

Table of Contents

Hollandsworth-Reed, Jennifer - #5604 - Supporting Care Partners of People Living With Dementia: Exploring Changes in Policy and Practice	1
Abstract submission for Institutional Repository	1



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Supporting Care Partners of People Living With Dementia: Exploring Changes in Policy and Practice

Jenn Hollandsworth Reed, MPH,¹ Walter D Dawson, DPhil,¹⁻⁴ Anaeliz Colon, MPH,¹ Devlin Prince, MA,¹ Sofia Chapela, MD, MSc,¹ Sherril Gelmon, DrPH¹

¹Oregon Health & Science University-Portland State University School of Public Health, Portland, Oregon, USA

²Institute on Aging, College of Urban & Public Affairs, Portland State University, Portland, Oregon, USA

³Layton Aging & Alzheimer's Disease Research Center, School of Medicine, Oregon Health & Science University, Portland, Oregon, USA

⁴Global Brain Health Institute, University of California, San Francisco, San Francisco, California, USA and Trinity College Dublin, Dublin, Ireland

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Abstract

Introduction

The multiple stressors associated with caregiving for someone living with Alzheimer's Disease and Related Dementias (ADRD) often place enormous burdens on care partners. To better understand the caregiving-related needs and priorities of people with lived experience as care partners of people living with ADRD, focus groups were convened with care partners who identify with historically and currently underserved communities who may have difficulty accessing culturally-specific services for people living with ADRD in and near the Portland, OR metropolitan area.

Methods

Between Fall 2022 and Spring 2023, focus groups (N=5) were conducted with care partners of people living with ADRD. In-depth interviews (N=24) were also conducted with local, state, and national organizations providing services that support people living with ADRD and care partners. The collection efforts centered on four communities historically underserved in the United States (Asian, Black, Indigenous, and Latinx).

Results

Unmet needs affect the ability of care partners to manage ADRD caregiving activities. Specific needs for care partner support varied across populations due to cultural traditions, multiple systemic inequities, and the legacies of structural racism. Many care partners who participated in focus groups were satisfied with the clinical care they and their care recipient received for ADRD, yet nearly all identified areas of social support where additional resources would be personally beneficial to themselves and their care recipient. The findings also identified several policy-related priorities for supporting care partners.

Discussion

New policies promoting access to services, education and training, and financing of supports must be developed and implemented in partnership with community-based organizations and ADRD care partners from underserved communities and communities that may have difficulty accessing culturally-specific services and supports. The findings also point to universal needs related to caregiving across all populations that could be addressed through new policy initiatives.