# CAREGIVER-CENTERED COMMUNICATION: A NEW TOOL FOR ASSESSMENT OF THE QUALITY OF COMMUNICATION WITH FAMILY CAREGIVERS

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Improved communication with caregivers can lead to reduced caregiver anxiety and burden, improved quality of life, and better coping during a stressful time. Even though caregiver communication with the health care team is essential in gerontology, we are lacking standardized instruments to assess quality of communication. We describe the initial development and testing of the Caregiver Centered Communication Questionnaire (CCCQ). The questionnaire has 30 items with 5 subscales: exchange of information, fostering health relationships with team/provider, recognizing and responding to emotions, managing care and decision making. We conducted a cross-sectional survey of 115 family caregivers of older adults in home care and hospice. Cronbach's  $\alpha$  for the scale was 0.97. Internal consistencies of subscales were high, ranging from 0.82 to 0.93. Preliminary testing indicates the potential of CCCQ in assessing engagement and quality of communication; further testing is required.

#### NOT JUST SITTING BY: FAMILY CAREGIVERS' PERSPECTIVES ON TRIADIC COMMUNICATION

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Most studies of communication in gerontology and palliative care focus on dyadic communication. In reality, encounters in palliative oncology very often involve three or more people: a healthcare professional, a patient, and a family caregiver. This triadic communication differs in important ways from communication involving only two parties. In this secondary analysis of qualitative data collected during a randomized controlled trial of a psychosocial intervention for family caregivers receiving palliative oncology services, researchers explored family caregivers' (n = 63) perspectives on triadic communication encounters involving themselves, the patient and one or more clinicians. Family caregivers tended to appreciate clinicians' efforts to involve them in communication, rather than regarding them as "just sitting by" the patient. Many perceived that their own wishes regarding information provision were often ignored and reported that their own coping and wellbeing were not often assessed outside of encounters with the specialist palliative care team.

### DIGITAL TOOLS TO ENHANCE CAREGIVER-CENTERED COMMUNICATION

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While it is recognized that caregiver engagement can improve processes and outcomes of care in gerontology, there are barriers to caregiver centered communication, including limited resources for health systems to devote services specifically to families, geographic distance and lack of time. Digital tools such as social media platforms and video-conferencing introduce opportunities for remote and often asynchronous communication. In this presentation, we discuss findings from two randomized clinical trials that explored digital tools to empower family caregivers. In the first we examined

ways to use video-conferencing to enable family caregivers to become virtual team members during hospice interdisciplinary teams, and in the second trial we examine the use of secret Facebook groups to meet informational and emotional needs of family caregivers during episodes of care that are often linked to increased social isolation and loneliness. We discuss challenges and opportunities in designing digital tools to facilitate caregiver engagement and empowerment.

#### **SESSION 5490 (SYMPOSIUM)**

## CAREGIVING TOGETHER: THE RELATIONSHIP BETWEEN PAID AND FAMILY CAREGIVERS IN THE HOME

Chair: Jennifer Reckrey Discussant: Robyn Stone

Family caregivers provide the lion's share of care that allows older adults with functional impairment to remain living at home. Yet as care needs grow, many older adults and their families turn to paid caregivers (e.g. home health aides, personal care attendants, and other direct care workers) to provide additional support. While evidence suggests that paid and family caregivers work together to provide increasingly complex care at home, research that describes this important collaboration is limited. In this symposium, we present innovative and interdisciplinary research that highlights the overlap between family caregiving and long-term care workforce research. We begin by presenting two studies that focus on populations where paid caregivers may have outsized impact on family caregivers: Reckrey et al report that receipt of 20+ hours of paid caregiving per week was associated with less caregiver strain among family caregivers of those with advanced dementia and Falzarano et al report that home care hours mediated the association between caregiver stressors and negative effects of caregiving among long-distance family caregivers. Franzosa et al then describe home health aides' perceptions of relationship dynamics as aides and family members negotiate care tasks in the home. Finally, Gallopyn et al explore scenarios where paid and family caregiver roles blur (e.g., family caregivers receiving payment for providing care, paid caregivers with extensive experience as family caregivers). Taken together, these studies describe critical ways paid and family caregiver experiences are intertwined and highlight the importance of ongoing research about this collaboration.

### WE TREAT THEM BETTER THAN THE FAMILY THEY HAVE: NEGOTIATING AIDE-FAMILY RELATIONSHIPS IN THE HOME CARE SETTING

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Unpaid and paid care in the home are closely intertwined, but a lack of outside supervision and support often forces family and non-family caregivers to negotiate care tasks and boundaries alone, leading to role conflict and role ambiguity. This analysis drew on two qualitative studies of home health aides (S1 n = 27, S2 n = 26) to explore 1) aides' perception of their caretaking role; 2) aides' experiences co-producing care with family members; and 3) factors affecting these

relationships. Data were analyzed through grounded theory and discourse analysis. We identified three relationship dynamics between aides and family members: independent, where aides and families provided care separately; competitive, where aides and families struggled over control of care tasks; and carative, where aides considered family part of the unit of care. We propose strategies for employer agencies to better support paid and unpaid caregivers in negotiating boundaries and co-producing care.

# USE OF HOME CARE SERVICES REDUCES CAREGIVING-RELATED STRAIN IN LONG-DISTANCE CAREGIVERS

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Long-distance caregivers (LDCs) comprise a growing yet relatively understudied segment of the caregiving population. The current study (N=166) investigated the mediating role of home care hours on the association between primary caregiving stressors (care recipient [CR] levels of cognitive and functional impairment) and LDCs' perceived strain (perceived interference of caregiving with other family responsibilities and work). Results from path analyses showed that home care hours fully mediated the negative effect of CRs' functional impairment on family interference and the negative effect of CRs' cognitive impairment on work interference. Further, the negative effect of CRs' cognitive impairment on family interference was partially mediated by home care hours. Thus, a mediating role of home care service hours in the associations between objective stressors and LDC strain was established for both family and work domains. Findings highlight the potential of home care services in alleviating strain in LDCs of community-dwelling CRs.

#### FORMAL AND INFORMAL CAREGIVING: IMPLICATIONS FOR PAID FAMILY CAREGIVERS UNDER THE CONSUMER-DIRECTED MODEL

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The case of paid family caregiving under the consumer-directed model introduces unique complexities to patient care, especially in the presence of other formal caregiving. The purpose of this study was to address the interface of paid and family caregiving by exploring scenarios where the two types of caregiving overlap or are merged into one role. Participants were 20 formal caregivers and 21 persons with significant disability, recruited with a purposive sampling approach. In-depth, qualitative interviews were conducted with caregivers and patients to triangulate information from different perspectives. Thematic analysis uncovered pathways into formal caregiving that involved a history of family caregiving, transitions from informal family caregiving to formal family caregiving under the consumer-directed model, and challenges that emerged when formal and informal caregivers

co-exist in the same environment. Implications for patient and caregiver experiences in care contexts where the boundaries between paid and unpaid care are blurred are discussed.

### DEMENTIA CAREGIVING: THE ASSOCIATION BETWEEN FAMILY CAREGIVING STRAIN AND RECEIPT OF PAID CARE

Jennifer Reckrey,¹ Evan Bollens-Lund,¹ Emma Tsui,² Kathrin Boerner,³ and Katherine Ornstein,¹ 1. Icahn School of Medicine at Mount Sinai, New York, New York, United States, 2. CUNY Graduate School of Public Health & Health Policy, New York, New York, United States, 3. University of Massachusetts Boston, Boston, Massachusetts. United States

family caregivers. Using data from three waves (2011, 2015, 2017) of the National Health and Aging Trends Study (NHATS) linked to the National Study of Caregiving (NSOC), we identified family caregivers of those with advanced dementia and compared caregiving strain among those with zero, <20, and 20+ hours/week paid care. Family caregivers of those who received 20+ hours (26% of the sample) reported less caregiver strain (mean score 3.27 vs 4.15, p=0.04) and less frequently reported having more to do than they could handle (46.1% vs 67.9%, p=0.01) or not having enough time for themselves (46.8% vs 72.2%, p<0.01). The association persisted in a multivariable model. These results support the conceptualization of dynamic and potentially multidirectional relationships between paid and family caregivers and suggest that paid caregivers impact both those receiving care and their families.

#### SESSION 5500 (SYMPOSIUM)

# CHALLENGES AND INSIGHTS: PSYCHOSOCIAL STRESSORS, PHYSIOLOGY, AND HEALTH DISPARITIES

Chair: Julie Ober Allen Discussant: Briana Mezuk

The persistence of health disparities demonstrates the need for more comprehensive research to better understand key methodological approaches and intervention leverage points among the complex relationships between psychosocial, environmental, and biological factors influencing patterns of health among older adults. Growing empirical evidence implicates differential exposure to chronic stressors that are rooted in the social environment and related social inequities in premature aging and development of chronic diseases among socially marginalized groups. This, in turn, leads to health disparities within the older adult population. Mechanisms linking stressors and health, however, remain poorly understood. This symposium assembles research examining challenges associated with measuring exposure to stressors, relationships between stressors and health outcomes, and the insight provided by stress-based frameworks for understanding mechanisms of health disparities. Allen and colleagues use comprehensive measures of exposure to stressors to identify stressor characteristics most closely associated with diurnal cortisol dysregulation and Black-White disparities, which are risk factors for adverse cardiometabolic health outcomes. Kalesnikava and colleagues will introduce methods for exploring relationships between self-reported