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## **Sleep Disturbances and Physical Health Problems in Caregivers of Children with ASD**

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### **Abstract**

*Objectives:* Caregivers of children with autism spectrum disorder self-report more physical health problems than controls. Sleep disturbances are also more prevalent in caregivers, and are positively associated with physical health problems. The negative impact of caring for a child with ASD on physical health therefore, might occur indirectly via poorer sleep.

*Methods:* Participants, of which  $n=43$  were caregivers and  $n=17$  were controls, completed self-report measures of physical health problems and, to capture objective measures of sleep, wore an actigraphy device.

*Results:* Physical health problems were greater in caregivers, as were subjective reports of disturbed sleep. Objectively, waking after sleep onset (WASO) and average number of awakenings were higher, as was sleep latency, and sleep efficiency was poorer, in caregivers. Total sleep time however, was greater in caregivers, as was time in bed. Physical health problems, while unrelated to actigraphy measures, were positively associated with self-reported sleep disturbances. Caregivers' increased risk for physical health problems occurred indirectly via greater self-reports of disturbed sleep.

*Conclusions:* Interventions that help alleviate caregivers' sleep disturbances might be effective, by reducing physical health problems, for improving quality of provided care, and this might be explored in future research.

**Key words:** ASD; caregiving; indirect effects; objective sleep; physical health problems

### **What This Study Adds?**

Caregivers of children with ASD are more likely to report physical health problems compared with controls. Sleep problems, known to affect health sensitive physiological processes such as endocrine and immune function, and associate in cross sectional and longitudinal research with increased self-reports of negative health, might provide one mediating pathway by which caring for a child with ASD is translated into poorer physical health. This was explored here. Sleep problems have been scarcely examined in caregivers of children with ASD, and studies to date, of which there are few, have relied heavily on self-report measures which are not always concordant with more reliable, objective assessments. Here, sleep was assessed objectively, using wrist actigraphy, and both subjective and objective sleep assessments explored as predictors of caregivers' physical health problems. The study found caring for a child with ASD to be associated with poorer sleep, as assessed using objective measures, and poorer sleep was associated with increased risk for physical ill health. These findings have implications for informing the decisions of healthcare professionals as they relate to better supporting caregivers of children with ASD, and the development of interventions that might, by improving caregivers' sleep and reducing their health problems, improve quality of provided care for the child.

## Introduction

The psychological impact of caring for a child with developmental disabilities (DD), like autism spectrum disorder (ASD), has been widely reported (Al-Farsi et al., 2016; Gallagher et al., 2008; Kennan et al., 2016; Lovell et al., 2014). The stress associated with caring for a child with DD can, and regularly does, lead to physical health problems. Indeed, caregivers of children with DD tend to be more vulnerable to commonly occurring ailments like coughs, colds, aches and pains, and visit their general practitioner (GP) more regularly, compared with their non-caregiving counterparts (Bella et al., 2011; Gallagher & Whiteley, 2012; Lovell et al., 2012a; Ruiz-Robledillo et al., 2013a; Smith et al., 2011). Alterations in health sensitive physiological processes such as endocrine and immune parameters, widely observed in caregivers of children with ASD, have been implicated as likely mediators of caregivers' poorer physical health (Gallagher et al., 2009; Lovell et al., 2012a; Ruiz-Robledillo et al., 2013b; Seltzer et al., 2010; Whittaker & Gallagher, 2019)

Sleep disturbances, known to be influential for endocrine and immune functioning, and associated in cross sectional and longitudinal studies with increased risk for physical health problems, might provide another mediating pathway by which caring for a child with ASD is associated increased reports of physical ill health (Afolalu et al., 2018; Paiva et al., 2015; Pawl et al., 2013; Pulpulos et al., 2020; Shattuck et al., 2018). To date however, studies exploring sleep disturbances in caregivers of children with ASD have been scarce, and tended to rely almost exclusively on subjective measures (e.g., sleep diaries, questionnaires). Studies using the Pittsburgh Sleep Quality Index (PSQI), one widely used self-report measure, found caregivers of children with a range of DD, of which ASD accounted for over 50% of the sample, were more impaired on all sleep parameters, of sleep latency, efficiency, duration, and overall quality, compared with age-matched controls. Caregivers were also more likely to be classified, using clinical cut-off values, as poor

sleepers (Gallagher et al., 2009). Other research, also using the PSQI, found caregivers of children with DD, including those with ASD, reported longer sleep latency and shorter sleep duration compared with controls (McBean et al., 2016). Other studies comparing caregivers' self-reported sleep disturbances with population norms and recommended sleep guidelines found caregivers of children with DD (including ASD) took longer, after getting into bed with the intention to sleep, to sleep (i.e., longer sleep latency) and were more likely, when they did sleep, to wake (Bourke-Taylor et al., 2013; Lee et al., 2017). Several review papers have also reported on the deleterious effect of caring for a child with ASD on subjectively assessed sleep, and in qualitative research, in which caregivers were asked to identify the most demanding aspects of their experience, sleep problems emerged as one prominent theme (Lee et al., 2013; Meltzer et al., 2008; Wallace et al., 2018)

Studies involving other caregiving populations such as elderly dementia caregivers have shown that self-reported sleep disturbances can be incongruent with data collected using more objective, electronic assessments. For example, in studies using actigraphy, in which inferences about disturbed sleep are based on electronic measures of rest/activity patterns (i.e., movement), caregivers could not be differentiated from controls with respect to sleep parameters such as waking after sleep onset (WASO), sleep latency and efficiency, and number of night-time awakenings. Group differences however, were observed using PSQI data, with caregivers' self-reported sleep disturbances found to exceed those of controls (von Känel et al., 2011). In other studies however, caregivers complained of more sleep problems, and objectively their sleep was poorer, compared with controls. Moreover, subjective reports of sleep quality were found to be highly correlated with actigraphy measures in these studies (Rowe et al., 2008; von Kanel et al., 2010). It is incumbent on researchers therefore, in order to more fully explore the impact of caregiving on sleep, to incorporate both subjective and objective assessments.

Sleep disturbances have been shown to be associated, through perturbations in physiological processes, especially HPA activity and immune functioning, with increased risk for physical ill health. Indeed, in studies involving familial caregivers, though not caregivers of children with ASD, WASO and sleep duration, assessed objectively using actigraphy, were related to concentrations of inflammatory biomarkers, CRP and D-Dimer (Schwartz et al., 2012; von Känel et al., 2009), and higher levels of these inflammatory agents have been prospectively associated with increased risk of negative health, particularly atherosclerotic disease (Seven et al., 2015). In studies involving caregivers of children with ASD, shorter sleep duration was associated with higher levels of fatigue (Giallo et al., 2011), and greater fatigue has been related, in other studies, with more frequent reports of physical health problems (Williamson et al., 2005). Other studies, also involving caregiving samples, found sleep disturbances, assessed using self-report measures, to be associated, using cross sectional data, with increased reports of physical health problems (Simpson & Carter, 2013).

To date, few studies have explored the impact of caring for a child with ASD on sleep, and objective measures have yet to be incorporated into research with this population. Caregivers of children with ASD typically self-report more sleep disturbances than controls, and reports of physical health problems, which are predicted by sleep disturbances, tend to be higher in the context of caring for a child with ASD. The aim of this study therefore, was to assess sleep problems, using both subjective and objective measures, in caregivers of children with ASD, and explore whether caregivers' increased risk for physical health problems might be partially mediated by poorer sleep. It was hypothesised that caregivers would self-report more sleep disturbances, and would be more impaired on objectively assessed sleep parameters, compared with controls. It was further hypothesised that any relationship between caring for a child with ASD and increased risk for physical health problems would be partially mediated by poorer sleep.

## Methods

### Participants

A sample of 88 participants, of which 61 were caregivers of children with ASD and 25 were controls (parents of neuro-typical children), were recruited via adverts placed on support and information pages, in parenting and caregiving groups, on social media sites. Inclusion criteria stipulated that participants must be: (a) aged >18 years, (b) caring for at least one neuro-typical child, or child with clinically diagnosed (by general practitioner, paediatrician or other health professional) ASD, and the child must be (c) aged between 3 and 21 years, and living at home full-time. ASD diagnosis was not clinically authenticated; parent reports, known to be reliable for confirming clinical diagnosis, were used (Rosenberg et al., 2009). It was also stipulated that participants should (d) not be caring another person (e.g., parent, partner, other relative, or friend) with chronic illness, and (e) not be managing, or have in the last 12 months managed, other chronic stressors such as divorce or bereavement. The institutional ethics board approved the study, and all participants provided informed consent.

In total, 14 participants did not return the participation pack, and a further 11 participants failed to complete self-report assessments of sleep or failed to collect any actigraphy data. These 25 participants therefore, were removed from the study, as were three participants who failed to collect actigraphy data for the minimum three consecutive days. *z* scores, generated for all outcome variables, were used to screen for univariate outliers, and Tabachnick and Fidel (2012) recommend jettisoning values  $\pm 3.29$ . No outliers however, were identified using these criteria. The final sample therefore, of  $n=60$ , was composed of 43 caregivers and 17 controls.

## Measures

Socio-demographic and lifestyle information, and information about the child with ASD

Data was collected with respect to caregivers' age, gender, relationship status, alcohol and nicotine consumption, and frequency of exercise. Age of the child with ASD was also recorded, as was age diagnosed, to safeguard against spurious relationships emerging between study variables.

### Physical health problems

The 33-item Cohen-Hoberman Inventory of Physical Symptoms (CHIPS) was used to quantify physical health problems experienced over the last two weeks (Cohen et al., 1983). Participants responded to each item (e.g., headache, cold or cough, dizziness, nausea, fatigue, aches and pains) using a five point Likert type scale (0 = not affected - 4 = extremely affected). Total scores, generated by summing across all items, range between 0 and 132, with higher scores reflecting greater physical health problems. Other recent studies (Benham & Charak, 2019) found the CHIPS to have good internal consistency ( $\alpha = .92$ ), as was the case here ( $\alpha = .94$ ).

### Self-reported sleep disturbances

The Pittsburgh Sleep Quality Index (PSQI), a 19 item questionnaire incorporating a four point Likert type scale (0 = not during the past month - 3 = three or more times per week), was used to assess sleep disturbances (Buysse et al., 1989). Total scores range between 0 and 21, and higher scores reflect greater sleep disturbances. The PSQI has been shown to have good internal consistency ( $\alpha = .86$ ) in studies involving caregivers of children with ASD (Gallagher et al., 2009), and this was also the case here ( $\alpha = .76$ ).



## Objective assessment of sleep

Standard objective measures of sleep, including waking after sleep onset (WASO), total sleep duration and time in bed, sleep latency and efficiency, and number of night-time awakenings, was derived using actigraphy. Participants were asked to wear an ActiGraph wGT3X-BT monitor on their non-dominant wrist for 24 hours per day (aside from bathing), for a minimum three, and maximum seven, days and nights. Actigraphy data were averaged, as per other studies of a similar nature, across all collection days (von Känel et al., 2012), and sleep parameters, as stated above, were derived using the ActiLife software (ActiGraph Corp, Pensacola, FL).

## Procedure

A study pack containing self-report measures of sleep disturbance and physical health problems, and the actigraphy device, was sent to participants by post. Instructions, also included in the pack, stated participants should wear the ActiGraph wGT3X-BT monitor on their non-dominant wrist 24 hours per day for a minimum three, and maximum seven, days and nights. Indeed, the American Sleep Medicine Association have stated that actigraphy data, to provide a reliable measurement of sleep, be collected over at least three days and nights. Prepaid envelopes were provided for returning all study materials back to the research team by post.

## Statistical analysis

A series of independent *t*-tests and, for categorical variables, chi-square ( $\chi^2$ ) tests were used to compare groups with respect to socio-demographic and lifestyle variables, and bivariate correlation was used to explore whether caregivers' physical health problems and sleep disturbances, both subjective and objective, might be related to characteristics of the

child with ASD. A series of ANOVAs were used to compare groups with respect to PSQI and CHIPS scores, and actigraphy parameters. Partial correlations, adjusting for group, were used to explore whether CHIPS scores might be related to PSQI scores and actigraphy parameters. The SPSS PROCESS macro, model 4, with bootstrapping (5000 iterations), as per Hayes (2012), was used to explore whether caregiving related disparities in physical health problems might be partially mediated by variations in sleep disturbances.

## Results

### Group differences with respect socio-demographic and lifestyle variables

Groups were statistically comparable with respect to all socio-demographic and lifestyle variables: gender ( $\chi^2_{(1)} = 2.55, p = .11$ ), age ( $t_{(46.08)} = .10, p = .93$ ), relationship status ( $\chi^2_{(1)} = .41, p = .52$ ), exercise ( $t_{(45.98)} = 1.83, p = .07$ ), nicotine ( $\chi^2_{(1)} = 1.14, p = .29$ ), alcohol ( $t_{(58)} = .45, p = .66$ ), and number of children ( $t_{(58)} = .72, p = .47$ ). Data also revealed age of the child with ASD (Mean = 8.6 years, Range = 2-19 years) and time since diagnosis (all  $ps > .41$ ) were unrelated, using bivariate (Pearson) correlation, to PSQI and CHIPS scores, and any actigraphy measures. None of these variables were included in further statistical analysis. Table 1 (see end of manuscript) displays sample characteristics by group.

### Group differences in sleep and physical health problems, and relationships between sleep and physical health problems

PSQI scores were higher in the caregiver group ( $F_{(1, 58)} = 11.30, p < .01, \eta p^2 = .16$ ), as were CHIPS scores ( $F_{(1, 58)} = 6.82, p < .01, \eta p^2 = .11$ ). Group differences also emerged, with the exception of average awakening length ( $F_{(1, 58)} = 1.95, p = .17, \eta p^2 = .03$ ), for all of the actigraphy measures. That is, sleep latency was longer ( $F_{(1, 58)} = 8.03, p < .01, \eta p^2 = .12$ ), as was WASO ( $F_{(1, 58)} = 10.52, p < .01, \eta p^2 = .15$ ), and sleep efficiency was poorer ( $F_{(1, 58)} =$

5.80,  $p = .02$ ,  $\eta p^2 = .09$ ), in the caregiving group. Interestingly, caregivers spent more time in bed ( $F_{(1, 58)} = 9.23$ ,  $p < .01$ ,  $\eta p^2 = .14$ ) and more time sleeping ( $F_{(1, 58)} = 6.59$ ,  $p = .01$ ,  $\eta p^2 = .10$ ), but woke more frequently during the night ( $F_{(1, 58)} = 8.50$ ,  $p < .01$ ,  $\eta p^2 = .13$ ).

Partial correlations, adjusting for group, revealed that CHIPS scores, while unrelated to any of the actigraphy measures (all  $ps > .19$ ), were positively related to PSQI scores ( $r = .44$ ,  $p < .001$ ). Only PSQI scores therefore, were taken forward for mediation analysis. Table 2 (see end of manuscript) displays means and standard deviations for CHIPS and PSQI scores, and actigraphy measures, by group.

### Mediation analysis

The SPSS PROCESS macro, model 4, with bootstrapping (5000 iterations), as per Hayes (2012), was used to assess whether the relationship between caring for a child with ASD and increased risk for physical health problems (CHIPS scores) might occur indirectly via greater self-reported sleep disturbances (PSQI scores). The regression, including caregiving status and PSQI scores, accounted for 53% of the variance in CHIPS scores ( $F = 11.11$ ,  $p < .001$ ). The strength of the relationship between caring for a child with ASD and poorer physical health was substantially reduced (79% reduction in variance of CHIPS scores explained by caregiving status), and became non-significant, after adjusting for PSQI scores ( $\beta = -6.74$ ,  $t = -1.14$ ,  $SE = 5.92$ ,  $p = .26$ ). Moreover, confidence intervals did not include zero ( $CI_{95} = -15.65, -2.84$ ), indicating the relationship between caring for a child with ASD and poorer physical health occurred indirectly via greater subjective reports of disturbed sleep.

## Discussion

This study explored the impact of caring for a child with ASD on sleep, assessed using subjective and objective measures, and examined whether poorer sleep provided one

indirect pathway by which caring for a child with ASD might be associated with increased physical health problems. Few studies have explored the effect of caring for a child with ASD on sleep, and this study is first, we believe, to incorporate objective assessments via actigraphy. Findings reported here, of higher PSQI scores in caregivers, are commensurate with other studies that found caregivers of children with DD, including ASD, were more likely to report disturbed sleep compared with controls (Bourke-Taylor et al., 2013; Gallagher et al., 2009; Lee et al., 2013, 2017). Here, caregivers were also more impaired than controls on actigraphy measures. Indeed, sleep latency and WASO were longer, sleep efficiency was poorer, and night-time awakenings, while no longer on average, were more frequent, in caregivers. Previous studies involving caregiving populations have observed a disassociation between subjective and objective sleep assessments. That is, caregivers, while complaining of more sleep disturbances, could not be differentiated from controls with respect to objectively assessed sleep parameters (von Känel et al., 2012). Findings in the current study however, were consistent; caregivers' subjective reports of disturbed sleep were greater, and they were more impaired on actigraphy measures of sleep latency and efficiency, WASO, and number of awakenings, compared with controls. This study, we believe, is first to incorporate objective measures of sleep, and to find them to be more impaired, in the context of caring for a child with ASD. The relationship between caring for a loved one with long-term illness and poorer objectively assessed sleep however, has been reported elsewhere. For example, in studies using actigraphy, elderly dementia caregivers, a group experiencing levels of distress and burden comparable with those caring for a child with ASD, experienced longer sleep latency and shorter total sleep time relative to age matched controls (Rowe et al., 2008; von Känel et al., 2010). Studies using polysomnography, another objective measure of sleep, also found sleep latency to be longer, sleep efficiency to be poorer, and total sleep time to be

shorter in the context of caring for a loved one with dementia (Fonareva & Oken, 2014; McKibbin et al., 2007; von Känel et al., 2006).

Interestingly, it was observed in the current study, using actigraphy data, that caregivers of children with ASD spent more time in bed, and slept for longer, compared with controls. This was an interesting finding, and might be explained by the fact that caregivers, experiencing more frequent night-time awakenings, spend more time in bed to compensate for more disturbed sleep. Oversleeping and spending prolonged periods in bed are characteristic of depression, and caring for a child with ASD has been associated, in multiple cross sectional and longitudinal studies, with greater depressive symptomology (Cantwell et al., 2015; Lovell et al., 2012a; Marshall et al., 2017). Caregivers of children with ASD have also been found to be more likely, compared with controls, to meet clinical criteria for depression (Cohrs & Leslie, 2017; Gallagher et al., 2008). In the current study, caregivers of children with ASD reported more physical health problems compared with controls, and it might be the case that caregivers, need to spend more time in bed, and more time sleeping, in order to recuperate from more frequent episodes of physical ill health. This finding, of caregivers reporting more physical health problems, resonates with studies that found caring for a child with ASD to be associated, using physiological outcomes, with increased risk for poorer physical health (Ruiz-Robledillo et al., 2013b; Seltzer et al., 2010), and with studies that link caregiving with more frequent visits to the GP (Gallagher et al., 2009) and greater self-perceived health complaints (Smith et al., 2011).

Here we explored whether the relationship between caring for a child with ASD and increased risk for physical health problems might occur indirectly via poorer sleep. Results revealed that physical health problems, while unrelated to actigraphy measures, were positively related to self-reported sleep disturbances (PSQI scores), and group disparities with respect to physical health problems became non-significant after adjusting for PSQI scores. It

would appear therefore, the relationship between caring for a child with ASD and poorer physical health occurs indirectly via greater self-reported sleep disturbances. It is interesting however, that it was greater subjective reports of sleep problems, and not objectively assessed sleep disturbances, which partially mediated caregivers' poorer physical health. It is important to note that because we did not include sleep diaries alongside actigraphy measures to confirm sleep and wake times, and because actigraphy only makes inferences about sleep quality from rest/activity patterns (i.e., movement), caution should be exercised when interpreting objective sleep data in the current study, and these findings might be deemed exploratory.

Findings reported here have clear implications for quality of life for the care recipient, and for intervention efforts. Indeed, the negative impact of impaired sleep on cognitive functioning has been widely reported (de Bruin et al., 2017; Kyle et al., 2017), and compromised cognition, particularly in domains such as memory, has been associated with greater difficulties completing the kinds of everyday tasks (e.g., medication management), that characterise the caregiving experience (Twamley et al., 2009; Woods et al., 2016). In a recent study involving caregivers of loved ones with memory loss, greater sleep problems, as measured using subjective reports, predicted poorer medication management (Sun et al., 2019). Sleep impaired caregivers are also more likely to report psychological distress (Richdale & Baglin, 2015), and care recipients of psychologically distressed caregivers find adjusting to their illness more challenging (Dockerty et al., 2000). Moreover, caregivers' and care recipients' sleep disturbances tend to be highly correlated (Russell et al., 2016), and greater sleep disturbances in children with ASD predict increased difficulties with daytime functioning (Lambert et al., 2016). Other studies also found quality of life for the child with DD, particularly in domains of social, emotional and physical functioning, to be closely related to the physical health of the care provider (Lovell, 2018). It is important therefore,

given the modulatory effect on physical health, and with quality of provided care in mind, to closely monitor sleep disturbances in caregivers of children with ASD and intervene where appropriate.

Encouragingly, sleep disturbances in caregivers of children with DD do appear to be amenable to improvement via psychological intervention. For example, psycho-educational interventions, in which caregivers are educated more about ASD, and about how to manage the problematic behaviours associated with ASD, have been shown to be effective for improving sleep (McCurry et al., 1998). Several other interventions, also incorporating aspects of psycho-education, were also found to be advantageous for alleviating caregivers' sleep disturbances (Simpson & Carter, 2010). It has been reported that children with ASD often experience sleep problems, and these predict sleep disturbances in the care provider (McCann et al., 2014). As such, whether more holistic interventions focussing on the caregiver-recipient dyad might be effective for mitigating caregivers' sleep disturbances have also being explored, and findings have been positive (Tilford et al., 2015).

The study, while boasting methodological strengths such as the use of objective assessments of sleep, was limited by its small sample size and cross sectional design, and findings reported here should be interpreted cautiously because of these limitations, and might be best viewed as exploratory. Other limitations are also noteworthy. Information about the problematic behaviours of the care recipient, known to predict physical health problems in the care provider (Lovell et al., 2015), and information about caregivers' medication use, which can affect sleep (Wichniak et al., 2017), ought to have been captured. All caregivers were recruited online via social support groups, and this recruitment strategy might have biased the sample. Indeed, socially supported caregivers report lower levels of stress, and caregivers reporting lower stress experience fewer sleep problems (Gallagher et al., 2010; Lovell et al., 2012b). Whether findings reported here, of greater self-reported sleep

disturbances partially mediating caregivers' poorer physical health, can be generalised to other caregivers with lower social support remains to be seen. In addition, the ratio of caregivers to controls here was disproportionate, and future studies aiming to consolidate and extend these findings might recruit a more balanced sample. Future studies might also move away from parent reports and clinically authenticate ASD diagnosis in the child.

In conclusion, caregivers of children with ASD self-reported more sleep disturbances, and were more impaired on objective measures of sleep, compared with controls. Physical health problems were also elevated in the context of caring for a child with ASD, and this effect occurred indirectly via greater subjective, but not objectively assessed, sleep disturbances. Interventions that alleviate caregiving related sleep disturbances might be effective, through reducing caregivers' physical health problems, for improving quality of provided care, and future studies might explore this.

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Table 1.

## Sample Characteristics by Group

|                                       | <b>Caregivers</b> | <b>Controls</b> |
|---------------------------------------|-------------------|-----------------|
|                                       | <i>n</i> =43      | <i>n</i> =17    |
| <b>Gender</b>                         |                   |                 |
| <i>Male</i>                           | 9 (21%)           | 7 (41%)         |
| <i>Female</i>                         | 34 (79%)          | 10 (59%)        |
| <b>Relationship Status</b>            |                   |                 |
| <i>Partnered</i>                      | 35 (81%)          | 15 (88%)        |
| <i>Not partnered</i>                  | 8 (19%)           | 2 (12%)         |
| <b>Smoking</b>                        |                   |                 |
| <i>Yes</i>                            | 7 (16%)           | 1 (14%)         |
| <i>No</i>                             | 36 (84%)          | 6 (86%)         |
| <b>Number of Children</b>             |                   |                 |
| <i>One</i>                            | 11 (26%)          | 3 (18%)         |
| <i>Two or three</i>                   | 30 (60%)          | 14 (82%)        |
| <i>Four or more</i>                   | 2 (14%)           | 0 (0%)          |
| <b>Mean Age (years)</b>               | 39.1 ±7.9         | 38.9±5.0        |
| <b>Mean Alcohol (drinks per week)</b> | 3.6±4.9           | 3.0±3.9         |
| <b>Mean Exercise (times per week)</b> | 2.9±2.5           | 1.9±1.6         |

Table 2.

## Physical Symptoms and Sleep measures by Group

|   | <b>Caregivers</b> | <b>Controls</b> |
|---|-------------------|-----------------|
|   | <i>n</i> =43      | <i>n</i> =17    |
| <b>CHIPS score</b>                        | 39.1±21.2         | 23.4±20.2       |
| <b>PSQI score</b>                         | 9.7±2.7           | 7.2±1.9         |
| <b>Actigraphy measures</b>                |                   |                 |
| <i>Sleep latency (minutes)</i>            | 1.0±0.8           | .41±.72         |
| <i>WASO (minutes)</i>                     | 44.9±1.17.7       | 28.5±17.4       |
| <i>Sleep efficiency (%)</i>               | 90.2±.3.6         | 92.6±.3.3       |
| <i>Total sleep time (minutes)</i>         | 449.2±87.8        | 382.6±97.4      |
| <i>Total time in bed (minutes)</i>        | 495.1±92.9        | 411.6±103.4     |
| <i>Number of awakenings</i>               | 14.1±4.7          | 10.3±4.3        |
| <i>Average awakening length (minutes)</i> | 3.4±1.3           | 2.9±1.3         |