

Recognizing Burden in Unpaid Caregivers of End Stage Renal Disease Patients

Joanne Affinito DNP, APN, C

William Paterson University of New Jersey & The National Kidney Foundation

BACKGROUND

Caregiving to an aging population is falling upon unpaid, informal caregivers, without warning, who do not possess any training in the care they are rendering (Carretero, Garcés, Rodenas, & Sanjose, 2009, & Schultz & Beach, 1999). The burden of caregiving can result in psychological distress, decline in physical health, economic and social problems, disruption of family relationships and a sense of losing control (Akinci, & Pinar, 2012). An estimated 65.7 million individuals, 29% of the U.S. population reported that they were informal caregivers (Alpert, 2014). Caregivers tend to neglect their own health needs which is a risk factor for mortality (Carretero et al., 2009, Lee, Coldits, Berkman, & Kawachi, 2003 & Schultz & Beach, 1999).

RESEARCH QUESTION, HYPOTHESIS

This study will assist healthcare providers to identify burden and to empower caregivers in developing strategies that may lessen their degree of burden. It may also support caregivers to identify the positive aspects in their caregiving role.

What is the relationship between the positive aspects of caregiving & the perceived degree of burden? **Hypothesis 1)** Caregivers with more positive aspects associated with caregiving will experience lesser degree of burden.

What is the relationship between self-assessed level of health and degree of caregiver burden? **Hypothesis 2)** Caregivers with higher levels of self-assess health will experience lesser degree of burden.

MATERIALS AND METHODS

Instruments

The Positive Aspects of Caregiving Scale (PAC), Tarlow el al. (2004).
The Caregiving Stress Appraisal (CSA), Abe (2006).
Self-Assessed Health Measure (SAH), Haug, Wykle & Namazi (1989).

Methodology

The National Kidney Foundation launched the descriptive survey to 3,233 members of it’s listserv utilizing Survey Monkey® for a convenience sample of 89 respondents (response rate of 0.027%).

RESULTS

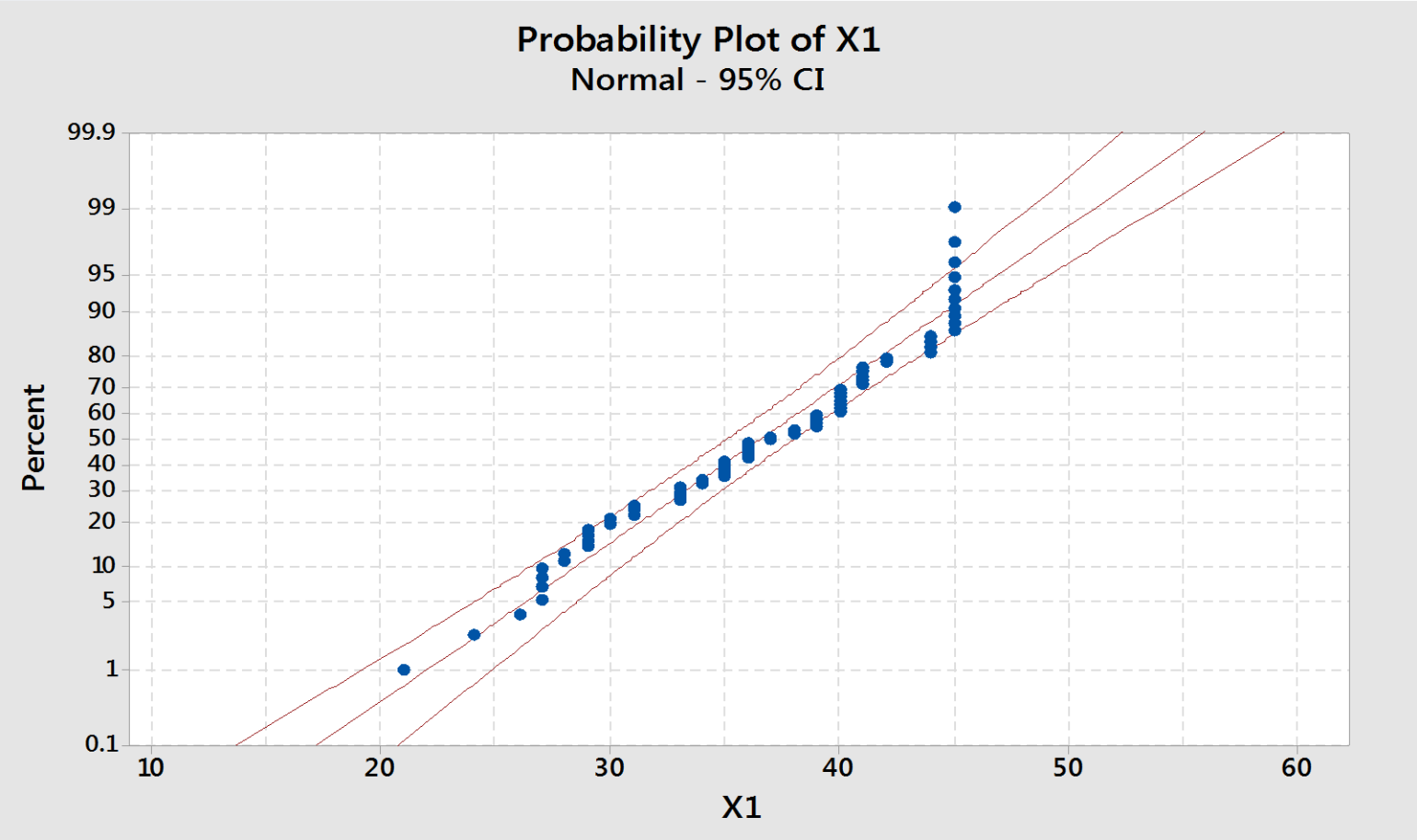
The majority of caregivers were female, Caucasian, and married.
Mean age was 58.53 years (SD = 13.6 years), a median age of 61 and an age range from 22-91 years.
Income level \$13,000 to \$300,000 with a mean of \$71,517.70 (SD = \$66,240.10).
Educational level was 3.83 (SD = 1.324) some college courses were coded “3” and college graduate “4.”
Caregivers not working (37.6%) and caregivers working full-time (32.7%) was close with a 4.9% difference.
Years of caregiving ranged from six months to 28 years with a mean of 4.131 years (SD = 5.61).

The caregiver’s PAC and SAH indicated a positive correlation ($r = 0.282, p = < 0.004$).

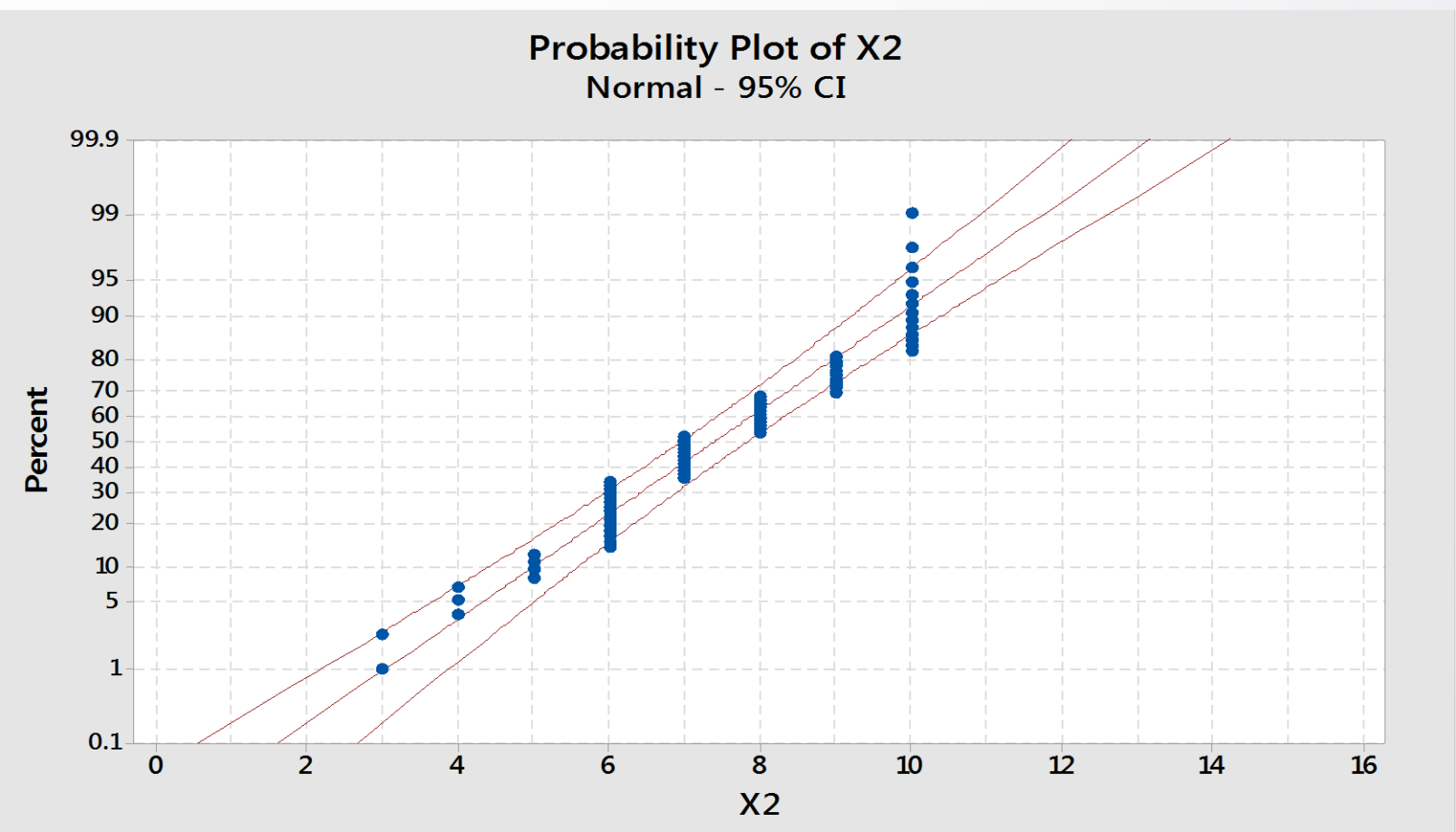
There is a strong correlation between degree of burden and SAH ($r = -.537, p = 0.00$); supporting **hypothesis 1)** that caregivers with more positive aspects associated with caregiving will experience lesser degrees of burden.

The significant correlation between degree of burden and PAC ($r = -.335, p = < 0.001$) also supports **hypothesis 2)** that caregivers with higher levels of SAH will experience lesser degrees of burden.

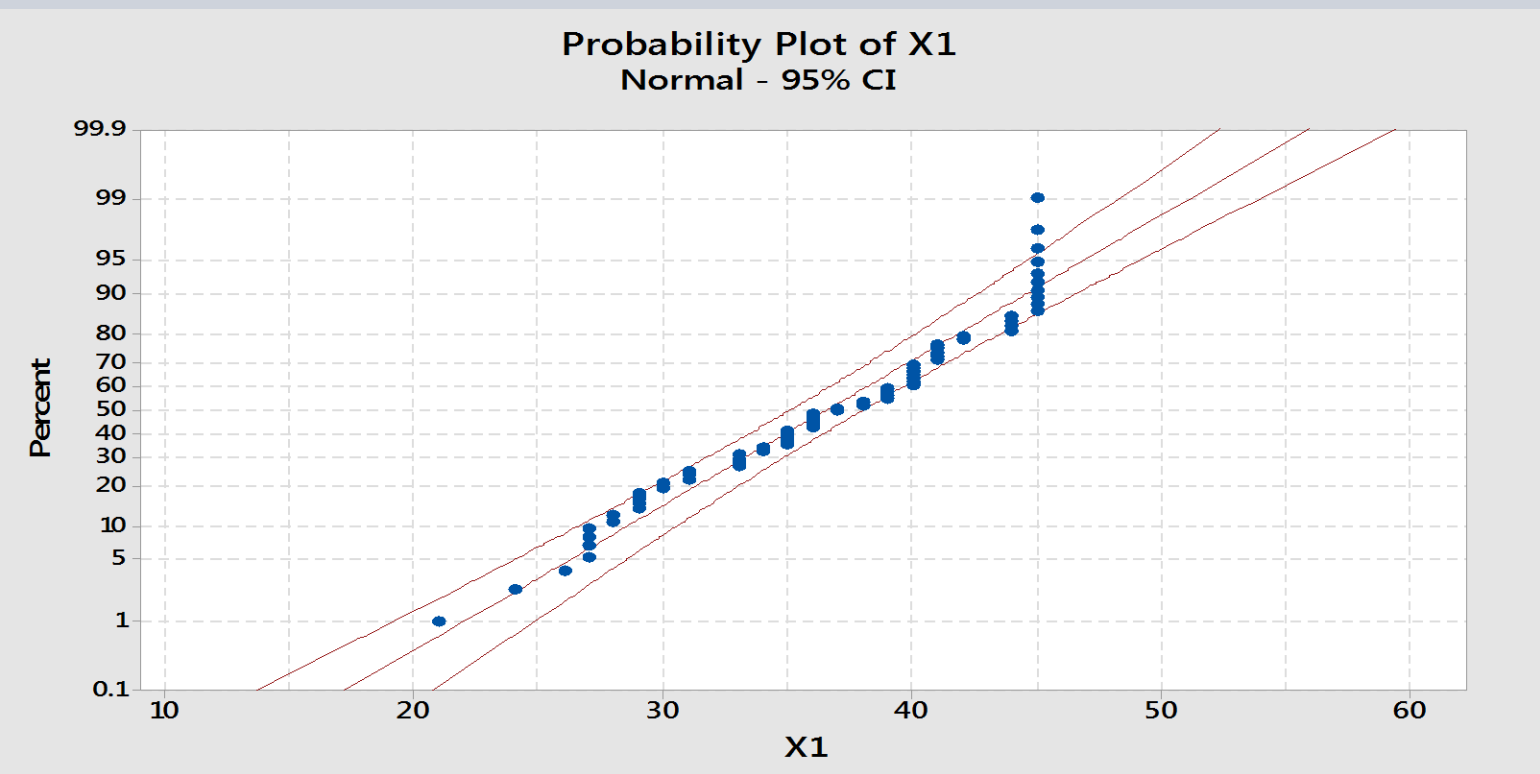
Probability Plot of PAC



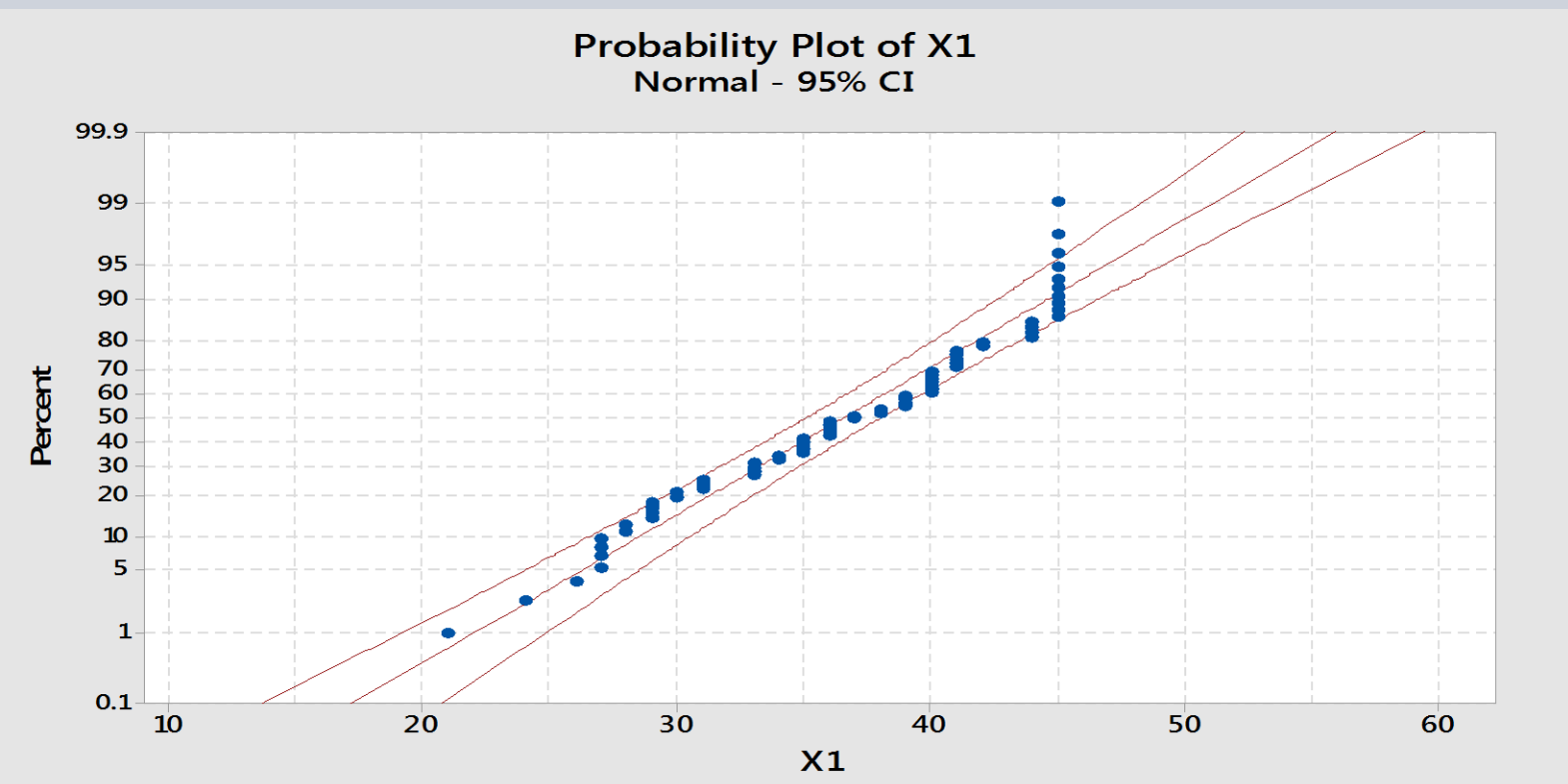
Probability Plot of SAH



Probability Plot of Burden



Probability of PAC, SAH & Burden



CONCLUSIONS & RECOMMENDATION

Burden may not be disease specific but may be a universal phenomenon of caring for care recipients of all ages with chronic illnesses (Garlo et al. 2010). ANP’s need to embrace the care recipient and the caregiver as a dyad to strategize plans of care that are beneficial to both participants. This study has important implications for clinicians to assess caregivers early in their new role and to provide interventions designed to minimize stress and to improve quality of life.

RECOMMENATION

Replication of this study with a larger sample size
Conduct future studies identifying caregivers experiencing burden that provide support and problem-solving strategies either face-to-face in an office or home setting, on the telephone, Face Time or a combination of the three with the goal of facilitating the positive aspects of the caregiving experience.

REFERENCE

Abe, Koji. (2006). Reconsidering the caregiving stress appraisal scale: Validation and examination of its association with items used for assessing long-term care insurance in Japan. *Archives of Gerontology and Geriatrics*, 44, 287-297.

Akinci, A. & Pinar, R. (2012). Validity and reliability of Turkish caregiver burden scale among family caregivers of haemodialysis patients. *Journal of Clinical Nursing*, 23, 352-360. Doi:10.1111/j.1365-2702.2012.04235.x

Alpert, P.T. (2014). “Who’s caring for the caregiver?” *Home Health Care Management & Practice*, 26(4), 266-268 doi: 10.1177/1084822314521210

Carretero, S., Garcés, J., Rodenas, F. & Sanjose, V. (2009). The informal caregiver’s burden of dependent people: Theory and empirical review. *Archives of Gerontology and Geriatrics*, 49, 74-79. Doi: 10.1016/j.archger.2008.05.004

Faison, K., Faria, S. & Frank, D. (1999) Caregivers of chronically ill elderly: Perceived burden. *Journal of Community Health Nursing*, 16(4), 243-253.

Garlo, K., O’Leary, J., Van Ness, P. & Fried, T. (2010). Burden in caregivers of older adults with advanced illness. *Journal of American Geriatrics Society*, 58(12), 2315-2322.

Haug, M., Wykle, M. & Namazi, K. (1989). Self-care among older adults. *Social Science & Medicine*, 29, 171-183.

Lee, S., Coldits, G., Berkman, L. & Kawachi, I. (2003). Caregiving and risk of coronary heart disease in U.S. women: A prospective study. *American Journal of Preventative Medicine*, 24, 113-119.

Schultz, R. & Beach, S. (1999). Caregiving as a risk factor for mortality, the caregiver health effects study. *Journal of American Medicine Association*, 282(23), 2215-2219.

Tarlow, B., Wisniewski, S., Belle, S., Rubert, M., Ory, M., & Gallagher-Thompson, D. (2004). Positive aspects of caregiving: Contributions of the REACH Project to the development of new measures for Alzheimer’s caregiving. *Research on Aging*, 26(4), 429-453. Doi: 10.1177/0164027504264493

Joanne Affinito DNP, APN, C
20 Brownstone Terrace
Hawthorne, New Jersey 07506
201-602-8374 affinitoj @ wpunj.edu or jaffinito@verizon.net