

LEARNING NEEDS OF DEMENTIA FAMILY CAREGIVERS DURING THE PANDEMIC

Carolyn Clevenger,¹ Fayron Epps,² Kenneth Hepburn,² Molly Perkins,³ and Glenna Brewster Glasgow,²

1. *Emory University, Emory University, Georgia, United States*, 2. *Emory University, Atlanta, Georgia, United States*, 3. *Emory University of Medicine, Atlanta, Georgia, United States*

The COVID-19 pandemic has dominated and transformed all caregiving contexts and situations. In a time of COVID-19, caregivers now have to learn how to take all of the complicated precautions to keep themselves and their persons from being exposed to the virus given their population's mortality rate from COVID-19 infections exceed 40%. As part of a larger initiative to develop an asynchronous online education program for family caregivers of persons living with dementia illnesses (PLWD) to prepare them to master the new demands of their caregiving role in this extraordinary circumstance of the COVID-19 pandemic, we conducted three focus groups with 13 dementia family caregivers to inform the structure, content, and "feel" of the course. Focus groups were conducted with a lead interviewer, via Zoom, audio and video recorded and transcribed for analysis. Participants were asked two groups of questions: their lived experience over the past year and course content for caregiving during crisis. Caregivers identified 4 themes regarding their lived experience of caregiving during the pandemic: (a) mixed feeling about the stay-at-home orders; (b) positive adaptation to telemedicine, (c) vaccine risks and benefits; and (d) impact of social isolation on the PLWD. The groups also recommended specific course content based on their experiences. Participants recommended specific course content based on their experiences, such as health system navigation and the logistics of what to do following the death of a PLWD. Results from these groups have been incorporated into an asynchronous online course to be pilot tested in coming months.

Session 9280 (Poster)

Family Caregiving II (SRPP Poster)

A SCOPING REVIEW OF YOUTH CAREGIVERS: ADDRESSING THE NEEDS OF THIS GROWING POPULATION

Heena Doshi,¹ Gracie Chen,² Norma Bostarr,³ Debra Cherry,⁴ Mary Mittelman,⁵ and Nihal Satyadev,⁶ 1. *Care Generation, Los Angeles, California, United States*, 2. *University of California, San Diego, Temple City, California, United States*, 3. *Care Generation, SF, California, United States*, 4. *Alzheimer's Los Angeles, Los Angeles, California, United States*, 5. *NYU Langone Health, NYU Grossman School of Medicine, New York, United States*, 6. *The Youth Movement Against Alzheimer's, Los Angeles, California, United States*

Generation Z, those who are born in 1997 or thereafter, account for six percent of the estimated 53 million family caregivers in the US – and this percentage is growing, especially given the health impacts of the pandemic. This review focuses on caregiving youth (ages 0-18) and young adult caregivers (ages 18-25) who assist household members who need regular assistance with ADLs and IADLs.

This presentation will analyze key trends in the literature of this demographic and identify gaps in research. Our review broadens the knowledge base of how caregiving done by this population impacts brain development, and hence their long term physical, emotional, and mental health. In spite of the significant number of caregiving youth and young adults, current publications on these demographics remain sparse, with most studies being conducted on spousal and adult caregivers. Our group found that the existing literature reviewed the adverse implications on the health and education outcomes for young adult caregivers. This included increased anxiety/depression compared to non-caregivers and for those in post-secondary education, the contribution of caregiving to college incompleteness. There are no known studies on this population who have entered the workforce and who also continue their caregiving role. Adequate understanding and characterization of caregiving youth and young adult caregivers will inform better interventions and future policy for them. Support for this demographic, in turn, may improve health outcomes for older adults, who are the majority of those in their care.

"WE'VE ALL LOST SO MUCH": THE EXPERIENCES OF ESSENTIAL FAMILY CAREGIVERS' LONG TERM CARE VISITATIONS DURING COVID-19

Charlene Chu,¹ Amanda Yee,² and Vivian Stamatopoulos,³

1. *University of Toronto, Toronto, Ontario, Canada*, 2. *University of Toronto, Calgary, Alberta, Canada*, 3. *University of Ontario Institute of Technology (UOIT), Oshawa, Ontario, Canada*

Family caregivers are integral to the care of long-term care (LTC) residents. COVID-19 public health policies initially restricted all essential caregivers from visiting LTC homes. In lieu of in-person visitations, caregivers were allowed technology-based visits then restrictive outdoor visits, followed by indoor visitations. This study aims to illuminate the experiences of essential caregivers' as they visited their loved ones in LTC during COVID-19's restrictive policies. We conducted seven caregiver focus groups (N=30) from Ontario and British Columbia, Canada. Thematic analysis and line-by-line coding were completed using NVivo. We found six themes that were common to all the visitation types: 1) "LTC Home disorganization" to facilitate visits and poor communication; 2) "Lack of staffing and resources"; 3) "Mistreatment from staff and management" as caregivers were seen as inconveniences; 4) "Shock and disbelief" when family members first saw their loved ones; 5) "Significant lack of person-centered or family-centered ethos" for example the residents' needs were ignored such that their cognitive and physical impairments sometimes made visitations impossible, as well as the burden of multiple weekly COVID-19 tests; and, 6) "Collateral damage" in the form of trauma and irreparable harm to the relationships between residents and families. These results emphasized caregivers who ultimately felt betrayed and ignored by the broader healthcare system. Our findings provide an in-depth understanding of how COVID-19 public health policies have impacted the essential caregivers and the long-lasting impacts on residents and caregivers alike. Understanding caregiver's experiences can inform future pandemic response policies and encourage more person-centered protocols.