The CARE Pathway Model for Dementia

Psychosocial and Rehabilitative Strategies for Care in Young-Onset Dementias

Darby Morhardt, PhD[a], Sandra Weintraub, PhD[a,b,c], Becky Khayum, MS, CCC-SLP[d], Jaimie Robinson, MSW[e], Jennifer Medina, PhD[a], Mary O'Hara, AM[a], Marsel Mesulam, MD[a,c], Emily J. Rogalski, PhD[a,*]

KEYWORDS

- Quality of life • Neurocognitive profile • Symptom-specific strategies
- Clinical care model • Primary progressive aphasia
- Behavioral variant frontotemporal dementia • Posterior cortical atrophy
- Dementia of the Alzheimer type

KEY POINTS

- Individuals with young-onset dementia can differ dramatically in the types of symptoms they express; therefore, a one-size-fits-all model of care for dementia is inadequate for this population.
- The Care Pathway Model for Dementia (CARE-D) prescribes tailored care based on results from psychosocial and neuropsychological assessments.
- Interventions focus on a person's abilities and strengths and are adapted over time as needs and abilities change.
- The psychosocial context is an essential component. Consideration should be given to the living situation, social supports, life stage, financial resources, and individual's and family's preexisting coping strategies.
- The goal is to enhance quality of life by maximizing independence and safety, identifying helpful modifications to activities and the environment, and providing emotional support for individuals with young-onset dementia and their families.

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[a] Cognitive Neurology and Alzheimer's Disease Center, Northwestern University Feinberg School of Medicine, 320 East Superior Street, Searle Building 11th Floor, Chicago, IL 60611, USA; [b] Department of Psychiatry and Behavioral Sciences, Northwestern University Feinberg School of Medicine, 446 East Ontario, Chicago, IL 60611, USA; [c] Department of Neurology, Northwestern University Feinberg School of Medicine, 710 North Lake Shore Drive, Chicago, IL 60611, USA; [d] MemoryCare Corporation, 634 Brooklyn Drive, Aurora, IL 60502, USA; [e] Christ Hospital Cancer Center, 2139 Auburn Avenue, Cincinnati, OH 45219, USA

* Corresponding author.

E-mail address: erogalski@gmail.com

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Abbreviations

bvFTD	Behavioral variant frontotemporal dementia
CARE-D	Care Pathway Model for Dementia
DAT	Dementia of the Alzheimer type
LBD	Cortical Lewy body disease
PCA	Posterior cortical atrophy
PPA	Primary progressive aphasia
WCST	Wisconsin Card Sorting Test

INTRODUCTION

Although aging is the leading risk factor for Alzheimer disease, it is estimated that at least 200,000 people under age 65 have what is commonly known as young-onset dementia.[1] Individuals with young-onset dementia can differ dramatically from those with older onset in the types of symptoms they express. Even those with the same clinical diagnosis (eg, dementia of the Alzheimer type [DAT]) can present with different neurocognitive profiles of impairment.[2–4] Individuals with young-onset dementia and their families have different needs, concerns, and access to resources than older adults who develop dementia.[5] This fact is related not only to the type of symptoms expressed but also to the time of life when the illness strikes. Individuals with young-onset dementia are likely to be healthier than individuals with late-onset dementia and less likely to have coexisting illnesses, such as cardiovascular disease, diabetes, or hearing loss and other sensory changes, making them good candidates for targeted therapies. Unfortunately, most psychosocial models of dementia care and intervention focus on a clinical diagnosis, usually dementia or Alzheimer disease dementia, without paying attention to the specific presenting symptoms. This approach may place individuals into programs or services solely based on a dementia diagnosis, regardless of whether or not a person is cognitively suited or age-appropriate for the intervention. One exception is the Tailored Activity Program.[6] This program trains occupational therapists to assess persons with dementia who exhibit behavioral symptoms for preserved capabilities that are then used to customize activities. The family and environment are included and considered critical to the intervention's success. Similarly, the CARE-D model identifies and builds on strengths based on a person's neurocognitive/behavioral profile and incorporates the family and environmental capacities; however, skills of both occupational therapists and speech-language pathologists are engaged to tailor appropriate interventions.

This article describes the conceptual design and implementation of CARE-D. The model is built on a framework provided by the neuropsychological characterization of cognitive and behavioral strengths and weaknesses in the early stages of illness and on a comprehensive psychosocial assessment (**Fig. 1**).

The model rests on the theory that psychosocial and rehabilitative interventions should address individual symptoms and distinctive neuropsychological profiles to improve quality of life and daily functioning for both the diagnosed individual and the family.[3,7,8] Although the model is targeted at mild and moderate stages of a dementia where there may be only one major area of difficulty, it can still be used in later stages when there are more cognitive and behavioral limitations and where the goal is to identify the most disruptive symptom needing intervention.

CARE-D was developed in a multidisciplinary outpatient clinical setting of behavioral neurologists, neuropsychologists, neuropsychiatrists, and social workers and