

Outcome Based Neuromuscular Care: Monitoring Patient Happiness as a Possible Physical Therapy Home Program Variable in Alzheimer's Disease

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Abstract

Alzheimer's disease has complicated the implementation of the new health care reform law because the incidence of the disease has been increasing in staggering proportions, with no known treatment or cure. We are already adding millions of uninsured patients to the health care system, and now, patients with Alzheimer's are intensifying the economic challenges of providing outcome oriented health care services to all Americans. There are no accepted "standard of care treatments" for patients diagnosed with that dreaded disease. Alzheimer's disease is the sixth-leading cause of death in America, currently affecting an estimated 5.4 million people. It is estimated that someone in America develops the disease every 69 seconds and by mid-century someone will develop Alzheimer's every 33 seconds. Monitoring an Alzheimer's patient's progress is important, since identifying the objective components of their physical and cognitive decline, is an essential element in the assessment of their rehabilitation outcome variables and functional independence. The incidence of Alzheimer's disease is not limited to the elderly, since people in their 30's, 40's and 50's can develop the disease. Finding an objective method to document an Alzheimer's patient's happiness might be clinically advantageous, because it might prove to be a meaningful reflection of their overall health. The Primary Caregiver Rating Index and the Patient Happiness Indicator has been proposed as a way to track an Alzheimer's patients' relative happiness, and thereby objectify one important component of their day-to-day function.

Introduction

Observed indications of happiness

The impairments of an Alzheimer's patient are the result of complex and progressive central nervous system, as well as related peripheral motor, sensory, and cranial nervous system dysfunction. The twelve cranial nerves are largely responsible for functions that affect human emotions and behaviors [1]. Smelling, seeing, focusing (motor vision), expressions (facial muscles), chewing food, tasting, swallowing, balance & coordination, hearing, talking (motor speech), digestion, appetite and general feelings of well-being, looking at things (neck or cervical mobility), and verbal articulation, are all controlled by the cranial nerves and are all important to our humanity and related to our emotions [2,3]. Most of the cranial nerves are located in the brainstem region, which includes the midbrain [4]. Patients with Alzheimer's disease, in varying degrees, have demonstrated difficulties with functions controlled by the cranial nerves [5]. They also have difficulty with expressing thoughts, feelings, ideas, concepts and emotions. The precise anatomical and physiological reasons why Alzheimer's patients experience such variable and complex neurological losses are not known. Empirically, the Alzheimer's patient may still seem to possess the ability to think and feel emotions. Possibly however, their unexpressed feelings or perceptions, originating in the frontal lobe or cerebral cortex, might also be the result of nerve impulse relay problems in the midbrain and brainstem [3]. Developing an adapted method to journal and document day-to-day feelings and experiences, as the disease progresses, would be a beneficial method to assist both the Alzheimer's patient and the caregiver, emotionally. Consciously thinking about, and then being able to express their feelings, would also exercise the neurological motor, sensory and relay pathways in the brain, which might also, secondarily, be beneficial physically to the Alzheimer's patient.

Purpose

The purpose of this report is to introduce and propose a caregiver assisted means of monitoring the emotional health of an Alzheimer's

patient. The long accepted method of keeping a journal to document feelings and experiences cannot be utilized with cognitively impaired individuals. An alternative strategy designed to meet the same human psychological needs in patients with dementia would be a helpful caregiver tool. Documenting the Alzheimer's patients' feelings and emotions over time might provide useful insights into the possible long term emotional and physical health of both the patient and the caregiver [6,7].

Method

A piece of the Alzheimer's puzzle: possible variables in predicting future prognosis

Alzheimer's disease is characterized by its common diagnostic symptoms but clinically may exhibit variability in day-to-day (within patient) and between patient functional symptoms. Working with patients diagnosed with dementia and Alzheimer's disease in a physical therapy and rehabilitation counseling agency, clinically, presents the therapist with a wide variety of functional diversity, both cognitively and physically [8]. Attempting to understand the cause-effect relationship between the underlying neuromuscular pathology and each Alzheimer's patients' psychomotor clinical dysfunction is an important component in evidence based or outcome oriented care [9,10]. The "evaluate and treat" physical therapy prescription

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for patients diagnosed with Alzheimer's disease has become the usual mode of referral, and an individualized plan of treatment is customary. It is important to document the long term benefits of the home therapy program over time for all patients, however, in a similar and consistent manner [11]. With Alzheimer's patients and caregivers, this includes their emotional as well as their physical health [12,13]. The psychological benefits derived from keeping a journal has been a rehabilitation counseling tool used for many years. However, the Alzheimer's patient has difficulty putting their feelings into words [14] An adapted method of communication would enable the accomplishment of the similar home rehabilitation goals realized by cognitively healthy patients, who keep a therapeutic journal of their feelings [15] We have developed a simple method to monitor the relative happiness and feelings of the Alzheimer's patient while they are at home.

Results

Monitoring & recording patient & primary care giver assessments: happiness as a predictor variable

Involving the patient in their own care is clinically beneficial, because the patient develops a sense of ownership in their treatment outcome [16]. Clinically, the use of subjective assessments are both efficient and effective, while at the same time contributing to the provision of evidence based care [17].

In an effort to monitor the Alzheimer's patient's happiness, the primary care-giver provides ratings on the following "Indexes", scoring each one on a 0-5 point scale where 0 is none and 5 is high: a) hope, b) vision, c) new ideas, d) new interests, e) sense of humor, f) physical strength, g) cooperation, h.) mobility.


Significant patient interaction and assistance from the physical therapist, and/or primary care-giver will be required each day; however the relative level of assistance may vary, and will be directly related to the degree of cognitive functional impairment experienced

Hope _____	Sense of Humor _____
Vision _____	Physical Strength _____
New Ideas _____	Cooperation _____
New Interests _____	Mobility _____


**Significant "patient interaction" with the physical therapist or primary care-giver will be required.

Figure 1: Care-giver Rating Scale "0-5" Index (Assessing "Alzheimer's Patient Weekly or Daily Progress)**.

I FEEL SAD



I FEEL HAPPY



PLACE A MARK WHICH BEST DESCRIBES YOUR FEELINGS as EITHER "SAD" OR "HAPPY"

**As a helpful "participation training technique", the therapist/primary care-giver can draw a "Smiley Face" or "Frowny Face" to explain & clarify the possible range of patient feelings

Figure 2: Mark the "Happiness Indicator" ** (figures from Microsoft Office 10/ Office.com).

by the Alzheimer's patient on that given day. A shared recovery and patient participation in their own rehabilitation process are important therapeutic goals of home programming in Alzheimer's disease.

Attempting to quantify progress in evidence-based neuromuscular care

Consistent with the effort to objectify treatment outcomes [18] the patients themselves would indicate how "HAPPY" they were, by marking the Happiness Indicator where the left side of the scale indicates "misery & despair" ("I FEEL SAD") and the right side of the line reflects "happiness and healing" ("I FEEL HAPPY") on a Likert-type scale. Again, depending upon the individual cognitive functional capacity of the patient, this endeavor will require a calm and supportive effort on the part of the physical therapist and/or primary care-giver [10] while assisting the Alzheimer's patient in making their "mark" on the line closest to their feelings at the time, either "SAD" ("not happy") or "HAPPY", as represented at each end of the scale.

Discussion

Summary of ways to objectify "patient progress" in Alzheimer's home programming

The "Primary Care-giver Rating Index" and the patient "Patient Happiness Indicator" might become simple and important ways to document progress over time, and to maintain an objective method to monitor and follow up with the Alzheimer's patient, as part of their home program. Traditional home programming techniques for Alzheimer's patients should be individually designed and outlined by a health care professional, and might include therapeutic exercises, walking (with assistance as necessary), diet (healthy choices such as eating a piece of fruit every day), cognitive activities (card games, reading, looking at picture books), and socialization (going to the mall or diner each day, for example. Meeting the patient "where they are", as individual human beings, and evaluating and treating them with "unconditional positive regard", implies the need for health care providers to interact with each patient first rather than just prescribing a "plan of treatment. Historically, the more complex the diagnosis, the more likely it was that the patient would not receive adequate treatment [12]. In the past, those individuals with diagnoses such as visual impairments, speech impediments, stuttering, learning disabilities, autism, psychological disorders such as clinical depression, solitary confinement and social outcast phenomenon, cerebral palsy, obesity, recurrent pain, fibromyalgia, chronic fatigue, bipolar personality disorder, infant failure to thrive syndrome, cerebrovascular accidents, rheumatoid autoimmune disease, etc., were typically dismissed by a healthcare system that simply did not have the time or energy required to treat "chronic syndromes". And yet increasingly, even with the new health care reform model, the principles of business and rationality, once again, are necessarily becoming the logical norm. Evaluating the cost-benefit ratio for all treatment is clearly necessary. The degree, to which an Alzheimer's patient maintains or improves their happiness over time, might be one indication of their rehabilitation prognosis [17]. In Alzheimer's disease, the "Happiness Indicator" might provide an objective means of evaluating an important human personality variable, potentially related to motivation, behavior change, and physical function.

Conclusion

The incidence of Alzheimer's disease is growing exponentially

throughout the world. It is a complex disease, from a variety of viewpoints, including neuroanatomical, psycho-educational, social, financial and cognitive perspectives. The disease causes families much emotional pain and frustration. Alzheimer's disease is responsible for \$183 billion in annual costs in the United States. Currently the disease affects an estimated 5.4 million people, resulting in nearly 15 million Alzheimer's and dementia caregivers who provide \$202 billion in unpaid care for their loved ones [19]. Given the nature of the disease, studying the Alzheimer's patient functionally, in the clinic or in their home, is necessary if the societal goal is to gain an understanding of how this neurological pathology affects human behavior. "Improving functional behavior" is a multifaceted goal, which is commonly included as the most important outcome variable in physical therapy and rehabilitation treatment. Monitoring an individual's "happiness" in the treatment of dementia may be one possible physical therapy home program methodology that will contribute to the Alzheimer's patient's "improved functional behavior".

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