

DICE: A FRAMEWORK FOR OCCUPATIONAL THERAPISTS WORKING IN
DEMENTIA CARE

A Thesis submitted to the faculty at Stanbridge University in partial fulfillment of the
requirements for the degree of Master of Science in Occupational Therapy.

by

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Certification of Approval

I certify that I have read DICE: A Framework for Occupational Therapists Working in Dementia Care by Cameron LeBato, Michaela Pelayo, Melody Pope, and Tayler Schmidt, and in my opinion, this work meets the criteria for approving a thesis submitted in partial fulfillment of the requirements for the degree of Master of Science in Occupational Therapy at Stanbridge University.

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Dedication

To the many families and health care workers that care for people living with dementia, we offer this thesis as our thanks for your dedication and hard work. We salute your strength and compassion.

To our parents, partners, family, friends, mentors, and classmates who shared their encouragement and advice to complete this thesis, we appreciate you.

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“Big things have small beginnings.”

-- Wes Berry

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Abstract

Dementia's prevalence is estimated to increase and impact 115.4 million people by the year 2050 (WHO, 2012). There is not a clear, systematic approach for occupational therapists to use when providing interventions for people living with dementia in the United States. The objective of the DICE (Delivery method, Individualization, Communication & Education for care partners) framework is to promote the use of evidence-based practice in occupational therapy and establish a framework that can guide practice. It addresses recurring themes in current literature to highlight effective aspects of occupational interventions and practice. The study's design employed a rapid review of 26 articles we examined for eight weeks alongside our thesis advisor. Results found that the delivery method, individualization of care, inclusion of communication strategies, and education for care partners produced the most positive and significant outcomes in this population's overall quality of life. With the framework's guidance, occupational practitioners can include effective strategies while providing the respect and dignity this population deserves.

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DICE: A Framework for Occupational Therapists Working in Dementia Care

Globally, dementia currently affects 50 million older adults (World Health Organization [WHO], 2019). By 2050, researchers estimate 115.4 million people will be living with some form of dementia (WHO, 2012). In the United States, the number of people 65 and older projected to nearly double from 48 million to 88 million by 2050 (National Institutes of Health, 2016). The increased incidence of neurodegenerative diseases is linked to longer life expectancies (Avila, 2010). Dementia is a chronic, progressive neurological disorder. There are physical changes in the brain, which typically lead to increased difficulty with reasoning, mood management, memory impairment, and personality changes (Smallfield, 2017) The global care costs associated with dementia are predicted to be \$2 trillion by 2030 (WHO, 2017). Public health efforts in Switzerland, Chile, Jordan, and Australia—based on WHO guidelines—have begun to develop and implement a dementia plan that prioritizes the dignity and quality of life for those living with dementia, their care partners, and families (WHO, 2018b). In the United States, the National Alzheimer’s Project Act, created in 2012, aims to better serve this population by funding more local care and working toward a cure or treatment for Alzheimer's disease by 2025 (U.S. Department of Health and Human Services, 2019). In 2013, \$26 million out of the \$80 million fiscal budget from the National Alzheimer’s Project Act was dedicated to supporting goals such as education for public and health care providers and expanding support for care partners of those with Alzheimer’s disease (U.S. Department of Health and Human Services, 2019). International efforts indicate health care providers, serving the older adult population, need to be prepared to support the often-unmet needs of people living with dementia.

Formal care partners, meaning those who are paid to care for a person living with dementia (PLWD) and informal care partners, who are unpaid persons caring for a PLWD face challenges in dementia care as a result of the unpredictable onset of symptoms. For example, an interview of general practitioners revealed sentiments that despite their desire to help, a lack of understanding cognitive symptoms led them to focus instead on physical symptoms like high blood pressure and diabetes (Wang et al., 2018). This highlights why dignity and quality of life are a challenge for those living with dementia. The same interview also gathered data from informal care partners including a wife who reported she was fearful to touch her husband (Wang et al., 2018). This illustrates the personal stress informal care partners go through, contributing to the complexity of care they need to deliver.

Dementia impacts a person physically, cognitively, spiritually, and emotionally. To meet their unique needs, a multidisciplinary team will need to collaborate to address the different ways dementia impacts one's life. Effective communication and time is needed to collaborate between disciplines, making these health care threads important to acknowledge as identified by the Master's of Occupational Therapy curricular threads. For example, a registered nurse focuses on disease management education; a speech-language pathologist screens a client's hearing and treats those with cognitive-communication and swallowing problems; a physical therapist helps reduce pain and prevent disability; and a pharmacist ensures that medications are appropriate, effective, and safe for the client (Alzheimer's Association, 2009). As dementia is a progressive disease, clinicians from all disciplines must be able to easily transition from a rehabilitative perspective to a habilitative perspective. A rehabilitative perspective

focuses on restoring a person's lost skills (Pawar, 2017). It focuses on regaining things like range of motion, coordination, and muscle strength. A habilitative approach values and maximizes a person's current skills in order to achieve independence and delay decline (Gateley & Trudeau, 2020; Raia, 2011). Internal factors, specifically emotions, are primarily considered in a habilitative approach where decline is expected. An occupational therapist assisting a client with a broken bone will use a rehabilitative perspective to regain lost hand function with little need to transition to a habilitative perspective. On the other hand, caring for someone living with Alzheimer's Disease may require a transition to a habilitative perspective (Raia, 2011). Noting the difference between rehabilitative, which focuses on recovery, and habilitative, which focuses on quality of life, demonstrates the complexity of dementia care.

The American Occupational Therapy Association (AOTA) identifies the role of occupational therapy (OT) within dementia care to be the following: (1) client's occupational performance and their functional implications, (2) family education, and (3) helping practitioners caring for a PLWD to effectively cope with the challenging role (Smallfield, 2017). Unlike other disciplines, OT's services are broad and cover the different dimensions of one's being, including their physical and mental wellness to improve their quality of life (QoL) and dignity. OT is committed to addressing the different factors that make one's identity, and places an emphasis on the holistic and personalized care. This makes occupational therapists (OTs) suitable leaders in the discussion of establishing a framework for standardized dementia care.

Statement of the Problem and Purpose

OT in dementia care targets the well-being of an individual by addressing their occupations as it relates to caring for others and leisure participation, client factors as it relates to physical and emotional health, performance skills as it relates to social interaction skills, performance patterns as it relates to routines and roles, and context and environment as it relates to educational status and temporal aspects (AOTA, 2014). OT also addresses aspects included in the International Classification of Functioning, Disability and Health such as relationships, attitudes, self-care, and community life (WHO, 2018a). One problem identified from the literature was that care partners experience burden and distress due to dementia symptoms like unexpected behaviors, delusions or hallucinations, and mood disturbances (Cheng, 2017). These symptoms negatively impact a care partner's QoL and limits their ability to remain healthy and engaged in their own meaningful occupations. OTs can provide interventions to prevent factors like occupational disengagement, occupational alienation, and occupational deprivation from increasing their risk of a sedentary and disengaged life.

OT uses evidence-based practice (EBP) when delivering interventions. This commitment to lifelong learning and effective clinical reasoning resonates with the Master of Science in Occupational Therapy curricular threads. AOTA's Centennial Vision supports this by stating that OT is a "science-driven" and "evidence-based profession" (AOTA, 2020). However, barriers like high productivity demands, expensive resources, and lack of research skills may limit the implementation of EBP (McCluskey & Taylor, 2017, p. 62). Clinicians currently use approaches lacking high-quality studies like Teepa Snow's Positive Approach to Care (PAC; Snow, 2018) and Warchol Best-

Abilities Care Experts (Crisis Prevention Institute, 2019). Clinicians often use their positive client outcomes to shape their reasoning in the future.

This study sought to develop a framework for guiding EBP in the field of OT. This framework is called DICE, an acronym which emphasizes the consideration of delivery methods, individualization, communication, and education for care partners in dementia care as they relate to care partner burden, QoL in the PLWD, and the incidence of positive outcomes in therapy. Its goal is to assist OT practitioners to deliver quality care to clients by ensuring that their current interventions are scientifically supported through this framework. Although the target audience for this research are OTs, we believe other health care professionals may benefit in applying these same pillars when providing interventions for clients living with dementia.

Ethical and Legal Consideration

The foundation of this study was developed using the regulations provided by the American Occupational Therapy Association Code of Ethics and the Institutional Review Board (AOTA, 2015). The code of ethics applied here align with the values of OT which are nonmaleficence, autonomy, and veracity. The potential ethical concerns for this study included bias, participant privacy, and the use of outdated research. To avoid promoting one form of intervention over another, we carefully critiqued each journal article.

The use of the most current evidence is important to stay relevant in the field. Keeping up with the newest and most effective modalities enables a therapist to provide better care. Using current evidence ensures that the therapeutic intervention is still the best way to treat a client. The value of “Do No Harm” is prevalent in the medical field, OT included. Thus, nonmaleficence is a vital part of our framework, as it is our

commitment as practitioners to refrain from harming others (AOTA, 2015). We chose studies that emphasized the protection of participants and the confidentiality of their outcomes. Additionally, we sought research that was current and did not convey any conflicts of interest among those involved.

Since our project does not meet the federal definition of research involving human subjects, no consent was necessary. We used Google Docs to compile and synthesize the research articles obtained.

Theoretical Framework

The Person Environment Occupation Performance (PEOP) model for OT is a client-centered approach congruent with our research goals. This model's focus is on occupations and performance, prioritizing the roles, tasks, and activities most relevant to the individual (Christiansen & Baum, 1991). Clients are asked to self-identify important functional areas to work on. The "Person" (the physiological, psychological, cognitive, and spiritual aspects of an individual) and the "Environment" (the physical, natural, and social surroundings of the individual) are considered in order to craft the most suitable intervention plan that factors in "Occupations" relevant to the individual and how they will "Perform."

We reviewed studies with themes common in the PEOP model. Morris, Horne, McEvoy, and Williamson (2018) emphasized that interventions requiring active participation in a skill and home-based delivery program produce the best results. The PEOP model supports a top-down approach to dementia care addressing the participation in an activity before addressing underlying client factors. Similarly, Gitlin et al. (2009) investigated the implementation of their Tailored Activity Program (TAP) and found that

therapy was most successful when therapists selected activities that used the preserved capabilities of the client, not the areas most impaired. The complex nature of dementia care calls for a guideline like the DICE framework to ensure that the PLWD and their care partners' needs are understood and addressed holistically.

The PEOP model fits well with the four pillars of our framework that are concerned with whom and where therapy is being delivered. In terms of how these pillars connect to the PEOP model, delivery method has relevance to the environment in that it is important to consider where therapy is taking place and how it can be administered given the client's surroundings. Individualized care focuses on the person and their specific needs. Communication is concerned with the cognitive and psychological factors of both the PLWD and their care partner as well as the social natures of the environment in which they interact. This leaves education of the care partner which, while also focused on both the person and environment, requires identification of the personal gaps in the care partner's knowledge and how they relate to their physical surroundings.

OTs working in dementia care are constantly adapting to a client's evolving needs, personality, and demands to facilitate a therapeutic relationship. The Intentional Relationship Model (IRM) is a framework that specifically focuses on the dynamics of OT and the relationship established during therapy (Taylor, 2020; Bonsaksen, Vollestad, & Taylor, 2013). The therapeutic modes are advocating, collaborating, empathizing, encouraging, instructing, and problem-solving, which are catered to a client's personality and needs (Taylor, 2020; Bonsaksen et al., 2013). These modes define the various applications of therapeutic use of self in interactions between the client and OT.

Therapeutic use of self establishes rapport and strengthens trust. As a result, the relational

component involved in dementia was a fundamental consideration as we developed the DICE framework.

The progressive nature of dementia indicates the need for a habilitative approach. This was considered for the selection of these two models. Under the PEOP model, the client or the individual caring for the client identifies the most important performance issues to address starting with areas of strength (Cole & Tufano, 2008). This is congruous with habilitation which aims to maintain retained capabilities and prevent further decline (Gately & Trudeau, 2017). Just as maintenance of skill retention is important for a habilitative approach in dementia, maintenance of the therapeutic relationship is crucial as well. Elvish, Cawley & Kealy (2014) designated “feeling connected and being understood” as one of the three common themes among the care partners of PLWD in their study. They elaborated on this stating that it was necessary for participants to be able to relate to their therapist who is ideally friendly, open-minded, understanding, and remembers information between sessions with which they can help care partners reflect and make plans. The IRM is an integral tool to use when explaining and establishing the therapist-client relationship and it is intended to complement rather than replace existing OT practice models (Taylor, 2020). It molds with the PEOP model to establish a well-rounded theoretical framework for DICE, one rooted in habilitation.

Methodology

Research Design and Protocol

We conducted a rapid review that analyzed 26 articles relevant to occupational therapy’s approach in dementia care. Our research question was framed using the population, intervention, comparison, and outcome (PICO) framework. Here, we

hypothesized that a dementia care framework for OT can facilitate EBP while also improving the QoL of both the PLWD and their care partners. Our target population is OTs that could apply the proposed DICE framework to dementia-related treatments, interventions, and programs. This study can also be extended to other health professionals, like social workers, nurses, or case managers, who work directly with clients by providing them a guideline on how to best approach their care. The studies included were centered around evidence-based dementia interventions that portrayed positive and/or significant results. Comparisons were then made between the different interventions observed in which recurring themes were noted and later analyzed. Intervention outcomes aimed at increasing a care partner's dementia knowledge, sense of competency and QoL or psychological strain from burnout and depression were then considered first. Decreasing the disruptive behavior of a PLWD and delaying their institutionalization were additional intervention outcomes discovered. Lastly, studies that encompassed evidence-based dementia care interventions associated with OT and other healthcare staff were included.

Literature Search

We used the following six journal article databases, search engines, and journals to review the current literature: ProQuest Nursing and Allied Health Source, Google Scholar, PubMed, AJOT, Cochrane Library, PsychInfo and EBSCO CINHAL. Search terms included: dementia, caregiver training, education, interventions, individualized, occupational therapy, tailored, communication, patient, client, care partner, carer. We used any combination of these key search terms with the conjunctions "AND" and "OR." Searches were conducted from November 2019 to June 2020.

Screening and Study Selection

Studies pulled from the databases were evaluated based on relevance to the focus of this study. We analyzed and evaluated the feasibility of these articles. We included peer-reviewed studies written in English or with an available translated format and published within the last ten years (2010-2020). 5 articles from 2003, 2005, 2006 and 2009 were exempt from exclusion as they were foundational in nature and presented relevant information relating to dementia care programming and interventions.

Synthesis

Findings from the examined articles were summarized using tables. We analyzed the tables through detailed discussions with an occupational therapist who was an expert in dementia care. We separated the article information detailed in these tables into the following categories: Author/year, PICO/study subjects, Oxford Centre for Evidence-Based Medicine (CEMB) level/design, subjects, sample size, setting, inclusion/exclusion criteria, intervention and outcome measures, results, study limitations, and implications for thesis. Articles were reviewed to determine the applicability of each to the foundational pillars of this study and an evidence table emphasizing the four pillars was created. The results table (see Table 1) highlighted the article's authors, origin, year of publication, study design and delivery method, intervention, outcome measures, findings for the PLWD and their care partners, and their corresponding pillars.

Data Collection

A table was created (see Table 1) to organize any significant results collected from the literature review and advisor meetings. We peer-reviewed each other's work to ensure everyone interpreted the data correctly and without bias. In addition, the advisor

evaluated our work to support appropriate processes, methods, analysis of data, and accurate conclusions.

Storage

All relevant articles and documents regarding this thesis are stored in a Google Drive folder. This is a password-protected site that only allows for the authors and adviser involved to view or edit files. The folder will be kept for the duration of the authors' master's program ending in November 2021.

Data Analysis

The selected articles were analyzed for their association with the recurring themes that developed from our review. These themes were used in establishing the DICE framework, aimed to guide future evidence-based interventions for a PLWD and their care partners. The following themes were observed: (1) delivery method, (2) individualization, (3) communication, and (4) care partner education.

Literature Review

For those involved in dementia care, the rewarding relationship established between individuals during the performance of self-care tasks contributes to a sense of purpose. However, such a role can be taxing and increases care partners' risk for depression and illness especially if lacking the support from family, friends, and the community (Kuipers, Onwumere, & Bebbington, 2010). Current literature suggests that addressing care partner needs is essential. It improves the quality of care provided and reduces institutionalization (Thinnes & Padilla, 2011). The existing void in dementia care for a framework increases the risk for substandard OT interventions due to a lack of set guidelines for formal and informal care partners. After a review of the current literature,

recurring themes of delivery method, individualization, communication methods, and education for care partners emerged as consistent measures for successful treatment interventions. These influenced the foundation of the suggested framework pillars of effective intervention for dementia care. Much like a building's framework, these themes provide structure and will improve the effectiveness of the interventions a practitioner chooses. These pillars support EBP, contributing credibility to our profession and fulfilling AOTA's Centennial Vision (AOTA, 2020).

The first pillar of our DICE framework is the delivery method of education and training courses for care partners. The effectiveness of an intervention is reliant on the needs of the care partner, the skills of the care partner, and the environment the education takes place in. The most effective strategies found were classroom and Telehealth programs (Teri, Huda, Gibbons, & Van Leynseele, 2005; Griffiths, Kovaleva, Higgins, Langston & Hepburn, 2018; Berwig et al., 2017).

Individualized care requires a holistic approach when treating a client and is the second pillar in our framework for dementia care. Every individual has a unique set of roles, meaningful occupations, habits, and defined environments. The functional ability of a PLWD limits their engagement and participation due to common symptoms of dementia. When treating a PLWD, symptoms are unique to each person, but they follow a predictable path associated with the condition causing the symptoms. Clients experience sensory changes, problem solving changes, and communication changes. The WHO (2019) states that "dementia affects each person in a different way, depending upon the impact of the disease and the person's personality before becoming ill." A holistic, client-centered approach provided by an occupational therapist is crucial in

supporting goal attainment. OTs can apply this pillar in their practice in two ways: Through the creation of personal storybooks (Grondahl, Persenius, Baath, & Helgesen, 2017) and the TAP approach (Gitlin et al., 2009). As changes in the brain are unique to the individual, every case is different, leading to this need for individualized care.

The third pillar of the proposed framework is the importance of communication strategies for care partners. Effective communication allows for one's needs, desires, and thoughts to be articulated and understood by another. This affirms a sense of connection. Care partners may feel unable to communicate with their care recipient due to limited exposure and education about dementia. Nursing students in Taiwan, for instance, only get a maximum of 4 hours of instruction about dementia (Chao et al., 2016). Precise information on curricular programs in the United States regarding dementia was not found. However, a study at Texas State University suggested that health care students would improve their dementia perceptions with additional dementia-related experiences (Segovia, 2019). At Stanbridge University, OT students receive approximately 12 hours of dementia knowledge from combined courses (V. Sharma, personal communication, July 22, 2020). Evidently, OT programs would benefit from further education in dementia care to advance their practice. In California, nurses in memory care are required to undergo 12 hours of further training for dementia care (Crisis Prevention Institute, 2014). This information reveals the value of acquiring additional education in dementia care, likely due to its complex nature. Family care partners also find communication a challenging experience because of their lack of formal instruction regarding strategies of being a care partner or even about dementia. Generally, because it is common for the

PLWD to experience changes in receptive and expressive language skills, effective communication is key in providing the best care possible.

In addition to addressing the communication needs in dementia care, the fourth and final recommended pillar for our DICE framework is care partner education. Education for care partners consists of teaching them how to effectively assist a PLWD, how to prepare for progression, and how to balance caring for themselves as well as a PLWD. Educating care partners about self-care management and stress reduction techniques were also factors that helped increase their QoL.

Delivery Method

An appropriate delivery method, the first pillar of our suggested framework, was a recurring theme in effective dementia care interventions. As health professionals, we assume the role of an educator to our clients. The term educator has shifted in meaning from providers of content to becoming a guide behind the scenes while assisting the client effort to accomplish their goals (Bastable, Gramet, Jacobs, & Sopczyk, 2011). When an appropriate delivery method is used, clients are able to actively engage during the sessions, promoting later comprehension, recall, and application of information (Bastable et al., 2011). Clients will engage more when the delivery method suits their learning needs and, while this is subjective to the client, as OTs we should have experience using a variety of delivery methods that engage the client.

A family caregiver training program found that lecture courses discussing communication, nutrition, toileting, transfers, bathing, and dressing significantly decreased caregiver burden (Dizazzo-Miller, Samuel, Barnas, & Welker, 2014). Hands on demonstrations were also included to ensure the care partners safely learned to

perform tasks, ensuring their health as well as the care recipient's. This combination of delivery methods showed a significant increase in knowledge after each module, as the 18-item Caregiver ADL Knowledge test was administered before and after each module. Results showed the greatest increase in knowledge gain happened during the first module, where caregivers learned about communication and nutrition. Participants' mean score on the Module 1 Caregiver ADL Knowledge test jumped from 73.87 to 92.13 which yielded a p-value of 0.000 (Dizazzo-Miller et al., 2014). The study lasted three weeks with a follow-up after 3 months. While only 10 out of 72 participants completed the 3-month follow up survey, those results indicated they had retained the knowledge gained during the course and continued to perform skills they were taught.

Gitlin, Winter, Dennis, Hodgson, and Hauck (2010) found similar results from a 16-week active phase that included up to 11 home or telephone sessions with health professionals and a control group who did not receive any intervention. OTs helped construct intervention goals and target problem behaviors demonstrated by the PLWD after observing them in their home environment. Observations helped to identify potential limitations of care, if communication needed to be addressed, and how to implement the intervention to best benefit the PLWD and their care partner. Primary outcomes measured at 16 weeks showed a statistically significant increase in care partner confidence associated with managing the target problem behavior (Gitlin et al., 2010). Secondary outcomes showed statistically significant differences between the control and experimental group in well-being, which includes burden, upset with problem behaviors, and perceived change (Gitlin et al., 2010). From the results, we can assume home-health

interventions are beneficial because the PLWD and their care partner can learn and practice in the environment in which they interact.

Additionally, Schaller et al. (2015) found tailored e-health services were able to fit the needs of the care partner by being accessible and user friendly. This online program connected the medical professionals treating the PLWD with their care partners, which allowed care partners to be more involved in the care process for the PLWD. Participants noted they found the individualized nature of this intervention to be helpful because it saved them time and they felt supported during care partner tasks (Schaller et al., 2015). Additionally, care partners were able to access resources to benefit their own health. The results of this study are relevant to today's aging society, as there is not only an increasing number of informal care partners, but also many advances in technology. If utilized properly, this intervention could help provide care to persons living with dementia who are unable to afford or do not qualify for insurance coverage of in-person OT services.

Individualized Care

Dementia is a disease that falls on a spectrum and because of this, standardized care is something that can be difficult to establish. Many interventions have tested the effectiveness of tailoring programs to the PLWD. STOMP (Skill-building through Task-Oriented Motor Practice) is, as the name implies, an example of therapy concerned with physical elements. STOMP has care partners and their PLWD choose meaningful goals they wish to address in therapy, analyzes the performances in those domains, and then breaks down the practicable activities to be used to improve performance (Ciro, Hershey, & Garrison, 2013). Researchers found that in both home and clinical environments, an

individualized task-oriented motor program like STOMP can have significant, long-lasting effects on a client's ability to perform activities of daily living (ADL; Ciro, Poole, Skipper, & Hershey, 2014).

Many of the interventions we have come across are concerned with the cognitive and behavioral well-being of both care partners and the PLWD. Substantial research has been done on an intervention known as TAP. Gitlin et al. (2009) emphasized how TAP approach differs from other activity interventions as it does not emphasize new learning. In a different study, Gitlin et al. (2009) also found care partners felt confident in their ability to care for the PLWD after a TAP. In TAP, researchers identified specific roles and habits of the PLWD which helped them to develop activities that were customized to their individual profiles (Gitlin et al., 2009). Although some procedural learning may be necessary, the goal is to avoid taxing areas of cognition that are most impaired. Instead, therapists should opt for the activities that build upon the perceived strengths of the individual.

It is important to recognize that, like STOMP, TAP focuses on those areas important to the individual in order to ensure a good fit for therapy. In self-reported responses, this approach was well received by both care partners and their PLWD (Gitlin et al., 2009). Another example of this can be seen in a study by Van Haitsma et al. (2015) on their Individualized Positive Psychosocial Intervention (IPPI). The IPPI focused on finding three activities best suited for the residents' personal interests and abilities. After a three-week treatment program at 3 days per week, results showed that the clients in the IPPI group portrayed higher levels in pleasure, alertness, engagement, positive touch, and positive verbal behavior when compared to the control group (Van Haitsma et al., 2015).

These studies provide evidence of how individualization is an important concept to consider when creating and implementing interventions for a PLWD and their care partners. OT deals with the whole person, therefore this idea is consistent with the underlying framework of the practice. Individualization provides the contextual base of client-centered care and has been observed to be effective in dementia care, making it a vital aspect of these guidelines.

Communication

Where individualized care is the frame of OT, communication is the foundation of building rapport in relationships. This pillar plays a vital role in the facilitation of a therapeutic relationship and can have an impact on the relationship between a care partner and a PLWD. Communication allows for all persons involved to express their needs and concerns, and effectively provides a pathway to be heard and feel heard. OTs suggest that social health is an important aspect of wellbeing and is essential for the overall health of an individual. This is observed to be the case in dementia care, as social participation tends to be diminished in a PLWD and their care partners. Dementia care partner peer support has demonstrated promising results. Charlesworth et al. (2016) found that a peer support system led to significantly better relationships between a PLWD and their caregivers. In relation to what Charlesworth and researchers found, Morgan et al. (2012) found a declining caregiver-patient relationship to be one risk factor in predicting a client's aggressive behavior. This research demonstrates the need to facilitate communication and relationships between the care partner and their client.

One occurrence that is seen in individuals living with dementia is Resistiveness to Care (RTC), which is defined as any challenging behaviors that prevent proper care.

Verbal aggression, physical aggression, or physical agitation are a few examples of RTC demonstrated by a PLWD. One common trend in the field of dementia care is the use of elderspeak, which has been found to be linked to RTC (Williams, Perkhounkova, Herman, & Bossen, 2015). Elderspeak is a form of communication imitating “baby talk” where the care partner speaks in a high-pitched voice. This tone of voice is perceived by a PLWD and other older adults as demeaning. A reduction of elderspeak was found to be significantly associated with a reduction in RTC (Williams et al., 2015). Some other risk factors of aggressive behavior and RTC are: a declining caregiver-patient relationship, higher levels of caregiver burden, increased nonaggressive physical agitation, and increased pain levels (Morgan et al., 2012). Learning how to communicate with clients living with dementia can be beneficial in preventing RTC from occurring, allowing for optimal care to be provided.

Communication training is a viable option for both formal and informal care partners of a PLWD. Normally, the therapeutic relationship involves only the client and the therapist, with some interactions with family members. However, for those living with dementia, rapport with family members becomes vital, as the family members may be the one making decisions for the PLWD. Their family members could potentially be their informal carers as well. Thus, informal care partner training is essential in ensuring that the family member is aware of how to communicate with the PLWD. Dizazzo-Miller et al. (2014) found that the use of a family caregiver training program was significantly effective in increasing the knowledge of how to communicate, to do transfers, and assist the PLWD with their ADLs.

Alternatively, formal care partners require different support. Formal care partners are professionals in the health care field who, although trained to help clients medically, may experience difficulties in communicating with a PLWD. Sprangers, Dijkstra, and Romijn-Luijten (2015) found training nursing aides to use short instructions, positive speech, and biographical statements led to an increase in positive speech and decreased caregiver burden. Communication training demonstrates promise in effectively increasing QoL of both the care partners and the PLWD.

Communication plays an essential role in relaying needs and wants between individuals. A PLWD has trouble with this, making communication a critical aspect for this population. Thus, understanding how to communicate and interact with the client living with dementia is important to include in dementia intervention.

Education for Care Partners

Care partner education and training is another recurring theme for dementia care. This is an important aspect of OT intervention because typically those involved lack adequate education and experience with a PLWD. For informal care partners, the sudden role change to care for someone aside from themselves may evoke overwhelming emotions as a result of dementia's unpredictable onset and progression. A care partner recalls the feeling of being "helpless and anxious" in the beginning and how irritated she was to take care of her husband all day (Wang et al., 2018). For formal care partners, insufficient information about the condition's impact may negatively affect an individual's mood. A qualitative study conducted in 2011 demonstrated concern as nurses claimed the following statements about dementia despite having graduate degrees and working experience: "we don't know how to treat it," and "we do not have knowledge

and without knowing the pathology well, we do not know how to deal with the patient and family” (Poltroniere, Cecchetto, & Souza, 2011). This alludes to the idea that standard nursing education does not delve into the complexity of dementia and the current evidence-based practices that exist to provide the best level of care. This becomes problematic because formal care partners play a significant role in the decision-making process for their clients. Care partners often serve as their care recipient’s advocate (Family Caregiver Alliance, 2019). By not possessing the most current information about dementia and how to properly manage and cope, care partners are unable to produce thoughtful resolutions concerning their care. Misinformation about dementia and poor management of symptoms also create a feeling of incompetence in care partners, leading to their feelings of burden and depression (Alzheimer’s Association, 2020; Alfakhri et al., 2018). Depression with care partners was found to be more prevalent in children of a PLWD and was associated with one’s employment status, meaning those care partners who are unemployed are heavily at risk of depression (Alfakhri et al., 2018). This implies that care partners who have a familial link to the PLWD are experiencing depression more and they are not only concerned about the physical aspect of caring for someone, but also the financial components involved with care. For this reason, additional training led by OTs about dementia for care partners should be incorporated in a practitioner’s intervention plan.

Through our literature review, interventions that included care partner education or training implemented (1) knowledge about dementia (Dizazzo-Miller et al., 2014; Pleasant et.al., 2017), (2) adaptation techniques (Gitlin et al., 2010; Gitlin et al., 2003), (3) role-play and/or case scenarios (Teri et al., 2005; Goyder, Orrell, Wenborn, &

Spector, 2012), (4) communication strategies (Gitlin et al., 2010; Haberstroh, Neumeier, Krause, Franzmann, & Pantel, 2010; Morris et al., 2018; Williams et al., 2015; Dizazzo-Miller et al., 2014) and (5) information about self-care and management of one's own well-being to enhance relationships and QoL for care partners and their PLWD (Thinnes & Padilla, 2011).

Addressing knowledge about dementia is important in a care partner program. For example, the Family Caregiver Training Program incorporated three modules: communication and nutrition, transfers and toileting, and bathing and dressing (Dizazzo-Miller et al., 2014). These modules educated care partners on appropriate body mechanics to avoid injuries when performing transfers and other basic activities of daily living (BADLs). A paired-samples *t* test was used to assess significance in the program's data which was indicated in the *p* values. Specifically, the communication and nutrition module resulted in $p < .000$, the transfers and toileting module resulted in $p = 0.003$, and the bathing and dressing module resulted in $p = 0.01$ (Dizazzo-Miller et al., 2014). These significant values support the importance of including similar modules that targets BADLs in an intervention. CARES, which stands for Connect, Assess, Respond, Evaluate, and Share with other team members, is an online care partner training program whose modules instructed participants about dementia, how to practice a person-centered care, how to use behavior as a means of communication in facilitating a positive attitude to care, and how to implement the CARES approach (Pleasant et al., 2017). This program demonstrated an increase in dementia knowledge for staff represented by a $p < 0.001$ value and even implying that "learning about dementia and its inevitable decline may sensitize the caregiver over time to the negative consequence . . . and negative feelings

toward the care recipient” (Pleasant, et al., 2017). These results disclose the meaningful role of a dementia-specific course for care partners that not only educates them about dementia, but also provides a model on how to approach challenging scenarios, ultimately preparing them for their role.

Next, teaching care partners adaptation techniques is an important aspect to a care partner program. Advanced Caregiver Training (ACT) is a program that taught care partners how to manage problem behaviors by adapting their physical environment, utilizing assistive devices, simplifying communication and tasks, and engaging the PLWD in activities (Gitlin et al., 2010). As mentioned in the description of the communication pillar, those who are in the moderate-severe stages of dementia may have difficulty expressing their needs using words, so a care partner heavily relies on their behavior to determine any pain or unmet needs they may have. Through simplification strategies and effective communication, this study of ACT illustrated the importance of adapting communication strategies for each patient. It also resulted in long term benefits to symptom reduction, QoL, and social acceptability (Gitlin et al., 2010). Another program that promoted adaptation strategies is the Environmental Skill-Building Program (ESP) which covered the demands of the physical, task, and social environment (Gitlin et al., 2003). Examples of techniques taught were: the purposeful placement of objects, verbal and tactile cueing, and helping care partners coordinate and communicate with formal providers (Gitlin et al., 2003). This program improved the care partner’s affect while also reducing their stress and feelings of distress towards disruptive behavior (Gitlin et al., 2003).

The use of role-play and exposure to case-scenarios were also key factors in care partner education. This approach allows participants to visualize and practice what they should do when a concerning issue happens. A highly rated group workshop that emphasized the values of dignity and respect for a PLWD called Staff Training in Assisted Living Residences (STAR) utilized role-play in one of their modules and generated significant changes towards care recipient's behavioral problems, depression, anxiety, and affective and behavioral distress (Teri et al., 2005; Goyder et al., 2012). Educating care partners paves the way to their better understanding of what their clients or loved ones are going through, inspiring them to design an understanding environment.

Incorporating communication training is auspicious for care partners given that clients who are in the later stages of dementia are often non-verbal and use behavior as their way of communicating. Attempting to correctly comprehend these indirect cues can pose challenges in one's ability to care. Programs such as ACT, which teaches strategies such as simplification of tasks (Gitlin et al., 2010), TANDEM, which categorizes communication into presentation, attention, comprehension, and remembering (Haberstroh et al., 2010; Morris et al., 2018), the Changing Talk (CHAT) program (Williams et al., 2015), and Family Caregiver Training Program (Dizazzo-Miller et al., 2014) recognize the integral importance of building appropriate communication skills in effective dementia care. Each intervention is focused on decreasing behavioral problems, RTC, and an overall improvement in connection between care partners and the PLWD through effective communication.

Educating care partners on the value of self-care and the importance of well-being facilitates their QoL and reduces caregiver burden. Informal care partners who are

a part of the “sandwich generation”— meaning those who are taking care of their parents who are at least 65 years old while also raising their own children (Hoyt, 2019)—were discovered to feel overwhelmed, guilty, and going through grief because of their inability to find balance in their responsibility of providing care for a parent living with dementia and a minor child (Schumacher, MacNeil, Mobily, Teague, & Butcher, 2012). To address this, the inclusion of psychosocial training for “emotional support, stress management, and problem-solving . . . are effective in reducing caregivers’ psychological morbidity, increasing family cohesiveness, and delaying institutionalization” (Thinnes & Padilla, 2011). Care partners require support to prioritize their own self-care and leisure activity participation due to the consuming work required to care for their loved one. Utilizing interventions such as cognitive behavioral therapy and support groups can ultimately improve the care partners’ overall well-being.

By accepting the progression of dementia, care partners were able to tackle challenges related to the condition regardless of its unpredictable and unique experience. This connection establishes a stronger relationship that informal care partners view as special and necessary to maintain (Poltroniere et al., 2011). Additionally, providing education to care partners gives them the fundamental knowledge and skills that supports their sense of competence and self-efficacy, resulting in an increased QoL and satisfaction and a decreased level of stress. Care partner education provides access to key concepts about engaging people living with dementia and supports advocacy for a high standard level of care focused on dignity and QoL.

Results

Table 1
Overview of the Included Studies

Reference	Design and Delivery Method(s)	Intervention	Outcome Measures	Care Recipient findings	Caregiver findings	Suggested Pillar(s)
DiZazzo-Miller et al. (2014) United States	one-group pretest-posttest with a 3-month follow-up (1) PowerPoint presentation (2) short explanations (3) group discussions (4) real-life demonstrations (5) role-playing	An informal CG training program led by a team of trained professionals-occupational therapist, patient advocate, training specialist, and rehabilitation administrator- to teach 6 ADLs (communication, nutrition, transfers, toileting, dressing, and bathing), followed by a hands-on demonstration to showcase their knowledge.	Caregiver ADL Knowledge Test (created by authors) GDS Quality Assurance Form (developed by local Alzheimer's Association chapter of Michigan) Baseline, 3 months	Decreased general doctor's visits. Increased doctor's visits regarding ADL-related reasons. Decreased general use of the emergency room. Increased visits in the emergency room due to ADL-related injuries.	Significant effect on CG knowledge in the feeding module. Positive effect on CG knowledge in transfer and dressing modules.	Delivery Method Communication Education for Care Partners
DiZazzo-Miller et al. (2017) United States	RCT w/ a 3-mo follow-up Both groups attended a workshop in a support group setting at a facility: (1) Experimental group received a 2 hour presentation about FCTP (2) Control group received a 90 minute standard care presentation about general information and resources.	Family Caregiver Training Program (FCTP) is a community-based training that educates informal CG about dementia, specifically ADLs.	Caregiver Context and Demographics BADLS ADL Knowledge Test Caregiver Confidence Scale Zarit Burden Interview Beck Depression Inventory-II WHOQoL-BREF Performance and satisfaction scale of COPM	CR outcomes not addressed by this study.	Improved dementia knowledge on ADLs (FCTP includes training in communication, eating, feeding, and nutrition which are not typically in standard care) Positive effect on QoL associated in one's physical health. No significant changes in satisfaction, performance, burden, and depression.	Delivery Method Communication Education for Care Partners

Gitlin et al. (2010)	RCT	Advancing Caregiver Training (ACT) is a telephone-based training program for CG experiencing problem behaviors. Teaches strategies on how to address triggers such as communication and environment to reduce unwanted behavior.	Patient and CG outcome	Symptom reduction-targeted problem behavior	Positive effect on CG well-being- decreased feelings of upset, negative communication, and burden. After 24 weeks, improvements in simplification strategies (environment, task, communication)	Delivery Method
United States	(1) telephone-based (2) 3 follow-up calls between 16-24 weeks to enforce strategies		Zarit burden 12-item measure CES-D: 10-item depression scale 13-item perceived change index for handling care challenges Task Management Strategy Index 11-item survey of CG perceptions on study's benefits	Undiagnosed conditions were referred for a physician follow-up		Individualization Communication Education for Care Partners
Gitlin et al. (2017)	RCT	TAP-VA (Tailored Activity Program for Veterans) focuses on the interests and spared/residual abilities of the CR. Starting with thorough assessment, an OT through self-report, CG interview, and direct observation to grade tasks appropriately for the CR. Intervention, emphasis is placed on educating CG in how to use activities for skill retention. This includes the building of CG abilities to model, role-play, simulate, etc. The overall goal is to help CGs recognize capabilities, and translate capabilities into goals. The ultimate objective is to reduce problem behaviors in CRs and overall CG burden.	Neuropsychiatric Inventory—Clinician to address number and frequency of CR behaviors multiplied by severity. Secondary measures included: functional dependence (Caregiver Assessment of Function and Upset Scale) Pain (Pain Intensity Scale) Emotional well-being (Centers for Epidemiologic Study Depression Scale) CG burden (self-report timesheet)	At 4 months Veterans receiving intervention showed improvements in behavior symptoms in 69.7% of the cases compared to 46.4% in the control group. Reduction in all of the secondary measures were recognized except affect.	At 4 months, CGs had less distress in TAP-VA intervention group than control. No significant improvements were found in terms of depression, burden, or time caregiving compared to control group, however results favored intervention.	Communication Education for Care Partners Delivery Method Individualization
United States	(1) Experimental group: 8 on-site OT visits focusing on CR assessment and CG training (2) Control: bi-monthly (up to 8) contacts via phone.					

Positive effect on staff's attitude to dementia, but "person-centre" scale did not significantly change.	Overall SCIDS scale did not significantly change, but positive results in CG's confidence and competency when building relationships with residents.	DVD and ABC module aspect of training was deemed most helpful	Self-reported increase in dementia-based knowledge and improved relationships with residents and other staff.	CG's mood significantly increased post-intervention. Significant increase in effective communication strategy use.	Communication Education for Care Partners
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FRAMEWORK FOR DEMENTIA CARE

	Goyder et al. (2012)	pre/post test	Closely following Teri et al. (2005)	Baseline, 8 week follow-up	Decrease in depression scores disruptive behavior No significant effect on QoL or anxiety.
Morgan et al. (2012) United States	Longitudinal study (1) Initial telephone screening for eligibility (2) 24 month observational period (baseline & 4-month intervals)	Relational observation of aggression and predictors of aggression.	Worst pain, a declining patient-caregiver relationship, and nonaggressive physical agitation predicted an increased risk of aggression in CR.	Higher levels of baseline caregiver burden associated with increased risk of aggression in CR.	
		Cohen Mansfield Agitation Inventory (CMAI) Dementia Rating Scale (DemRS2) Hamilton Rating scale for Depression Burden Interview Mutuality Scale			
Morris et al. (2018) United Kingdom	Systematic review (1) Review of 38 studies	Overview of 38 communication training interventions for a PLWD and their CGs. 22 focused on professional carers and 16 focused on informal carers	Studies did not find significant changes in the PLWD QoL, depression, or well-being.	Improved communication and knowledge found for informal carers due to communication interventions.	
Pleasant et al. (2017) United States	pretest, posttest, 30 days follow up (1) One session for 4 hours of 4 online modules	CARES stands for Connect, Assess, Respond, Evaluate, and Share with other team members. This is an online training program developed by HealthCare Interactive in which informal and formal CG learned about dementia, person-centered care, and behavior as communication.	CR outcomes not addressed by this study.	Significant improvements in attitude and self-efficacy. Positive effect on CG dementia-based knowledge, but retention of information decreased in follow up. No significant effect on video items which tested the person-centered aspect of the program.	QoL significantly increased in CR
		16 multiple-choice questionnaire about dementia knowledge Sense of Competence in Dementia Care Staff Scale (SCIDS) CG video scenario where they watched a video and identify the 5 person-centered associated techniques out of 8 choices		Delivery Method Individualization Communication Education for Care Partners	

<p>Teri et al. (2005)</p> <p>United States</p>	<p>RCT</p> <p>(1) in-person group workshop that incorporates didactic, case studies, discussion, and group exercises.</p> <p>(2) in-person individualized classes to test staff's skills.</p>	<p>STAR is a dementia-specific training program for care partners in assisted living residences. The focus is to reduce client's affective and behavioral distress by modifying their environment and care partner's interaction. Program taught identification of client's individualized ABCs, which are activators, behaviors, and consequences of behavioral distress.</p>	<p>GDS, RMBPC, ABID, SSCQ</p> <p>Clinical Anxiety Scale</p> <p>Mini-Mental State Exam (MMSE)</p> <p>Pretest and Posttest for resident's affective and behavioral distress, staff job satisfaction and skill</p>	<p>Positive effect on resident behavior problems, depression, and anxiety.</p> <p>Reduction in dementia-related problems.</p>	<p>Improved reactions to behavioral issues. Better job competence and satisfaction.</p> <p>Preferred on-site sessions and feedback than scheduled appointments.</p>	<p>Delivery Method</p> <p>Individualization</p> <p>Education for Care Partners</p>
<p>Sprangers et al. (2015)</p> <p>Netherlands</p>	<p>RCT</p> <p>(1) Observation of nursing staff</p> <p>(2) In-person communication training</p>	<p>Training program focused on nursing aid on producing effective communication skills for dementia care (i.e. short instructions, general biographical statements, positive speech).</p>	<p>Mini-Mental State Exam (MMSE)</p> <p>Communication Skills Checklist (CSC)</p> <p>Observation Form of General Communication (OFGC)</p> <p>Cohen-Mansfield Agitation Inventory (CMAI-D)</p> <p>Utrecht Work Engagement Scale (UWES)</p> <p>Neuropsychiatric Inventory Questionnaire (NPI-Q)</p>	<p>CR outcomes not addressed by this study.</p>	<p>Decreased levels of CG distress from intervention groups.</p> <p>Significant increases in the number of short instructions and positive speech.</p>	<p>Individualization</p> <p>Communication</p> <p>Education for Care Partners</p>

<p>Thinnes & Padilla (2011)</p> <p>United States</p>	<p>Systematic Review</p> <p>Lectures, readings, discussion groups, joint-multimodal, support groups, counseling, home-based technology-based (telephone, video, internet)</p>	<p>Overview of 43 different OT educational and supportive interventions for CG of a PLWD.</p>	<p>Studies were included if they at least measured one of the following: QoL, health, wellness, and client/care partner satisfaction.</p>	<p>CG Psychosocial training delayed institutionalization and increased family cohesion. 5 studies conveyed improvements in CR skills and a decrease in disruptive behavior and their need for assistance.</p>	<p>Combination of supportive and educational strategies were the most useful interventions to CG. Dementia training, emotional and social support, individualized problem solving, referral to community resources, strategies to reduce CR disruptive behavior, and differentiating familial role from CG duties should also be incorporated in basic OT dementia care.</p> <p>Follow-up telephone-based support for CG reduced stress and improved QoL.</p> <p>Telesupport groups enhanced social support of older CG.</p>	<p>Delivery Method</p> <p>Individualization</p> <p>Education for Care Partners</p>
<p>Williams et al. (2015)</p> <p>United States</p>	<p>RCT</p> <p>(1) On-site didactic workshop. (2) Participants were to attend once a week for 3 weeks.</p>	<p>The CHAT (CHanging Talk) is a communication intervention with aims to sensitize nursing staff to elderspeak and its negative effects on the dementia population. Primary focus is on the reduction of Resistiveness to Care (RTC) due to elderspeak.</p>	<p>MDS 3.0</p>	<p>Significant reduction in RTC from CR.</p>	<p>Significant reduction in CG's use of elderspeak.</p>	<p>Communication</p> <p>Education for Care Partners</p>

<p>Barnes et al. (2018) United States</p>	<p>RCT Lecture delivered by the author of the Talking Sense Programme, an introduction to effective communication between dementia care recipient and caregiver, on three different occasions for one hour over the course of eight weeks.</p>	<p>Talking Sense Programme explores 9 different steps to address communication difficulties between caregivers and care recipients with dementia. The steps are delivered in order to each carer who was seen at home on 3 different occasions for 1 hr over a course of 8 wks. Intervention was delivered by the author of the programme utilizing slides from the manual.</p>	<p>The Hospital Anxiety and Depression Scale (HADS) Adult Carers Quality of Life scale (ACQoL) The Communication Self Efficacy Scale (CSES) The General Self Efficacy Scale (GSES) The Communication Competence Scale (CCS) The Therapeutic Engagement Index (TEI)</p>	<p>CR outcomes not addressed by this study.</p>	<p>CSES (fewer communication difficulties happening) and one subscale of ACQoL (felt more valued by their relative) differences between groups were found to be significant. CCS (perceive relative to be more communicatively competent) scores were extremely close to significance at $p = .052$</p>	<p>Communication</p>
<p>Ciro, C. A., Hershey, L. A., & Garrison, D. (2013) United States</p>	<p>Case Study In person implementation of STOMP (Skill-building through Task-Oriented Motor Practice) protocol</p>	<p>STOMP (Skill-building through Task-Oriented Motor Practice)</p>	<p>Pre-test COPM Post-test COPM</p>	<p>Pre and post-test COPM finds the following: Participant met goal of standing from recliner (GAS = 0), Participant did not meet goal of brushing teeth (GAS = -1), and participant exceeded goal of donning glasses (GAS = 1).</p>	<p>CG outcomes not addressed by this study.</p>	<p>Individualization</p>
<p>Ciro, C. A., Poole, J. L., Skipper, B., & Hershey, L. A. (2014) United States</p>	<p>Quasi-Experimental In person implementation of STOMP (Skill-building through Task-Oriented Motor Practice) protocol in home vs in a clinical setting</p>	<p>STOMP (Skill-building through Task-Oriented Motor Practice)</p>	<p>COPM Cornell Scale for Depression in Dementia (CSDDD) Caregiver Burden Scale (CBS) Goal Attainment Scale (GAS)</p>	<p>Participants made significant improvements in ADLs.</p>	<p>No significant CG findings.</p>	<p>Individualization Delivery Method</p>

<p>Griffiths et al. (2018) United States</p>	<p>Convenience sample Telehealth</p>	<p>Tele-Savvy, an online version of the Savvy Caregiver Program (an educational program for caregivers)</p>	<p>Zarit Burden Inventory- Short Form Center for Epidemiological Studies Depression Scale Pearlin Caregiver Mastery Scale Revised Memory and Behavior Problem Checklist</p>	<p>Researchers found significant decreases in CR BPSD for participants that reported a higher baseline CR BPSD.</p>	<p>Researchers found significant decreases in CG burden and depressive symptoms, and a significant increase in self-reported competence.</p>	<p>Delivery Method Education for Carepartners</p>
<p>Serwe et al. (2017) United States</p>	<p>Convenience sample (1) Telehealth (2) Six 90-minute sessions which followed the same format as the face-to-face program</p>	<p>Pilot study for transitioning PTC (Powerful Tools for Caregivers) program from face-to-face to Telehealth.</p>	<p>Caregivers' experience of PTC with Telehealth</p>	<p>CR outcomes not addressed by this study.</p>	<p>Participants felt they were more prepared because they learned strategies for self-maintenance and realized caregiving is a normal process. Additionally, participants felt connected to a group where they wanted to participate.</p>	<p>Delivery Method Education for Carepartners</p>
<p>Callan et al. (2014) United States</p>	<p>Randomized clinical trial Telehealth</p>	<p>Examined the feasibility of an online application called APVSAT (Adaptive Paced Visual Serial Attention Task), an adaptation of the paced auditory serial task (PASAT). The PASAT is a working memory intervention that aims to improve prefrontal cortex function to assist in executive control and regulating emotions.</p>	<p>Frequency of using the APVSAT Performance while using the APVSAT</p>	<p>CR outcomes not addressed by this study.</p>	<p>Researchers found the average number of times participants used the APVSAT to be 43.59 times during the entire experiment, which lasted, on average, 28 days. Participants improved their speed during task performance by almost 50%.</p>	<p>Delivery Method Education for Carepartners</p>

Author(s)	Systematic Review	25 studies were analyzed for the use of errorless learning techniques in various dementia intervention programs.	Studies used number/percentage of correctly executed steps or the number of correct responses given at the baseline and post-intervention assessments	17 of the 25 studies demonstrated statistically significant superior effects from the use of EL strategies compared to EF or no treatment. EL helps CR to create positive, meaningful memories associated with skill building and reacquisition.	CG outcomes not addressed by this study.	Delivery Method
de Ward et al. (2013) Netherlands	Systematic Review At-home, and unknown.					
O'Brien et al. (2018)	Pre and post test Computer and live simulations and workshops	Utilized experiential learning theory to engage HCPs in simulations of working with a PLWD	CODE (confidence in Dementia Scale) Dementia Knowledge Test Dementia Communication test	CR outcomes not addressed by this study.	Significantly increased confidence in dementia communication knowledge, confidence in guiding conversations, confidence in motivating and directing a PLWD	Communication Education for Care Partner
Charlesworth et al. (2016) United Kingdom	Factorial pragmatic randomized trial (1) At-home (2) telephone (3) community venues	Care Supporter Programme group attended 12 weekly 1hr meetings followed by 22 hrs worth of meetings over the next 5 months. Meetings were focused on listening, encouragement and moral support from volunteer carer supporters. Remembering Yesterday Caring Today group attended twelve 2 hour weekly sessions taking place in community venues covering themes related to the lifespan, utilizing multisensory triggers and activities, such as group discussions & activities, as well as handling objects, acting or improvisation, and singing. After weekly sessions, monthly sessions continued for 7 months.	CGs-UK Short Form-12 Health Survey (UK SF-12) (physical functioning, social/role functioning, vitality, bodily pain, mental and general health) Emotional Loneliness Scale QCPR CRs- QoL-AD HADS QCPR ADCS-ADL (Alzheimer's Disease Cooperative Study—Activities of Daily Living Inventory)	CR outcomes not addressed by this study.	Peer support either separately or combined with reminiscence therapy improved carer's perceived relationship with the person with dementia	Education for Care Partner

<p>Gitlin et al. (2003) United States</p>	<p>RCT (1) At-home (2) telephone</p>	<p>Environmental Skill-Building Program. Addresses 11 domains centered around potential areas of difficulty for CGs. Goal is to help family CGs reduce disparity between environmental factors and personal competence by providing skills to manage both domains.</p>	<p>CRs: RMBPC, dependence in ADLs, and dependence in IADLs. CGs: Seven measures of stress reduction, four measures reflecting enhancement effects, caregiver burden (objective vs. subjective), skill enhancement, and well-being</p>	<p>Where previous research had found reports from CGs of slower rate of decline in CRs, this study did not garner the same results. This is potentially due to the nature of how advanced the levels of dementia were in this sample.</p>	<p>Caregivers in the experimental group reported less stress with memory-related behaviors, a decreased need of assistance, and better affect compared to control. Spouses reported feeling less upset with disruptive behaviors. Men specifically reported less spent time with daily oversight. Women specifically reported less need for help from others, better affect, enhanced management ability, and overall well-being.</p>	<p>Education for Care Partner</p>
<p>Van Haitsma et al. (2015) United States</p>	<p>RCT On-Site (Nursing home)</p>	<p>Individualized Positive Psychosocial Intervention (IPI): Researchers and clinicians collaborated on activities appealing to that resident. Activities fell under 5 categories (Physical, Music, Reminiscence, ADL's, Sensory stimuli)</p>	<p>Direct observations in the form of 10-min "behavior streams." Resident behavior, location, and affect state were recorded.</p>	<p>IPI group displayed significant increases in pleasure and alertness, and positive verbal and non-verbal behavior. Both IPI and AC groups displayed more positive behaviors compared to the Usual Care group.</p>	<p>CG outcomes not addressed by this study.</p>	<p>Individualization</p>
		<p>Attention control (AC): one-on-one interaction where resident discussed magazine with CNA</p>				

<p>Grondahl et al. (2017)</p> <p>United States, Northern Ireland & Australia</p>	<p>Systematic mixed studies review</p> <p>(1) Creating a life storybook or collage made of photos and captions based on interviews, observations & documentary analysis</p> <p>(2) Family Biography Workshop where families and staff completed exercises to know the life of a PLWD</p>	<p>3 quantitative and 2 qualitative studies were analyzed to see the impact of using individualized life stories when caring for a PLWD.</p>	<p>Included studies addressed the impact of incorporating life stories for the PLWD and care partners.</p>	<p>4 studies improved CR's sense of confidence in being heard and acknowledged for their life and accomplishments.</p> <p>Life storybook increased CR's autobiographical memory, cognition, depression, positive mood, and communication</p>	<p>Care partners gained better competency in calming CR with use of life stories and understanding their behavior.</p> <p>Positive effect on family/formal care partners' holistic perception of the PLWD</p> <p>Care partners saw benefit in relationship-centred care over task-oriented care.</p>	<p>Delivery Method</p> <p>Individualization</p>
<p>Berwig et al. (2017)</p> <p>Germany</p>	<p>RCT</p> <p>(1) In-person lecture</p> <p>(2) Telehealth</p> <p>(3) Caregiver notebook as a social tool in relating to other caregivers' experience</p>	<p>REACH II was delivered by healthcare professionals that had completed a master's program to inform dementia caregivers. At baseline, caregivers identified three problem areas they wanted to work on during the intervention process. The intervention lasted 6 months and included 12 sessions: 9 in-home sessions, 3 phone sessions, and 5 structured telehealth group sessions.</p> <p>DE-REACH is an adapted online version of REACH II where the focus is psychotherapy and skills-training to decrease risk in 5 informal CG domains (knowledge, security, challenging behavior, ability to care, emotional and physical well-being, and perceived social support). A caregiver notebook was used for dementia knowledge, self-care, common CG problems, and community resources.</p>	<p>Zarit Burden Inventory</p> <p>Patient Health Questionnaire</p> <p>PHQ- module somatization</p> <p>SF- 36 Health Survey</p> <p>Enriched Social Support instrument</p> <p>RMBPC-24 frequency</p> <p>Reaction to RMBPC-24</p>	<p>CR outcomes not addressed by this study.</p>	<p>Post-intervention results indicated slight decrease in burden, stress-reaction in response to CR challenging behaviors and stress somatization.</p> <p>Favoring effects on psychological health associated with QoL and increased participation in social support groups</p> <p>Follow-up assessment conveyed an increase in burden in both groups (more in control), likely due to ineffective application of coping strategies for challenging behaviors.</p>	<p>Individualization</p> <p>Delivery Method</p> <p>Education for Care Partners</p>

Note: This table summarizes the articles used in this study.

CG=caregiver, CR=care recipient, ADLs=activities of daily living, GDS=Geriatric Depression Scale, RMBPC=Revised Memory and Behavior Problems Checklist, ABID=Agitated Behaviors in Dementia, NPI=Neuropsychiatric Inventory, SSCQ=Short Sense of Competence Questionnaire, QoL=Quality of Life, CSDD=Cornell Scale for Depression in Dementia, RAID=Rating Anxiety in Dementia Scale, RMBPC=Revised Memory and Behavioral Problem Checklist, QoL-AD=The Quality of Life-Alzheimer's Disease Scale, MMSE=Mini-Mental State Examination, ADQ=Approaches to Dementia Questionnaire, SCIDS=Sense of Competence in Dementia Care Staff, SSFQ=STAR Staff Feedback Questionnaire, BADLS=Bristol Activities of Daily Living Scale, WHOQoL-BREF=The World Health Organization Quality of Life-Brief, COPM=Canadian Occupational Performance Measure, BPSD=Behavioral and Psychological Symptoms of Dementia, HADS=Hospital Anxiety and Depression Scale, QCPR=Quality of Caregiver-Patient Relationship

Discussion

We formulated the DICE framework to promote EBP and establish a guideline for OT dementia care. The four recurring pillars we identified were delivery method, individualization, communication, and education for care partners. An overview of our

results, seen in Table 1, illustrates the complex nature of the 26 evaluated studies, where they overlap as they contribute different elements to multiple pillars. These evidence-based interventions define what aspects are effective in improving the QoL of both the PLWD (e.g., delayed institutionalization, improved behavior and mood) and care partner (e.g., dementia knowledge, burnout, depression, and competency with care).

Care partner training and education were commonly featured in our review, evident in 19 out of 26 analyzed articles. 14 of these articles were associated in improving care partner's QoL through reduction of burden and improvements in mood, social well-being, and physical health (Berwig et al., 2017; Charlesworth et al., 2016; DiZazzo-Miller, Winston, Winkler, & Donovan, 2017; Gitlin et al., 2003; Gitlin et al., 2010; Gitlin et al., 2017; Goyder et al., 2012; Griffiths et al., 2018; Haberstroh et al., 2011; Pleasant et al., 2017; Serwe, Hersch, Pickens, & Pancheri, 2017; Sprangers et al., 2015; Teri et al., 2005; Thinnes & Padilla, 2011). This supports the importance of OT in addressing care partners' well-being and QoL in dementia care through interventions such as employing a notebook to track care partners' self-care routine and community resources (Berwig et al., 2017), teaching strategies for care partners' self-maintenance (Serwe et al., 2017), and training them to use positive speech and biographical statements for effective communication (Sprangers et al., 2015). Incorporating care partner education increases their knowledge in dementia and feelings of competency as they learn to acknowledge and manage the dementia-related symptoms and challenging behaviors they encounter when caring for a PLWD as seen in 12 articles (Callan et al., 2015; DiZazzo-Miller et al., 2014; DiZazzo-Miller et al., 2017; Gitlin et al., 2003; Goyder et al., 2012; Griffiths et al., 2018; Morris et al., 2018; O'Brien et al., 2018;

Pleasant et al., 2017; Teri et al., 2005; Thinnes & Padilla, 2011; Williams et al., 2015).

Teaching care partners concrete information such as identifying how to efficiently handle ADLs for a PLWD (DiZazzo-Miller et al., 2017), how to fill out legal forms (Thinnes & Padilla, 2011), and using behavior as a means for a PLWD to communicate (Pleasant et al., 2017) were found to be valuable topics to consider. According to AOTA, OT plays a role in maximizing one's potential for occupational participation through environment modifications and adaptations (AOTA, 2011). Despite this emphasis on modification training, only 2 articles implemented this in OT interventions (Gitlin et al., 2010; Sprangers et al., 2015). This suggests two things: One is that OT needs to further promote research so the literature supports the importance of such interventions, and two, OT needs to pause on a focus on occupational modification when working with this population as a result of this deficit in observable prevalence and significant results. Including the concept of therapeutic relationship in care partner education was also paramount in many studies, as a focus on this strengthens the bond between the PLWD and their care partners. Specifically, recognizing and making distinctions of familial versus care partner roles positively influenced the perceived relationship of care partners towards the PLWD (Charlesworth et al., 2016). Psychosocial training such as stress and coping management, cognitive behavioral therapy, and support groups increased family cohesion and care partners' self-efficacy (Thinnes & Padilla, 2011). The overlaps between the framework's pillars further validates the importance of their intervening concepts. Delivery method, for instance, was found to be another major influence in structuring the intervention to best fit the client's needs, abilities, and environment.

Care for each PLWD is approached differently and care partner education requires the same type of attention to the unique needs of the individual. Care partners' feedback supports effective delivery methods including lecture-based courses, online and Telehealth training, and home meetings. In-person lecture-based courses with practical skills training and role-play scenarios showed statistically significant results (Diazzo-Miller et al., 2014). Participants demonstrated retention and transfer of knowledge from the classroom to working with a PLWD. Another in-person delivery method is in-home education which was found to be useful because clinicians can observe care partner interactions with the PLWD to support adherence to individualized programs and interventions (Gitlin et al., 2003; Thinnes & Padilla, 2011). Although delivery methods like Telehealth offer convenience and efficacy, care partners' limited familiarity with technology poses a barrier in these forms of delivery.

Effective dementia interventions require clear communication. In 12 out of 26 articles the use of modified communication supported QoL. Some of the articles particularly deployed the use of a workshop to diversify their methods with the example of Diazzo-Miller et al. (2014) using PowerPoints, role-play, group discussions and real-life demonstrations. The 12 communication articles used one of the following delivery methods: lectures, in-person communication training, workshops, live simulations, telephone-based training and online modules. Additional education that improved communication between care partners and PLWD included learning more about the progression of dementia and training that helped care partners decrease behavior problems in the PLWD. Many studies focused on in-person training. This indicates the importance of clear person-to-person training. Research supports that body language is a

major aspect of communication interactions. However, those articles that used virtual, computer-simulated, or telephonic interventions also demonstrated increases in technical dementia communication knowledge. This demonstrates the feasibility of a virtual communication training as an intervention for improving dementia-related communication knowledge for care partners. With regards to findings under the communication theme, half of the articles did not focus on care recipient outcomes. The remaining 6 articles reported: reductions in problem behavior; significant reductions in RTC; improvements in behavior symptoms; increased risks of aggression from a declining patient-caregiver relationship and increasing non-aggressive physical agitation; and one with no significant changes found in QoL, depression, or well-being in the PLWD. Such findings highlight the therapeutic benefit indirectly attributed to the PLWD through a care partner's communication training as a client derives their energy from their care partner. One explanation for the lack of focus on care recipient outcomes could be credited to our finding multiple articles related to care partner training, with most articles preferring to look at how communication interventions affect the care partner. While it is important to properly train the caregiver, the field of dementia care would benefit from understanding specifically how the training of the caregiver affects the PLWD. Another possible explanation could be the various types of communication that need to be used when interacting with a PLWD. Expressive and receptive language loss, confusion about time and place, and difficulties with self-regulation increase the challenge for the PLWD to express their needs. More studies in the future need to focus on addressing the outcomes of communication training on the PLWD, as the primary concern of care should first and foremost be about the client.

Care partners often experience burnout or compassion fatigue. However, studies found that care partners experienced improvements in their mood, increased QoL, increased confidence in dementia care, and decreased levels of caregiver distress when they felt they could clearly communicate to resolve unmet needs. Care partners also indicated communication training increased their effectiveness in communication, decreased use of elderspeak, and increased feelings of self-efficacy (Williams et al., 2015). It is important to note, however, that one article did not find any significant improvements in mood caregiver burden. Morgan et al. (2012) found higher levels of caregiver burden to be associated with an increased risk of aggression in the PLWD. Overall, positive results indicate the need for communication interventions for care partners of the PLWD. When working with individuals with dementia, understanding how to communicate clearly can create better conditions for the caregiver, potentially translating to better patient outcomes as well.

Lastly, our research supports a need to always consider individualization in dementia care. Dementia is a disease that limits people's lives in various ways. In particular, studies have shown it is important for interventions to focus on the retained skills of the individual, as well as their areas of interest. Implementing individualized care while creating interventions for PLWD promotes a higher success rate in their ability to achieve goals and connects them, personally, to their care. From this analysis, it appears that errorless learning combined with activities related to the PLWD's preserved capabilities (as seen with TAP) may be the most effective way of maintaining overall function. In rehabilitative settings, the concept of errorless learning is used as a method to instruct individuals with memory and executive function deficits involving interventions

targeted toward reducing the number of errors throughout the learning process (de Ward, Boelen, Olde Rikkert, & Kessels, 2013). Errorless learning ensures a path of least resistance by preventing mistakes from occurring, and guaranteeing success in the PLWD which, according to de Ward et al (2013), improves overall mood, and therefore helping to create positive memories during skill acquisition that aids in the consolidation and retrieval of information. As seen in the research of Gitlin et. al (2009), tailoring the tasks to the interests of the PLWD engages the person by preserving a sense of identity and supporting continued participation in meaningful tasks. Individualization incorporates care partner training by using biographical statements to increase effective communication (Sprangers et al., 2015). One example is creating life story books to support the relationship between the care partner and a PLWD (Grondahl et al., 2017). Skilled observation and analysis of a person's current and past roles is essential in creating effective interventions.

Nationally, a standardized dementia care plan of action for OT has not been implemented, resulting in a myriad of interventions being used by practitioners in different settings. These findings suggest that our DICE framework can help guide the OT profession to promote their client's sense of being.

Limitations

Given the limited nature of a rapid review, there is still room for development in the DICE framework. Current literature does not equally support the pillars, evident in the individualized aspect of the framework only seen in 11 out of 26 articles (see Table 1). Future studies focusing on individualization would likely uncover valuable evidence. We conducted this rapid review over seven months. The time constrictions posed a

limitation in the choice of the study's design, thus a higher level, more inclusive study would be beneficial in advancing these findings. Database access was also a limiting factor in which articles were included for data collection. We are aware of the possibility that other relevant studies exist but were not readily available to us for inclusion. The exclusion of grey literature is important to note and is a major limiting factor as well. The final limitation we recognize is our restriction to the review of articles only written in or translated to English.

Implications for Future Research

This rapid review suggests that a consistent framework for dementia care, such as DICE, is promising in creating a sense of uniformity and credibility to the multiple interventions currently being administered by practitioners. Given that most of these interventions are not yet evidence-based, having a framework that emphasizes the importance of delivery method, individualization, communication, and care partner education within the realms of dementia may be time-efficient in informing and structuring the interventions of busy practitioners. Many of the interventions reviewed were executed by an occupational therapist along with other health care professionals, making the DICE framework applicable to several disciplines working with this population. Future implications for researchers include utilizing a more comprehensive and objective measure when creating the themes to amplify the significance of the pillars chosen. The comparison of the DICE framework to current and non-evidence-based interventions is warranted to examine the feasibility of the framework. Suggested interventions include PAC and Warchol Best-Abilities Care Experts, which are currently being implemented by OTs.

This study was originally developed and rooted in analyzing current evidence-based dementia interventions associated with Teepa Snow's PAC which is growing in practice and focuses on the person-centered approach that our research has shown to be effective. An important aspect of OT is using evidenced based interventions during practice. PAC, among others, is one dementia intervention that is currently practiced, but the model continues to require more research to be truly evidence-based. This framework suggests a model that future researchers can use to better analyze interventions, one that can be used to better understand PAC as it relates to clinical trials. When approaches like PAC become more evidence-based, more OTs seek certification which helps increase their sense of competence in handling the complexity of dementia care. Furthermore, a rigorous randomized controlled trial using an intervention guided by this framework can advance our results and strengthen our framework's effectiveness and relevance to dementia care.

Implications for Occupational Therapy Practice

OT practitioners can apply the results of this rapid review in their dementia-care practice. For instance, they can advocate for a standardized framework in dementia care to promote EBP and reduce the implementation of interventions not supported by research. They can also compare their current interventions with the DICE framework to see if their interventions include some or all of the suggested pillars. Practitioners may also benefit in developing interventions that align with the DICE framework to increase consistency and time efficiency within their practice. Training other OTs, healthcare professionals, and appropriate personnel in utilizing the DICE framework may also help

prevent institutionalization, improve a PLWD's affect, increase dementia knowledge and competency, and decrease care partner burnout and depression.

Additionally, OTs working with clients diagnosed with dementia must remember to advocate for their continued treatment with dignity and respect given that a PLWD cannot speak for themselves. This concept will be difficult to uphold in a practice setting because of the progressive nature of dementia, but by taking a habilitative approach, "which focuses on maintaining retained capacities and preventing further decline," OTs can minimize and compensate for the deterioration of function a PLWD experiences (Trudeau & Gately, 2015). With continued maintenance intervention, practitioners can increase the QoL of the PLWD and their care partner.

Conclusion

The proposed pillars of delivery method, individualized care, communication, and care partner education intend to advance dementia care. It is a proposed guideline for practitioners providing dementia-related interventions across all care delivery settings. The first pillar of our proposed DICE framework for dementia care is delivery method. This highlights the importance of interventions to meet the needs of the PLWD and their care partners. Practitioners should also examine and be aware of which delivery methods best support the carryover of skills from treatments and interventions to daily life. As each individual PLWD is different, their care should be tailored to their unique needs. This is why individualized care is the second pillar of our proposed DICE framework. Thinking about dementia care from an OT perspective, the interventions supporting dignity and QoL require a holistic and client-centered approach. OTs can achieve this by building a positive relationship with their client and providing interventions based on

client interests and needs. To build this relationship, the client, therapist, and care partner must communicate effectively. The varying realities of each PLWD makes communication a key aspect in a successful encounter, which is why communication is our third pillar. In order for a care partner to positively support a PLWD, they too must engage in meaningful activities, maintain a balanced routine, and be aware of the progression of dementia. Care partner education is the fourth and final pillar of the DICE framework. Literature supports the power of focusing on care partners' outcomes in dementia care. Interventions that provide strategies in effectively addressing unwanted expressive communications and learning about self-care management and stress reduction techniques ultimately improve both the PLWD and their care partners' QoL. The burden care partners feel from dementia's unyielding progression gives more reason as to why we need to arm them with the autonomy they need to prosper in their caring for their PLWD. The DICE framework, along with OT's habilitative approach ensures that a PLWD will maximize their function as clinicians are able to provide effective EBP interventions.

The DICE framework aims to improve the standardizing of quality of care for those living with dementia within the practice of OT. The use of EBP enables clinicians to offer effective interventions to this growing population and establishes credibility for the profession as highly qualified providers. All health care professionals caring for a PLWD should be familiar with these pillars to deliver an effective intervention.

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Appendix

Institutional Review Board Approval

IRB Application Number	MSOT009-008
Date	03/26/2020
Level of Review	Exempt
Application Approved	X
Conditional Approval	
Disapproved	
Comments	Please refer to comments above.
Signature of IRB Chair	