

Title: *Family-Centred Service: What Is It, and Why Should I Care? Lessons from Families of Children with Disabilities*

Speaker: Peter Rosenbaum, MD, FRCP(C), Professor of Pediatrics
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Abstract:

Family-centered service (FCS) is a philosophy of service delivery to families raising children with chronic disorders of health or development. The evidence-based FCS framework outlines behaviors that parents find helpful, and that form the basis for a reliable and valid way to measure FCS. Experiences of FCS are correlated positively with parent satisfaction with services and with parent mental health, and negatively with stress in dealing with service systems. The first part of this talk will report briefly on our group's explorations of FCS, and illustrate how the style and content of services matter to caregivers.

In the second part of this talk I will illustrate some of the data we have reported on the physical and mental health of parents of children with cerebral palsy (much worse than comparative Canadian adults' health), and bring the talk full circle by returning to FCS as a preferred model for service delivery. I will end with some thoughts about the research questions still to be answered in order to move health service delivery from philosophy to consistent and effective action – to the presumed benefit of caregivers (and even of service providers)!

Title: *Comparison of Emotional and Biological Parameters in Mexican American and White Male and Female Caregivers of Patients with Alzheimer's disease*

Speaker: Sharon L. Lewis, R.N., Ph.D., F.A.A.N., Professor, Schools of Nursing and Medicine
University of Texas Health Science Center

Purpose: Aging baby boomers and longer life spans will result in a caregiver crisis in the near future. Although family caregivers perform an incredibly valuable service, they do so at a considerable cost to themselves, emotionally and physically. The purpose of this study is to compare emotional responses of male and female Mexican Americans and white caregivers to being a family caregiver of a patient with Alzheimer's disease using quality of life measurements, biofeedback parameters, and immune measurements.

Methods: The four groups of family caregivers included Mexican American females, white females, white males, and Mexican American males from 2 Southwestern cities. Instruments used to collect quality of life data included Sense of Coherence, Perceived Stress, Kellner Symptom Questionnaire, Screen for Caregiver Burden, Center for Epidemiologic Studies Depression, Coping Resources, SF-36 Health Survey, and Personal Resources. Percentage of NK (CD3⁻CD56⁺CD16⁺) cells was also determined. One way ANOVA was used with a Bonferroni post hoc test to determine differences among the groups. Biofeedback measurements were used to obtain psychophysiological data.

Results: Coping resources were similar among all four groups. White male caregivers, as compared to white and Mexican American females, had significantly less subjective burden, stress, anxiety, depression, and somatization, and significantly higher sense of coherence, general health, social function, physical function, vitality, and natural killer cell percentage. White males had significantly higher general health and physical functioning and less somatic symptoms than Mexican American males. There were no statistical differences on any of the measurements between Mexican American and white females. On stress reactivity biofeedback measurements, there were significant differences between Mexican Americans and whites. For example, Mexican Americans reacted to a think stressor with greater increases in skin conductance than whites.

Conclusions: Mexican American caregivers have more emotional distress than white caregivers. White male caregivers had a higher quality of life as compared to white female caregivers and Mexican American caregivers of both genders. In summary, unique gender and cultural issues need to be addressed when strategies are implemented to assist the increasing number of family caregivers as our society ages.

Title: *Systematic Review of Advance Care Planning and Caregiver Burden and Satisfaction With Quality Of Care at the End-Of-Life*

Speaker: Anne Wilkinson, Ph.D., M.S., Senior Behavioral/Social Scientist and Director, Palliative Care Policy Center, RAND Corporation, Washington, DC.

Research Objective:

An adequate evaluation of end-of-life resource use must be informed by an understanding of what and how to evaluate quality of end-of-life care and where the state-of-the-art and industry experience stands. We conducted a systematic review of the literature on salient aspects of end-of-life quality care, including patient advance care planning and caregiver burdens and satisfactions with end-of-life care in order to identify the evidence base on the quality of care. [71 words]

Study Design:

In support of the National Institutes of Health State-of-the-Science Conference on End-of-Life Care in December, 2004, we systematically reviewed the professional literature (English) from Medline, Database of Reviews of Effects (DARE), the National Consensus Project for Palliative Care bibliography, and several recent unpublished systematic reviews from the National Institute for clinical Excellence (NICE) and Health Canada between 1990-2004, with an update through November, 2005. From 24,423 total citations, we identified 6,381 titles. Reviewers screened 5,216 abstracts and included 15 systematic reviews, 57 intervention studies, and 42 observational studies related to advance care planning or caregiver burden and satisfaction with care at the end-of-life in the final review. [106 words]

Population Studied:

We evaluated the extent to which published and unpublished patient advance care planning and caregiver studies addressing three paradigmatic late life conditions: cancer, congestive heart failure, and dementia. In addition, we investigated end-of-life care by setting. [36 words]

Principal Findings:

The literature indicates that traditional advance directive (AD) interventions focused on written decisions to forgo future medical treatments have been disappointing in their success in improving either completion rates or end-of-life care. Outcome measures have focused on documentation and completion rates without addressing the impact of advance directives on quality of care. Major problems with advance directives have been their lack of consistency, utility in informing current treatment decision-making, and accessibility. Advance care planning, a more comprehensive and continuous process of communication, information exchange, patient/family identification of values and life-goals, and provider supported decision-making that is tailored to the patient's current clinical status produces modest benefits in reducing aggressive care at the end-of-life.

Interventions focused on caregiver burdens (education, counseling, support groups, home health services, hospice or palliative care services) and satisfaction with care covered various types of caregivers (spouse, daughter, daughter-in-law) and were primarily provided to caregivers singly or in groups. Overall, the literature reported inconsistent results. However, larger treatment effects were found for individual, as compared to group, interventions (especially for minority and female caregivers). Dementia caregiver interventions showed small positive effects and cancer caregiver interventions demonstrated moderate positive effects (especially home care services). [196]

Conclusions:

Comprehensive and timely advance care planning should reflect changing preferences and patient and family circumstances. Advance directives written prior to the treatment decision have less effect than discussions and education at the time a decision needs to be made. In addition, inconsistent results for diverse caregiver intervention studies suggest that caregiver burden and satisfaction appear to be multi-dimensional and may be too complex to be measured in a single scale, improved by single component or short-term interventions, or generalizable across diverse caregiver populations. [81 words]

Implications for Policy, Delivery or Practice:

This literature review adds to our understanding of the domains of advance care planning and the burdens and satisfactions with end-of-life care and will be helpful in distinguishing healthcare performance in different settings and in enhancing the patient and caregiver experience.[41]

Primary Funding Source:

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Title: *The Task of Caregiving: Catastrophe or Celebration?*

Speaker: Chloe JonPaul, M.S., Maryland State Representative, Caregiver Community Action Network, National Family Caregivers Association

The task of caregiving: will it be a catastrophe or celebration? Chloe Jon Paul will offer participants an opportunity to examine the saving graces of caregiving by offering some insights through her own experiences in that role. Anecdotal, funny, and inspirational, her presentations promises to be a morale booster for caregivers.