

Discussant: Howard Degenholtz, *University of Pittsburgh, Pittsburgh, Pennsylvania, United States*

In 11/2016 Robert and Rosalie Kane began a 3-round Delphi study to re-imagine long-term care (LTC), which took as a starting premise that LTSS in the United States fails to comport to the values and preferences of consumers. The Delphi study is “modified” from more typical Delphi designs because of 1) a sample sizes over 100, 2) an unusually broad topic--optimal LTC systems if not constrained by existing programs, financial arrangements and regulations; and 3) incorporation of new sample at each round. Round 1 asked respondents to rate and add to a list of values important to LTC but largely was an open-ended request for respondents' ideas, Round 2 was fielded in 6/2018 with all data collection completed by 11/2018 (the delay partly due to Robert Kane's sudden death on March 6, 2017 and also the time needed to analyze, summarize and present the complex and detailed responses to the first round). Round 3, to be fielded in 4/2019., will provide participants with the ratings of values, principles and programmatic building blocks at Round Two, and the open-ended comment of respondents in explanation of their ratings. Each Round is analyzed cross-sectionally and can be considered a separate “virtual town square.” Ellen McCreedy and Rosalie Kane, respectively, present quantitative and qualitative results from the first two rounds. Discussants will each comment briefly from their perspectives as 1) state LTC policy developer, 2) LTC university-based researcher; 3) consumer advocate, followed by audience and presenter discussion of the implications of the findings.

#### QUALITATIVE FINDINGS AND THEMES IN REIMAGINING LTC: RESULTS ROUND 1 AND 2 OF THE NATIONAL DELPHI STUDY

Rosalie A. Kane,<sup>1</sup> and Audrey Workman<sup>2</sup>, *1. Division Health Policy & Management, School of Public Health, University of Minnesota, Minneapolis, Minnesota, United States, 2. U of MN School of Public Health, Minneapolis, Minnesota, United States*

From Round 1 we developed programmatic building blocks, which we classified as: housing suggestions; services suggestions; housing and/or technology heavy suggestions; policy or regulation suggestions; new philosophical approaches; and long-range social engineering. Besides the quantitatively ratings of the importance of each building block, respondents explained what they liked and disliked about each. They frequently commented that environments rich in design features, amenities and activities would not be practical for low-income people. Respondents felt that some ideas would not be suitable for people with dementia because they would be insufficiently protected. Principles that seemed to be incompatible could be highly endorsed; e.g., the principle that we prioritize people staying in their own homes and a principle that frail elderly persons living alone should relocate to group residential settings to avoid social isolation. This paper concludes with a list of areas for further discussion by work groups.

#### QUANTITATIVE RE-IMAGINING OF LTC : RESULTS FROM ROUNDS 1 AND 2 OF A NATIONAL DELPHI STUDY

Ellen McCreedy,<sup>1</sup> and Caleb Hoover<sup>2</sup>, *1. Brown University, School of Public Health, Providence, Rhode Island, United*

*GSA 2019 Annual Scientific Meeting*

*States, 2. Hennepin County Medical Center, Minneapolis, Minnesota, United States*

At Round 1, 110 participants answered an open text question about how they would redesign LTC if starting fresh without regulatory or financial constraints. They also rated a list of values as to whether they were reflected in the respondents' suggestions. From analysis of Round 1 open text, principles for LTC were extracted and 20 programmatic building blocks created. At Round 2, respondents rated the importance of the original value list (after Round 1 results were shared) and rated the principles and building blocks. This paper presents those findings and highlights inconsistencies in results: for example, both a universal LTC and a means-test benefit were endorsed. Participants preferred the term Long-Term Services and Support for the subject matter but no strong term was the favorite for service users. Alternate ways of displaying endorsement of individual items (mean value, different score cutoffs) resulted in the same most popular and least popular items.

#### REFLECTIONS FROM THE PERSPECTIVE OF A STATE POLICY MAKER

LaRhae Knatterud<sup>1</sup>, *1. Minnesota Department of Human Services, St. Paul, Minnesota, United States*

From her perspective as Director of Systems Transformation, Minnesota Department of Human Services, and her role as planner and policy analyst in state agencies, this presentation briefly comment on the implications of the findings. Using the theory of disruptive innovation, she will suggest next steps for these results.

#### REFLECTIONS FROM THE PERSPECTIVE OF AN ADVOCATE AND CASE MANAGER

Tracy Keibler<sup>1</sup>, *1. ApparentPlan, Eden Prairie, Minnesota, United States*

From her perspective as director of ApparentPlan, a nonprofit care agency to assist low income consumer of LTC, and as co-founder and director of the MN Long-Term Care Think Tank, an advocacy organization. Ms. Keibler will reflect on these findings and next steps.

#### SESSION 3245 (PAPER)

##### ROLES AND EXPERIENCES OF GRANDPARENTING

##### GRANDPARENTHOOD AND RISK OF MORTALITY: FINDINGS FROM THE HEALTH AND RETIREMENT STUDY

Lea Ellwardt,<sup>1</sup> Karsten Hank,<sup>2</sup> and Carlos F. Mendes de Leon<sup>3</sup>, *1. University of Cologne, Cologne, Germany, North-Rhine Westphalia, Germany, 2. University of Cologne – Institute of Sociology & Social Psychology, North-Rhine Westphalia, Germany, 3. University of Michigan School of Public Health, Ann Arbor, Michigan, United States*

Grandparenthood is a significant social role for older adults and may have important health implications. Parenthood itself has been associated with some protective health effects, although findings have been mixed. Whether grandparenthood is associated with important long-term health effects such as mortality is largely unknown. This

study examines the grandparenthood-mortality nexus, and whether it is modified by gender and education. Longitudinal data from the Health and Retirement Study (HRS) were used, comprising twelve biennial follow-up waves from 1992 to 2014 with linked data on vital status derived from the National Death Index. Submodules assessed participants' family structure during follow-up. The sample included 24,325 participants aged > 51 years with at least one child. Cox proportional hazard models were used to test the association between grandparenthood and mortality risk with adjustment for socio-demographic variables, for social variables including characteristics of and contact with children, and for health variables, including measures of overall, functional and mental health. Stratified models assessed these associations separately by gender and education. Grandparenthood was associated with a substantially increased mortality risk in women (fully adjusted HR = 1.65; 95% CI 1.27-21.14), and increased with larger number of grandchildren. No significant association was found for men (fully adjusted HR=1.25; 95% CI 0.97-1.62). Mortality risks associated with grandparenthood were highest among grandparents with low levels of education. The findings are among the first to suggest a potential grandparenthood survival "penalty", especially for grandmothers. Higher levels of education appear to mitigate this negative survival effect among grandparents.

#### GRANDPARENTING CHILDREN WITH DISABILITIES AND ITS IMPACT ON GRANDPARENT HEALTH

Ynesse Abdul-Malak,<sup>1</sup> and Madonna Harrington Meyer<sup>2</sup>, 1. *Colgate University, Hamilton, New York, United States*, 2. *Syracuse University, Syracuse, New York, United States*

Across the US, millions of grandparents are providing vital care for their grandchildren with disabilities when their adult children are in need of assistance and public programs do not provide needed supports. Research suggests the impact on grandparent physical health is mixed. This paper draws on in-depth interviews with 50 grandparents to explore how caring for grandchildren with disabilities shapes their physical wellbeing. We use life course perspective to assess the choices grandparents make from available resources and options at different stages of their lives and the effects on their health. We find in addition to providing routine care, helping with feeding, bathing, and dressing, some grandparents provide constant supervision and medically intense care, such as tending to feeding tubes, catheters, and oxygen lines. Many grandparents said care work has improved, or at least helped sustain, their overall level of fitness, while other grandparents find that care work has adverse impacts. Often there is too much chasing, bending, and lifting for their aging bodies. This paper suggests that stronger social programs for children with disabilities and the grandparents who step in to help them would decrease the negative effects of care work on grandparent health.

#### GRANDPARENTS' ROLES IN THE CONTEXT OF ADVERSE CHILDHOOD EXPERIENCES: THE VOICES OF EMERGING ADULTS

Athena Chung Yin Chan,<sup>1</sup> Doris Leung,<sup>2</sup> Bessie Chan,<sup>2</sup> and Grace Wing Ka Ho<sup>2</sup>, 1. *Department of Family Social Science, University of Minnesota, Saint Paul, Minnesota, United States*, 2. *School of Nursing, The Hong Kong Polytechnic University, Kowloon, Hong Kong*

The influence of grandparents, in the context of adverse childhood experiences (ACEs), is largely understudied. With strong kinship in Asian families, grandparents may provide a crucial resource to their grandchildren; not limited to those living together, but having close emotional proximity. This qualitative study used secondary analysis to explore the roles of grandparents, upon reflection of participants' childhood adversities. Semi-structured interviews were conducted with 19 emerging adults, between 18 and 24 years old in Hong Kong, China. Participants were eligible if they: (1) reported at least one ACE, namely, abuse (physical, emotional, sexual), neglect (physical, emotional), witnessing domestic violence, or a dysfunctional household (due to parental divorce/death, household member substance use, incarceration, mental illness); and (2) described their interactions with grandparents during the interviews. Participants were asked to think of a challenging time during their childhood, and strategies they used to overcome them. All interviews were audio-recorded and transcribed verbatim. Data regarding the interactions with grandparents were coded and analyzed by four researchers following interpretive description. Preliminary findings described four primary roles grandparents played in the context of ACEs, which were sometimes positive and/or negative. Grandparents were portrayed as being unique persons in participants' lives that influenced how they faced their childhood adversities. We will discuss how grandparents' stewardship may significantly shape cultural patterns of how families cope with ACEs. In particular, our findings, examined against literature, will discuss how grandparents may enhance resilience of young people with ACEs.

#### NUTRITIONAL NEEDS AND PREFERENCES AMONG AFRICAN AMERICAN CUSTODIAL GRANDMOTHERS: A QUALITATIVE STUDY

Kellie E. Mayfield,<sup>1</sup> Deborah Whitley,<sup>1</sup> and Susan J. Kelley<sup>1</sup>, 1. *Georgia State University, Atlanta, Georgia, United States*

This presentation summarizes a qualitative analysis from focus groups with African American, urban dwelling grandmothers raising grandchildren in parent-absent households. Nutritional needs of custodial grandparents are an under explored area of research. Previous studies on custodial grandparents have acknowledged the physical, social, and familial burdens they endure as caregivers of their grandchildren. Limited financial support is a consistent concern. One manifestation of having scarce monetary resources is not being able to meet daily nutritional requirements. As a result, adverse health outcomes related to the onset of diet-related diseases (e.g., obesity, hypertension, diabetes) are too common, especially for custodial grandparents of color. The present study qualitatively explores grandmothers' (N=9) experiences and ideas about food choices/options, decisions about when and where to purchase food, and the involvement of grandchildren in food-related practices and traditions. Grandparent participants were recruited from a community-based intervention, a program that provides health and social support services to grandparents raising grandchildren in Atlanta. Each of the focus groups consisted of 4-6 custodial grandmothers, facilitated by a doctoral-level community nutritionist. The major themes summarized from the qualitative group interviews were framed within a feminist/race theoretical context. Dominant themes from the focus group