Dementia Caregiving East and West

Dementia Caregiving East and West:

Issues of Communication

Edited by

Boyd H. Davis and Margaret Maclagan

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To all those living with dementia
and those who love and care for them

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CHAPTER 1

INTRODUCTION: TALKING ACROSS THE WORLD

BOYD H. DAVIS AND MARGARET MACLAGAN

Work with dementia is inherently multilingual, interdisciplinary, and cross-cultural. This collection illustrates the value and the necessity of sharing caregiver experiences and materials in multiple media from dementia care researchers in each hemisphere. Accordingly, it includes studies by dementia care researchers from Japan, New Zealand, Taiwan, and different regions of Germany and of the United States.

Dementia occurs in each country and each culture, although it may be acknowledged differently and may or may not be stigmatized or hidden. Information about ways of looking at dementia caregiving and how to interact with one or another dementia is not always available or convenient. Different countries around the world have different systems and policies governing aging, healthcare, and caregiving, as do the different cultures within them.

Estimates by major health organizations prophesy a growing number of people living with dementia, culminating with the current prediction that it will have almost doubled by 2030 (see WHO Fact-Sheets, 2021) and tripled by 2050, particularly since more people are aging than babies are arriving. Daily, the need for caregiving for dementia grows more crucial as highlighted in the projected world prevalence of dementia in *Lancet* (Schwarzinger and Dufouil, 2022) or the forecast by the World Health Organization: "WHO and the World Bank estimate a need by 2030 for 40 million new health and social care jobs globally and about 18 million additional health workers, primarily in low-resource settings" (WHO, 2017: 2). And for 2022, after two years of a pandemic, they often aren't available – check the header in the Kaiser Health Newsletter for the USA: *Pandemic-Fueled Shortages of Home Health Workers Strand Patients Without Necessary Care* (Graham, 2022). It may not be surprising that "Older

Americans were sicker and faced more financial barriers to health care than counterparts in other countries" (Osborn et al., 2017).

In the USA and elsewhere, healthcare support staff such as daycare workers are also poorly trained: Sengupta reports that US aides in residential and daycare settings received very brief training in caregiving techniques, with daycare aides receiving much less training than those working in residential care (Sengupta, 2021). And daycare workers are far outnumbered in the US by Home Care or Residential Workers who make up, according to PHI (Public Health institute) 53% of direct care workers (PHI 2021: 2). PHI adds "Residential care aides are primarily women [81 percent], people of color, and/or immigrants" (2021: 13). And about im/migrants, Zallman et al. (2019: 919) noted in 2019 that 13 million older and disabled persons could live at home because they were cared for by direct care workers, nearly a third of these workers were im/migrants, 30% of whom had little or no English.

Similarly, by 2012, foreign workers outnumbered local Taiwanese paid care workers by 3 to 1 (Chen, 2016) and by 2015 Taiwan became the most common destination for migrant nurses from Indonesia (Nursalam et al., 2020). Liang (2021: 1) summarizes the situation: families employ live-in migrant care workers because in a cultural context of filial piety, both public services and governmental support are limited.

Once again, language is often a barrier, just as it is in the UK, Germany, Italy and Poland (Rogalewski and Florek, 2020). We personally have turned to graphic medicine. Whether as a graphic novel, a manga, anime, or comic, it is increasingly popular in multiple formats. In addition to paper-bound print, these can be available in video, animation, virtual reality and possibly even augmented reality, all of which can be "read" on cellphones, tablets, mini-tablets or computers. These are all *multimodal*. Reading any of these requires the ability to interpret symbols, decipher overlapping text and images, understand cultural references and appreciate differences in storytelling between countries.

Anime/manga/comics represent "a conversation along with the hidden, unspoken meaning behind the words…what we say is not always what we mean" (Green and Myers, 2010: 575). They illustrate graphic medicine exercises that are currently being used in many medical schools. The Library Guide at the University of Southern California identifies a number of reasons graphic medicine can be useful (https://libguides.usc.edu/graphicmedicine). Graphic medicine

- reduces stigma around illness
- creates a safe space to express criticism of healthcare

- allows for health literacy and illustrated informed consent
- helps build community and a sense of connection
- provides a means of effective patient outreach and communication
- reflects or changes cultural perceptions of medicine and healthcare products

As for which kind of graphic medicine, why not let the dementia caregiver choose. We have just piloted a small multiracial photograph-based paper "comic" in American English with 17 caregiver families. They endorsed it, adding that they often learned new things about care and found it reassuring. It has just been translated into Spanish and the photos expanded for a fotonovela. Both are being expanded in terms of content as the US English speaking families requested more "stories" and additional formats beyond paper. Taiwanese college students in Industrial Design have created storyboards for 15 Chinese dementia caregiving "stories" using graphic design. Graphic design supports people in changing behaviors and expanding skills. We have piloted these in Taiwan and are currently exploring responses from Asian Americans. A pilot set of Taiwanese nurses felt they were culturally congruent. In New Zealand, the original comic is having its stories as well as its photos expanded, and the scenarios moved into New Zealand ways of talking. We're about to do a pilot test with Filipino nurses for our Tagalog set, and are eagerly anticipating three other sets in Indonesian, Vietnamese, and Haitian Creole.

And there you have it, don't you? More and more old people across the world, with probably one out of seven developing dementia, and there are fewer and fewer available people who know how to provide care as it becomes needed. At the same time, dementia care researchers in every country are identifying key issues and questions, working across languages and cultures and disciplines, the arts, sciences, medicine, and technology. We were limited by space and could only ask colleagues from five countries, representing Eastern and Western approaches, to report on what they are finding, using different approaches and techniques.

Section 1

Talking directly to you, the reader, and insisting that you look at these issues is focused on the West, and deals with English-language situations.

Meredith Troutman-Jordan develops a research review on *Successful aging and dementia: Finding meaning and purpose for caregivers and care recipients* in order to counter popular belief that "successful" aging means that the older person must keep near perfect health. She argues that aging adults with mild cognitive impairment or dementia, when encouraged to adjust to the best of their capacity, are indeed able to age successfully. She notes that in the USA, roughly 80% of care is given by family caregivers who could learn to work from such a perspective: developing a potentially progressive and debilitative condition does not mean one is a failure at successful aging as long as the person is being supported to the best of their capacity.

Jacqueline Guendouzi and Jamie Magee collect interview evidence from South-East Louisiana to voice the question asked by social work students to 237 people living there: *Who should care for people living with dementia.* The costs of day care or long-term care and whether one lives in an area with easy access to care facilities can often block the route to resources. Regional services are neither integrated nor coordinated, and few citizens have comprehensive long-term health care insurance. Clips from Guendouzi and Magee's interviews illustrate concerns about government and healthcare support.

Dena Shenk, Christin Wolf and Andrea Freidus illustrate care worker concern with their *Caregiving for people living with dementia in a time of COVID: Voices of caregiving staff in the USA.* Selecting 15 long term residential care communities in North Carolina, they interviewed 76 administrators and hands-on caregiving staff in 2020. Reading through the extensive selections from those interviews and the authors' contextualizing interpretations shows just how obvious it is that the US system of professional caregiving has been "fractured" by the global pandemic:

> The rapid changes in understanding about the disease, policies and guidelines, have been difficult for caregivers, and caring for people with cognitive impairment has offered additional challenges in regard to helping them understand the use of masks, the need to isolate, changes in visitation and use of technology. (See p. 45.)

Section 2

Asking across the world: how do we work from two languages simultaneously? The authors of these articles use Spanish, English, German, and Japanese to focus on three different situations: bilingual interaction between a researcher and people living with dementia, two parallel online dementia caregiver forums in two different languages, and what can/might happen to perceptions of the language of people living with dementia when one backs away from the inviolability of research models keyed to perceived characteristics in one specific language in the face of other languages whose characteristics differ.

Carolin Schneider focuses on language choices by bilinguals in *"¿Te hablo en ingles?" Code choice negotiation in caregiving with bilinguals who have Alzheimer's disease.* Her example is a set of three conversations between bilingual (Spanish-English) persons with dementia, who live in Florida, and their caregivers and the author, who is fluent in both of their languages (as well as her first language, German). The issue is which language will the persons living with dementia want to use with the author as a newcomer to their community, and under which circumstances? In addition, since everyone wishes to be polite as well as communicative, the study illuminates how the persons negotiate language (or code) choice, turn by turn.

Sonya Kleinke and Birte Bös use interactional sociolinguistics and pragmatics studies to ground a mixed-methods and cross-cultural analysis of *Dementia through the lens of family care partners: Carework-discourses in German and British public online discussions.* Selecting specific and representative sections from German and British caregiver forums, each sponsored by their country's Alzheimer's Association, they identify German and UK frames out of which perspectives the care partners conduct peer-to-peer online discussions. Of especial interest is how participants in each forum present their stances on institutions in general, institutional care as opposed to family-based care, and their own positioning regarding dementia and dementia care.

Yoshiko Matsumoto emphasizes interactional and interpersonal communication among persons living with "compromised cognitive conditions" in *Shifting to interaction in dementia language research: Drawing on usage in Japanese.* Not every model, and not every theory, can be restricted to having been developed in and for English. Here, Matsumoto shows how looking at perspectives about communicative interactions that are not exclusively based on cognition – as illustrated in several kinds of interpersonal Japanese interactions – allows us to better comprehend the importance of context for identifying the communicative competence that remains with persons living with cognitive impairment.

Section 3

From hands-on talk and arts to hands-on technology: Interventions from the East. In this section we move from mainly Western languages to the East and consider care work approaches that range from relatively low-tech art therapy to high-tech digital media applications.

Shumin Lin and Chia-Hsun Hsueh illustrate the immediate benefits of *Task-plus communication: Beyond the binary of task talk versus social talk in dementia care.* Task-talk is used by a caregiver to get the person living with dementia to **do** something: brush their teeth, sit up… and similar actions. It is usually a very brief utterance with the force of a command (though one hopes it is said kindly). It doesn't expect the person living with dementia to say anything in response. And if you ask the caregiver in a long-term wing, or a memory care or daycare why they do not proffer relational or social interaction, they will respond that their custodial work takes all their time. And that kind of work must be done. However, incorporating what Lin and Hsueh call a "task-plus" orientation, the care worker can change the framework of the interaction from custodial task to one of social interaction or even therapy. An excerpt from her qualitative analyses plus an illustration walk the reader through how to change a short activity task into a real interaction.

Naiwen Hsu is one of the few professional art therapists in Taiwan. In this discussion she identifies the multiple layers that underlie *Using elements of nostalgia in art therapy for older people living with dementia.* For one layer, the therapist needs to be able to pull from the vocabulary and interests of a period before the therapist was born. In a fascinating figure that Hsu calls a retrospective chronology chart, she shows how to contextualize key moments in an older woman's life, beginning with her birth, juxtaposed with key events in Taiwan's national, regional, and local sociocultural history which would have affected her. Choices of media, themes and objects for drawing or painting can reflect a part of her life story that she can share with others and allow her to revisit images and music.

Ching-Yi Kuo and Shu-Chuen Chen are also interested in using a form of artistic expression for helping older people reminisce in their *Visualization of life stories through sandtray work with older adults.* Here, they adapt a qualitative Western model, typically used with children, to Taiwanese older adults who place miniature figures and objects in a tray filled with sand, to identify key components in their life story. Kuo and Chen analyze sandtray compositions by cognitively impaired and unimpaired persons, to demonstrate that the technique can be used across cultures as well as genders, ages and cognitive status.

Shu-Chuan Chen hopes to alleviate depression among people living with dementia and encourage social interaction with the support of technology in the form of social companion robots. In her *Attachment relationships with social robots and older adults with dementia in Long Term Care,* a mixed methods study, she first reviews earlier work with PARO, a social robot who is a cuddly seal (see Shibata et al., 2021). In the present study, she looks at therapy with PARO for adults in long term care who have two attachment styles: attachment anxiety and attachment avoidance. She finds significant differences in their depression scores when compared to controls. She hopes her findings that attachment style is a key factor in interpersonal interaction and engagement with companion robots will improve robot design as well as therapy implementation.

Shu-Chiao Tsai and Ya-Jun Zheng combine technology, art and reminiscence in their *Introducing an interactive audio-visual digital system for initial engagement with older adults.* In this mixed methods study, they report on the first trial of their prototype of an interactive audio-visual digital system. They elicited participants' perceptions from trying the interactive audio-visual digital system through a questionnaire survey of 49 persons who were over fifty years old. The prototype allows photos, music, videos and pictures to be incorporated in the system. Findings included high motivation among participants who were then encouraged to customize such a system for themselves.

The studies in section 2 were conducted in Spanish, German and Japanese as well as English. Those in the last section were conducted in Mandarin, and their authors saw to their translations into English. Should you wish to discuss the studies as developed in languages other than English, we encourage you to write to the individual writers, using the list of affiliations. We are all online with each other, and we welcome you to a wider world of dementia caregiving research.

References

Chen, Chen-Fen. (2016). Insiders and outsiders: Policy and care workers in Taiwan's long-term care system. *Ageing & Society,* 36(10), 2090–2116. doi: https://doi.org/10.1017/S0144686X15001245

Graham, Judith. (2022). Pandemic-fueled shortages of Home Health Workers strand patients without necessary care. *Kaiser Health News,* February 3, 2022.
https://khn.org/news/article/pandemic-fueled-home-health-care-shortages-strand-patients/

Green, Michael and Kimberly Myers. (2010). Graphic medicine: use of comics in medical education and patient care. *BMJ Clinical Research,* 340, c863. doi: https://doi.org/10.1136/bmj.c863

Liang, Li-Fang. (2021). Managing work and care: Does employing a live-in migrant care worker fill the gap? The example of Taiwan. *Social Policy & Society,* 1-13. doi:
https://doi.org/10.1017/S1474746421000233

Nursalam, Nursalam, Ching-Min Chen, Ferry Efendi, Eka M. M. Has, Laily Hidayati, and Setho Hadisuyatmana. (2020). The lived experiences of Indonesian nurses who worked as care workers in Taiwan. *Journal of Nursing Research* 28(2), e 78, 1-7.
doi.org/10.1097/jnr.0000000000000355

Osborn, Robin, Michelle M. Doty, Donald Moulds, Dana O. Samak, and Arnav Shah. (2017). Older Americans were sicker and faced more financial barriers to health care than counterparts in other countries. *Health Affairs,* 36(12). https://doi.org/10.1377/hlthaff.2017.1048

PHI [Public Health Institute] (2021). *Direct care workers in the United States.*
https://phinational.org/resource/direct-care-workers-in-the-united-states-key-facts/

Rogalewski, Adam and Karol Florek. (2020). *The future of live-in care work in Europe: Report on the EESC country visits to the United Kingdom, Germany, Italy and Poland following up on the EESC opinion on "The rights of live-in care workers".* European Economic and Social committee. Brussels, Belgium. doi:10.2864/67086

Schwarzinger, Michaël and Carole Dufouil. (2022). Forecasting the prevalence of dementia. *The Lancet Public Health*, 7(2), e94–e95.
https://doi.org/10.1016/S2468-2667(21)00277-2

Sengupta, M. and F. Ejaz. (2021). *Personal Care Aides in Residential Care Communities and Adult Day Services Centers: Differences in Training Hours, Benefits, and Caregiving Roles.* Poster, GSA 2021 Annual

Scientific Meeting, Portland, OR. [cf *Innovation in Aging*, 01 Jan 2021, 5(Suppl 1):855-855; cf https://europepmc.org/article/pmc/pmc8681755]

Shibata, Takanori, Lillian Hung, Sandra Petersen, Kate Darling, Kaoru Inoue, Katharine Martyn, Yoko Hori, Geoffrey Lane, Davis Park, Ruth Mizoguchi, Chihiro Takano, Sarah Harper, Geroge W. Leeson and Joseph F. Coughlin. (2021). PARO as a biofeedback medical device for mental health in the COVID-19 era. *Sustainability*, 13(20), 11502; https://doi.org/10.3390/su132011502

Zallman, Leah, Karen Finegan, David Himmelstein, Sharon Touw, and Steffie Woolhandler. (2019). Care for America's elderly and disabled people relies on immigrant labor. *Health Affairs*, 38(6), 919-926, doi: 10.1377/hlthaff.2018.05514

WHO (2017). *Global action plan on the public health response to dementia 2017 – 2025*. Geneva: World Health Organization; 2017. Licence: CC BY-NC-SA 3.0 IGO.
https://apps.who.int › iris › 9789241513487-eng

WHO (2021). *Dementia fact sheet*.
https://www.who.int/news-room/fact-sheets/detail/dementia

SECTION 1:

TALKING DIRECTLY TO YOU, THE READER, AND INSISTING THAT YOU LOOK AT THESE ISSUES

CHAPTER 2

SUCCESSFUL AGING AND DEMENTIA: FINDING MEANING AND PURPOSE FOR CAREGIVERS AND CARE-RECIPIENTS

MEREDITH TROUTMAN-JORDAN

Successful Aging

Successful aging has been defined in a host of ways, with varying emphases on absence of disease and disability (Rowe and Kahn, 1998), spirituality (Crowther et al., 2002), well-being, social connectedness and adaptation (Baltes and Baltes, 1990; Jeste, Depp and Vahia, 2010). Rowe and Kahn's sentinel work could be seen as detrimental in that it implies older adults have failed at aging if they experience any disease or disability, or less than high cognitive/physical function: this health profile is unrealistic, and excludes a majority of older adults.

Recent authors have proposed more holistic and inclusive conceptualizations of successful aging. Key attributes of successful aging include active engagement with life, positive adaptation, life satisfaction, independent living, gerotranscendence, health, personal growth, happiness/contentment, independence, relationships, appreciation/valuation of life, and longevity (Jeste et al. 2010; Knight and Ricciardelli, 2003; Tornstam, 2005). Definitions inclusive of these features suggest that successful aging may be possible for more older adults than those according to the criteria initially set forth by Rowe and Kahn. Emphasis on adaptation is of particular relevance and has practical implications for older adults and their support networks. If we embrace a broader, more holistic, personalized approach to successful aging, with emphasis on *adaptation to the best of one's ability*, then it is possible that older adults who develop mild cognitive impairment (MCI) or dementia could be supported to adjust to the best of their capacity and age successfully.

Approaching successful aging from a perspective emphasizing acclimation to the best of one's capacity, use of creative problem-solving, and care strategies (Troutman et al., 2011) creates opportunities for caregivers and care recipients to cultivate meaningful partnerships with potential for promoting successful aging in both members of the care dyad. Family caregivers are vital to the health promotion, safety, and well-being of many older adults; about 80% of help in the home is provided by family caregivers (Kaplan and Berkman, 2021).

Caregiving can cause various negative effects, including stress, health problems, loneliness, isolation, fatigue, and feeling frustrated or overwhelmed, potentially leading to caregiver burnout (Kaplan and Berkman, 2021). Care dyads in which the care recipient has MCI or dementia experience additional challenges. Anger, anxiety, impulsivity, and inappropriate behaviors add stress to an already tough job for caregivers of persons living with dementia (PLWD) (Daily Caring, 2021). Experiencing mild cognitive impairment (MCI) can also be frustrating and challenging for both members of care dyads. Multiple domains of health-related quality of life are affected in individuals caring for someone with MCI (Carlozzi et al., 2018).

Not everyone with MCI develops dementia, and like dementia, MCI is not an illness, but rather a cluster of symptoms that describes changes in how one thinks or processes information (Family Caregiver Alliance, 2020). Living with uncertainty is another dilemma for care dyads in which dementia *or* MCI is present. Both caregiver and care recipient could benefit from a holistic approach tailored to the recipient's symptomology and the nature of their relationship with each other, with the intent of fostering a meaningful relationship and late life experience for both. However, most intervention programs targeting care dyads involving PLWD have exclusively focused on the caregiver *or* the recipient (Czaja, Lowenstein and Weingast, 2021).

Care Dyad Needs and Successful Aging Strategies

Treatment approaches directed at PLWD include pharmacological treatments, cognitive training, and exercise (Czaja, Lowenstein and Weingast, 2021). However, some therapeutics can benefit both members of care dyads. Support and promotion of brain health is vital for everyone. Therefore, knowledge of steps for promoting one's brain health and the ability to recognize various symptoms that could indicate differing conditions of dementia, delirium, and depression (and signal need for further intervention) are important for caregivers and care-recipients.

Prior research on older adults with normal cognition suggested community-dwelling Black and White older adults had moderate to high knowledge about the nature, consequences and strategies for promoting brain health (Park et al., 2014; Troutman-Jordan and Deem, 2014). However, Ayalon and Areán (2004) found that certain ethnic groups lack adequate information about Alzheimer's Dementia. Knowledge deficits signal the need for dialogue with healthcare providers and care dyads.

Risk factors for cognitive decline are important for caregivers and PLWD to know about. Vanoh et al. (2019) examined gender and MCI related to successful and usual aging. Poor fitness levels increased the risk of cognitive decline in older men and women. High blood glucose was a significant risk factor of cognitive decline among older men, and lower education level, hyperlipidemia, and poor involvement in mentally-demanding tasks were associated with poor cognitive functioning in men. In older women, low fiber intake was associated with cognitive decline, while successful aging in women was related to a good fitness level, adequate fiber intake, optimal control of blood cholesterol levels, no disabilities, and frequent practice of calorie restriction.

These findings are consistent with Vanoh, et al.'s (2019) earlier findings that usual agers are at higher risk of being diagnosed with chronic diseases, of having minimal functional limitations, slight memory impairment and no dementia. Lack of knowledge about Alzheimer's Disease and brain health, and established risk factors for cognitive decline are compelling reasons for fostering brain health in care dyads. Caregivers need to preserve their own mental and physical health for what is an indeterminate and possibly very long-term caregiving relationship. Safety, physical well-being, and a sense of purpose are vital for both the PLWD and the caregiver as they face the uncertainty of a devastating disease.

It is never too late to strive to maintain as optimal a cognition as possible for PLWD. Providing clear, specific information about how to encourage brain health is important. Education, coaching and counseling on physical activity/exercise strategies, healthy nutrition and metabolic health (suitable levels of blood sugar, triglycerides, high-density lipoprotein cholesterol, blood pressure, and waist circumference) (Araújo Cai and Stevens, 2019) are crucial.

Specific Needs, Benefits, and Opportunities

Both members of care dyads have health promotion, social support and safety needs. Nonpharmacological interventions are valuable medication alternatives for preserving cognitive functioning, managing cognitive and behavioral symptoms, and improving the quality of life for care dyads (Carbone et al., 2021; McDermott et al., 2019). Nonpharmacological interventions include cognitive stimulation-based interventions, which involve engaging PLWD in a series of activities and discussions, usually in groups, to improve their cognitive and sociorelational functioning and well-being (McDermott et al., 2019).

"Brain health refers to how well one's brain functions across several areas, including cognitive health and the ability to clearly think, learn, and remember" (National Institute on Aging, 2020). Cognitive stimulation is a useful practice for promoting brain health. Cognitive stimulation comprises a broad range of activities that stimulate thinking and memory. Activities may include discussion of past and present events and topics of interest, word games, puzzles, music and practical activities such as baking or gardening (DementiaUK, 2021). For the PLWD, cognitive training (a form of treatment that focuses on guided practice on tasks that target specific cognitive functions, such as memory, attention, or problem-solving) (Bahar-Fuchs et al. 2019) may yield some benefits in overall cognition, as well as in more specific cognitive abilities such as verbal fluency, and these improvements may last for at least a few months. Caregivers experiencing chronic stress may be at greater risk for cognitive decline, including loss in short-term memory, attention and verbal IQ (Vitaliano et al., 2005) making promotion of cognitive health, in addition to stress reduction, important for caregivers.

Bahar-Fuchs et al. (2019) reviewed 33 studies of cognitive training and found moderate-quality evidence showing a small to moderate effect of cognitive training on global cognition. No adverse outcomes were found. They concluded that, for people with mild to moderate dementia, standardized cognitive training may lead to small improvements in overall cognition. Similarly, cognitive stimulation therapy (a series of mental exercises that stimulate the brain) offers healthy older adults higher levels of mental activity, reducing the risk of developing dementia later in life, and thus building cognitive resilience (Fit Minds, 2016). Cognitive stimulation therapy has also shown benefits for PLWD, including improved cognition, quality of life (Aguirre et al., 2013), and cognitive function (Young et al., 2019).

Everyday activities to stimulate and optimize brain health and cognition include working puzzles (Fissler et al., 2018), playing cards (Schultz et al., 2015), building vocabulary (Anderson and Ruan, 2016), dancing (CDC, 2018), sensory stimulation to engage all five senses (such as picking fruits or vegetables from a garden while focusing on smelling, touching, tasting, seeing, and hearing all at the same time) (Quak, London, and Talsma, 2015) and learning a new skill such as quilting or photography (Park et al., 2014). These are enjoyable activities that could provide benefits for care dyads beyond promoting brain health and cognition: they might feel an enhanced sense of self-worth and accomplishment. Other positive outcomes include provision/promotion of safety (through reduction of fall risk) (Sherrington et al., 2017), social interaction/support (Fit Minds, 2016) and general health benefits for the dyad.

Exercise

There is overwhelming research support for the benefits of physical exercise, including exercise combined with cognitive stimulation (Karssemeijer et al., 2019). Northey et al.'s (2018) systematic review of 39 studies involving physical exercise interventions in community-dwelling adults older than 50 years, found physical exercise improved cognitive function regardless of participants' cognitive status. Types of physical exercise varied: in particular, aerobic exercise, resistance training, multicomponent training, and tai chi all led to significant gains. 45-60 min per session and at least moderate intensity, were associated with benefits to cognition. Studies incorporating a component of aerobic or resistance training showed similar estimates of improvement. Northey et al.'s (2018) review and meta-analysis suggests aerobic exercise is beneficial to the cognitive functioning of older adults, a critical finding, as they note that results of prior reviews (e.g. Kelly et al., 2014; Young, et al., 2015) together provided limited evidence of aerobic training benefits for this age group. Their investigation confirms Gates et al.'s (2013) suggestion that resistance training may play an important role in improving cognitive function in older adults. Additional compelling reasons for care dyads to engage in some form of exercise (as willing and able) are safety and general health promotion. Physical exercise is well-established for reducing fall risk (Thomas et al., 2019) and therefore critical for the well-being of care dyads.

Mental well-being

Caregiving has multiple effects, which include depression, anxiety, loss of self-identity, lowered self-esteem, excessive worry, feelings of uncertainty, loss of control over one's life, and exhaustion (Fordyce, 2021). Fordyce adds that assessment of caregiver needs should lead to a care plan with support services, caregiver education and support programs, respite to decrease caregiver burden and primary care interventions that address caregiver needs.

It is equally imperative to promote the dignity and health of the PLWD. Bosco et al. (2019) assert that person-centered care promotes decision-making and user engagement in health care planning, while striving to promote the personhood of the PLWD through an existentialist and humanistic consideration of their needs, values and beliefs. Their systematic review of the literature on personhood in dementia, utilized a meta-ethnographic approach. A scoping review and analysis of 14 empirical studies yielded seven overarching themes: participation, family, environment, behavior, policy and law, health care partnership, and autonomy (Bosco, et al., 2019). From these themes, Bosco et al. developed an integrated model of care to promote person-centered care for PLWD. Their model incorporates behaviors, participation, support, recognition and respect, environment, personal/dyadic space, communication, and autonomy. Specific standards and indicators of dignity in care are described. For example, related to participation, caregivers' views are not collected on behalf of the PLWD, rather they are gathered to complement the PLWD's views when the PLWD lacks capacity (Bosco et al., 2019). The authors provide a detailed list of actions supporting dignity in care. Readers are referred to Bosco et al.'s study for further reading.

Quality of life

"Quality of life is one's perception of their position in life in the context of one's culture and value system and in relation to their goals, expectations, standards and concerns" (World Health Organization, 2021). As such, quality of life is relevant for both individuals in the care dyad. Farina et al. (2017) recognize the tremendous impact of caregiving on quality of life for both members of the care dyad. They conducted a systematic review, resulting in a sample of 41 studies to identify factors that affect the quality of life of family caregivers of PLWD derived from qualitative and quantitative literature on the topic. Ten themes were identified: demographics, caregiver–patient relationship, dementia characteristics, demands of caring, caregiver health, caregiver emotional well-being, support received, caregiver independence, caregiver self-efficacy, and worrying about the future. Quality of life of caregivers of people living with dementia is a complex construct, affected by multiple factors. Interventions to support care dyads need to be holistic in nature to best target the multiple domains affecting quality of life.

Consistent with Farina et al.'s 2017 findings, Contreras, Mioshi and Kishita's (2020) comprehensive meta-analysis of predictive factors of quality of life among family caregivers found that anxiety was the only significant risk factor predicting old age-specific quality of life and psychological flexibility was the only significant protective factor predicting quality of life. They concluded that improving caregivers' anxiety and psychological flexibility may be particularly important in promoting their old age-specific quality of life. Interventions should target these key variables to achieve improved quality of life for caregivers. Thus, interventions directed toward anxiety levels and psychological flexibility would likely be aligned with those characterized by Farina et al. (2017).

Similar to both Farina et al. (2017) and Contreras, Mioshi and Kishita (2020), Pilonieta et al. (2020) investigated factors that might influence burden and family quality of life. They found a relationship between family quality of life and caregiver personal characteristics: greater family quality of life was associated with greater self-reported resilience. Similarly, higher scores on the Pearlin Mastery Scale (Pearlin and Schooler, 1978, https://www.hsph.harvard.edu/health-happiness/pearlin-mastery-scale/) were associated with lower levels of burden, while higher caregiver neuroticism was associated with higher reported burden. Thus, there is repeated evidence to suggest that individual personality traits and family dynamics/relationships are important aspects to consider in order to develop realistic and useful interventions to support care dyads and promote quality of life and well-being.

Opportunities for Meaning, Personal Growth and Successful Aging in Context

If supportive interventions are tailored on the basis of personality characteristics and the relationship of the care dyad, this creates opportunities for meaning, personal growth and successful aging for both members as individuals and as care partners. Harris (2008: 43) suggests that we might strive to promote resilience in care dyads: “the true quest as we age should not be for successful aging, but our goal should be for resilience, an undervalued and not fully examined concept in aging”. Harris conceptualizes resilience as distinct from successful aging, in her assertion that, unlike traditional notions of successful aging, developing resilience is possible for many older adults regardless of social and cultural backgrounds or physical and cognitive impairments. She notes research evidence that some individuals, after the initial shock of a dementia diagnosis, continue to live meaningful lives. However, she asserts that presence of a supportive social-psychological environment is vital to resilience in PLWD. Key features enabling resilience are assets and protective factors (use of coping strategies, having a positive attitude, maintaining a strong positive concept, social support networks, use of community resources, and a person-centered environment). Capitalizing on these assets and protective factors could help facilitate a more meaningful relationship for the care dyad, aimed at resilience (and hence successful aging).

TimeSlips (https://www.timeslips.org/) is a person-centered, supportive social-psychological approach to "bringing meaning to late life through creative engagement" that is congruent with Harris' resilience framework. The *TimesSlips* approach shifts from the expectation of memory of the PLWD, to the freedom of imagination, using the emotional and symbolic language of the arts. Care dyads can connect through use of sound, words, and images. The *TimeSlips* creativity center (https://www.timeslips.org/resources/creativity-center) presents tools to spark meaningful engagement. One example is Have a Gentle Conversation, "prompts to inspire a brief poetic exchange", where various pictures are posted and questions are posted for dyads, such as "What feelings come to mind? Phrases? Colors? Places?" and dyads are encouraged to write these down or perhaps draw a picture. Then, they can save, publish or print their work on the *TimeSlips* page. They can also read and view other dyads' stories or artwork related to the prompt.

Gifford, Marmelat, and Beadle (2021) suggest interpersonal synchrony (matching or similarity of movement, emotions, hormones, or brain activity) as another person-centered, supportive approach that could help to sustain caregiving relationship dynamics by promoting feelings of connection and empathy through shared behavior and experiences. Fu et al. (2021) describe interpersonal synchrony through use of movement and physical resistance exercises (for example, care dyads sit in chairs facing each other, while one pushes different body parts of his/her partner and the partner resists with equal force) which may lead to moments of connection in the care dyad. Gifford et al. (2021) assert that interpersonal synchrony can be influenced by one's living environment (i.e., living with a caregiver for decades), and can be facilitated through interventions focused on motor synchrony (i.e., tapping, or moving to music) or affiliative touch.

Caregivers are essential and play a vital role in supporting PLWD as both members of the care dyad cope with a devastating and degenerative disease that affects the health of both individuals. Therefore, we need meaningful, practical and effective strategies to preserve and promote the health and well-being of both members of a care dyad.

Conclusion

A broader conceptualization of successful aging is imperative, as are more holistic and comprehensive approaches to interventions to promote health and maintenance of successful aging for care dyads. As the older adult population becomes increasingly diverse, the manifestations of successful aging, as well as the experience of MCI and dementia will become similarly diverse, with cultural, ethnic, and cohort-specific nuances. Similarly, as people live longer, our conceptualization of successful aging needs to be rethought. Furthermore, individuals with chronic health conditions, including dementia, are the very people we need to be targeting to encourage successful aging. Individuals who struggle with overwhelming diagnoses such as MCI or dementia are some of the ones in most need of health promotion interventions to optimize and continue their successful aging to the greatest extent possible.

References

Aguirre E., Z. Hoare, A. Streater, A. Spector, B. Woods, J. Hoe and M. Orrell. (2013). Cognitive stimulation therapy (CST) for people with dementia–who benefits most? *International Journal of Geriatric Psychiatry,* 28(3), 284–290. doi: 10.1002/gps.3823.

Anderson, Tom and C.-H. Ruan. (2016). *Vocabulary and the brain: Evidence from neuroimaging studies*. Retrieved December 28, 2021 from: https://arxiv.org/abs/1611.10003.

Araújo, Joana, Jianwen Cai, and June Stevens. (2019). Prevalence of optimal metabolic health in American adults: National Health and Nutrition Examination Survey 2009–2016. *Metabolic Syndrome and Related Disorders*, 17(1), 46–52. http://doi.org/10.1089/met.2018.0105.

Ayalon, Liat and Patricia Areán. (2004). Knowledge of Alzheimer's disease in four ethnic groups of older adults. *International Journal of Geriatric Psychiatry,* 19(1), 51-57. doi: 10.1002/gps.1037.

Bahar-Fuchs, Alex, Anthony Martyr, Anita My Goh, Julieta Sabates, and Linda Clare. (2019). Cognitive training for people with mild to moderate dementia. *Cochrane Database of Systematic Reviews*, 3(3), Art. No. CD013069. doi: 10.1002/14651858.CD013069.pub2.

Baltes, Paul and Margaret Baltes. (1990). Psychological perspectives on successful aging: The model of selective optimization with compensation. In P. B. Baltes and M. M. Baltes (Eds.), *Successful aging: Perspectives from the behavioral sciences.* Cambridge: Cambridge University Press. 1–34.

Bosco, Alessandro, Justine Schneider, Donna Coleston-Shields and Martin Orrell. (2019). Dementia care model: Promoting personhood through co-production. *Archives of Gerontology and Geriatrics*, 81, 59–73. doi: 10.1016/j.archger.2018.11.003

Carbone, Elena, Simona Gardini, Massimiliano Pastore, Federica Piras, Margherita Vincenzi and Erika Borella. (2021). Cognitive Stimulation Therapy for older adults with mild-to-moderate dementia in Italy: