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Facilitating ADLs by Caregivers of Persons with Dementia: The C3P Model

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Abstract

The purpose of this paper is to explicate a change model for caregivers of persons with dementia to assist them in facilitating meals in the home, at community-based programs and in institutional settings. Building on a Social Ecological Model, the *C3P Model—Change the Person, Change the People, Change the Place* offers a clear method to adapt care strategies to foster independence while providing appropriate support as the person with dementia cognitively and functionally declines. Meals are highly embedded within a culture and are ritualized events within a family requiring an individualized approach when modifications are needed.

Keywords

Caregivers; dementia; feeding behavior; meals; social ecological model; training

INTRODUCTION

The number of people over age 65 is rapidly expanding and by the year 2050, the number of persons with dementia (PWD) is expected to nearly triple, from 5 million to over 13 million (Gaugler et al., 2013). Of those, the clear majority are cared for by family caregivers who yearly provided 17.5 billion hours of unpaid care with an average of 9 hours spent per day caring in some way for the PWD (Fisher et al., 2011; Gaugler et al., 2013). Additionally in a recent survey of 3,941 US nursing homes, unlicensed staff caregivers comprise the greatest amount of direct care for residents (30.4 FTEs/100 residents); however care often occurs in

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an environment that focuses primarily on tasks to be accomplished minimizing process components (Amella, 2002; Castle & Anderson, 2011).

Within the realm of Alzheimer's disease and related dementias, managing mealtimes becomes an activity that caregivers slowly assume, often without realizing the scope of the consequences if not managed well. Acquiring adequate nutrition is one of the desired outcomes of all meals as it directly affects the overall health of all persons, especially older adults, who tend to be at higher nutritional risk due to altered metabolic rate related to sustained inflammation from chronic illness, change in satiety, oral health issues, inadequate strength to manage the process of preparing and eating an entire meal, and increased risk for both hospitalization and nursing home placement (Alagiakrishnan et al., 2013; Bell et al., 2013; Haumschild & Haumschild, 2009; Jensen et al., 2013; Wang et al., 2013).

Furthermore, the other prominent outcome of meals that relates to socialization and quality of life is compromised by loss of mealtime companionship, life-long routines, and favorite foods especially when an older adult moves to a residential facility, and depression related to loss of function and severe chronic disease (Fjellstrom, 2004a; Rasheed & Woods, 2013; Young et al., 2011). For those older adults with progressive loss of memory and function through dementia, the caregiver bears responsibility for assuming components of both the task and process components of meals as behavior changes.

During the last decade, the National Institute on Aging and the National Institute for Nursing Research supported training programs that were able to improve caregiver's health parameters and quality of life, and increase their perceived ability to handle behavioral issues. Exemplary programs included the multi-site *Resources for Enhancing Alzheimer's Caregivers Health: Offering Useful Treatments* (REACH OUT) project, the *Staff Training in Assisted-living Residences—Caregivers* (STAR-C) program, and the Savvy Caregiver Programs (Burgio et al., 2009; Hepburn et al., 2003; Hepburn et al., 2007; Teri et al., 2005). However, these projects were composed of multiple sessions and outcomes were focused on the caregiver; functional or behavioral outcomes in the PWD were secondary. Using traditional sites of care – institutions and the home, they neglected to include the other important pool of caregivers – volunteers. Volunteers provide care to PWD in the community through the Senior Companion Program, a branch of the federal Senior Corps, that sends volunteers to community centers for PWD (Corps, n.d., 2013) and social-model respite programs for PWD. Both programs rely primarily on long-time unpaid volunteers who are often family members of PWD (Brookdale, n.d.). These centers offer support services to families and caregivers of PWD and use a novel social model for meaningful activities, socialization, and sharing both a snack and lunchtime meal. It was in these community settings of respite care that a model, *C3P – Change the Person, Change the People, Change the Place*, was developed to teach family and volunteer caregivers ways to facilitate activities of daily living (ADL)s, especially meals, for the PWD. The model was further tested in skilled nursing facilities to teach certified nursing assistants (CNAs) and directly in the home setting (Aselage, 2011). This paper describes the CP3 model and ways that it can be used to help caregivers across settings design a dynamic plan of care that preserves independence, yet provides appropriate support as the PWD declines.

BACKGROUND

Models of dementia caregiving need to focus on the dyadic experience of the PWD and whoever is regularly assisting. Meals are an excellent venue in which to explore the interaction between these dyads, as most people prefer to eat with another person. For some caregivers of PWD, it can be both the most pleasant, yet most frustrating ADL since lack of ingestion of food at meals directly results in compromised nutrition and in most cultures rejecting food is seen as a social rejection (Fjellstrom, 2004b; Robinson & Gallagher, 2008). Both the *Katz Index of ADLs* and the Functional Assessment Staging Test place the loss of the ability to self-feed at the end of the dementia behavior trajectory (Auer & Reisberg, 1997; Katz et al., 1970). However, clinicians and families note that changes in mealtime behavior, often idiosyncratic, occur before the later stage of dementia.

Social ecological models are helpful in examining complex behaviors that cannot simply be explained as the sole purview of one individual or one situation. Explaining and changing most behavior requires an examination of at least the dyadic experience between two people, and/or the interaction of a person with his or her environment. Mealtime could be framed as such an experience, as it is both a socially and culturally laden event, sometimes with ethical overtones in the case of a person who is “refusing” to eat (Amella, 2004). Consider the first three constructs comprising McLeroy’s ecological perspective on health promotion, which are: *Intrapersonal* – Individual behavior change; *Interpersonal* – Family, friends, peers, household roles and structures, and kinship systems; and *Organizational* – Churches, stores, and community organizations. We adapted and tailored these three perspectives to include: (1) the person with compromised function and cognition; (2) the caregivers (e.g., family, volunteers, and CNAs); and (3) the respite care centers, skilled nursing facilities (McLeroy et al., 1988). A simple model was needed that could be used across settings, adapted as change presented in the disease process, and which enhanced the problem-solving capacity of the caregiver to provide care accounting for the contextual issues. We also needed an acronym that the caregiver could recall when the care situation was challenging and changing, thus, *C3P Model* – *Change the Person; Change the People; Change the Place* emerged.

TRAINING IN USE OF THE MODEL

The C3P model is explained to caregivers as a way to assess, make a change, and then evaluate the change under two situations, specifically when something is not “working right” or when something is “working very well.” Caregivers are asked to briefly step back from the task and consider the process, describing what is happening with the *Person* (the person with dementia), the *People* (the caregiver or other assistants), and the *Place* (the context of care).

Caregivers, volunteers or CNAs, are presented the model in an adult-education program with the best evidence in mealtime care for older adults (Amella & Aselage, 2012). When given to CNAs and respite volunteers, information is shared in two 45-minute programs that primarily focus on the interplay of all three components as key to realizing a positive

mealtime experience. Participants receive a binder with text and scenarios that is comprised of the following sections:

- dementia – what does it mean;
- mealtime – more than food;
- need driven behavior and dementia – striking the balance;
- finding out about mealtime problems;
- the C3P model (that can be tailored based on questions from the “Finding out” section); and
- coaching adults.

Stressed in the presentations and accompanying information is the need to promote independence and provide tailored support when appropriate for the PWD. “Strike the right balance” is used as a way to recall this process. In the second session, principle ideas are reviewed and caregivers then use role-play of scenarios in which various problems, primarily behavioral, arise. An additional train-the-trainer program was developed for “volunteer coaches” in the respite centers to help family caregivers of respite participants with dementia develop their own tailored plan for their family member.

CHANGE THE PERSON

The initial component of this triadic approach, *Change the Person*, is introduced first since the usual medical model approach, as we need to “fix” what’s “wrong” with the patient is how problems are often confronted. Caregivers are no different and often see the problem only residing with the PWD. Questions about swallowing issues act as a screen for the process. If the PWD has as an established diagnosis of dysphagia and is under treatment, or if there are obvious signs of aspiration, the caregiver is referred back to their provider for clearance, as we defer to whatever protocol is established for the PWD.

As an overview, general questions are asked about weight loss or gain and known long-standing preferences about meals and mealtime rituals (e.g., blessing of food and vegetarian/vegan diets). Caregivers are asked to describe things that make meals go well for the PWD and things that seem to trigger “challenging” behaviors. The only established instrument to assess eating problems in persons with late-stage dementia, the *Edinburgh Feeding in Dementia Scale* is then used to identify level of assistance/supervision required, and specific behaviors related to meals (e.g., does the person turn his/her head away when being assisted?) (Watson et al., 2001). Using these data, the caregiver is given a list of evidence-based activities that could help to modify behavior so that the individual is able to remain independent and be supported as needed. The following are among the items discussed in detail if pertinent:

- If the person has any problems with pain, make sure they get their pain medication at least 30 minutes before they eat so they can sit up and enjoy their food.
- Insure that the person with dementia has clean teeth, or dentures or plates.

- Assist the person to wash their hands; some religious or cultural groups have special hand-washing rituals as well as rules about what hand can be used to touch food. Find out what these are.
- If a blessing or any other ritual was used before or during meals, continue those activities.
- If the person with dementia is sitting in a wheel chair and can be moved to a dining room chair, the caregiver should help them sit there. A chair with a firm seat and straight back will let them have a normal and safer posture at meals. The ideal is to sit with our feet on the floor and our back straight. A few of us eat better if our chin is slightly tucked when we eat. This will help us eat more normally and safely.
- Make sure that the person is using their eyeglasses and hearing aids at meals. This will let them enjoy conversation and hear the directions the caregiver gives. Eyeglasses will not only help the person see the food they are eating; they will help them be more independent.
- Using special equipment at meals, such as built up plates, silverware with grips on them that make it easier to grab, and mugs rather than cups or glasses, may help some people. If the person with dementia has other problems such as arthritis or has movement problems (e.g., hemiplegia and Parkinson's disease), the caregiver should ask their provider to see an occupational therapist who can prescribe needed equipment.
- After the meal, make sure that the mouth and teeth are cleaned. If this is a problem, talk with the dentist or dental hygienist for good ideas to make this happen.

CHANGE THE PEOPLE

Many caregivers do not recognize that their own emotions are conveyed to the PWD, especially those who may not share a long-term relationship such as CNAs in a nursing home. Partners/spouses or parents and children often have a long shared history of eating together and thus realize how their behaviors have historically affected the PWD before they developed dementia. Asking about this dynamic often allows family caregivers to reflect on how behavior affects the PWD. Volunteers in respite centers may use their life-long interaction with their own family member with dementia as a template for generalized care to others and need to be reminded that what occurred with their loved one may not hold with participants. Two primary principles are shared in explaining this component: (1) even though the PWD may not understand or use language well, the caregiver's level of anxiety and frustration will be displayed through body language and/or facial expressions and (2) PWD do not display challenging behavior "out of spite," as the disease (e.g., Alzheimer's disease, vascular dementia, etc.) causes erratic, inappropriate or protective behavior that is not planned. To assess the caregiver's behavior and feeling, we ask them to describe situations in which they felt pleased with the way the meal went and situations where they felt "bad" about the meal. In general, probing questions include questions about feeling "rushed," concerns about meals and the amount/quality of food the PWD is consuming, the caregiver's behaviors during meals (e.g., getting up and down from the table and not eating with the PWD), any "spiteful" behaviors, and for family caregivers, what were meals like in

their home before the PWD developed dementia. In order to establish the caregiver's own priorities, we ask an open-ended question at the close of this assessment. For example, "If you had a magic wand and could make one thing better at meals, what would it be?" The following items may be discussed if relevant:

- Make sure your behavior fits with what you want to "say" to the person with dementia. Try not to rush, feel anxious, or just try to get the meal done. Remember what it is like to enjoy a pleasant meal. Then try to act that way while you help the person with dementia by smiling and focusing your conversation on the PWD.
- Get all the food on the table before you have the person with dementia sit down to eat. When you jump up and down to get things, that may make them want to do the same or will break their focus on eating.
- Allow the person with dementia to perform those parts of the meal that they can. Try to serve foods that are easy to pick up. When people are struggling or just not capable of helping themselves, gently help them. Try to think of this process in a positive way if you can.
- Try not to rush the meal, whether the caregiver is helping or the person is managing while the caregiver just watches. Rushing is a sure way to say, "let's get this done! I'm too busy."
- Encourage the person with dementia with simple cues: "Open your mouth; close your mouth; chew; swallow" are a few common reminders so they can manage the process of eating. Talking in a clear, calm voice helps more than yelling or nagging.
- If the person with dementia is getting distracted or seems to be ready to leave before the meal is done, try using a gentle touch to redirect them to stay. Often a gentle touch on the arm and a reminder that they have not finished is enough to get them back on the task of eating.
- The caregiver needs to be relaxed and flexible. This is probably the toughest thing we can ask a busy and often tired caregiver to do, but it is important to encourage them to leave their worries behind, sit down, and enjoy this time. If the person with dementia seems to want something different and this cannot be changed, try to go with the new behavior, even if it means going away from the table and then returning later.

CHANGE THE PLACE

Changing one's environment is one of the most challenging tasks as changing the environment usually includes and affects others within a system. It has long been recognized that environmental adaptation is challenging for caregivers of PWD, and some individuals may be either resistant or reluctant to make changes, or may need to make change more slowly over time (Gitlin et al., 2001). Caregivers need time to adapt long established ways of constructing their environment in the home, or in institutions may not be empowered to change protocols or the institutional nature of meals (Caspar et al., 2013). This aspect of change is strengthened by the use of the ecological nature of the C3P model. The system

really has to be considered within change or the possibility of less that ideal outcomes become very real.

Assessment is made of the place and other players present both while meals are being served, as well as what occurs proximal to the meal. Caregivers are asked to describe the room in which meals are eaten including the noise, clutter, movement of others including pets, and odors. Preferred place at table or within the room (e.g., back to the wall) are ascertained. The caregiver is asked what the PWD sees from his/her vantage and asked if this could be distracting? They are asked to recall the setting where or when positive meals occurred and meals that did not go well. The following items are discussed if pertinent:

- Prepare foods the PWD has enjoyed. Caregivers often know what the person with dementia enjoyed eating, as well as how they liked food cooked. For persons on restrictive diets, speak with the healthcare provider or nutritionist about ways to keep food as close to the way it used to be prepared or looked as this may trigger memories of past food and meals.
- Pleasant music and friendly conversation has been shown to increase the amount of food eaten.
- Preparing food close to the time it will be eaten, if possible, allows for the cooking odors to stimulate the appetite. For example, the smell of toast and coffee brewing at breakfast means it's almost time to eat. Frying a little onion before a meal can be very stimulating to some people.
- Offer foods that do not need lots of "handling" with silverware. For example, instead of serving spaghetti and meatballs, serve a meatball sandwich with a little sauce, or serve vegetables that someone could pick up such as slices of yellow squash, rather than a squash casserole. We often hear about "finger foods" and we think of either sandwiches or fried foods, but many foods can actually be picked up include vegetables and fruits or frozen foods. Try to serve soups or cereals in a mug.
- Eat meals in rooms where meals are usually served. For example, when eating at home move to the kitchen or dining room at mealtime if that is where meals used to occur, rather than staying in the living room. These rooms make us focus on food, not other distractions.
- Provide good lighting. Older people have a difficult time seeing in low lighting. Make the room bright and pleasant. Provide contrasting, solid placemats, preferably a plain dark background with simple lighter serving pieces.
- If you are going to take the person with dementia out to a special event with food (e.g., a family party), it might be easier to have a quiet meal at home first. This way the person with dementia will not be distracted by hunger, as they may enjoy the event more. You can also enjoy the time and not worry about the person with dementia getting enough to eat.

For volunteer coaches who were training other volunteers or family caregivers at the respite center, information was included about coaching adult learners. The coach is instructed to

use assessment data and prior triggers of behavior, building on the caregiver's knowledge to develop a plan that will work for both members of the dyad. We adopted a train-the-trainer approach for the coaches, first using the two-part training the coaches in a group, then observing as each coach trained a caregiver, and giving "booster sessions" monthly until the coaches are proficient and comfortable with the process.

EVALUATION

To date the C3P model has been tested for both training outcomes and caregiver/PWD outcomes in three proprietary nursing homes in North Carolina and one in South Carolina, and in two respite care centers in South Carolina. The process of testing the C3P model in private homes and respite centers was approved by the Institutional Review Boards for Human Subjects at the Medical University of South Carolina, and the testing of the model in nursing homes was approved by the University of North Carolina Wilmington. Our greatest success with the model has been in the respite care centers where our volunteer coaches had sufficient time and resources to implement the process, and there was a real dedication by the management team and staff to change the culture of meals. In these cases, PWD experienced positive outcomes in behavior, meal intake, and weight gain. Additionally, caregivers reported greater satisfaction with the quality of meals. Staff and volunteers both championed the process and used the model as a way to examine other issues within these social programs for possibility of change with family caregivers reporting an ability to adopt most of the changes in the home.

IMPLICATIONS FOR PRACTICE

Implementing a change in an event that happens three times a day, and sometimes more, over the entirety of our lives, such as meals, may on the surface seem simplistic. However, meals are such an embedded and ritualized process that the change must be addressed on several levels, especially when dealing with a population with a cognitive impairment. For occupational therapists, the activities of eating, preparing or enjoying mealtime are essential tasks for clients and should be considered within the complexity of the familial roles and routines. Using a model that addresses the complexity of this change, such as the Social Ecological Model, that can be reframed into an easily assimilated process (e.g., the C3P model) may be effective. Additionally and importantly, this model could be adapted to facilitate change in other ADLs within the dyad as the PWD declines. As clinicians who work with caregivers of PWD often hear, "I just managed to figure out how to accomplish this task and then he/she changed," progressive cognitive loss results in change in ability to perform simple tasks. Caregivers need to have a model that offers them flexibility in their thinking as well as a basic toolkit of actions that could work across their loved one's life.

An interprofessional team approach supports change by caregivers and offers a holistic approach to complex issues. Whether in a residential facility or in the community, the rehabilitation professions, especially occupational therapy, are key players in promoting nutritional and oral health among PWD (Bellomo et al., 2005; Dolhi & Rogers, 2002). The focus of the C3P model on preserving strengths for as long as possible while providing appropriate support is fundamental to the occupational therapist's practice. Occupational

therapists would be instrumental in assessing the functional capacity of the PWD to manage the “process” of eating and to promote oral health (i.e., *Change the Person*) and provide appropriate adaptive equipment for the meal and for oral care (i.e., *Change the Place*), as well as the caregiver’s capacity to provide assistance while supporting the individual’s remaining functional strengths (i.e., *Change the People*). Ongoing evaluation by the occupational therapist would result in adaptations to mealtime and oral health strategies that could be taught to the caregiver as the PWD declines. Thus, the occupational therapist in conjunction with healthcare team members preserves the dignity of the PWD and the social relationship with the caregiver at mealtimes.

Finally, in the face of no Advance Directives, caregivers may be questioned about their preference for “feeding options” in late-stage dementia. Since major geriatric medicine and palliative care groups no longer recommend the use of tube feeding for PWD in late stage, caregivers can be assisted to make decisions for care by knowledgeable health care team members (Fischberg et al., 2013; Hanson et al., 2013; Workgroup, 2013). For these individuals where total hand feeding assistance is needed, clinicians need to recall that family caregivers may be more willing to accept this final change if the caregivers know that their loved one is receiving the tailored care they need (Lopez & Amella, 2012).

SUMMARY

The purpose of this paper is to explicate a change model for caregivers of PWD to assist them in facilitating meals in the home, at community-based programs and in institutional settings. Building on a Social Ecological Model, the *C3P Model – Change the Person, Change the People, Change the Place* offers a clear method to adapt care strategies to foster independence while providing appropriate support as the person with dementia cognitively and functionally declines. This paper described the process of incorporating this model in settings, examples for training, and how occupational therapists and other health professionals can contribute to this important activity, especially within the domain of mealtimes, that promotes quality of life throughout life.

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References

- Alagiakrishnan K, Bhanji RA, Kurian M. Evaluation and management of oropharyngeal dysphagia in different types of dementia: A systematic review. *Archives of Gerontology and Geriatrics*. 2013; 56(1):1–9.10.1016/j.archger.2012.04.011 [PubMed: 22608838]
- Amella E. Resistance at mealtimes for persons with dementia. *Journal of Nutrition, Health and Aging*. 2002; 6(2):117–122.
- Amella E. Feeding and hydration issues for older adults with dementia. *Nursing Clinics of North America*. 2004; 39(3):607–623. [PubMed: 15331305]
- Amella, E.; Aselage, M. Mealtime difficulties. In: Boltz, M.; Capezuti, E.; Fulmer, T.; Zwicker, D., editors. *Evidence-based geriatric nursing protocols for best practice*. 4. New York City: Springer Publishing Company; 2012. p. 453-468.

- Aselage, M. PhD Dissertation. Medical University of South Carolina, UMI Dissertations; 2011.
Feasibility of implementing a web-based dementia feeding skills training module for nursing home staff. AAT 3485013
- Auer S, Reisberg B. The GDS/FAST staging system. *International Psychogeriatrics*. 1997; 9(Suppl 1): 167–171. [PubMed: 9447440]
- Bell CL, Tamura BK, Masaki KH, Amella EJ. Prevalence and measures of nutritional compromise among nursing home patients: Weight loss, low body mass index, malnutrition, and feeding dependency, a systematic review of the literature. *Journal of the American Medical Directors Association*. 2013; 14(2):94–100.10.1016/j.jamda.2012.10.012 [PubMed: 23246236]
- Bellomo F, de Preux F, Chung JP, Julien N, Budtz-Jorgensen E, Muller F. The advantages of occupational therapy in oral hygiene measures for institutionalised elderly adults. *Gerodontology*. 2005; 22(1):24–31. [PubMed: 15747895]
- Brookdale, F. The National Group Respite Program. n.d. from <http://www.brookdalefoundation.org/Respite/respiteprogram2008.html>
- Burgio L, Collins I, Schmid B, Wharton T, McCallum D, DeCoster J. Translating the REACH caregiving intervention for use by area agency on aging personnel: The REACH OUT program. *The Gerontologist*. 2009; 49(1):103–116.10.1093/geront/gnp012 [PubMed: 19363008]
- Caspar S, Cooke HA, O'Rourke N, Macdonald SW. Influence of individual and contextual characteristics on the provision of individualized care in long-term care facilities. *Gerontologist*. 2013; 53(5):790–800.10.1093/geront/gns165 [PubMed: 23292437]
- Castle NG, Anderson RA. Caregiver staffing in nursing homes and their influence on quality of care: Using dynamic panel estimation methods. *Medical Care*. 2011; 49(6):545–552.10.1097/MLR.0b013e31820fbca9 [PubMed: 21577182]
- Corps S. Senior Companions: Making independence a reality. n. d., 2013. Retrieved October 12, 2013, from <http://www.nationalservice.gov/programs/senior-corps/senior-companions>
- Dolhi CD, Rogers JC. Dementia, nutrition, and self-feeding: A systematic review of the literature. *Occupational Therapy in Health Care*. 2002; 15:59–87. [PubMed: 23952023]
- Fischberg D, Bull J, Casarett D, Hanson LC, Klein SM, Rotella J, et al. Five things physicians and patients should question in hospice and palliative medicine. *Journal of Pain and Symptom Management*. 2013; 45(3):595–605.10.1016/j.jpainsymman.2012.12.002 [PubMed: 23434175]
- Fisher GG, Franks MM, Plassman BL, Brown SL, Potter GG, Llewellyn D, et al. Caring for individuals with dementia and cognitive impairment, not dementia: Findings from the aging, demographics, and memory study. *Journal of the American Geriatrics Society*. 2011; 59(3):488–494.10.1111/j.1532-5415.2010.03304.x [PubMed: 21391939]
- Fjellstrom C. Mealtime and meal patterns from a cultural perspective. *Scandinavian Journal of Nutrition*. 2004a; 48(4):161–164.
- Fjellstrom C. Mealtimes and meal patterns from a cultural perspective. *Scandinavian journal of Food & Nutrition*. 2004b; 48:161–164.
- Gaugler, JE.; James, B.; Johnson, T.; Scholz, K.; Weuve, J. 2013 Alzheimer's Disease Facts and Figures. Vol. 9. Chicago, IL: 2013.
- Gitlin LN, Corcoran M, Winter L, Boyce A, Hauck WW. A randomized, controlled trial of a home environmental intervention: effect on efficacy and upset in caregivers and on daily function of persons with dementia. *Gerontologist*. 2001; 41(1):4–14. [PubMed: 11220813]
- Hanson LC, Ersek M, Lin FC, Carey TS. Outcomes of feeding problems in advanced dementia in a nursing home population. *Journal of the American Geriatrics Society*. 2013; 61(10):1692–1697.10.1111/jgs.12448 [PubMed: 24083403]
- Haumschild MS, Haumschild RJ. The importance of oral health in long-term care. *Journal of the American Medical Directors Association*. 2009; 10(9):667–671.10.1016/j.jamda.2009.01.002 [PubMed: 19883892]
- Hepburn K, Lewis M, Sherman CW, Tornatore J. The Savvy Caregiver Program: Developing and testing a transportable dementia family caregiver training program. *The Gerontologist*. 2003; 43:908–915. [PubMed: 14704391]

- Hepburn K, Lewis M, Tornatore J, Sherman CW, Bremer KL. The savvy caregiver program: The demonstrated effectiveness of a transportable dementia caregiver psychoeducational program. *Journal of Gerontological Nursing*. 2007; 33(3):30–36. [PubMed: 17378189]
- Jensen GL, Compher C, Sullivan DH, Mullin GE. Recognizing malnutrition in adults: Definitions and characteristics, screening, assessment, and team approach. *JPEN: Journal of Parenteral and Enteral Nutrition*. 2013; 37(6):802–807.10.1177/0148607113492338 [PubMed: 23969411]
- Katz S, Downs T, Cash H, Grotz R. Progress in the development of the index of ADL. *The Gerontologist*. 1970; 10:22. [PubMed: 5421020]
- Lopez RP, Amella EJ. Intensive individualized comfort care: making the case. *Journal of Gerontological Nursing*. 2012; 38(7):3–5.10.3928/00989134-20120605-02 [PubMed: 22765512]
- McLeroy KR, Bibeau D, Steckler A, Glanz K. An ecological perspective on health promotion programs. *Health Education Quarterly*. 1988; 15(4):351–377. [PubMed: 3068205]
- Rasheed S, Woods RT. Malnutrition and quality of life in older people: A systematic review and meta-analysis. *Ageing Research Review*. 2013; 12(2):561–566.10.1016/j.arr.2012.11.003
- Robinson GE, Gallagher A. Culture change impacts quality of life for nursing home residents. *Topics in Clinical Nutrition*. 2008; 23(2):120–130.
- Teri L, McCurry S, Logsdon R, Gibbons L. Training community consultants to help family members improve dementia care: A randomized control trial. *The Gerontologist*. 2005; 45:802–811. [PubMed: 16326662]
- Wang SY, Shamliyan TA, Talley KM, Ramakrishnan R, Kane RL. Not just specific diseases: Systematic review of the association of geriatric syndromes with hospitalization or nursing home admission. *Archives of Gerontology and Geriatrics*. 2013; 57(1):16–26.10.1016/j.archger.2013.03.007 [PubMed: 23578847]
- Watson R, Green S, Legg L. The Edinburgh Feeding Evaluation in Dementia scale #2: Convergent and discriminant validity. *Clinical Effectiveness in Nursing*. 2001; 5:44–46.
- Workgroup ACW. American Geriatrics Society identifies five things that healthcare providers and patients should question. *Journal of the American Geriatrics Society*. 2013; 61(4):622–631.10.1111/jgs.12226 [PubMed: 23469880]
- Young K, Bunn F, Trivedi D, Dickinson A. Nutritional education for community dwelling older people: A systematic review of randomised controlled trials. *International Journal of Nursing Studies*. 2011; 48(6):751–780.10.1016/j.ijnurstu.2011.03.007 [PubMed: 21550606]