Chronic Perceived Stress, Social Isolation, and Perceived Loneliness as a Symptom Cluster among Dementia Caregivers

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Background
- 15.5 million unpaid dementia caregivers in the U.S.; over 5 million individuals living with Alzheimer’s disease (AD), projected to reach up to 16 million in 2050; most live in the community, assisted by unpaid caregivers
- $9.7 million/year in healthcare costs
- Contribute $217 billion/year in labor
- Experience chronic stress, depressive symptoms, anxiety, burden, quality of life, social isolation & perceived loneliness

Caregivers’ Multifactorial Stress
- ADLs & neuromotor disturbance: more intense caregiver involvement needed compared to older care recipients with non-dementia illnesses
- Behavioral & psychological symptoms of dementia (BPSS): more supervision
- BPSS may trigger caregivers’ acute stress
- Caregiving hours: employment & family difficulties; sandwich caregivers
- Employment risks: work hours, financial insecurity
- Social isolation and/or perceived loneliness: potentially changed relationships

Link Between Endogenous Mechanisms & Exogenous Factors
- Association between social isolation & morbidity, including diseases of inflammatory pathogenesis
- Association between perceived loneliness & altered gene transcription
- Chronically high subjective social isolation
- Underexpression of genes that carry anti-inflammatory glucocorticoid response elements & genes required for antibody synthesis & B lymphocyte maturation
- Overexpression of genes that carry response elements for the pro-inflammatory transcription factor – nuclear factor kappa B protein complex & genes that regulate pro-inflammatory cytokine signaling, cellular transcription events, cell cycle course, & prostataglandin formation
- Similar findings among individuals living with chronic stress – caregivers for persons with glioblastoma

Objectives
I. Review evidence on dementia caregivers’ health through the lens of endogenous mechanisms of chronic stress & exogenous factors that may contribute to social isolation and perceived loneliness. II. Examine whether chronic stress, social isolation, and perceived loneliness may occur as a symptom cluster, and what may serve as a marker of the proposed cluster.

Methods
- Study design: Review: randomized controlled trials (RCTs), systematic reviews of RCTs, meta-analyses, quasi-experimental investigations, case-control or cohort studies, systematic reviews of qualitative or descriptive studies, single qualitative or descriptive studies, expert opinions, Publication years & language: 1980 – 2015, English, Search strategy: PubMed, PsyCINFO, CINAHL, Web of Science, & EMBASE databases; reference lists.
- Study selection: I. Report endogenous mechanisms of chronic stress and/or exogenous factors that contribute to dementia caregivers’ social isolation or perceived loneliness. II. Aimed at informal caregivers of community-dwelling persons with dementia (AD, frontotemporal, Lewy body, vascular, or mixed).

Results

Caregivers’ Multifactorial Stress
- ADLs & neuromotor disturbance: more intense caregiver involvement needed compared to older care recipients with non-dementia illnesses
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Exogenous Factors

Hypothalamic-Pituitary-Adrenal (HPA) Axis
- Proinflammatory cytokines TNF-α & IL-10
- Proliferation of T lymphocytes – active immunity
- Shortened telomere length in peripheral blood mononuclear cells (PBMCs)

Neuroimmunological Dysregulation & Depressive Symptoms
- Heart rate, blood pressure, cardiovascular output
- Blood glucose
- Production, secretion, & efficacy of cytokines
- Migration of white blood cells (WBCs) to cellular injury sites

Adaptive vs. Maladaptive responses
- Chronic Stress
  - Hormone secretion downregulation of expression & function of receptors on WBCs that bind cortisol
  - Persistent hypercortisolina

Disruption of Neuroendocrine & Immune Regulatory Pathways with Chronic Stress
- Proinflammatory cytokines
- Immune system communicates with brain

Discussion & Implications

Chronically physically demanding work of caregiving: fatigue, pain, & depression
- Healthy adults who self-perceive as lonely exhibit greater synthesis of TNF-α & IL-6 by PBMCs stimulated by lipopolysaccharide, following acute stress
- Dementia caregivers who perceive themselves as lonely may exhibit similar inflammatory phenotype
- Relevant given high risk of acutely stressful events associated with BPSS: agitation, aggression, wandering
- Dementia caregivers who perceive themselves as lonely: at a risk for a three-component symptom cluster – fatigue, pain, & depression

Exogenous Factors

Perceived Loneliness & Social Isolation
- Change in family roles
- Likely loss of relationship with the care recipient
- Prevalence of conflict in caregiving families
- Reduction of work hours may further limit non-family social connections

Dementia Caregivers’ Chronic Diseases
- HTN & arthritis: most prevalent conditions among caregivers who are baby boomers
- HTN: may lead to acute events or heart failure
- May be able to maintain social connections; not willing to be seen ill
- May worsen social isolation and/or perceived loneliness
- Arthritis: may be instrumental ADL performance & ability to engage in social activities
- Financial burden of caregivers’ own illnesses coupled with expenses of caregiving

References

Acknowledgments
Ms. Carolyn Brown, Dr. Elizabeth Corwin, Dr. Ann Rogers