



North American Association of Christians in Social Work
A Vital Christian Presence in Social Work

PO Box 121
Botsford, CT 06404
www.nacsw.org
888.426.4712

**SPRINKLING SPIRITUALITY THROUGHOUT THE ALZHEIMER'S
CAREGIVER'S JOURNEY**

By: Sally P. Moore

**Presented at:
NACSW Convention 2012
October, 2012
St. Louis, MO**

Sprinkling Spirituality
Throughout the
Alzheimer's Caregiver's Journey

By

Sally P. Moore, Alzheimer's Caregiver, MSW, LCSW

Presented at:

NACSW Conference 2012

St. Louis, MO

October 2012

Abstract

This qualitative study examined the multidimensional role of the Alzheimer's caregiver.

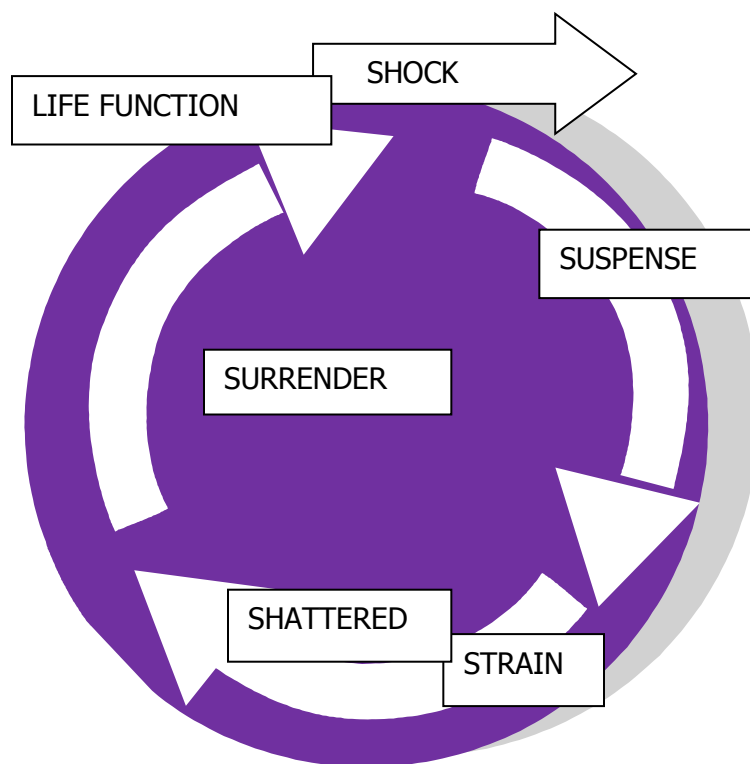
Several issues were explored, specifically:

- the unique characteristics of and demands placed on the caregiver
- coping strategies, particularly the role of spirituality
- the impact of the disease and caregiving on work and family.

Implications for practice were discussed.

“SURVIVING TODAY-AN ANCHOR FOR CAREGIVERS”

*ANTICIPATORY GRIEF WHEEL



*Adapted from Donna O'Toole's "Grief Wheel" (1982) by Sally Moore, MSW

July 2006

Caregiver's Anticipatory Grief Wheel Notes

SHOCK

Shield for protection after hearing, "Your loved one has CA, AD, ALS, etc." or, "There is nothing more I can do, have you considered Hospice?"

- ❖ **Sponge** to absorb the remainder of the physician's message

As shock wears off, caregiver begins to remember what physician said

SUSPENSE

- ❖ **Focus:** on Loved One
- ❖ **Image:** Gray skies (from dark to fluffy white with blue sky)
- ❖ **Characteristics:**
 - ✚ Parental instinct to shield loved one from reality of diagnosis
 - ✚ Grasping for straws
 - ✚ Second/third opinions
 - ✚ Contradictions
 - ✚ Searching for any answers to make sense of what is going on

STRAIN

- ❖ **Focus:** on caregiver
- ❖ **Image:** Black or White (no in between)
- ❖ **Characteristics:**
 - ✚ Self-pity
 - ✚ Guilt
 - ✚ Resentment
 - ✚ Family and friends: either supportive or disappear

SHATTERED

- ❖ **Focus:** Hopelessness of situation/ Helpless: no way out
- ❖ **Image:** Slivers of a rainbow in dark sky
- ❖ **Characteristics:** one of three scenarios
 - ✚ Death of caregiver
 - ✚ Abandonment of loved one
 - ✚ Survivor: usually one defining moment in time

SURRENDER

- ❖ **Focus:** Caregiver and Loved One
- ❖ **Image:** (Sunrise that will eventually lead to the glorious final Sunset)
- ❖ **Characteristics:**
 - ✚ Live the moment
 - ✚ Journey together
 - ✚ Strong bond (“Fall in love all over again”)

When gray clouds appear, they look for a rainbow

* * * * *

SOCIAL WOKER'S ROLE

- ✚ Gently guide caregiver through stages
- ✚ Validate feelings
- ✚ Normalize reality
- ✚ Listen, listen
- ✚ Plant seeds

Intellectually, the caregiver knows what is best for her loved one.

Emotionally, the caregiver may be unable to “play God” when I comes to making tough decisions.

Spirituality

“is the devotion to the immaterial part of humanity & nature rather than worldly things such as possessions” Barker, R.L. (1999) The Social Work Dictionary (4th ed.)

“the human sense of & search for transcendence, meaning, & connectedness beyond the self” Sherwood, D.A., (1998) Spiritual assessment as a normal part of social work practice: Power to help & power to harm Social Work & Christianity, 25 (2).

Spiritual Beliefs

Important in meeting daily challenges by:

- Nurturing
- Assisting
- Strengthening

Relied on to get them through the day:

- Guidance
- Support
- Comfort

Transcendence

“the ability to rise above an environment that lacks nurturing & denies legal & civil rights & still maintain one's sense of self-worth & integrity” Barker, R.L. (1999) The Social Work Dictionary (4th ed.)

Transcendent Properties

- Live in the moment
- Face death on a daily basis
- Personal relationship with God
- Limitless compassion
- Abiding gratitude
- When all else failed, faith remained

Approaching **S**pirituality

Start the conversation

Probe for feelings

Mindful of the caregiver's **s**piritual beliefs

Stay in the caregiver's NOW

Proclaim her/his **s**truggles

Messages of **s**trength

Say it **s**imply

Platitudes are NO-NOs

Moments of **s**ilence

References

- Fannan, C. J., Miller, B. H., Kaufman, J. E., Donner, E., & Fogg, L. (1999). Finding meaning through caregiving: Development of an instrument for family caregivers of persons with Alzheimer's disease. *Journal of Clinical Psychology, 55* (9), 1107-1125.
- Ford, G. R., Goode, K. T., Barrett, J. J., Harrell, L. E., & Haley, W. E. (1997). Gender roles and caregiving stress: An examination of subjective appraisals of specific primary stressors in Alzheimer's caregivers. *Aging and Mental Health, 1* (2), 158-165.
- George, L. K., & Gwyther, L. P. (1986). Caregiver well being: A multidimensional examination of family caregivers. *The Gerontologist, 26*, 253-259.
- Haley, W. E., & Prado, K. M. (1987). Relationship of severity of dementia to caregiving stressors. *Psychology and Aging, 4*, 389-392.
- Horowitz, A. (1985). Family caregiving to the frail elderly. *Annual Review of Gerontology/Geriatrics, 5*, 194-246.
- Lieberman, M. A., & Fisher, L. (1999). The effects of family conflict resolution and decision making on the provision of help for elders with Alzheimer's disease. *The Gerontologist, 39*, 159-166.
- Mezey, M., Miller, L., & Linton-Nelson, L. (1999). Caring for caregivers of frail elders at the end of life. *Generations, 23* (1), 44-51.
- Monahan, D. J., & Hooker, K. (1995). Health of spouse caregivers of dementia patients: The role of personality and social support. *Social Work, 40*, 305-314.
- Monahan, D. J., & Hooker, K. (1997). Caregiving and social support in two illness groups. *Social Work, 42*, 278-287.
- Ory, M. G., Hoffman III, R. R., Yee, J. L., Tennstedt, S., & Schulz, R. (1999). Prevalence and impact of caregiving: A detailed comparison between dementia and nondementia caregivers. *The Gerontologist, 39*, 177-185.
- Pearlin, L. I., Mullan, J. T., Semple, S. J., & Skaff, M. M. (1990). Caregiving and the stress process: An overview of concepts and their measures. *The Gerontologist, 30*, 583-594.
- Pruchno, R. A., & Resch, N. L. (1989). Mental health of caregiving spouses: Coping as mediator, moderator, or main effect? *Psychology and Aging, 4*, 454-463.
- Reese, D. R., Cross, A. M., Smalley, D. L., & Messer, S. C. (1999). Caregivers of Alzheimer's disease and stroke patients: Immunological and psychological considerations. *Gerontologist, 34*(4), 534-540.
- Rose-Rego, S. K., Strauss, M. E., & Smyth, K. A. (1998). Differences in the perceived well-being of wives and husbands caring for persons with Alzheimer's disease. *Gerontologist, 38* (2), 224-230.
- Rubio, D. M., Berg-Weger, M., & Tebb, S. S. (1999). Assessing the validity and reliability of well-being and stress in family caregivers. *Social Work Research, 23*, 54-65.
- Straw, L. B., O'Bryant, S. L., & Meddaugh, D. I. (1991). Support system participation in spousal caregiving: Alzheimer's disease versus other illness. *Journal of Applied Gerontology, 10* (3), 359-371.
- Townsend, A., Noelker, L., Deimling, G., & Bass, D. (1989). Longitudinal impacts of interhousehold caregiving on adult children's mental health. *Psychology and Aging, 4*, 393-401.