ ) scores on the BDI ( $M = 14.24 \pm 4.88$ ), than low burden caregivers ( $M = 8.60 \pm 6.31$ ). Higher burden caregivers ( $M$

=  $25.06 \pm 7.85$ ) also had significantly lower scores ( $F [1,33] = 7.80, p < 0.009$ ) on the PACE index than low burden caregivers ( $M = 33.00 \pm 8.90$ ). Higher burden caregivers also had significantly higher BAI scores ( $U = 87.50, p = 0.018$ ).

## DISCUSSION

This pilot study examined the relationship between diet quality, stress and caregiver burden among long-term caregivers. These survey findings indicate that the sampled caregiver population is experiencing a number of stressors. This sample is much like the samples others have reported on, which suggests that even though we have a small sample size, our results are likely generalizable. The majority of our sample is female; aged 55-64 years; live with their care recipients; provide more than 40 hours per week of care; and have experienced employment changes due to their caregiving responsibilities. In comparison, the 2015 national Caregiving in the U.S. Report found that the majority of caregivers are women; aged 50-64 years; care for a family member; provide 41 or more hours of care per week; and more than half of all caregivers reported employment changes due to their caregiving responsibilities (Gibson Hunt et al., 2014). Additionally, the 2015 report states that caregivers providing more than 20 hours of care per week reported higher levels of emotional stress than lower hour caregivers (Gibson Hunt et al., 2014).

This study found that higher burden caregivers scored significantly higher on the BDI and BAI, and lower on the PACE than lower burden caregivers. Despite the stress that caregivers experience, they do see the value of caregiving, particularly those with lower levels of burden and some who have been caregiving for longer than 5 years. These findings are supported by the

literature which shows caregivers are more likely to experience depression and stress (e.g., Bastawrous, 2013), as well as recognize positive aspects of their caregiving duties (e.g., Schulz & Sherwood, 2008).

The results support our hypothesis that the caregiver population will have an overall poorer quality diet than the national average. We found that all caregivers, regardless of level of burden, consume less servings of fruits and vegetables than the USDA recommends, or than the average American consumes. It is of note that most of our study participants are well-educated (74% completing college or graduate degrees) and are financially well-off (61.5% making \$60,000 or more annually). Considering that higher education levels and income are indicators of higher health literacy and positive health outcomes (e.g., Levin-Zamir, D., Baron-Epel, O., Cohne, V., Elhayany, 2016), it is surprising that fruit and vegetable consumption are significantly lower among participants than the national norms and recommendations.

There are limitations of this study that should be recognized. The sample size (n=39) is small, indicating the sample may not be an accurate representation of the caregiver population. The survey was also distributed through a number of academic settings and organizations, which might have recruited a higher educated population than the average caregiver sample. Participants did not receive any incentive for participation, which may have prevented an already stressed population from participating. The survey was only available online, which could have kept caregivers without access to a computer or smartphone from participating. The survey did not ask participants about all food and drink they consume, but rather focused on vegetable and fruit intake, therefore providing only a partial understanding of caregiver diet. Additionally, participants may not have accurately recalled how often they do or do not eat certain foods (either over or under estimating), a critique of the FFQ (Steinemann et al., 2017).



## CONCLUSION

While many studies discuss the emotional and physical risk factors and health outcomes of caregivers, little is known about the diet quality of caregivers. Our pilot study found that not only are caregivers facing a number of psychosocial stressors, but they are also spending large amounts of time caregiving, facing employment changes due to caregiving responsibilities, and do indeed have a poor-quality diet lacking in fruits and vegetables. Not only are caregivers consuming less fruits and vegetables than the USDA recommends, but they are also consuming less than the national average. While this pilot study has taken a first step in better understanding caregiver diet quality, it is still unclear what a dietary intervention would look like with this unique and growing population. Further research should be conducted to better understand the diet of caregivers, beyond fruits and vegetables, including the consumption of all other nutrients (e.g. protein, carbohydrates, fats, etc.), patterns of eating (e.g. fast food, homemade meals, delivery kits, etc.) and other factors related to diet quality such as time and financial status. The caregiving population continues to grow and would benefit from a dietary intervention to potentially reduce their risk of developing chronic disease. Future studies should consider the limitations of this study.

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ADDENDUM

Figure 1. Frequency of Consumption

Frequency of Consumption

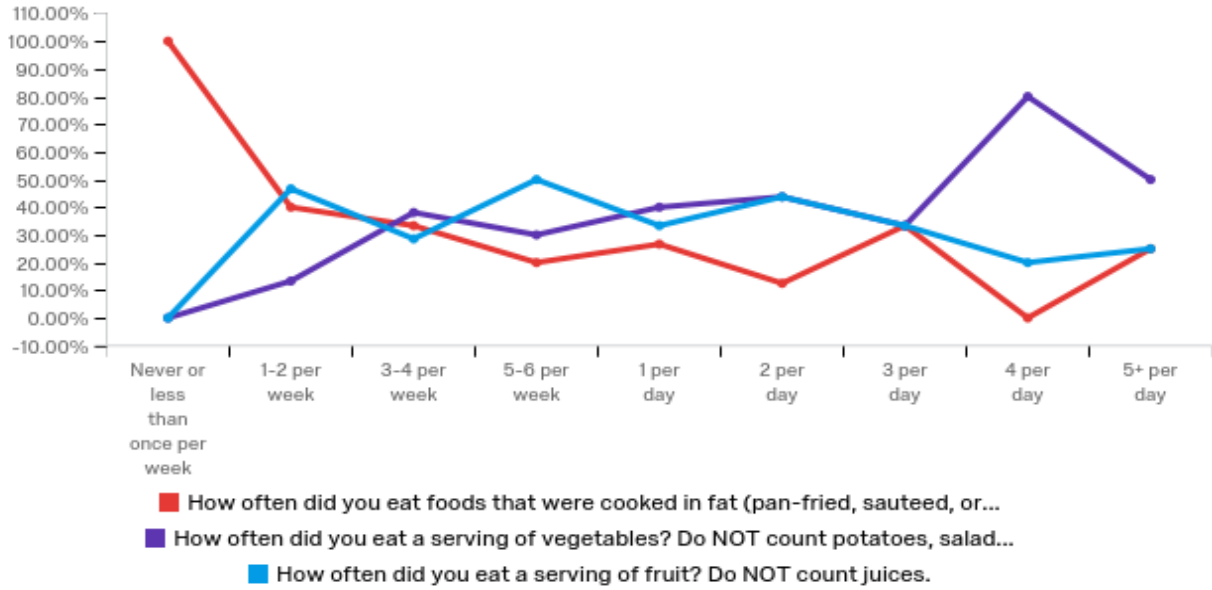
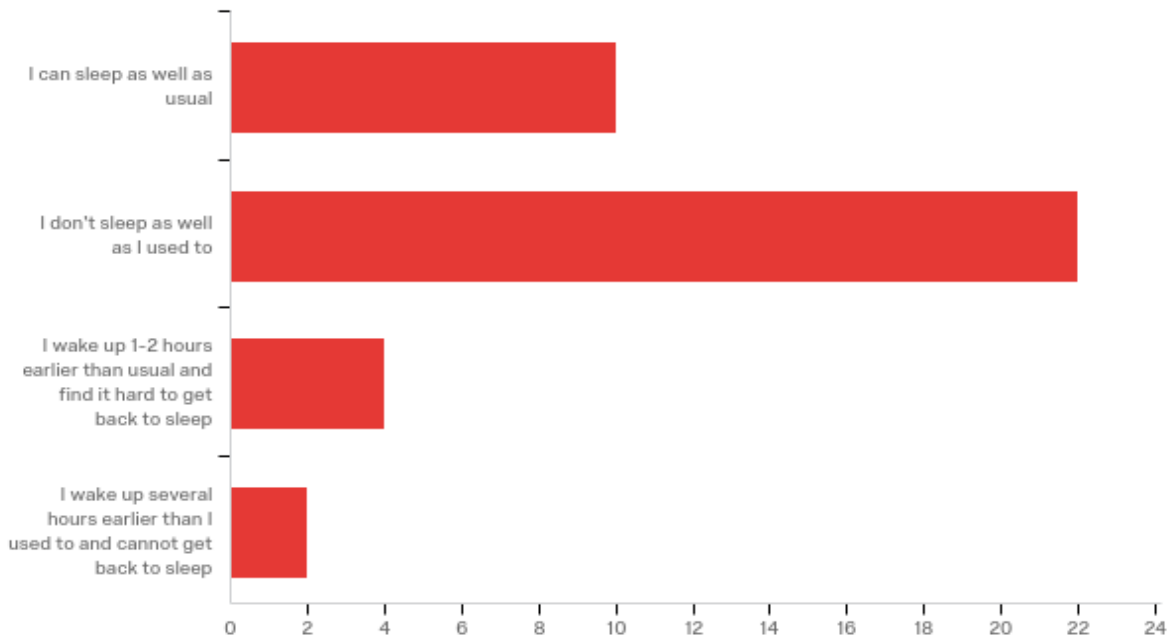
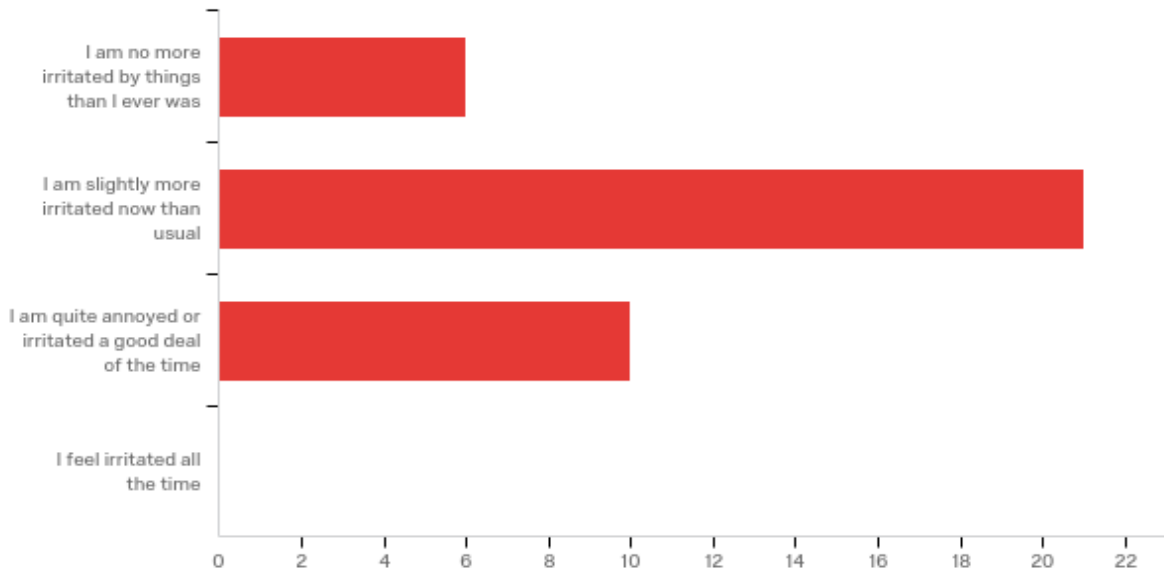


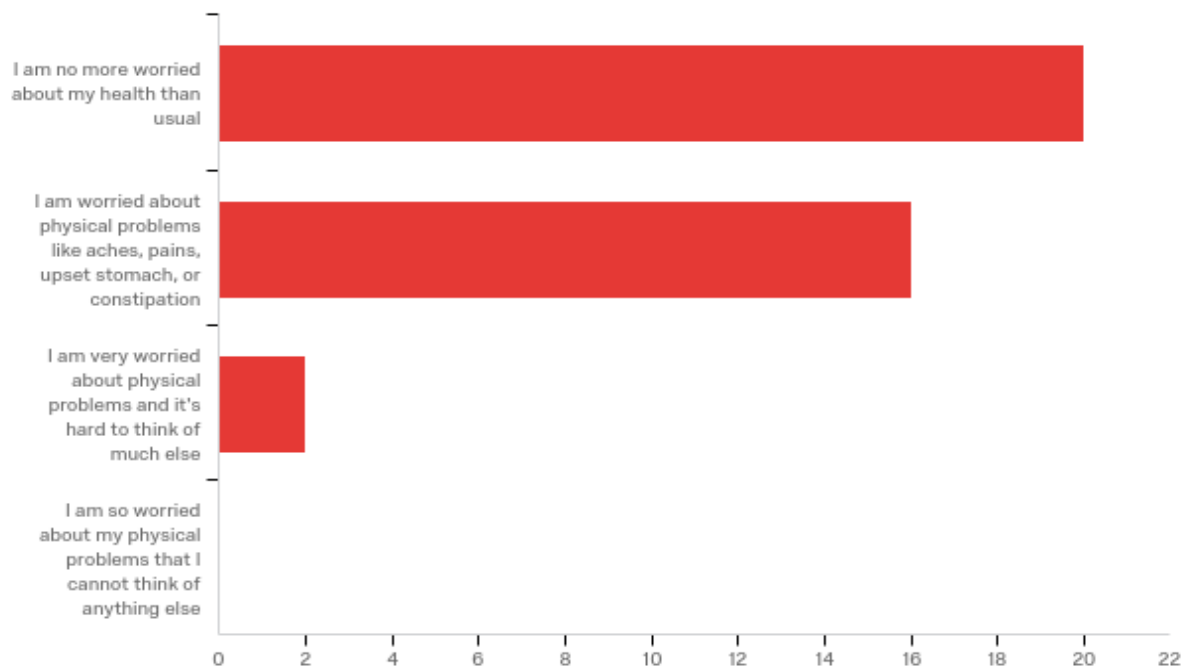
Figure 2. Sleep



**Figure 3. Irritability**



**Figure 4. Self-reported Health Concern**



**Figure 5.** Satisfaction

