Alzheimer's disease as a "trip back in time"

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Abstract

Persons with Alzheimer's disease (AD) seem to vary from day to day in their recall of loved ones' names and faces. Such erratic fluctuating and regressive cognition is often puzzling and stressful to caregivers. This paper explores the possibility of conceptualizing AD as a "trip back in time" to help caregivers understand the variation in an AD person's memory, behavior, and physical abilities. Clinical observations suggest that these individuals experience a cognitive, emotional, social, physical and functional regression with AD. The "trip back in time" paradigm uses aspects of Piaget's theory of adult development in reverse, Reisberg and associates FAST and GDS, and other cognitive, behavioral, and affective research on AD. Using past research to indicate how patients tend to lose many of their functions, the conceptualization goes further to advance a non-linear regression model of AD. This paradigm of AD as a "trip back in time" uses connecting loops spiraling downward to depict the fluctuating regression. Previous theoretical frameworks have tended to rely solely on fixed stage regression models of AD. The insight this model provides will hopefully increase gerontologist/caregivers' understanding and provide new ways to develop strategies to enhance future caregiving techniques.

Introduction

The purpose of this paper is to propose a new theoretical conceptualization and model of Alzheimer's disease (AD) as a "trip back in time." This model offers a new approach to understanding the cognitive, emotional, social, physical and functional journey of an AD victim. The "trip back in time" was developed as a non-linear model to explain the variations in functioning throughout the course of AD. The paradigm builds on the linear theory of development of Piaget in reverse and the seven stage AD model of Reisberg and Associates as is seen in their Functional Assessment Staging (FAST Scale) as well as their Global Deterioration Scale (GDS) research.[1-8] The "trip back in time" uses a downward spiral with connecting loops to demonstrate the fluctuating non-linear, but progressive regression of the disease. The "trip back in time" model can account for the AD victim's ability to fluctuate in both memory and/recognition of family members as they travel back through time. The primary benefit of this model is a sensitive provision and explanation of AD for caregivers as well as a theoretical and clinical tool for the regression of AD. This theoretical paradigm can also serve as an insightful pedagogical aide for both clinicians and caregivers.

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Alzheimer's disease: A brief overview

Alzheimer's disease (AD) has been called the disease of the century, and is more likely to occur as a person ages. About 10 percent of those over age 65, and 47 percent of those past age 85 are estimated to have AD.[9] The literature suggests that over half of all causes of dementia is the result of AD.[10,11] Furthermore, demographic trends and age-related rates of AD suggest that it will become increasingly prevalent in the United States as we move into the new millennium.[12,13] Dementia is believed to affect 50 to 60 percent of the 1.3 million individuals in long term care facilities and may account for greater than half of the $26 billion spent annually on institutionalization.[14]

AD is characterized by failing memory, intellectual deterioration, functional decline and frequent behavioral disturbances. The result of this decline can be seen in the steadily diminishing mental capacity coupled with a shortened life expectancy. There have been reports suggesting that the age of onset determine the severity of illness.[15] The youngest documented age of an AD victim is

about age 28.[16] Ironically, with the exception of the very old (85 or older) who have other maladies, the young patients seem to die sooner.[17] It has been asserted that early onset (under age 65) cases may progress more rapidly and move through the stages of the disease more quickly than late onset cases.[18] Yet, scientists do not clearly understand why this happens. The decline of cognitive abilities in AD typically begins with short term memory loss and progresses at varying rates to a state in which virtually no cognitive abilities are spared.[19]

With the progressive nature of AD-related intellectual deterioration, caregivers often assign unrealistic behavioral expectations to their AD loved ones. This frequently happens by either over estimating or under estimating the AD person's potential for understanding, ability and cooperation. Due to the fact that AD patients' abilities are erratic and are often misunderstood, caregiver expectations are often unrealistic. What makes the situation worse is that some caregivers believe that the AD person is in a particular stage where only regression is possible. These expectations and subsequent reactions may trigger the person with AD to react adversely by exhibiting frustration, anxiety or a catastrophic reaction.[20-22]

Linear models

Scientists have a goal of increasing scholarly understanding and prediction of decrements in cognitive functioning. The pathological process of deterioration has a profound effect on the biological age of individuals, such that the chronological age is no longer a valid and reliable indicator of the age of the individual.[23] The key issues in addressing order in theories of adult development pertain to:

- Concepts regarding the theoretical and clinical basis for universally invariant sequences of achievement;
- Concepts concerning the rate people progress along developmental sequences.[24]

The first issue is not often addressed and when addressed, is usually rapidly answered by outlining innate organismic processes which occur. The second issue is more frequently addressed in a normative fashion, thereby creating the impression that chronological age is not correlated with, but is a causal determinant of, individual progress. However, several lines of evidence suggest the need to disassociate the notion of developmental sequence from chronological age.[25,26]

Over the duration of AD, there appears to be deterioration in mental function that is developmentally reversed and hierarchically consistent. Thirty years ago, de Ajuriaguerra demonstrated that the functional decline in those suffering from AD closely resembles Piaget's developmental stages in reverse.[27] The description of AD patients' behaviors as childlike make it seem logical that Piaget's theory could be utilized to examine the performance of AD patients on "typical" developmental tasks. This theoretical insight has facilitated further understanding of the disease process. Moreover, it provided some guidelines for the organization of scientific studies to substantiate the observations of immature or childlike behaviors that are often associated with AD patients.[28] In fact, some studies have used Piaget's model to chart the regressive course of AD persons traveling cognitively back from adulthood to childhood.[29-31] Thornbury showed how the use of Piaget's theory in reversal could even be applied to aid in caregiving techniques with AD persons. Such linear stage models of AD have helped caregivers learn to progressively take on more responsibility in providing care and planning for the future as the AD victim loses abilities.

For over a decade, Reisberg's seven-stage model of AD has provided clinicians with a means to describe the anticipated time course and progression of the disease. The clinical findings support a theory that the stages in AD appear to reverse normal human functional development. Reisberg's[32] protocol tool was based on:

- The definable consistency of AD;
- The idea that dementing processes associated with other causes progress differently than AD;
- The notion that functional decrements can be described in universal terms.

The FAST stages of AD were numbered to correspond with the Global Deterioration Scale's (GDS) stages of normal aging to facilitate comparison.[33] Reisberg's FAST has very defined deficits that AD patients experience as they go through each of the seven stages. This is an advancement over the shorter stage theories that dominated the 1970s and 1980s.

Although the FAST, GDS and Piaget's adult development in reverse have been extremely useful clinical tools—they have limitations. The linearity of these stage theories fail to account for the day to day and month to month fluctuations in behavior, memory and recall that occur with AD persons throughout the course of the disease (See Table 1).

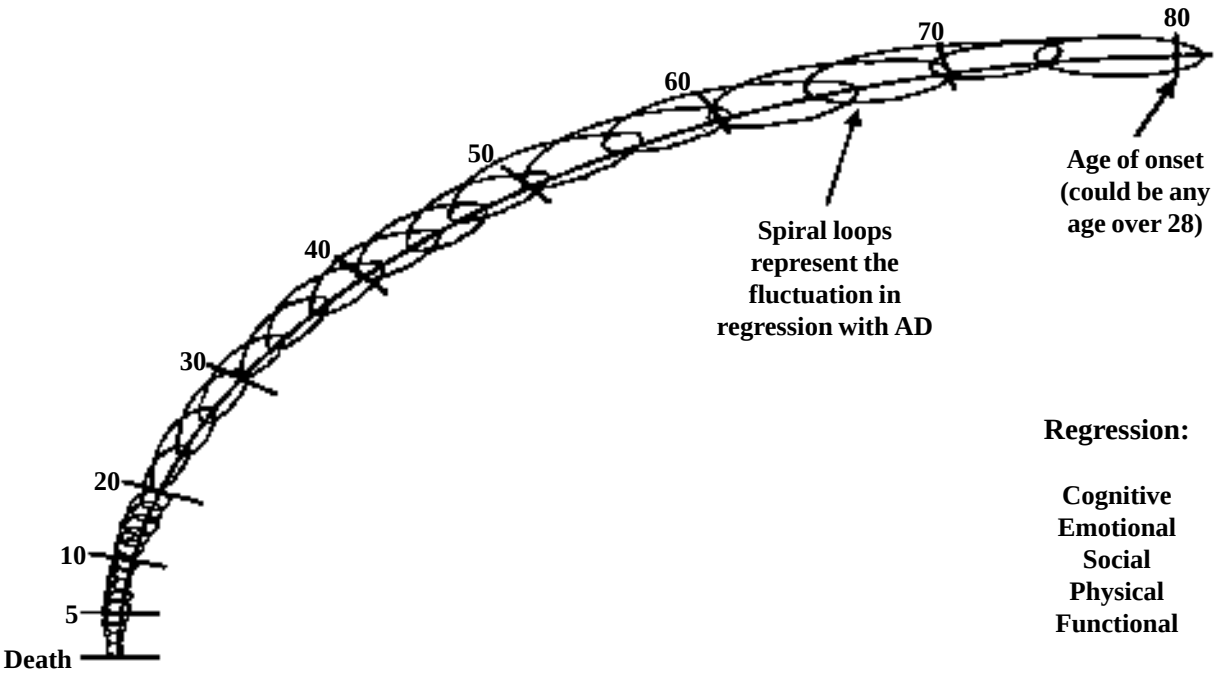
In 1962, Thomas Kuhn presented an argument that challenged a linear view about scientific activity and progress. Based on historical studies of the physical sciences, Kuhn

Table 1. Correspondence of functional assessment stages in AD to normal human development

FAST stage	Characteristics	Clinical DX	Estimated duration in AD*	Approximate age at which function is acquired**
1	No decrement	Normal adult	50 years	Adult
2	Subjective deficit in word finding	Normal aged adult	15 years	Adult
3	Deficits noted in demanding employment settings	Compatible with incipient AD	7 years	Young adult
4	Requires assistance in complex tasks, such as handling finances, planning dinner parties	Mild AD	2 years	8 years to adolescence
5	Requires assistance in choosing proper attire	Moderate AD	18 months	5 to 7 years
6	a. Requires assistance dressing	Moderately severe AD	5 months	5 years†
	b. Requires assistance bathing properly		5 months	4 years†
	c. Requires assistance with mechanics of toileting (e.g., flushing, wiping)		5 months	48 months‡
	d. Urinary incontinence		4 months	36 to 54 months§
	e. Fecal incontinence		10 months	24 to 36 months†‡§
7	a. Speech ability limited to about a half-dozen intelligible words	Severe AD	12 months	15 months†‡
	b. Intelligible vocabulary limited to a single word		18 months	12 months†‡
	c. Ambulatory ability lost		12 months	12 months†‡
	d. Ability to sit up lost		12 months	24 to 40 weeks†‡
	e. Ability to smile lost		18 months	8 to 16 weeks†‡
	f. Ability to hold up head lost		Not applicable	4 to 12 weeks†‡

* In subjects who survive and progress to the subsequent deterioration stage; ** Similar to Piaget's stages of adult development; † Eisenberg[19]; ‡ Vaughn[20]; § Pierce[21]

Figure 1. Alzheimer's as a "trip back in time"



wrote that scientific knowledge advances in two ways:

- First by gradual elaboration of fundamental understandings through the testing of particular hypothesis and the refinement of research technology; and

- Second by alterations in fundamental understandings that provide new frameworks for interpreting old and emergent facts.

Kuhn called the first concept normal science and the second one scientific revolution.[34] This paper provides a revolutionary new framework or paradigm for conceptualizing the course of AD as a "trip back in time." The attempt here is to alter the current view of the course of AD from fixed stage models to that of a fluid, non-linear model.

So far, research has tended to adopt either linear or fixed stage models, as with Reisberg, et al, and Piaget to describe the course of AD.[35,36] Linear models are based on the assumption that decline tends to be uniform, in fixed stages showing only incremental variations throughout the course of the disease. Unfortunately, studies indicated over a decade ago that the decline in individual mental functions with AD is far from uniform.[37] Individuals vary tremendously in the rate and progression of AD which make it difficult to predict time tables and fixed regression paths for the course of the disease.[38-40] In addition, based upon age of onset and other variables, not all people with AD exhibit the same pattern of cognitive, physical and functional deficits. Therefore, it is improbable that a single developmental pattern of decline can actually portray the course of the disease.[41]

The "trip back in time"

The concept of the "trip back in time" offers a new theoretical model of the course of AD. It uses a downward spiral with connecting loops to demonstrate the fluctuating, non-linear, but progressive regression of the disease. This regression is both fluid and fluctuating while the AD person travels from the age of onset of the disease back through time to his or her earliest years. The "trip back in time" model can account for the AD victim's ability to fluctuate in both memory and/recognition of family members as they travel back through time.

The use of the downward spiral diagram with loops (see Figure 1) suggests that the loops are all connected allowing for cognitive flow and fluctuation. The capabilities of the AD person are going to change throughout the course of the disease, beginning with short term memory loss followed by long term memory loss. The AD person's physical regression goes from normal to super human strength, then to problems with ambulation, and finally to the fetal position in a bedridden state similar to an infant in the womb.

Table 2. The multifaceted regressions of Alzheimer's disease	
Cognitive regression	Short term memory loss is followed by long term memory loss. As they travel back to different ages through their life, they remember details specific to that time frame that can be positive or negative. Concomitantly, the AD person often goes through a regressive personality change in a "trip back in time" from adulthood to infancy.
Emotional regression	Rational thinking is lost, but the person actually becomes more in touch with their emotions. Child psychologists paradoxically suggest that infants are more emotionally in touch and honest than adults.
Social regression	Past self, people, places, and things have meaning whether positive or negative based upon where they are on their trip back in time." Reality orientation may frustrate them versus validation which legitimates their cognitive world.
Physical regression	At first, they have normal physical strength that typically turns into super physical strength which is followed much later by psychomotor retardation with falling, swallowing difficulties, and choking. Eventually the person with AD is no longer able to ambulate, and is finally curled up into a fetal position in a metamorphic womb-like state in bed.
Functional regression	Activities of daily living change through time restricting independence. Movement from verbal to non-verbal communication is the norm. Hence, communication patterns are lost in a similar way in which they are gained from infancy to adulthood.
* There is typically no upward movement physically as opposed to the other areas.	

The connecting "loops" progress downward which accounts for the adult development in reverse aspect of AD as delineated by Reisberg and others. However, this new theoretical model accounts for the non-linear variances on a daily basis through time, with both recall and functional abilities. The connected loops explain how an AD person's memory can make small or quantum leaps springing back up from the past to the distant present for brief time spans. Although until now it has not been labeled, past studies have suggested that a theoretical "trip back in time," involves a cognitive, emotional, social, physical and functional regression back to infancy (see Table 2).

The case of Mrs. Park

Through clinical observations, Mrs. Park, an 89-year-old grandmother has cognitively regressed back approximately to age 59 and will typically not recognize her grandchildren at that point. Yet Mrs. Park frequently experiences lucid moments where she cognitively returns back up to age 89, clearly recognizing her grandchildren again. What accounts for this extreme variation in Mrs. Park's memory? For most people, normal brain function allows for good days and bad, with some variation in mental acuity. However, for the cognitively impaired persons, these variations can be exaggerated. Eventually, decline is inevitable and the 89-year-old grandmother will continue on a downward spiraling path, fluctuating back and forth, while she cognitively travels back to infancy. AD persons rarely return to the present time but on a few occasions can, as will be pointed out later. How much variation (*e.g.*, a decade or two decades?) either downward or upward, will require future research?

As the AD person regresses back and forth in time vortexing downward toward infancy, these variations in functioning make it extremely frustrating for caregivers. They often do not understand this aspect of the disease, because one day the grandchildren are recognized and the next day they are not. This may make caregivers think that the person with AD is playing a game or not trying hard enough to remember. For example, one of the co-authors clinically observed a confused nursing home resident respond one day to being called Ms. Jones (her first husband's name), and the next day to Ms. Davis (her second husband's name), and then back to Ms. Jones again. This example describes her fluctuating regression downward on a path through time headed toward her family of origin where

eventually only her maiden name would be remembered. At other times, we have observed that the AD person may mistake their children for a sibling one day and the next day not recognize them at all.

This model (Figure 1) suggests that the person with AD is on a "trip back in time" to earlier ages or time periods where the person with AD is making short time shifts reliving positive, negative and sometimes traumatic experiences of their life again. Studies show that the younger the dementia victim is, the quicker they regress through the course of the disease to death.[42] Perhaps the "trip back in time" may shed some light on why younger Alzheimer's patients die sooner than the norm. Maybe it is because younger victims have a shorter journey to infancy than the older patients who typically live longer with AD.

The case of Mr. Joe

Currently it is not clear why on certain occasions victims may make brief mega-shifts in memory moving upward through three or four decades for retrieval of information (recall). In the final bedridden state, the AD person becomes more rigid with extra pryamidal symptoms and primitive reflexes. Other primitive release signs (sucking and grasping reflexes) paralleling infancy occur and weight loss is often severe.[43] We have clinically observed a patient in a nursing home who was bedridden and in a semi-fetal position. This patient had not spoken in full sentences for over a year and was basically non-verbal. One day however, as his daughter entered his room, Joe said, "Susan, your new hair style looks nice." Using a linear model discussed earlier, this interaction would not be explainable or plausible. However, the "trip back in time" model with connecting loops offers some explanation to this erratic cognition that is often puzzling and stressful to caregiver perceptions. Toward the end of the journey of AD, these patients cannot ambulate, suffer from psychomotor retardation, are non-verbal and typically only recognize pictures of their family of origin. In addition, the bedridden victims who have cognitively time travelled back to their childhood years, do not recognize or even respond to any of their nuclear family unless they resemble an extended family member. Nevertheless, at any given time the AD person can make tremendous cognitive shifts upward to the present. Such phenomena as in the above case, indicate that AD persons not only vary from day to day in their recall of loved ones' names and faces, but may be capable of making brief quantum leaps in memory. Hence, the use of the "trip back in time" model can help caregivers understand the presence of variation that can occur no matter how short the time period is.

Summary

The fluctuation of cognition in AD is often puzzling and stressful to caregivers. The conceptualization of AD as a "trip back in time" with connected loops on a downward spiral offers caregivers new insights into the unpredictable variation their AD loved ones may experience. The paradigm of the "trip back in time" may increase gerontologist and caregiver understanding by using a non-linear model versus a fixed stage regression of AD. This explanation of the course of AD provides a paradigm shift referred to by Thomas Kuhn as scientific revolution offering a new approach to enhance future caregiving techniques. Therefore, it is suggested that instead of conceptualizing steady predictable linear stages, future theory and research should take into account the non-linear spiral effect of connecting loops or varying shifts in the AD victim's trip back in time.

As Carrie Knowles so eloquently stated in her book, *Alzheimer's: The last childhood*:

> "It is not always easy to understand what is happening. Alzheimer's does not come on full blown, nor does it attack in a clean clear cut manner. It is often muddied by a family's history. It is camouflaged by the quirks of aging and all those rough edges you don't want, or just plain refuse, to see in someone you love."[44]

By utilizing this "trip back in time" model as a basis for competency-based care, researchers may in turn caution against overestimating or underestimating the capacities of AD patients. Then perhaps, caregivers and health care providers would be less likely to inappropriately assign the AD person a fixed deficit and reinforce dependency and exaggerated helplessness.

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