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CNE and Person-Centered Care vs. the Distorted Medical Model (Revised)

SPENCER M. ROBINSON

Abstract

A great culture change movement and a rigorously researched, whole new paradigm in understanding cognitive and behavioral disorder (i.e., so-called "mental disorder") together offer a potent, dramatic new approach to addressing elder care and both the prevention of and recovery from cognitive decline, dementia and other neurobehavioral sequelae that particularly affect elders, especially so those residing in a long-term care facility. The culture-change movement embraces the concept of person-centered care (PCC), while the innovative cognitive and behavioral intervention model, referred to as Cognitive Neuroeducation (CNE), fuses a neuroscience-informed base with a human-values orientation, both PCC and CNE rejecting the distorted medical model.

This paper outlines the affinity of the philosophy and objectives of the PCC and CNE paradigms, elucidates the misdirection of the medical model, and suggests that CNE and PCC, in a fully integrated approach, can give a whole new lease on life for the elder, redefining elderhood as a meaningful, rich, and rewarding stage of life, even in physical decline and when living in a long-term care facility.

The Culture Change Movement and the Distorted Medical Model

There is a startling culture change movement that is gaining ever more traction within the community of caregivers for elders in long-term care facilities. This movement and the initiatives it inspires are referred to by a variety of similar terms, such as: person-centered care, patient-centered care, person-and family-centered care, resident-centered care, client-centered care, person-directed care, etc., which we will herein simply refer to generically as "person-centered care," and, though each of the different initiatives propose their own specific guidelines, they all embrace a philosophy that focuses on the humanity of care, recognizing that every individual is a unique personality, every long-term care resident an individual with a unique set of needs, and that life in a residential care facility need not, and most definitely *must not* deny the resident the fundamental right to maintain her/his individuality with dignity and respect. In this philosophy, the long-term care facility, rather than a place that simply provides for the rudimentary physical needs of a dead-end existence, becomes the hub of a nourishing environment that facilitates the engagement of life, providing challenge and growth to the fullest of each individual's capacity that continues to develop and expand, revealing new strengths and activities that excite the individual's interests and promote: a) a sense of accomplishment, b) bonding with others; c) joy of the moment; and d) a keen anticipation of the discoveries, camaraderie and achievements tomorrow may bring.

We refer to this culture change movement as startling because it repudiates the dominating medical model constructed on a distorted concept of pathology and the overuse of pharmaceuticals for every behavioral difficulty and physical discomfort that accrue in residents in the traditional nursing home or long-term care environment, "remediating" every condition through drugs that numb tactile sensation and cognitive and emotional reaction, stifling awareness and personality into a zombielike state for easy management. The medical model treats as pathological the physical and psychological manifestations of the distress of the dead-end environment, with its miasma of futility and its depressing, restrictive institutional structure lacking adequate social and physical outlets so necessary to physical and psychological/cognitive well-being, ignoring the individuality of the elder possessing social and psychological needs like everyone else, choosing instead to drug the elder rather than address unmet needs and the stagnant environment that induces distress and triggers the onset and progression of both physical and cognitive degeneration.

The culture change movement is startling when considering the strength of the person-centered care advocates' commitment and courage and most enlightened perspectives to resolutely resist the dominance of the commercial juggernaut of Big Med and Big Pharma and the pervasive dogma of the medical model, especially in the medical model's approach to pathologizing situations and circumstances whereby negative situations or pressures, particularly in situations perceived by an individual to be inescapable and of interminable duration, or of sudden, dramatic trauma inducing counteractions designed to obfuscate or distort reality as a built-in psychological defense mechanism protecting one's core psyche from the full realization of one's loss or the desperate position in which one has been entrapped, the resulting behavior labeled by the medical model as inappropriate, disruptive, uncooperative, unresponsive or even hostile or threatening, whereas, however, the problem is the situation, not the behavior, which, initially, is only a reaction to a situation,

that, if allowed to persist, in the long-term often results in serious cognitive disorder. It is the negative situation that must first be resolved, then inappropriate behavior can be modulated by *naturally* reestablishing cognitive integrity in eliciting and constantly reinforcing more positive, self-affirmative and productive behavioral outcomes.

To come to this realization in the face of Big Med bullying, and to dare to challenge the purported scientific authority of Big Med in rejecting the medical model, even when such progressive person-centered care advocates as the various national and regional Alzheimer's societies as well as many long-term care facilities that have fully implemented the person-centered care approach absolutely depend on medical advice and support, mostly from "experts" wholly indoctrinated in the medical model, is dramatic testimony to the amazing strength of conviction that the proponents of the person-centered care approach have in the integrity and efficacy of that approach drawn from a heartfelt humanitarian concern and a deep well of experience working directly with elders and providing care to individuals in all stages of dementia in long-term care facilities.

It is the experienced healthcare workers at the front line daily interacting directly with elders in long-term care and the responsive behaviors associated with dementia in addition to the more extreme behaviors falling under the umbrella of the equivocal diagnostic category of BPSD (behavioral and psychological symptoms of dementia) and those very residents in long-term care and individuals living with dementia themselves that are the real experts in the field. However, in spite of the valor of the advocates of the person-centered care approach and the inherent veracity of that approach, there remains a critical problem, which is, the tension in repudiating the medical model while simultaneously depending on the medical profession trained in the medical model. Not only does this tension create great conflicts between the person-centered care workers and the physicians, psychiatrists, psychologists, social workers and nurses treating the residents in the long-term care facility, but also drives a troublesome wedge between the person-centered care approach and the authority of the medical field that seeks to regulate all practices related to disease intervention and mental healthcare.

While the dramatic results in improvement in cognitive functioning, behavioral stability and sense of well-being of residents in long-term care facilities that have fully implemented a person-centered approach have convinced a number of medical professionals of the power and efficacy of the approach, the dogma of the medical model remains entrenched within the vast majority of the medical community simply unaware of the problem, indifferent for either lack of concern or for self-serving interests, or fearful of challenging the distorted concept of the pathology of behavior. In spite of the resistance of the medical community per se, many forward-thinking individuals within the medical community recognize that the drug-oriented, pathology obsessed approach to cognitive and behavioral disorganization is exceedingly narrow and theoretically vacuous – the fundamental nosology inconsistent and even contradictory, and, in clinical practice, often causing more harm than good. This nosology is transcribed in the *Diagnostic and Statistical Manual of Mental Disorders* (DSM) of the American Psychiatric Association, considered the "bible" of the field [the European-based counterpart, the *International Classification of Diseases* (ICD), presents a similar nosology].

Up to the fourth edition of the DSM (DSM-IV) the nosology totally ignored the most obvious fact that behavioral problems are very often basically problems in adjustment to environmental conditions and are frequently embedded within the context of a conjunction of tensions between social pressures, cultural constructions, self-concept and core values. DSM-IV gave some lip-service to the sociocultural dimensions of behavioral problems by introducing the Outline for Cultural Formulation, a sophomoric, vacuous view of the effect of social situations and cultural perspectives on behavior. The current fifth edition (DSM-5) claims to update and extend the Outline for Cultural Formulation, primarily through a ludicrous 16-item questionnaire [the Cultural Formulation Interview (CFI)] that attempts to define: a) an individual's cultural domain and the impact of that domain on the presenting clinical problem; and b) the individual's perception of the problem (as well as that of those identified as significant members of the individual's social network through the Informant Version of CFI) as a means to clarify diagnosis and "improve therapeutic efficacy."

In the DSM-5, just 10 out of more than 950 pages address the social and cultural impact on human behavioral outcomes and just 16 items on the CFI (17 on the Informant Version) propose to construct a revealing composite of the unique nature of an individual and define the presenting problem and its treatment from the individual's perspective. This approach most disturbingly reveals the utter lack of understanding of: a) the fundamental concepts of human behavior and the neurophysiology and cognitive processes of the antecedents of human behavior; b) the whole person as a unique individual; and c) the myriad intricate interactions of finely nuanced cultural and social dimensions by which every individual is self-defined and continuously and subtly but meaningfully redefined by the experiences of life unfolding day-by-day.

Like its earlier editions, the DSM-5 is based on categorizing some arbitrarily assembled behavioral characteristics (so-called "symptoms") as pathologies, i.e., organic disorders or diseases, distinguishable solely by a specific aggregate of symptoms – defining behavioral disorganization as fundamentally a biological process, and though giving some lip-service to social and cultural agents contributory to behavioral disorganization, the DSM-5 basically ignores environmental factors (inclusive of factors relating to lifestyle) as major causes of cognitive and behavioral dysfunction as well as organic pathology. Of course many instances of cognitive and behavioral dysfunction are sequelae of physical injury or organic pathology, but which was the initial cause, environmental factors resulting in organic pathology inducing cognitive and behavioral dysfunction, or environmental factors resulting in cognitive and behavioral dysfunction inducing organic pathology? In both cases the root of the problem is environmental, and these sociocultural factors must be addressed as the front line of intervention.

Paraphrasing Liah Greenfeld (2013), the DSM-5, in spite of its changes, simply carries on the fundamental problem of all the preceding DSM editions, that, predicated on the medical model of behavioral pathology, fail to provide a fundamental understanding of the human mental processes, i.e.; the human mind, and fail to answer the critical questions: 1) what is a dysfunctional human mind as opposed to a functional one, i.e.; what are the criteria for

determining whether a certain manner of cognitive reaction or character of behavior is dysfunctional or not, and most importantly, 2) what are the bases for such criteria and what are the causes of cognitive and behavioral dysfunction and the attendant principles by which such dysfunction may be remediated.

Because of its nearly exclusive biological focus and fundamental distortion of equating mind with brain, the medical model minimizes (in clinical practice, often repudiating) the role of the sociocultural environment in the adaptation and ongoing modification of human behavior in response to the interpretation of experience, basically ignoring the very components that motivate and drive human behavior and the essential sociocultural avenues by which cognitive and behavioral dysfunction may be remediated. Thus, the medical model and the DSM in all its editions neither reflect the reality of human experience nor provide any helpful understanding of cognitive or behavioral disorganization or realistic avenues of remediation thereof.

The essential problems with the DSM-5 and the entire medical model of mental health include: 1) the total lack of theoretical grounding; 2) the enormous overlap of so-called "symptoms" from one diagnostic category of so-called "mental disorder" to another; 3) the lack of definitive etiological bases distinguishing different alleged disorders; 4) the blind dismissal of the critical importance of the role of sociocultural factors as a source of cognitive disruption and psychological distress in the onset of cognitive and behavioral dysfunction as well as organic disorder; and 5) the growing number of alleged disorders in each subsequent edition of the DSM resulting in the medicalization (i.e., pathologization) of typical socialized defensive responses to different situations as shared cultural traits of a particular socioculturally defined population while ignoring the negative, destructive behavior inculcated by the "sick society." Within all this is the constant jockeying of self-serving interests for political power among the various factions competing for authority and influence in both professional and academic circles and a larger share of the vast commercial enterprise of Big Med and Big Pharma— the motivation is clear, as it cannot be denied that the medical/healthcare industry is the world's largest commercial sector, "Big Business" with a capital "B."

CNE and Person-Centered Care

Cognitive Neuroeducation (CNE), an activities-based, social-integration-oriented modality for the prevention of and recovery from cognitive and behavioral disorder, signifies a major breakthrough in understanding and addressing the causes of cognitive and behavioral disorganization. In identifying the basic principles of brain-mind-behavior interaction, the CNE framework applies these principles to broadly stimulate and exercise the brain to build brain and cognitive reserves as a neuroprotective shield and renew or expand cognitive acuity in reclaiming or discovering one's selfhood and one's social instincts in engagement with others and one's environment.

The CNE curriculum, unique among all behavioral modalities and cognitive rehabilitation programs, centers on an enriched environment of highly eclectic learning and bonding activities in a cohesive group dynamic that combines high cognitive functionality with emotionally compelling social engagement that emphasizes group interaction and teamwork; individual responsibility; perspective taking; social context appraisal; empathetic, attentive listening; constructive feedback; individual initiative, facilitation of the voice of the individual, and the confirmation of self.

The major features that distinguish CNE from all other cognitive and behavioral intervention modalities are as follows:

1) ***Originating from a platform with a proven track record***
CNE is derived from the highly vetted, highly successful cognitive rehabilitation modality Cognitive Enhancement Therapy (CET), which is backed by more than 15 years of clinical trial studies as well as a history of program outcomes from different mental health facilities running CET clinics, and formal recognition by the APA (American Psychological Association) and SAMHSA (The United States of America Substance Abuse and Mental Health Services Administration) [Robinson 2018, pp. 2-3]. A listing of CET background research reports and clinical trial results may be found in Robinson and CASN 2018.

2) ***Theoretically grounded from basic principles validated by an extensive body of studies***
CNE is neuroscience-informed, built on well-established principles in a rigorous theoretical framework defining the antecedents of human behavior and the mechanisms in environmental-neurophysiological interactions that lead to cognitive and behavioral disorder and the prevention thereof and recovery therefrom. These principles are validated in an extensive body of studies, a representative example of which is presented in Robinson and CASN 2018.

3) ***Inherently person-centered, human-values oriented***
While research-based and neuroscience-informed, CNE, like the person-centered culture-change movement in elder and dementia care, repudiates the distorted medical model, replacing a negative, pathologically oriented medical model with one that fosters human values with emphasis on the individual and an environment that provides enriching activities and promotes self-identity, social integration, the joys of companionship, the positive engagement of life and self-fulfillment.

4) ***Provides the vital mental health component missing from person-centered care***
With its human-values emphasis, CNE can effectively address the missing component of person-centered care. This vital missing component is a dedicated framework and curriculum for the prevention of and recovery from dementia and other age-related neurobehavioral sequelae within a seamless person-centered intervention-care environment.

Cognitive decline and behavioral disorientation severely impact an individual's well-being. In addition, the stress placed on personal support workers (PSWs), other interprofessional staff as well the residents in a long-term care home (LTC) by the disruptions and difficulties caused by responsive behaviors or more serious so-called behavioral and psychological

symptoms of dementia (BPSD), can be wearing and produce a tense atmosphere disturbing the ambiance and harmony within the facility. Preventing cognitive decline and maintaining cognitive and behavioral stability while stimulating the cognitive growth of the residents fosters their self-fulfillment and more understanding and cooperation between residents and staff leading to more involvement of the residents in their own care, reducing the burden of care in more compatible, smoother-running care and living conditions.

CNE, with its rigorously researched base and legacy derived from a foundation with a proven track record, offers a real, viable efficacy in nonintrusive, nonpharmacological intervention in cognitive and behavioral disorder. CNE is founded on a major breakthrough in mental health. In distinction from conventional atheoretical, generally baseless psychotherapies with a history of dubious outcomes, CNE effectively rebuilds cognitive acuity and behavioral balance even in the presence of organic damage (where tissue damage has not exceeded a threshold of neuroplasticity), while both supporting and enhancing the person-centered environment of care in a seamless person-centered intervention-care model with the principles and philosophy of the person-centered care movement built into CNE and fully implemented within its framework from its inception.

5) ***Ready framework for intergenerational programming and building strong community connection***

CNE, restoring and expanding cognition and balancing behavior through a *cohesive group dynamic*, can provide intergenerational programming and community mental health services through its highly flexible curriculum and group structure, expanding the social network of the program participants as well as the services provided by the retirement or long-term care home.

"It has been demonstrated that well-designed contact between people from the broader community and nursing-home residents contributes to the psychological well-being and physical health of the residents (Chamberlain, Fetterman and Maher 1994; Lambert, Dellmann-Jenkins and Fruit 1990; Newman, Lyons and Onawola 1985; Ward, Kamp and Newman 1996). There are also potential educational and attitudinal benefits for those who visit, particularly young people. As early as 1975, the U.S. government sponsored programs that involved transporting senior citizens to schools in order that they might participate in classroom activities. Research has attempted to describe guidelines for successful intergenerational programs. These guidelines include intimate rather than casual contact (Amir 1969); predictable, scheduled visits (Schulz 1976): *mutually rewarding, cooperative activities* [emphasis added] rather than 'performances' by the children (Seefeldt 1987); integration into the school curriculum (McCollum and Shreeve 1994); and careful preparation of all participants (Griff, Lambert, Dellmann-Jenkins and Fruit 1996)" [Hamilton and Brown et al. 1999, p. 235].

In their 1999 paper, Hamilton and Brown et al. describe how planned, coordinated and regularly scheduled and more enduring intergenerational contact resulted in both increased health and a new "zest for life" for the LTC residents. While this 1999 paper and the studies it references focus on contact between young children and elders, the benefits of intergenerational interaction for elders in long-term care has been well known for years and

more recently great attention has been directed at sustained contact between young adults and elders, for example, in such experiments as intergenerational living where the LTC doubles as a student dormitory (Jansen 2015).

While the experiments reported by Jansen have been highly successful to-date, there still remains the lack of an integrated person-centered orientation dedicated to directly addressing cognitive and behavioral disorder in a stable, on-going, structured program of prevention and remediation.

CNE fluidly solves this problem as well as perfectly matching the general guidelines for successful, efficacious intergenerational programming as suggested in the Hamilton and Brown et al. 1999 paper. The CNE curriculum, centered on an enriched environment and engaged through a cohesive group dynamic, combines the constancy of a well-formulated structural base with an enormous flexibility in curriculum content and procedural arrangement designed for tailoring to specific circumstances. The basic CNE structure consists of placing CNE program participants in stable groups of 6-8 individuals who interact interdependently in a group dynamic in a prescribed schedule of specific activities and learning situations.

It is in this group dynamic that participants learn to value each other's input as well as their own – where success in learning and accomplishing tasks, and engagement and enjoyment of the moment are products of group and individual effort, leading to growth of the individual and the group, to self-confirmation, bonding with others, identification with the group and sense of belonging. It is these interactions in the group dynamic in an on-going CNE program that, paraphrasing the guidelines stated in Hamilton and Brown et al. 1999, provide "intimate rather than casual contact," "predictable, scheduled interaction," "mutually rewarding, cooperative activities," "integration within an ongoing curriculum" and "careful preparation of all participants," the latter as an inherent component of the CNE group structure and its dependence on the cooperation, constructive feedback and planning that constitutes teamwork.

Taking full advantage of the flexibility built onto the CNE framework, CNE group activities can be tailored to include individuals from the surrounding community (hereinafter referred to as "nonresidents") as stable group members. Nonresident members may include those seeking recovery from cognitive or behavioral disorder, those seeking to build stronger brain and cognitive reserves for the prevention of dementia or other cognitive and behavioral disorder, or volunteers who simply wish to participate in the activities designed to help elders in long-term care to rebuild their cognitive faculties, expand their social networks and enjoy life.

Nonresident participants may include a wide range of ages, with the group dynamic and activities tailored to specific situations, such as an orientation whereby the elders in a group that includes a child or children act as mentors for specific activities within the group or the elders assuming roles as surrogate grandparents in a dynamic that emphasizes bonding, or a group dynamic that switches mentor roles between young adults and elders. Group composition can be periodically varied in different activities to give both residents and non-residents a rich range of experience in wider opportunities for social networking and

interpersonal interactions. LTC vacancies and respite beds can be put to use in providing full accommodation for fixed periods for nonresidents requiring a more complete absorption within the enriched environment in recovering from cognitive and behavioral disorder, or an LTC may find that is to its advantage to expand in dedicating more resources for non-resident fixed-period accommodation as a major community center for mental health in CNE programs that bring youth, community and LTC residents together in closer and more enduring interaction.

Together, in a seamlessly integrated enriched environment, the person-centered care approach and CNE can end the tyranny of the distorted medical model that pathologizes behavior and stigmatizes individuals, and instead promote new life, dignity, selfhood, meaning and self-fulfillment to those residing in a long-term care home, in turn giving a new vibrancy to the LTC as well as a new important role as an intergenerational community center and major community resource for the provision of mental health services.

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