The Impact of Culture and Faith in Dementia Care

The Impact of Culture and Faith in Dementia Care:

Psycho-Social-Spiritual Healing

Edited by

Michael Silbermann and Ann Berger

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To my beloved wife, Gisela, who has been struggling for years courageously and tenaciously with this cruel disease: Dementia, and my two daughters Anat and Ronit who served as the family's pillar throughout.

Special thanks go to Ronit, whose patience, understanding and encouragement made this publication possible.

- **Michael Silbermann**
Technion - Israel Institute of Technology, Haifa, Israel

To my spouse and children: Carl, Stephan and Rebecca. Whose love and support have made my work possible.

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FOREWORD

We are living longer and healthier. We hear that "seventy is the new fifty" and read about exceptional centenarians who run marathons or begin a new chapter of their life. The numbers broadcasted by demographers and epidemiologists confirm the feeling that we are aging better and longer than before.

These changes followed substantial improvements in living conditions, successful preventive strategies, and better care of chronic diseases. Not surprisingly, the extraordinary accomplishment of longer life is celebrated by the media, as the success of humans overcoming the entropic forces of nature. And yet, people are realizing in their everyday lives that longer life come with baggage. Over the last century, what we have gained of total life expectancy have been shared almost equally before the healthy life and the life that we live burdened by chronic disease and disability. Though, every man and woman affected by severe morbidity will tell you that the years of disability feel longer than those of healthy life.

At the population level, there is a substantial expansion of the percentage of people in the population who live with some disability. At the personal level, every single one of us has somebody ill and/or disabled in their family, and while we are often asked to help, we feel inadequate and unprepared to address this challenge. The reality is that we live with the completely unfounded certainly that both us and our close relatives will live for long time and never get ill or disabled. How to deal with the physical or cognitive disability that affect everybody at the end of life is not part of our culture, worse than pornography, a topic to be avoided and to keep away from our mind, and certainly not to be part of the formal and informal education of our children. The illusion that our parents or our friends will live many beautiful years and then.... suddenly disappear in a flash, is borne from fear that, if confronted by reality, will not know how to handle the situation. At the extreme, developing dementia is the feared nightmare for both patients and member of a surrounding family.

In most cases the response to dementia is denial. Children refuse to recognize that those "strange behaviors" are part of the pathology, which

often results in long conflicts. Shifting the attention from an interpersonal to a medical problem is another avoidance strategy. Attempting expensive and complex diagnostic procedures and treatment regiments that we know well are unlikely to improve function and independence are a frequent response. Yet, it is not true that there is nothing that we can do. Years ago, when I was a geriatrician working "from the trench", I learned that talking to patients who are becoming aware that their mental capacity is getting shaky or to families and informal caregivers who are caring for a person with dementia can be extremely effective. The trick is to understand what dementia is, what does to the brain and how it changes the relationship with others and reshuffle the rank of priority for individuals and those around him. Understanding is key, and the more dimensions are brought into the picture, and the better the network of people involved can find some sort of equilibrium. In my experience, understanding is a powerful tool, much more effective than any drug that we have identified so far. This is why the arguments conveyed by this book are so important, because they improve our understanding of the dyadic relationship between the person with dementia and the surrounding personal and architectural environment. The call to spirituality can be amazingly powerful, especially if rooted in experiences of previous life.

This book reminds me of Moyra Jones, an extraordinary therapist that I met many years ago when I was visiting the health care system for the elderly in British Columbia. Moyra had an insightful understanding of people suffering from dementia and emphasized the need of looking after the whole person; body, mind, and soul. She rejected any treatment program aimed at modifying behavior and instead encouraged caregivers and institutions to make the journey through Alzheimer's Disease as untraumatic as possible. Her program, called *Gentlecare* focused on attitudes, grooming to communication, find way to adapt the environment to the person instead of the person to the environment. It looks for ways to cherish the person whose mind is turning in some unexpected direction. This is not an easy journey but may be quite rewarding in the quality of care provided but also in the gaining of understanding on the person we care for and, perhaps more profoundly, our own mind. Perhaps even more important, the right approach cannot be universal, because the journey though cognitive decline is infused by the many cultural elements and tradition that a person have been breathing over a lifetime. Thus, the careful evaluation of how Religion, Spirituality and Culture should shape and inform the management and care of patients suffering from dementia is one of the key to success. From this perspective, the chapters referring how different religions may affect the

complex, reciprocal relationship between caregivers and people who are cognitively impaired are innovative and represents a singularity of this book, that hopefully will stimulate more research in this field.

Someone would think that the solution is to find a drug treatment that prevent or cure the different clinical forms of dementia. Of course, as a scientist and as a Geriatrician, I would not disagree. However, until then, studying the clues provided by this book are pearls to researchers, caregivers and health providers.

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PREFACE

PSYCHO-SOCIAL-SPIRITUAL HEALING: THE IMPACT OF CULTURE AND FAITH IN DEMENTIA CARE

MICHAEL SILBERMANN AND ANN BERGER

Most of the relevant books contain very little about the process of aging, which precedes the outset of dementia, and how it affects those around them. With time patients with dementia grows depressed and enfeebled, while friends and colleagues avoid them. Only when we encounter such a case within the family, we the professionals realize how unready we are to help them. But admitting this and helping the patient cope with it seems beyond us. We, therefore, are able to offer only very limited comfort or guidance.

Nowadays, people live longer all over the world, and the management of aging and its consequences is currently handled by health care professionals who, for the most part, are not prepared for it due to the lack of health care providers trained in geriatrics and palliative care and trained to treat people with dementia. When the medical profession faces a situation that can be cured or managed, it has the means to do it. But if it cannot? The fact that to date we have no adequate solution to the difficult issues associated with dementia is troubling and causes extraordinary suffering to both the patient and his caregivers.

By and large, modern medicine has succeeded in postponing the fatal moment of many diseases farther into the future. Patients with certain cancers, for example, can continue their active life quite long after their diagnosis. Their cancer becomes a chronic disease whereby their symptoms come under control. Yet their disease, while slowed, continues progressing. However, in a matter of months or a few years, the body becomes overwhelmed. That is unfortunately the case with neuro-life threatening

diseases such as dementias. This book provides the reader with a deeper understanding of the symptom burden, difficulties in caregiving, palliative care and the psycho-social-spiritual assessment and treatment of dementia patients by medical, paramedical and volunteer personnel. In doing so, the hope is this book will strengthen palliative care services by improving upon the existing ones and stimulating further research in this field.

The book offers an overview of how to deal with the various psychological-social and spiritual based therapy options for patients with dementia at different stages of their disease. It addresses the unique role of different cultures throughout the world and how this impacts psycho-social –spiritual healing. As an up-to-date text on psycho-social-spiritual and cultural care for patients with dementia, this book is an invaluable resource for professionals in most parts of the globe. All chapters in this book are written by experts in their fields and include the most current clinical and scientific information available. The book takes a multidisciplinary and global approach, providing insightful models of care and integrates clinical, psycho-social-spiritual and cultural data for practical management to enhance the efficacy of treatment while relieving suffering.

I

MEDICAL DIMENSIONS AND SYMPTOMS IN DEMENTIA

1

NON-PHARMACOLOGICAL ASPECTS OF PALLIATION IN ADVANCED-STAGE DEMENTIA PATIENTS

AANCHAL SATIJA, PHD[1]

Abstract

Dementia is a clinical syndrome caused by a heterogeneous group of disorders and characterized by a gradual, progressive impairment of cognition. People living with dementia experience a multitude of distressing symptoms during the course of their illness that affect their quality of life, such as eating problems, neuropsychiatric symptoms, pain, dyspnea, and cachexia. This chapter discusses the non-pharmacological therapies that may be provided to them for palliation of symptoms. Overall, these interventions have a potential for relieving patients' symptoms, but high-quality research is required to generate conclusive evidence. Meticulous assessment of symptomatic needs and an individualized approach to the delivery of non-pharmacological therapies can provide holistic healing for patients.

Keywords: Advanced dementia; Behavior; Cognition; Non-pharmacological; Palliative care

Introduction

Dementia affects more than 55 million people globally and is the seventh-leading cause of death in the world, with approximately 10 million new cases reported every year. Of these, more than 60% are in low- and middle-income countries (World Health Organization 2022). Dementia is usually a late-life disease that affects women more frequently than men. Because of

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the increase in the elderly population, its prevalence is estimated to double every five years and is projected to increase to nearly 153 million cases in 2050 (GBD 2019 Dementia Forecasting Collaborators 2022). Dementia is a clinical syndrome characterized by a gradual and progressive impairment of cognition across various cognitive domains such as memory, reasoning and judgement, visuospatial ability, language functions, and personality or behavioral change. The cognitive impairment is manifested as a significant decline from the previous level of functioning. It is not a usual consequence of aging process and cannot be explained by other psychiatric illnesses (McKhann et al. 2011).

Of the various forms of dementia, Alzheimer's disease is the most common, followed by other forms such as vascular dementia, frontotemporal dementia, and dementia with Lewy bodies (World Health Organization 2022). Dementia progression may be categorized according to the severity of the disease. The need for assistance with activities of daily living increases as dementia progresses. Features of advanced dementia include extreme memory deficits and inability to ambulate independently, to perform activities of daily living, maintain urinary and fecal continence, and communicate with others. Individuals with advanced dementia experience severe disability and eventually become completely dependent for their daily activities in the final year of life (Mitchell 2015).

Palliative care needs in advanced dementia

Common symptomatic needs of patients with advanced dementia are eating problems (such as oral or pharyngeal dysphagia), cachexia, urinary or respiratory infections, pain, dyspnea, and neuropsychiatric symptoms (such as psychosis, agitation, or depression). This is accompanied by other significant concerns such as advanced care planning, institutionalization, place of death, and caregiver support (Mitchell 2015; Navia and Constantine 2022). Recognizing the life-limiting nature of advanced dementia, it may be considered a terminal illness. The goals of care should be, therefore, mainly palliative rather than curative, i.e., providing comfort and improving quality of life, which can be achieved via both pharmacological and non-pharmacological interventions (Eisenmann et al. 2020). The purpose of this chapter is to provide an evidence-based overview of the use of non-pharmacological interventions (NPIs) for the symptomatic management of patients suffering from advanced dementia.

Non-pharmacological interventions for dementia

It is important to understand that the goal of NPIs is not to cure dementia but to improve or maintain cognitive function, quality of life, and overall well-being of the individual (Lodha 2019). Interestingly, NPIs or non-drug treatments clearly specify what treatments are not included but do not distinctly define what interventions are included under this heading. The umbrella term "NPI" includes numerous treatment approaches, such as behavioral or psychosocial therapies, complementary or alternative medicines, nutritional interventions, physical exercise training, etc. Apparently, it is difficult to provide a mutually exclusive classification of the plethora of interventions that are covered under NPIs (Sikkes et al. 2021).

Broadly, the NPIs for managing dementia can be classified into four categories: (1) cognitive/emotion-oriented interventions such as validation therapy, reminiscence therapy, and simulated presence therapy; (2) sensory stimulation interventions such as aromatherapy, acupuncture, music therapy, light therapy, massage or touch therapy, sensory garden intervention, transcutaneous electrical nerve stimulation, and Snoezelen multisensory stimulation; (3) behavior management techniques; and (4) other interventions such as animal-assisted interventions, movement-based interventions, and energy therapies and spiritual interventions.

Cognitive/emotion-oriented interventions

Validation therapy

Developed by Naomi Feil, validation therapy is based on the typical principle of validation, i.e., to accept and confirm one's feelings or experiences (Neal and Barton Wright 2003). The therapist empathizes with the emotions and meaning of the behavior and speech of people with dementia (Lodha 2019). This is usually attained via use of simple words spoken in an empathic and clear voice, rewording indistinct words, and responding to actions through the effective use of non-verbal and verbal communication techniques (Abraha et al. 2017). An earlier systematic review to evaluate the efficacy of validation therapy did not provide sufficient evidence for use in people with dementia (Neal and Barton Wright 2003); however, recently it has proven beneficial in reducing stress and behavioral disturbances (Berg-Weger and Stewart 2017).

Reminiscence therapy

Reminiscence therapy is based on the fact that recent memories (e.g., a meal taken a little while ago) are impaired to a greater extent than remote ones (e.g., the wedding of a close family member). Using prosthetic memory aids such as photographs, videos, audios, or other familiar items of personal importance, the patients are motivated to talk about events and experiences from their past life (Cammisuli et al. 2016). Such conversations with the patients help them feel more socially connected, overcome loneliness, and develop an empathetic bond with the caregiver. Recent meta-analyses revealed that reminiscence therapy may be effective in reducing neuropsychiatric symptoms and depression and improves cognition and quality of life in people with dementia (Thomas and Sezgin 2021; Saragih et al. 2022).

Simulated presence therapy

Audio-video recordings consisting of cherished memories or conversations from earlier life are played to the dementia patient. It aims to stimulate old memories and make the patient's environment more familiar, thereby reducing behavioral symptoms (Abraha et al. 2017; Lodha 2019). However, well-designed studies assessing the effect of simulated presence therapy for managing behavioral symptoms are lacking, and quality of evidence is poor (Abraha et al. 2020).

Sensory stimulation interventions

People with cognitive impairment are less likely to probe their surroundings for sensory inputs; hence, appropriate sensory stimulation is not achieved. The latter, in turn, may lead to behavioral and psychological disturbances (Chung et al. 2002). Sensory stimulation interventions use various approaches to stimulate either single or multiple senses to treat a range of symptoms such as agitation, anxiety, pain, stress, mood, sleep, cognition, and quality of life in the advanced stage of dementia (Strøm, Ytrehus, and Grov 2016; Prins et al. 2020).

Aromatherapy

Aromatherapy is an olfactory sensory stimulation intervention that involves the use of aromatic plant oils such as lavender, rosemary, or lemon via topical application on skin, inhalation, or ingestion (Smith and D'Amico

2020). Individual studies have demonstrated its potential for reducing agitation and challenging behavior; however, a Cochrane review did not offer conclusive evidence for the same (Ball et al. 2020).

Acupuncture

Acupuncture is an age-old Chinese intervention based on the principle of harmonizing *yin* and *yang* energies. Hair-thin needles are inserted at acupoints and then stimulated manually or through various means such as electricity, heat, or laser (Satija and Bhatnagar 2017). Studies have demonstrated its beneficial effect on cognitive performance, activities of daily living, sleep quality, nocturnal behavioral disturbances, and quality of life in dementia patients (Prins et al. 2020; Ma et al. 2021). However, compliance and tolerance of dementia patients for acupuncture may be diminished.

Music therapy

Music affects our thoughts and emotions, and hence can impact body functions in multiple ways. The use of music as an NPI is relatively new (Satija and Bhatnagar 2017). Music interventions, e.g., listening to songs or musical instruments, singing, or music with movement, activate the limbic system and subcortical circuits, thereby eliciting feelings of pleasure (Strøm, Ytrehus, and Grov 2016; Moreno-Morales et al. 2020). It has been observed that dementia patients retain their ability to respond to music even when they are not able to communicate verbally (Moreno-Morales et al. 2020). A recent systematic review and meta-analysis by Moreno-Morales et al. demonstrated that music therapy has a positive impact on cognitive function, long-term depression, and quality of life for six months after the intervention. However, continuous and progressive therapy is recommended for sustained therapeutic benefit (Moreno-Morales et al. 2020).

Light therapy

Often, general sensory output is reduced in people with dementia, and they are less exposed to environmental bright light. Additionally, dementia progression causes degenerative changes in the suprachiasmatic nucleus of the hypothalamus, which generates the circadian rhythm responsible for regulating rest-activity and sleep-wake cycles. Light therapy comprises providing additional controlled light through different modes such as light boxes, ceiling lights, a light visor worn on the head, or dawn-dusk

simulation. The additional light may stimulate neurons in the suprachiasmatic nucleus and reverse disturbances of the endogenous circadian rhythm (Forbes et al. 2014). Light therapy has been demonstrated to have a positive effect on the management of challenging behavior and on the reduction of affective symptoms and sleep disturbances (Cibeira et al. 2020; Kolberg et al. 2021; Tan et al. 2022).

Massage or touch therapy

Massage or touch therapy is a tactile sensory stimulation intervention that involves application of pressure to different body parts such as the hands, feet, or back by a trained therapist using rubbing, rolling, stroking, pressing, kneading, or other movements (Satija and Bhatnagar 2017; Margenfeld, Klocke, and Joos 2019). It stimulates the pressure receptors, thereby increasing vagal activity and decreasing cortisol levels. It promotes blood circulation and relaxation of muscles, and reduces stress and pain, and hence is widely accepted in the general population for a variety of medical conditions (Satija and Bhatnagar 2017; Field 2016; Kapoor and Orr 2017). Margenfeld et al. demonstrated evidence for the use of massage therapy in improving behavioral and psychological symptoms in individuals with dementia. The use of aroma oil during massage therapy showed better outcomes. Massage may also be used to relieve pain in people with dementia (Margenfeld, Klocke, and Joos 2019).

Sensory garden intervention or horticulture therapy

In general, both passive and active involvement with nature has a pleasant effect on human beings. Gardening is a multisensory intervention that is increasingly appreciated as a means to improve health outcomes. Gardens designed for gardening interventions come in several forms: there are "sensory gardens", which stimulate the senses through touch, smell, sight, and hearing (Gonzalez and Kirkevold 2014); "healing or therapeutic gardens", where therapeutic benefits are anticipated, such as reduction in stress and restoration of physical and mental well-being (Momtaz 2017); and "wander gardens", which provide a safe environment for patients with high elopement risk (Detweiler et al. 2008). The term "horticultural therapy" is often used interchangeably with "therapeutic horticulture" and is based on the use of plants or plant-related activities for improving the overall well-being of participants through their passive or active involvement (Gonzalez and Kirkevold 2014). The use of gardens and gardening interventions may improve affect, behavior, sleep, well-being, incidents of falls, and use of psychotropic drugs. So far, limited research has

been performed in this field, yet the results seem promising (Gonzalez and Kirkevold 2014; Murroni et al. 2021).

Transcutaneous electrical nerve stimulation

Transcutaneous electrical nerve stimulation (TENS) intervention consists of application of electric current generated by the TENS machine via electrodes attached to intact skin surface (Johnson et al. 2022). It is primarily used for pain management and seldom for neuro-psychiatric ailments such as depression, headache, and alcohol or drug abuse. Early researchers believed that TENS could retard neural degeneration and stimulate regeneration by modifying the activity of cholinergic, noradrenergic, or serotonergic neurotransmitters. It was suggested that TENS may improve physical and psychosocial functioning, verbal fluency, short- or long-term memory, and the circadian rhythm of patients (Cameron, Lonergan, and Lee 2003). TENS can decrease pain arising due to pressure and improve gait ability, balance, and muscle strength, thereby demonstrating functional enhancement in patients with dementia (Hahm, Suh, and Cho 2019). While TENS may provide short-lived beneficial effects, more research is required to reach definite conclusions for its usage in dementia patients (Cameron, Lonergan, and Lee 2003; Hahm, Suh, and Cho 2019).

Snoezelen multisensory stimulation

The term “Snoezelen” is a combination of two Dutch words *“snoezel”* and *“doezelen”*, i.e., to sniff and to doze respectively. The Snoezelen approach is a multisensory stimulation intervention that provides a balance between restful and sensorial activity (Lotan and Gold 2009). The intervention is provided in a custom-designed space known as a “Snoezelen room” by a trained facilitator. It allows controlled stimulation of auditory, visual, olfactory, and tactile senses of the participant by modalities such as calming music, light effects, aromatic oils, textured balls, fiber-optic cables, and colored water columns (Maseda et al. 2018). Studies conducted to demonstrate its effect on behavior, mood, interaction, and perceptual abilities of dementia patients have not provided conclusive evidence. Though short-term benefits can be observed, more studies need to be conducted to establish long-term therapeutic effectiveness (Smith and D’Amico 2020).

Behavior management techniques

Difficult behaviors of dementia patients are associated with caregiver strain, and the behavior of stressed caregivers may further elicit more challenging behaviors of dementia patients. Therefore, interventions targeted at managing behavior can focus on either the patient, or at times, caregiver attitudes (National Collaborating Centre for Mental Health (UK) 2007). These include a host of interventions such as cognitive-behavioral therapy, communication training, functional analysis of specific behaviors, habit training, token economies, and personalized behavioral reinforcement approaches (O'Neil et al. 2011). Though earlier systematic reviews found limited evidence for the use of behavior management techniques (O'Neil et al. 2011; Moniz Cook et al. 2012), recent reviews of systematic reviews depicted their effectiveness and suggested using functional-analysis based interventions as the first line of NPIs for managing behavioral symptoms in dementia patients (Abraha et al. 2017; Dyer et al. 2018).

Other interventions

Animal-assisted interventions

Animal-assisted interventions involve human-animal teams for the therapeutic benefit of humans. They include both informal human-animal interaction and well-designed interventions. The International Association of Human-Animal Interaction Organisations (IAHAIO) has defined animal-assisted therapy as "goal oriented, planned and structured therapeutic intervention directed and/or delivered by health, education or human service professionals, including e.g., psychologists and social workers" with a focus "on enhancing physical, cognitive, behavioral and/or socio-emotional functioning of the particular human recipient either in the group or individual setting" (IAHAIO 2018). These interventions help the recipient develop a bond and companionship, thereby feeling socially integrated, which decreases feelings of boredom, loneliness, or isolation (Lai et al. 2019). While dogs are the most common intervention animal studied, any animal can serve as the intervention such as cats, horses, or fish (Yakimicki et al. 2019). The picture below demonstrates a cow-assisted activity, where a 90-year-old woman living with dementia is feeding the cows at the *"gowshala"* or cowshed (Fig. 1).

Fig 1: A 90-year-old woman living with dementia is feeding the cows at a *gowshala* during the last days of her life

Interactive and therapeutic pet-robot interventions are being used as an alternative to animal-assisted interventions (Park et al. 2020). The literature provides significant evidence for the effectiveness of animal-assisted interventions in reducing behavioral and psychological symptoms—especially depression—in dementia patients. Significant improvements were not observed for cognitive function, agitation, quality of life, and activities of daily living (Park et al. 2020; Chen et al. 2022). However, strict supervision is necessary to guard against possible infection risk and animal aggression (Lai et al. 2019).

Movement-based interventions

People with severe dementia are weak and frail, for the most part, yet display agitated and wandering behaviors. They can be trained and motivated to "move" to obtain improvement in daily functioning. Movement-based interventions include any interventions that involve bodily movements. These may be simple, interactive physical activities such as passing a ball or clapping hands, or structured and assisted activities such as walking, dance, aerobic exercises, yoga, or tai chi (Holliman, Orgassa, and Forney 2001; Barreto et al. 2015; Ojagbemi and Akin-Ojagbemi 2019). The preventive and therapeutic benefits of physical activities and exercise are well established for both healthy and diseased populations. Exercise considerably affects vascular and neuronal health by maintaining cerebral perfusion, promoting neurogenesis, and regulating

neuroplasticity (Forbes et al. 2015). Many studies have investigated the effects of exercise or physical activity on outcomes such as activities of daily living, cognitive function, neuropsychiatric symptoms, and quality of life in dementia patients. Significant improvements have been observed in the ability to perform activities of daily living, cognition, and depression (Forbes et al. 2015; Barreto et al. 2015; Jia et al. 2019).

Energy therapies and spiritual interventions

Various cultures across the globe believe that the human body is made of subtle energy, also known as ch'i, qi, prana, or spirit. Energy or biofield field therapy involves the use of specific techniques by a skilled practitioner to modulate this subtle energy in order to promote intrapersonal and interpersonal healing for the self and other individuals. Such therapies impart physical, emotional, mental, and spiritual balance by cleansing the energy centers of the body, thereby providing holistic healing. They includes practices such as reiki, qigong, healing or therapeutic touch, johrei, and pranic healing (Satija and Bhatnagar 2017; Jain et al. 2015). The limited understanding of the mechanism through which these therapies operate restricts their use in clinical practice (Jain et al. 2015; Henneghan and Schnyer 2015). A review by Henneghan et al. demonstrated potential benefits of energy therapies in providing symptomatic relief and improving quality of life during end-of-life care (Henneghan and Schnyer 2015). It included three studies on people with dementia: two randomized control trials of the use of therapeutic touch (Woods, Beck, and Sinha 2009; Hawranik, Johnston, and Deatrich 2008) and a report on case studies (Meland 2009) of the use of reiki in dementia patients. The studies found lower levels of restlessness, distress, and anxiety in the study group.

Both cognitively intact and cognitively impaired individuals have spiritual needs, which if unmet during serious illness such as advanced dementia can lead to negative outcomes. The spiritual needs of dementia patients are not adequately understood. Only after understanding their spiritual needs, specific spiritual care interventions can be designed for this population (Camacho-Montaño et al. 2021; Palmer et al. 2022).

Only a few studies have been conducted on the use of energy therapies and spiritual interventions for dementia patients. Advanced dementia patients are unable to express their unmet needs and are completely dependent on the caregiver. In such a scenario, energy healing provided by other therapists may have favorable outcomes. However, research in this field is

still nascent and the issue needs to be understood, explored, designed, and planned.

The Way Ahead

This chapter has provided an overview of the commonly used NPIs for symptomatic management in dementia patients. Along with the management of behavioral symptoms, NPIs have also been used for managing pain in dementia patients, though the evidence is not conclusive (Liao et al. 2021; Bao and Landers 2022). Multimodal NPIs may have a better effect on the symptomatic profile of patients, and hence are strongly recommended (Sharew 2022). NPIs definitely have a promising potential in reducing symptom burden in dementia patients. They usually have no major adverse effects and are well tolerated by the patients, and therefore healthcare professionals are encouraged to recommend NPIs in their routine practice. However, "one size does not fit all". Consequently, there is a need for a personalized approach, which in itself is challenging while conducting large-scale studies (National Collaborating Centre for Mental Health (UK) 2007). The DICE approach—Describe the behavior, Investigate the underlying causes, Create intervention, and then Evaluate the intervention—may be used by healthcare professionals to systematically identify and manage the distressing symptoms (Kales et al. 2017).

A plethora of literature, including case reports, primary studies, systematic reviews, reviews of systematic reviews, and meta-analyses, is available to evaluate the effectiveness of NPIs in dementia patients. Because of the heterogeneity of the studies in terms of methodology, intervention, and target population (i.e., patient, caregiver, or the patient-caregiver dyad), it is difficult to determine first-line NPIs for people living with advanced dementia. There is a dire need for a global consensus document that would provide guidance for the classification and implementation of NPIs and for conducting methodologically sound research to generate conclusive evidence for the use of NPIs in people with dementia. Additionally, the prevalence of dementia might increase in the post-pandemic era because of the long-term impact of the SARS-CoV-2 infection on cognitive function (Pyne and Brickman 2021; Liu et al. 2022). Therefore, healthcare workers, policymakers, and dementia care experts across the globe must come together to strategically plan the systematic implementation of NPIs.

In conclusion, the promising potential of NPIs must be acknowledged and utilized. A careful assessment of the unmet palliative care needs of dementia

patients will help clinicians identify relevant interventions to reduce suffering and improve quality of life during the advanced stage of this illness.

References

Abraha, Iosief, Joseph M. Rimland, Isabel Lozano-Montoya, Giuseppina Dell'Aquila, Manuel Vélez-Díaz-Pallarés, Fabiana M. Trotta, Alfonso J. Cruz-Jentoft, and Antonio Cherubini. 2020. "Simulated Presence Therapy for Dementia." *The Cochrane Database of Systematic Reviews* 4 (4): CD011882. https://doi.org/10.1002/14651858.CD011882.pub3.

Abraha, Iosief, Joseph M. Rimland, Fabiana Mirella Trotta, Giuseppina Dell'Aquila, Alfonso Cruz-Jentoft, Mirko Petrovic, Adalsteinn Gudmundsson, et al. 2017. "Systematic Review of Systematic Reviews of Non-Pharmacological Interventions to Treat Behavioural Disturbances in Older Patients with Dementia. The SENATOR-OnTop Series." *BMJ Open* 7 (3): e012759. https://doi.org/10.1136/bmjopen-2016-012759.

Ball, Emily L, Bethan Owen-Booth, Amy Gray, Susan D Shenkin, Jonathan Hewitt, and Jenny McCleery. 2020. "Aromatherapy for Dementia." *The Cochrane Database of Systematic Reviews* 2020 (8): CD003150. https://doi.org/10.1002/14651858.CD003150.pub3.

Bao, Zhuming, and Margaret Landers. 2022. "Non-Pharmacological Interventions for Pain Management in Patients with Dementia: A Mixed-Methods Systematic Review." *Journal of Clinical Nursing* 31 (7–8): 1030–40. https://doi.org/10.1111/jocn.15963.

Barreto, Philipe de Souto, Laurent Demougeot, Fabien Pillard, Maryse Lapeyre-Mestre, and Yves Rolland. 2015. "Exercise Training for Managing Behavioral and Psychological Symptoms in People with Dementia: A Systematic Review and Meta-Analysis." *Ageing Research Reviews* 24 (Pt B): 274–85. https://doi.org/10.1016/j.arr.2015.09.001.

Berg-Weger, Marla, and Daniel B. Stewart. 2017. "Non-Pharmacologic Interventions for Persons with Dementia." *Missouri Medicine* 114 (2): 116–19.

Camacho-Montaño, Lucía Rocío, Jorge Pérez-Corrales, Marta Pérez-de-Heredia-Torres, Ana María Martin-Pérez, Javier Güeita-Rodríguez, Juan Francisco Velarde-García, and Domingo Palacios-Ceña. 2021. "Spiritual Care in Advanced Dementia from the Perspective of Health Providers: A Qualitative Systematic Review." *Occupational Therapy International* 2021: 9998480. https://doi.org/10.1155/2021/9998480.

Cameron, M., E. Lonergan, and H. Lee. 2003. “Transcutaneous Electrical Nerve Stimulation (TENS) for Dementia.” *The Cochrane Database of Systematic Reviews* 2003 (3): CD004032. https://doi.org/10.1002/14651858.CD004032.

Cammisuli, D. M., S. Danti, F. Bosinelli, and G. Cipriani. 2016. “Non-Pharmacological Interventions for People with Alzheimer’s Disease: A Critical Review of the Scientific Literature from the Last Ten Years.” *European Geriatric Medicine* 7 (1): 57–64. https://doi.org/10.1016/j.eurger.2016.01.002.

Chen, Hongyu, Yuanyuan Wang, Minyi Zhang, Ning Wang, Yao Li, and Yan Liu. 2022. “Effects of Animal-Assisted Therapy on Patients with Dementia: A Systematic Review and Meta-Analysis of Randomized Controlled Trials.” *Psychiatry Research* 314: 114619. https://doi.org/10.1016/j.psychres.2022.114619.

Chung, J. C., C. K. Lai, P. M. Chung, and H. P. French. 2002. “Snoezelen for Dementia.” *The Cochrane Database of Systematic Reviews* 2002 (4): CD003152. https://doi.org/10.1002/14651858.CD003152.

Cibeira, Nuria, Ana Maseda, Laura Lorenzo-López, José L. Rodríguez-Villamil, Rocío López-López, and José C. Millán-Calenti. 2020. “Application of Light Therapy in Older Adults with Cognitive Impairment: A Systematic Review.” *Geriatric Nursing (New York, N.Y.)* 41 (6): 970–83. https://doi.org/10.1016/j.gerinurse.2020.07.005.

Detweiler, Mark B., Pamela F. Murphy, Laura C. Myers, and Kye Y. Kim. 2008. “Does a Wander Garden Influence Inappropriate Behaviors in Dementia Residents?” *American Journal of Alzheimer’s Disease and Other Dementias* 23 (1): 31–45. https://doi.org/10.1177/1533317507309799.

Dyer, Suzanne M., Stephanie L. Harrison, Kate Laver, Craig Whitehead, and Maria Crotty. 2018. “An Overview of Systematic Reviews of Pharmacological and Non-Pharmacological Interventions for the Treatment of Behavioral and Psychological Symptoms of Dementia.” *International Psychogeriatrics* 30 (3): 295–309. https://doi.org/10.1017/S1041610217002344.

Eisenmann, Yvonne, Heidrun Golla, Holger Schmidt, Raymond Voltz, and Klaus Maria Perrar. 2020. “Palliative Care in Advanced Dementia.” *Frontiers in Psychiatry* 11: 699. https://doi.org/10.3389/fpsyt.2020.00699.

Field, Tiffany. 2016. “Massage Therapy Research Review.” *Complementary Therapies in Clinical Practice* 24 (August): 19–31. https://doi.org/10.1016/j.ctcp.2016.04.005.