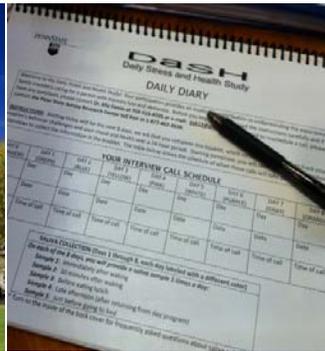


DAILY STRESS AND HEALTH OF FAMILY CAREGIVERS STUDY

PENNSTATE



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FINAL REPORT OF THE DAILY STRESS AND HEALTH STUDY (DASH)

With tremendous gratitude for your patience and persistence, we would like to thank you for your participation in the Daily Stress and Health of Family Caregivers Study (DaSH). In the 18 months since our last newsletter, we have been busy continuing to analyze the findings and preparing papers that report our results. We want to provide you with a final summary of the findings from the DaSH study.

DaSH: A Breakthrough for Caregivers' Health

The results of the DaSH Study are a breakthrough for understanding the effects of stress on health of family caregivers and how to protect them from the harmful consequences of

daily stress. In this report, we describe the findings of the study and their implications.

How Daily Stress Affects Our Health and Emotions

We begin with some background about stress. Our lives are filled with many challenges and stressors. On a daily basis, each small, stressful event leads to physiological and emotional reactions. As shown in the figure on the next page, our bodies react to stress by producing hormones, including the hormones that we studied in DaSH: Cortisol and DHEA-S. At an emotional level, we feel a mix of emotions—worry, fear, and apprehension about the everyday events in our lives. These

physiological and emotional reactions to stressful events are normal, usually brief, and helpful to us to respond to a threatening or challenging event. But when the stress is continual and relentless, the physiological and emotional reactions can run out of control and begin to take a toll on a person's emotional and physical health. That is what can happen to caregivers who provide daily support and care for a loved one who has dementia.

About DaSH: Why Did We Interview You for 8 Consecutive Days?

We wanted to get information from you on different types of days and

The DaSH Study is a collaborative effort that involves many organizations across several states: Pennsylvania, New Jersey, Virginia, and Colorado. The research team would like to thank our study assistants and research interviewers for their tireless dedication to the project. We would also like to thank the adult day programs, their staff, and the almost 200 families who gave their time and effort generously to support the study. Thank you! ~The DaSH Research Team



MEET THE DASH RESEARCH TEAM

The Daily Stress and Health Study brought together a collective expertise of over 100 years of experience. Meet them now!



Dr. Steven Zarit is a renowned researcher in the field of caregiving with 35+ years of experience. He is the Principal Investigator of DaSH and our fearless leader.



Dr. David Almeida of Penn State has done groundbreaking work on studies that use daily diary approaches, including the diary interview that you completed for DaSH!



Dr. Laura Klein studies how stress affects health, in particular, the hormones that we use in the DaSH Study. She is our very own saliva specialist!



Drs. Peter Molenaar and Michael Rovine use mathematical models to test theories of health processes, including those that we study in DaSH.



Dr. Elia Femia was DaSH's Project Manager, responsible for the day-to-day operations of the project. She made sure things ran smoothly.



Dr. Caryn Goodman was the study's Research Coordinator. She was the first voice that many of you heard from the DaSH Study.



Madelyn Wagner oversaw the interviews conducted by the Penn State Survey Research Center. Her staff had enjoyed the privilege of working with you.

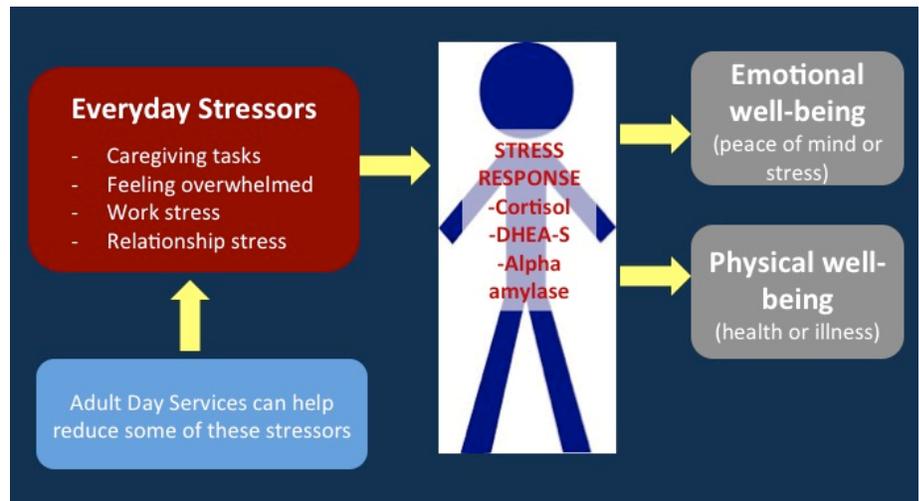


Figure 1. How Everyday Stressors Affect Us

experiences. This included the days that your relative used Adult Day Services and other days when you provided most or all of the care. We wanted to study how your body's stress response differed on these different types of days. To do this, we made statistical comparisons of your stress hormones and emotions on days you used Adult Day Services for your relative and days you did not. By interviewing you for 8 days, we were able to collect a lot of rich information from which we could make valid statistical comparisons.

Why Did We Ask for 5 Saliva Samples a Day?

A person's stress hormones vary in predictable ways throughout the day. We needed 5 samples across the day to study your pattern for that day. You may recall that you gave us samples immediately after you woke up, 30 minutes after you got out of bed, before lunch, before dinner, and just before going to bed. By having 8 day's worth of information, we could examine how your patterns changed from day to day depending on when you had high or low stress on a day.

Our Main Finding: Using Adult Day Services Is Beneficial to Health

The main finding in DaSH is that getting regular breaks from providing care to a loved one who has dementia can have a beneficial effect on a caregiver's health. The respite that an Adult Day Service program provides can interrupt the physiological and emotional responses to the chronic stress associated with caregiving. For each day per week caregivers in the study used Adult Day Services, the effects of stress on their physiological and emotional responses were reduced. A reduction in stress can translate to a decrease in a person's risk for stress-related illnesses. The specific findings are described below:

Cortisol ("the stress hormone")

Cortisol is a hormone that the body needs to prepare itself for stressful experiences. Having a normal pattern of cortisol is important because it safeguards the body against physiological and emotional "attacks." For people who have normal levels of stress (everyday stress at work, at home, in relationships, and so on), the body is able adjust to the stress

because cortisol is doing its job to ward off the negative effects.

A person who experiences exceptionally high levels of stress or is continually stressed, however, often has non-normal patterns, or dysregulated levels of cortisol. This is because the body is either always “on guard” or has “given up” in terms of its cortisol functioning. Dysregulated cortisol puts a person at greater risk for depression and illness.

The DaSH Study found that at a physiological level, cortisol levels were better regulated on days that caregivers utilized Adult Day Services. These results suggested that caregivers gained relief from stress by using Adult Day Services, which led the body to resume a more normal pattern of daily cortisol. In the long term, this lowers the risk of depression and illness. *DaSH is the first study to demonstrate improvement of daily cortisol in a chronic stress situation.*

To put this finding in perspective, dysregulated cortisol is often seen among military personnel and other individuals experiencing post-traumatic stress syndrome or PTSD. Similar dysregulation is seen among family caregivers of someone who has dementia, but these effects can be reversed when caregivers get days off from providing care by using Adult Day Services programs.

DHEA-S (“the anti-stress hormone”)

Dehydroepiandrosterone-sulfate (DHEA-S) is an important hormone that works synchronously with cortisol and counteracts its harmful effects. Increased levels of DHEA-S have an “anti-stress” effect -- improving the body’s reaction to stress, increasing energy levels, improving mood and sleep quality, feeling more relaxed, and

lowering the risk for illness.

The DaSH Study found that DHEA-S levels improved with Adult Day Service Use. This effect was seen not on the same day caregivers used Adult Day Services for their relative, but on days *after* their relative attended the adult day program. These findings suggest that getting a break from the stress of providing care allows the body to replenish DHEA-S. As with cortisol, this change in DHEA-S lowers risk of depression and illness.

Emotional Benefits of Using Adult Day Services

We found improvements in daily emotions as a result of using Adult Day Services. On days caregivers in DaSH used Adult Day Services, they reported lower feelings of anger. In other words, getting a break from care during the day allowed them to respond more calmly to the challenges that occurred that day.

We also saw what is called a “stress buffering” effect. On days when stressors were higher than normal and caregivers were providing all the daily care for their relative, their reports of depression went up. On days when stressors were higher than normal, but their relative attended Adult Day Services, caregivers’ report of

depression was low. As with anger, this finding suggests that on days when caregivers were not providing all the care for their relative, they were able to respond to daily challenges without getting as upset or feeling depressed. Like the changes in stress hormones, staying calmer in the face of stressful events reduces the risk of harmful effects of stressors on health.

Long-term Benefits of Adult Day Services Use

Many of our DaSH participants completed telephone interviews at 6 and 12 months following the initial set of 8 daily interviews. With the information that you provided, we were able to study your health over that period of time. We found a statistical relationship between using Adult Day Services and maintaining good functional health, which included activities such as, walking, lifting heavy objects, and carrying out other physical activities. In other words, use of Adult Day Services prevented decline in caregivers’ functioning health. Because we did not collect your saliva at this follow-up,



Presentations by the DaSH Team at Scientific Conferences and in the Media

Findings from the DaSH study have been presented at scientific conferences in the United States, Europe and Asia, including the Gerontological Society of America, the International Association of Gerontology and Geriatrics, the Nordic Gerontology Congress and at other meetings. Stories about DaSH findings have appeared in many newspapers and in blogs in the New York Times and the AARP

we could not examine the long-term changes in stress hormone regulation.

Why These Findings Are Important

We know that high stress, in particular, the stress associated with caring for someone with Alzheimer's disease or another type of dementia, can be harmful to a caregiver's health. By improving regulation of stress hormones and emotions, use of Adult Day Services reduces the likelihood that chronic stress will cause changes such as tissue damage and weakening of the immune system that make people more vulnerable to illness. In sum, regular use of an Adult Day Services program can reduce the harmful effects of stress and its risk to your health.

It is our hope that our positive findings will contribute to a discussion by states and by the federal government for increased funding for caregivers of persons with dementia to use Adult Day Services or other programs that provide respite. Adult Day Service program are a practical and effective way to reduce health risks for caregivers, while providing a safe and stimulating environment for persons living with

Alzheimer's disease or other chronic illnesses. To help caregivers, more government funding is needed to make these programs more affordable.

We also know that many family caregivers do not get timely information about the help that is available and often do not use programs such as Adult Day Services until they find themselves under a lot of stress. The findings from DaSH say to family caregivers—getting help is important. The respite from using Adult Day Services will preserve your health and allow you to be a caregiver to your relative for as long as you feel that home care is the best way to go.

From the day Bobby started going, things got better. . .

Suddenly he had a reason to get up in the morning. He had a place to go and a structure to his life.

Suddenly there was less claustrophobia for us—as much of the burden of caretaking was lessened.

~ Bobby's Brother

The Study's Success Was Due to You!

DaSH was a complicated study that used cutting-edge methods for studying stress. To make it work, we asked our study participants to do a lot – 8 daily interviews and 5 saliva samples on a precise schedule for each of those days. Our participants, including you, provided 89% of the scheduled daily interviews and 96% of saliva samples, or more than 6,600 samples. You were fantastic! By sticking with our protocol, you made the success of the study possible. Your participation contributed to new knowledge about how we can make the caregiving load easier to bear for caregivers in the future.

Special Thanks to the Programs that Brought You to Us...And to Our Incredible Interviewers...

Sherri Boxer, Mary Brodland, Joan Burns, Anthony Giannoumis, Nicole Greeland, Amy Klein, Judy Milio, Carol Sussman-Skalka, Rachel Thompson, & Erica Zwilling.

Publications in Scientific Journals from the DaSH Study

You can read summaries of the articles by entering the "doi" number in your internet browser. For complete copies, contact Dr. Steven Zarit at szarit@psu.edu. The last article was just accepted for publication and is not yet available on-line.

- Zarit, S. H., Kim, K., Femia, E. E., Almeida, D. M., & Klein, L. C. (2014). The effects of adult day services on family caregivers' daily stress, affect and health: Outcomes from the DaSH Study. *The Gerontologist*, 54, 570-579. doi: 10.1093/geront/gnt045
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- Klein, L. C., Kim, K., Almeida, D. M., Femia, E. E., Rovine, M. J., & Zarit, S. H. (2014). Anticipating an easier day: Effects of adult day services on daily cortisol and stress. *Gerontologist*, doi:10.1083/geront/gne060.
- Liu, Y., Kim, K., Almeida, D. M., & Zarit, S. H. (2014). Daily fluctuation in negative affect for family caregivers of individuals with dementia. *Health Psychology*. <http://dx.doi.org/10.1037/hea0000175>
- Liu, Y., Kim, K., & Zarit, S. H. (in press). Health trajectories of family caregivers: Associations with care transitions and adult day service use. *Journal of Aging and Health*.