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Exhausted and trapped in isolation. Caring for a spouse with dementia during the Covid-19 pandemic

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relationships between social location factors and life satisfaction. Overall, the results provide support for integrating welfare state/family care regime type and intersectionality factors into the stress process model as applied to the context of informal caregiving. The results also have policy and practice implications with regards to which social location and stress process factors explain specific disparities in life satisfaction between informal caregivers residing in different welfare state/family care regimes.

#### THE OTHER CAREGIVERS: INFORMAL NON-SPOUSAL MALE CAREGIVERS FOR PERSONS WITH DEMENTIA

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Informal caregivers for persons with Alzheimer's disease and related dementias (ADRD) have become an integral part of the long-term health care system. They are relied on to provided day-to-day care that is challenging, complex, and often spans several years. Most of the research on informal caregivers for persons with ADRD have focused on spousal caregiving, mother-daughter dyads, and daughters. There is sparse literature on informal non-spousal male caregivers for persons with ADRD. The objective of this research was to obtain an understanding of the experiences of informal non-spousal male caregivers for persons with ADRD. This descriptive qualitative pilot study consisted of in-depth one-on-one interviews with three informal non-spousal male caregivers for persons with ADRD. Four themes emerged through data analysis: 1) the male perspective and experience of caregiving, 2) relationship dynamics, 3) caregiving challenges, and 4) finding meaning within caregiving.

**Conclusion:** Similar to other caregivers, informal non-spousal male caregivers assisted with transportation, managing medical appointments, as well as bathing and personal care. Differences with other caregivers, specifically female caregivers, emerged in terms of descriptions of traditional versus non-traditional gender roles. The implications of this study are that public policies, support services and medical professionals need to understand and be able to address the different experiences and needs of informal non-spousal male caregivers.

#### THE SHAPE OF CARE: PATTERNS OF FAMILY CAREGIVING AMONG CHINESE ADULTS IN THE MIDDLE TO LATER STAGE OF LIFE

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Due to the lack of institutional support, families have long been the primary caregivers in China. Most studies to date only focused on one single care activity during a particular life course stage. Nonetheless, older adults today are more likely to care for multiple family members concurrently or sequentially (serial caregivers). The studies on discrete snapshots of care activities failed to capture the patterns of family caregiving overtime. Utilizing four waves of longitudinal data from CHARLS (2011-2018, N=17,039), this study particularly focuses on care activities to grandchildren, parents, and spouse, and maps out the family caregiving patterns overtime. Using latent profile analysis, this study identifies five family caregiving patterns: 1). Light grandchild caregivers (27%),

who on average provided 4.3 years' grandchild care mostly; 2). Heavy grandchild caregivers (11%), who on average on provided 7 years' grandchild care mostly; 3). Light caregivers for grandchildren and parents (7%), who sequentially provided 1-year care to grandchildren and parents; 4). Heavy serial caregiver (6%), who mostly provided care to spouse and grandchildren with higher overlapping years; 5). Overall light caregivers (49%), who on average provided less than one year of care to any recipient. The preliminary results suggest that heavy serial caregivers (6%) far worst in terms of depressive symptoms and more likely to report worsened self-rated health; and overall light caregivers (49%) have the lowest depressive symptoms and more likely to report good self-rated health.

#### Session 9270 (Poster)

##### FAMILY CAREGIVING (HS POSTER)

#### AGING IMMIGRANT FAMILY CAREGIVERS HEALTH, SOCIAL ENGAGEMENT, AND HEALTH LITERACY

Mary Dioise Ramos, *Kennesaw State University, Kennesaw, Georgia, United States*

Family caregiving is evolving in multiple ways. There is an increasing recognition of the role of informal or unpaid family caregivers. Extensive body of research shows that family members who provide care to individuals with chronic or disabling conditions are themselves at risk. However, most evidence on family caregiving gear towards Caucasian middle-class populations. There is limited research that exists about aging immigrant family caregivers who are ill-prepared for their role and provide care with little or no support. The specific aim of this study was to assess and determine the association of health status, social engagement, and health literacy among aging immigrant family caregivers. This study utilized a non-experimental, cross-sectional, correlational design. Most of the participants are female married Asian women, who are retired, living with their spouses, and taking care of their family members more than 4 hours a day with Alzheimer's, Parkinson's, and cardiovascular disorder. Most participants have existing medical condition such as hypertension, diabetes, high cholesterol, and heart disease. Most participants experienced problem with sleep and difficulty falling asleep. While some participants experienced fatigue and having trouble doing regular leisure activities with others. There is an association between sleep disturbance and ability to participate in social roles and activities among aging immigrant family caregivers. Inclusion of people from different ethnicities, backgrounds, and socioeconomic position in caregiver research is vitally important. There is a need for a greater understanding of the contextual factors of family caregiving and recognizing the prevalence and characteristics of aging immigrant family caregivers.

#### EXHAUSTED AND TRAPPED IN ISOLATION. CARING FOR A SPOUSE WITH DEMENTIA DURING THE COVID-19 PANDEMIC

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Even before the Covid-19 pandemic, spouse carers of persons with dementia (PwDs) found their care responsibilities overwhelming and had little time to focus on their own lives. To minimize the risk of being infected with Covid-19, older persons are recommended to self-isolate in their homes, while formal support such as respite care and day care centers are withdrawn. This study involved semi-structured interviews with 24 spouse carers of community-living PwDs, with the aim of describing their situation during the pandemic. The interviews were analyzed with qualitative content analysis. Results revealed that they commonly declined help because of the perceived risk of their spouse being infected with Covid-19 and thus also possibly causing their death. They described feelings of being trapped in their situation, as they experienced having no choice than take all responsibility for the care of their partner themselves, with cost of being unable to take necessary breaks. This was described as making an already strained situation almost unbearable, which led to conflicts with their partner. However, the spouses also described positive aspects due to strategic changes in health and social care provision to prevent the spread of the virus, such as greater staff continuity in home care services, and patient transportation service. These made the PwD less stressed and influenced their everyday life positively. It could be concluded that the extent burden during the Covid-19 pandemic calls for extensive development of tailored support to better tackle the rapid changes that can occur in a society.

#### FAMILY ADVOCACY FOR RESIDENTS IN NURSING HOMES DURING THE COVID-19 PANDEMIC

Cristina de Rosa, Yanjun ZHou, Amy Lyons, and Yu-Ping Chang, *University at Buffalo, Buffalo, New York, United States*

To protect one of the most vulnerable populations from COVID-19, nursing homes enacted and enforced visiting restrictions and other measures to limit the spread of this communicable disease. Family members, many of whom are former caregivers, were suddenly cut off from nursing home residents, and struggled to maintain connection with their loved ones residing in nursing homes. The purpose of this study was to describe the experiences of family members of residents in nursing homes in advocating for residents and themselves during a time of uncertainty and many challenges. This study used a qualitative descriptive approach to conduct individual interviews. Ten family members of residents of two nursing homes in a Northeastern state were interviewed by phone or videoconference using a semi-structured guide. Interviews were transcribed verbatim and analyzed using Braun and Clarke's Reflexive Thematic Analysis. Family members expressed concerns for the lockdown's impact on residents' psychosocial wellbeing in addition to the potential physical dangers of COVID-19. They explored creative means of meeting needs for information and interaction, but often felt that these efforts fell short of replicating the connectedness of in-person visits. Family members identified multiple missed opportunities for involvement in care, and voiced willingness to comply with infection prevention guidelines, such as maintaining distance, to be present with

residents. Our findings indicate that family members advocated for residents' interests to ensure quality care. Future research and policy should consider family members as a potential resource for providing care and companionship during times of crisis.

#### FAMILY CAREGIVER BURDEN OF MEDICATION ADMINISTRATION FOR OLDER ADULTS ADMITTED TO HOME HOSPICE

Jennifer Tjia,<sup>1</sup> Margaret Clayton,<sup>2</sup> Jennifer Smith,<sup>2</sup> Olivia Wood,<sup>3</sup> Susan Hurley,<sup>3</sup> Geraldine Puerto,<sup>4</sup> Vennesa Duodu,<sup>4</sup> and Susan DeSanto-Madeya,<sup>5</sup>, *1. University of Massachusetts Medical School, University of Massachusetts Medical School, Massachusetts, United States, 2. University of Utah, The University of Utah, Utah, United States, 3. Care Dimensions, Care Dimensions, Massachusetts, United States, 4. UMass Medical School, UMass Medical School, Massachusetts, United States, 5. University of Rhode Island, University of Rhode Island, Rhode Island, United States*

**Objective:** To characterize FCG burden of medication administration for older adults in home hospice.

**Methods:** Pilot clinical trial of a hospice-staff level communication and medication review program to facilitate goal-concordant prescribing, including deprescribing, for older adults in home hospice. Patients newly admitted to hospice were eligible if  $\geq 65$  years, prescribed  $\geq 5$  medications and had a FCG. Exclusion criteria included being non-English speaking or having a Palliative Performance Score  $< 40$ . Measurements include 24-item FCG Medication Administration Hassle Scale (range 0-96) at hospice admission and at 2-, 4-, 6-, 8-weeks and monthly until death. Descriptive statistics characterize baseline FCG Hassle score.

**Results:** In this actively recruiting study,  $n=9$  patient-caregiver dyads are enrolled to date. Mean patient age is 80.6 years (range 69-101). Of 9 caregivers, 7 were female, 5 children, and 3 spouses. The majority (67%) of caregivers were extremely involved in medication management. Mean FCG Hassle Score = 17.1 (SE 5.9; range 2-58), and differed between spouses (mean = 5 [SE 1.7; range 2-8]) and children (mean = 31.4 [SE 9.53; range 3-58]). The highest burden concern was recognizing medication side effects, followed by feeling comfortable making medication decisions, arguing with the care-recipient about when to take medications, knowing why a medication is being given and whether it is effective, and knowing when to hold, increase, decrease a dose or discontinue the medication.

**Conclusion:** FCGs of older adults in home hospice report different levels of medication administration hassle depending on their relationship to the patient. The most bothersome concern is recognizing medication side effects.

#### FRAUDULENT DATA DETECTION AND PREVENTION WITHIN THE NATIONAL CAREGIVER SURVEY

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The National Caregiver Survey is an online, incentivized survey that aims to gather information about the health and coping strategies used by Black family caregivers of