Verna Benner Carson ·
Katherine Johnson Vanderhorst
Harold G. Koenig

Care Giving for Alzheimer's Disease

A Compassionate Guide for Clinicians and Loved Ones

Springer

Care Giving for Alzheimer's Disease

Verna Benner Carson • Katherine Johnson Vanderhorst • Harold G. Koenig

Care Giving for Alzheimer's Disease

A Compassionate Guide for Clinicians and Loved Ones

Springer

Verna Benner Carson
C&V Care Specialists, Inc.
Fallston
Maryland
USA

Katherine Johnson Vanderhorst
C&V Care Specialists, Inc.
Williamsville
New York
USA

Harold G. Koenig
Dept. of Psychiatry Behavioral Science
Duke University Medical Center
Durham
North Carolina
USA

ISBN 978-1-4939-2406-6 ISBN 978-1-4939-2407-3 (eBook)
DOI 10.1007/978-1-4939-2407-3

Library of Congress Control Number: 2015933827

Springer New York Heidelberg Dordrecht London

Printed on acid-free paper

Springer New York is part of Springer Science+Business Media (www.springer.com)

Foreword

In this excellent and informative book Verna Carson introduces the public to the concepts of retrogenesis and the importance of these concepts for understanding persons with dementia, especially the dementia of Alzheimer's disease. Retrogenesis has been defined as "the process by which degenerative mechanisms reverse the order of acquisition in normal human development." As Verna points out in this book, this process has long been recognized in a certain sense, for example, by some of the most famous playwrights of all time. Even before the playwrights, a famous mathematician and philosopher who gave the world some of the "a, b, c's" of mathematics, also provided the "a, b, c's" of life. In the sixth century B.C., Pythagoras famously stated that for a right angle triangle, the square of the abscissa (a^2), plus the square of the ordinate (b^2), equals the square of the hypotenuse (c^2) or "$a^2+b^2=c^2$." All of us who studied geometry in high school have learned these truths, still called "the Pythagoras theorem." However, what Pythagoras may ultimately be known for is having provided us with the "a, b, c's of life." As a philosopher, Pythagoras stated that there are five phases of life. He said that the last two phases of life are "the senium" in which the brain returns to the first epoch of its infancy.

In the 1980s, I, together with my associates, systematically described the stages of brain aging and Alzheimer's disease. These descriptions have been proven to be scientifically valid, and also very useful. For example, our Global Deterioration Scale is used by the Alzheimer's Association to help the public understand the course of brain aging and Alzheimer's disease (www.alz.org/AboutAD/Stages.asp). Shortly after we developed the Global Deterioration Scale, we realized that functionally it was possible to describe the course of progressive brain aging and Alzheimer's disease in particular detail and we showed that a total of 16 successive "functional" stages of brain aging and Alzheimer's disease could be described with a measure called the "FAST," the Functional Assessment Staging Tool procedure. In the process of developing the FAST, we recognized that these functional stages are a very precise reversal of the order of acquisition of the same stages in normal human development (Reisberg, *Geriatrics*, 1986).

With these insights we set out to answer three questions: (1) In what other ways does the aging and Alzheimer's disease process reverse normal human development?

(2) How can these insights help in the care of persons with Alzheimer's disease? and (3) How do these discoveries relate to the cause of Alzheimer's disease?

The first and foremost question that we addressed was: do thinking abilities also reverse normal development, and if so, how close are the parallels? Working with investigators in Japan, especially Kenichi Meguro and Masumi Shimada, we showed close relationships between decline in Alzheimer's disease on a well-known intelligence test and the progression of functional loss on the FAST, and that these losses closely mirrored the corresponding developmental ages (Shimada and colleagues, *Psychogeriatrics*, 2003). Also, because in the later portion of the FAST scale persons with severe AD are untestable on traditional tests designed for children, we took infant intelligence test measures and adapted them for severe Alzheimer's disease patients. When we tested the severe Alzheimer's disease patients we found a very close correspondence between the performance in the severe Alzheimer's disease patients and that of infants at the corresponding points of Alzheimer's functional losses and infant functional attainment (Sclan and colleagues, *Psychiatric Journal of the University of Ottawa*, 1990 and Auer and colleagues, *Journal of the American Geriatric Society*, 1994). Most recently, investigators in Spain led by Jordi Peña-Casanova and Rubén Muñiz took the final, conclusive step. They, directly compared Spanish school children from ages 4 to 12 with elderly persons with normal aging, mild cognitive impairment, or progressively more severe Alzheimer's disease. They found strikingly strong parallels between the losses in aging and Alzheimer's disease and the corresponding acquisition patterns in children for both thinking (cognition) measures and functioning measures (Rubial-Álvarez and colleagues, *Journal of Alzheimer's Disease*, 2013).

Also, we and others showed that in many other interesting ways, the progression of Alzheimer's disease reverses the normal human development process. For example, we showed that reflexes in infants emerge in Alzheimer's patients at the corresponding developmental age related Alzheimer's disease stages in a series of publications by Emile Franssen and our other colleagues. Also, in terms of brain structure (anatomy), the process of brain aging has been shown to reverse the normal human development pattern. For example, the brain contains cells called "neurons" which have extensions similar to arms or wires called "axons" that are used to communicate with other brain cells. These axons (the nerve cell wires) are progressively covered with a fat-like substance, similar to the rubber which insulates a wire, and which aides nerve cell communication with other nerve cells. The fat-like substance on the nerve extensions is called "myelin." The process of nerve cell "rubberization" called "myelination," continues from infancy to late life. Several early investigators in Alzheimer's disease brain changes noted that the unmyelinated and most recently and therefore, most thinly myelinated brain regions are the first to be affected by Alzheimer's type brain changes. These early investigators included Arne Brun, Elisabet Englund and Lars Gustafson in Sweden, Patrick McGeer in Canada, and Heiko Braak in Germany. With the advent of new brain imaging techniques called diffusion tensor imaging, we were able to begin to directly verify the validity of this process in Alzheimer's persons (Choi and colleagues including Kelvin Lim and Isabel Monteiro, *Journal of Geriatric Psychiatry and Neurology*, 2005).

Subsequently, a large study in several US centers strongly supported these observations (Stricker and colleagues, *Neurology*, 2009). There is also evidence that other brain changes, especially the loss of brain energy, called metabolism, also reverses the normal brain developmental patterns. Building on these observations we (especially Sunnie Kenowsky, Stefanie Auer and I), developed a science of Alzheimer's disease management and treatment based upon the knowledge of the developmental age (DA) of the Alzheimer's disease (AD) person (Reisberg and colleagues, *International Psychogeriatrics*, 1999 and Reisberg and colleagues, *American Journal of Alzheimer's Disease and Other Dementias*, 2002). With this management science, we translated the AD stages into correspondingly developmental ages. We have shown that the management needs and care requirements of AD persons at the AD stages mirror the corresponding DAs. Many of the emotional changes, activity needs, and other aspects of AD persons also reflect the DA. We have also noted differences between AD persons and their DA "peers." For example AD persons do not undergo a physical retrogenesis, so they are, for example, larger and potentially stronger than children at the same DA. Also, AD persons are older and prone to the illnesses (comorbidities) of older persons, unlike children. Additionally, Alzheimer's persons have a history, for example, of speaking, which infants do not. Hence, the "science of AD management" includes differences in the model as well as similarities. Recently, in part by applying this retrogenesis model to AD person's management and care, Dr. Kenowsky and I, have been getting very dramatically positive results in persons with moderately severe AD (Reisberg, et al., *Neuropsychopharmacology*, 2013 [abstract]).

Finally, I believe these findings are moving us towards a better understanding of the "cause" of AD. Basic brain mechanisms including brain anatomy (structure) and physiology (energy utilization), appear to be reversing development. In many ways we have found that even the time course of AD losses reverses normal developmental attainments, although there are also some differences. These observations point to a brain developmental reversal, perhaps, fueled by losses in brain energy (i.e., metabolic decrements). Accordingly, conditions which interfere with brain energy utilization (for example, condition which are diabetogenic), such as obesity, inactivity, etc., are increasingly being found to be risk factors for AD. Ultimately, the cause of AD, of course, requires further investigation. In the interim, advances in our understanding of AD persons can help these increasingly needy and potentially increasingly disturbed AD persons, as the disease process advances, today. Because of these possibilities and findings, this year, in 2014, the National Alzheimer Society of Spain (CEAFA) implemented a care model requiring familiarity with the use of our FAST scale of the progression of Alzheimer's disease related functional losses, and the retrogenic concepts of care needs and care possibilities, as compulsory in all nursing homes in Spain.

Director, Fisher Alzheimer's Disease Program
Clinical Director, Aging & Dementia
Clinical Research Center
New York University Langone Medical Center

Barry Reisberg, M.D.
Professor of Psychiatry

Preface

This book is written by three providers who care deeply about and are intimately involved with caregivers who struggle on a daily basis to provide loving and patient care to those diagnosed with Alzheimer's disease or one of the other dementias. Dr. Harold G. Koenig is a professor, a geriatric psychiatrist, and a researcher who delivers care to patients afflicted with one of the many dementias, while at the same time providing support to the caregivers of these individuals. Dr. Verna Benner Carson is a psychiatric nurse and President of a consulting company, C&V Senior Care Specialists, Inc. She developed a program entitled *Becoming an Alzheimer's Whisperer* and along with her business partner, Katherine Johnson Vanderhorst, also a psychiatric nurse, they traverse the country training family as well as professional caregivers—nurses, occupational therapists, physical therapists, and social workers—to "think outside of the box" when trying to manage the challenging behaviors of those with dementia.

They accomplish this by teaching and applying the Theory of Retrogenesis, developed by Dr. Barry Reisberg. This theory posits that those afflicted with dementia regress in a backwards fashion from adulthood to infancy. The theory does not suggest that a caregiver should "talk down" to the person with Alzheimer's or use "baby talk" but it does guide caregivers towards an accurate appraisal of what the individual is and is not capable of doing. Anyone who has seen or cared for an individual in the end stage of Alzheimer's cannot ignore the fact that the individual has lost many of the skills we associate with being an adult—the person is in a fetal position, cannot speak, lift his/her head up, sit up or walk, is incontinent and requires complete care—very much like an infant. The theory allows caregivers to understand the challenging behaviors in a different and more acceptable manner and leads to a problem solving approach that opens up a wide range of interventions. Additionally, the theory is correlated with damage to specific areas of the brain, so that caregivers learn that when their loved one repeats the same question over and over again they do not intend to be troublesome but this repetition occurs because the hippocampus, the storehouse of short term memory, is broken. Once caregivers know and understand the physiological origin of a behavior, they are free to "think outside of the box" to arrive at behavioral strategies.

Our hope is that within this book there are enough examples of such creative thinking that caregivers feel encouraged to allow their own inventiveness to lead them to discover interventions that are loving, patient, and effective in managing the challenging behaviors that characterize Alzheimer's and other dementias.

Contents

Chapter 1
Going Back to the Beginning: The Theory of Retrogenesis

As baby boomers age, the projected number of those who will develop Alzheimer's is staggering—not only for family caregivers who might still be raising children but also for the health-care system of the USA. Consider these statistics from the 2014 edition of *Alzheimer's disease Facts and Figures, Alzheimer's and Dementia* (Alzheimer's Association 2014; Auer et al. 1994; Bobinski et al. 1996).

One in nine (11%) of those 65 and older has the disease.
One third of those 85 and older (32%) have the disease.
Eighty two percent of those with Alzheimer's disease are 75 or older.

It is predicted that between 2010 and 2030, the number of older Americans will double to a staggering 72.1 million people, and by 2050 the number of older Americans will reach 88.5 million! For the first time in our history, people over 65 will outnumber children under five (Penny Wise, Pound Foolish: Fairness and Funding at the National Institute on Aging 2011).

Every level of health-care provider, primary care as well as specialty physicians, nurses, nurse practitioners, social workers, occupational therapists, physical therapists, and speech and language pathologists will be challenged to meet the needs of persons diagnosed with Alzheimer's. Additionally, these providers will be called on to meet the needs of family caregivers who are desperate for strategies to manage challenging behaviors and to keep a promise that is so often made to the elderly family member, "I will never place you." How will we meet these needs? What advice will we give to that struggling daughter, wife, or husband who says, "I don't know if I can do this anymore! My wife pushed me down in the bathroom. I needed stitches to the gash that I had on my scalp. I know I promised that I would never place her but I never counted on this behavior and I don't know how to manage it. Help me!"

You are about to be introduced to an innovative approach based on the *theory of retrogenesis* developed by Dr. Barry Reisberg (Reisberg 1988; Reisberg and Franssen 1999; Reisberg et al. 2002). This approach called *Becoming an Alzheimer's Whisperer* is "gentle and loving" easy to learn, and based on concrete evidence that will absolutely help you answer the desperate pleas for help that you hear from family caregivers.

V. Benner Carson et al., *Care Giving for Alzheimer's Disease,*
DOI 10.1007/978-1-4939-2407-3_1

The theory of retrogenesis is a stage theory that describes changes in the person's cognitive and functional abilities as he/she progresses through Alzheimer's disease. The theory posits that the brain of the person afflicted with Alzheimer's deteriorates in the reverse order that the brain developeds from birth. That is, the last area to be fully developed, or myelinated, is the first area to be damaged in Alzheimer's. The phrase "returning to a second childhood" and the word "dotage" defined in part as "childishness of old age" are captured in this theory. These changes can be understood in light of where the person is in her/his decline. Simply put, a person at stage 6, for instance, is functioning at the level of a toddler. Caregivers should never use the knowledge of the functional assessment staging tool (FAST) scale to justify talking to someone with Alzheimer's in a belittling manner but should adjust expectations and activities to the person's cognitive and functional level. In Chap. 2 you will read how this damage correlates not only to the function of specific areas of the brain but also to specific challenging behaviors.

The idea that some people "go backwards" in Alzheimer's is not a novel idea. As early as 423 BC, Aristophanes wrote a play in which he noted that "old men are like children twice over" (Aristophanes 1938). In Shakespeare's play, *All the World's a Stage"* Jacques's soliloquy compares the extreme old age of a man to a "second childhood." He loses control over his senses and becomes dependent on others just like a child (Agnes Latham 1967). In the early 1960s the term "returning to a second childhood" was a way of describing Alzheimer's. During that time, people who displayed the symptoms of what we now know as Alzheimer's disease were said to have "senile dementia" or "organic brain syndrome" and might be placed in one of the large state psychiatric hospitals until they died. But even much earlier than the 1960s, the disease of Alzheimer's (although not called Alzheimer's) was known. The number one risk factor is living into old age—and as health care improves we see that on average people are living much longer than they did in the mid-twentieth century.

Where did the name "Alzheimer's come from? It was the name of a German physician, Alois Alzheimer, who pioneered in linking specific behavioral symptoms to microscopic brain changes. He treated Auguste D., a patient who suffered from profound memory loss; she harbored unfounded suspicions about her family and a host of other worsening psychological changes. When she died, Dr. Alzheimer performed an autopsy. He noted dramatic shrinkage of her brain and abnormal deposits in and around nerve cells. He was a friend of Dr. Emil Kraepelin, a German psychiatrist, who worked with Dr. Alzheimer. When Dr. Kraepelin wrote the eighth edition of his book *Psychiatrie,* he named the disease documented by his friend as Alzheimer's disease.

In the late 1980s, Dr. Barry Reisberg began his work on the *theory of retrogenesis*. He published the FAST in 1988; this is an assessment tool that allows for specific identification of where someone is in her/his progression through Alzheimer's. Not only does the tool allow us to identify the appropriate stage of progression but also to know the appropriate interventions for each stage.

Let us take a look at the stages of the FAST scale and how we should respond to each stage (Reisberg 1988; Franssen et al. 1993; Reisberg and Franssen 1999).

Table 1.1 Dementia Care Specialists. (http://www.crisisprevention.com/Resources/Article-Library/Dementia-Care-Specialists-Articles/The-Adapted-FAST-Introduction-and-Application. Accessed, June 1st, 2014)

Stage on FAST	Scale Level of Cognition/ Dementia	Abilities at Each Stage	Response of Caregiver
Stage 1	Normal adult	Abilities consistent with expectations for a normal adult	Response is to a normal adult
Stage 2	Normal older adult	Very mild memory loss	Response is to a normal adult
Stage 3	Early dementia or mild cognitive impairment (MCI)	Early dementia—mild cognitive impairment	Memory problems apparent to coworkers and family members; individual with memory problems denies that he/she has a problem Stage lasts approximately 7 years
Stage 4	Mild dementia	Mild dementia functional level 8–12 years of age "great foolers" still looks good; can engage in a conversation; careful listening may reveal the holes in this person's memory	Asks the same question repeatedly, has difficulty managing finances—easily taken advantage of financially, driving skills deteriorating—might get lost even in familiar places—seek doctor's advice regarding driving—obtain a driving evaluation from occupational therapist, based on OT's findings doctor may need to send a letter to Motor Vehicle Administration based on result of OT's driving evaluation; Experiences difficulty in shopping for groceries and in preparing meals for guests. Has difficulty writing the correct date and amount on checks. May also find it difficult to order from a menu in a restaurant and might defer to spouse to order for both. Person with AD is usually in profound denial Stage lasts approximately 2 years
Stage 5	Moderate dementia	Functional level 5–7 years of age Should not live alone	Needs assistance with dressing—may need help in sequencing clothing, needs oversight for appropriateness of dress for weather and/or occasion; can participate in personal care; responds to music; likes to do repetitive behaviors, i.e., clipping coupons, folding laundry, sorting coins, likes to sing and listen to music of his/her era Can no longer live independently—someone needs to provide adequate and appropriate food, pay the rent and utilities and handle finances Can inconsistently recall information such as name of current president, current address Stage lasts approximately 1.5 years

Stage 6	Moderately severe dementia	Functional Level 4 years to—24/36 months	About 5 min of short-term memory; can still read—a powerful remaining ability; Needs help with all activities of daily living, loses ability to dress self independently and perform any personal hygiene tasks—lose the ability to brush teeth and handle mechanics of toileting; will become incontinent- first of urine then of stool, resists bathing—need to find bathing approaches other than
			showering, still enjoys engaging in repetitive behaviors, challenging behaviors become more apparent—maybe due to untreated pain—music very powerful! Challenging behaviors become more prevalent—mean duration of this stage 2–5 years
Stage 7	Severe dementia	End stage-functional level less than 24 months—deteriorating to 4–12 weeks old Stage 7C—eligible for hospice care under Medicare	7a.Only has six or fewer words 7b.Speech limited to the use of a single intelligible word—may be repeated over and over again 7c. Hospice eligible under Medicare—cannot walk without personal assistance 7d. Ability to sit up without assistance is lost-will fall over if there are not lateral rests (arms) on the chair 7e. Cannot smile

AD Alzheimer's disease

Let us take a look at some general caregiving strategies for each stage of the FAST.

During stage 3, many people who are experiencing mild cognitive impairment are too frightened to have their memory evaluated. Even when family and friends comment on the individual's failing memory, profound denial kicks in and the person can provide explanations for not remembering, i.e., "I was overly tired and that's why I forgot."; "I was preoccupied and didn't hear the directions."; "You mumbled and that is why I didn't do what you asked me to do." Any explanation for a faulty memory—other than the explanation of Alzheimer's will do. This denial is so powerful that most people at this stage avoid seeking evaluation from a physician.

During stage 4, the person still retains good social skills and can convince anyone who does not look too closely that he/she is okay. She or he might be called "a great Fooler"! The story of Mildred illustrates her ability to "fool" even the physician.

> Mildred went to see her primary care doctor for a routine checkup and to have her insulin level evaluated. Mildred was accompanied by her daughter who had taken her mother to the lab to get her lab work completed. The results of a recent HbA1c test were not encouraging to the doctor. He said, "Mildred, what is going on? Your blood work is not what it should be. Are you eating more sugar or sweets than you should be eating?" He said this with a smile but was quite alarmed with the lab results. The doctor expressed concern that Mildred's test results showed a high level of blood sugar indicating that Mildred's diabetes was not being adequately controlled. He asked Mildred to tell him what she had eaten for breakfast. Without hesitation, Mildred spouted off a perfect diabetic meal. She told him that