What Caregivers have Taught Me: Reflections from an Adult Day Care Setting

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Abstract: According to the National Study of Long Care Providers, there are 4,800 adult day centers nationwide (Centers for Disease Control and National Center for Health Statistics, National Study of Long Term Care Providers, 2012). I had the privilege of being a founder and owner of one of these centers for 17 years. This narrative reflection focuses on my professional experiences with caregivers' decision-making journey in adult day services. As I reflect back on the process, I was on my own quest to solve a problem I had identified while working in long–term care. I queried how to deliver supervised care to older adults without it feeling like congregate care. In another town, there was an adult day center which was located in a single family home. After seeing this center, I realized I had found the answer and subsequently started a center in a caregiver palatable house. I did not realize at the time that the customers and caregivers were a packaged deal. The reflections I offer are based on my professional understanding and growth through direct practice experience with caregivers, and what I have learned from caregivers about their decision-making process in adult day services.

Keywords: relationships, aging

Reflections on Care Giving Decision-Making

There are approximately 270,000 participants in adult day services who have many different reasons for needing out-of-home care (Harris-Kojetin, et al, 2013). Admissions to centers serve a variety of customers including those who need respite care, therapy, nursing services, and physical and/or mental stimulation. (Illinois Department on Aging, August, 2015). The mainstay of adult day center care is that customers are able to remain in their homes, or the homes of a loved one, while receiving care at the center during the day time (Gitlin, et al, 2006). The center I owned had a customer population based on the admission criteria of adults 18 years or older. The population included adults with closed head injuries, developmental disabilities, seniors with Alzheimer's disease or related dementias, or individuals in stages of recovery from acute illness.

Reasons for admission to the center were as varied as the attendance schedules of the customers. From my experience as a center owner, I have learned the complexities of caregiving. Caregiving is a generic term used to describe how anyone, from the mailman or the grocery store clerk, simply looks out for another person, and may provide some physical assistance. In literature, they are often divided into two categories, paid (formal) and unpaid (informal) caregivers, who do different parts of activities of daily living. Roth and colleagues (2015) discuss these definitions and look at caregiving in a refreshingly new way by posing the idea that caregiving isn't always a burden. Caregivers come in all different shapes, sizes, ages, and represent many different family groups. (American Association for Retired Persons and National Alliance for Caregiving Report, 2015). Most commonly, the caregivers in adult day services were spouses, significant others, children, grandchildren, siblings, and on occasion, hired professional or private caregivers. Not all of these caregivers considered the process a burden. Some would verbalize to me that it was a privilege to care for a loved one. Attitudes about care giving can change from generation to generation, based upon the history of relationships, cultural heritage influences, and belief systems (Sun, et al, 2012).

While gaining experience working with caregiving families and support groups, I discovered that caregivers either wanted to be responsible for decisions, or that they were not used to making decisions. Many seemed to have difficulty realizing and deciding when it was time to place their loved one in an out-of-home setting.

Culturally Diverse Caregiving

Different cultures often take care of their care recipients according to the beliefs and values of their cultural heritage (Dilworth-Anderson, Gibson, 2002).

However, if the caregiver has become Americanized, there is a possibility that there may be conflicting generational beliefs (Sun, 2012). I have observed that it is especially challenging for care recipients with dementia who are from a different culture and who speak English as a second language. I experienced this first hand with several customers who were born in other countries and moved here to live with relatives. It was a difficult adjustment for these customers to be introduced to a new culture at this stage in their lives, especially those with dementia. It seemed to decrease their ability to tolerate the communication difficulties surrounding their care needs. The customers would call out in their native language, and often became agitated when direct care was given. Some individuals with dementia may not be able to adjust to an adult day center care, unless they participate in a culturally relevant center. In larger cities this can be an option. In Chicago, for example, there are adult day centers that offer care to culturally diverse populations such as Russian, Chinese, Korean, Vietnamese and Hispanic (Illinois Department on Aging, 2007). An organization, the Coalition of Limited English Speaking Elderly, has member agencies that address some of these concerns in their resource of language lists for older adults. Customers may be at risk, as their dementia progresses, to revert back to their language of origin (Alzheimer's Association, 2014). The most difficult decision faced by caregivers was their original decision, if or when to start out-of-home care.

Initial Decision-Making Observation

Often at my center, the decision to enroll would be deferred to the client who had the memory loss. When caregivers left the decision to attend adult day care to the care recipient, they often chose not to attend. Through the experience of working in direct practice with caregivers, I was able to observe the difficulty a caregiver had in making that initial decision to use out-of–home care. When faced with a caregiver who is having decision difficulty, I had success with breaking down the process into eight steps, taking one step at a time (see Figure 1 below).

Figure 1: Decision to Place in ADS: The Eight Step Process

Making the Decision: An the Eight Step Plan

The plan begins with the identification of decision-makers, legal and emotional, who should be included in the process. A family member of a potential client taught me this lesson by informing me one day, after meeting with her for several weeks, by saying ,"I think I should talk to my sisters about taking mom to the center." All the decision-makers should be identified before the process begins. Decision-makers should create a list of what they see as the pros and cons of adult day services for their loved one. After the lists are complete, it is the professional's responsibility to take each item and conduct a group review. Discussion points should include a new interpretation of services, such as considering adult day services as a treatment approach to memory loss or other physical and mental issues. Another focus point should be benefits caregivers may never have considered. Example focal points may be easy access to medical questions, therapy services, or transportation to doctor's appointments. The best results from these discussions were achieved when all decision-makers had input at the same time. In some instances, this may require evening home visits. The extra time is an investment in rapport development and creates a non-intimidating and friendlier environment for discussion.

I like to think that adult day services invented the offer of a flexible schedule in health care. Centers can be open up to six days a week (some seven) and have hours that accommodate caregivers' work schedules; they can also bill by the hour, day, week or month, and often offer sliding fee scales (Met Life, 2010). Services may vary according to the type of center (NSLTCP, 2012). This schedule flexibility appeals to caregivers because it offers the ability to gradually introduce the center to the care recipient. Routine schedules of at least two days a week should be established in consideration to both groups (Savard, Leduc, Lebel, Beland, & Bergman, 2009). This will help the caregiver plan stress-relieving activities, and the care recipient–especially with those with memory loss–to find comfort in a routine (Zarit, et al, 2014).

I recommend the pre-paid trial time period to encourage caregivers to commit to their decision of adult day services instead of a more intimidating contract. As you utilize this plan, there may be a point at which you could include the care recipient in the process. The decision as to when and how to include the care recipient should be determined by the degree and type of impairment.

Once a decision is made to use adult day services and the pre-paid trial schedule is confirmed, transitioning into accepting the center's population is the next hurdle for the caregiver and care recipient. This part of the process is similar to applying the theory of teenager's tough love as a persuasion technique. This approach from a caregiver's perspective is evaluating their motivation to be a caregiver and keep their loved one out of more confined care. Additionally, they must remain healthy, both physically and mentally, to deliver care (Schulz & Sherwood, 2008). This means they must get enough rest, maintain healthy eating habits, exercise, and take time for themselves. The need for caregiver wellness is often stressed by researchers (Pallor, et al, 2014). Without a wellness commitment, their loved one may need to be moved into more confined congregate care. This is not the outcome families are looking for in adult day care (Zarit, et al, 2011). In actuality, the tough love approach is an avenue that caregivers relate to and appreciate. I recall a situation in which this technique assisted a working daughter in getting her mother to accept adult day care as the better choice. The daughter embraced the tough-love approach and successfully utilized the concept by convincing her mother to attend starting out on a part-time basis and turning into full–time. Another approach for the refusal process which a caregiver taught me was pointing out to her mother that she, as caregiver, also had to work to support her family, but still wanted to care for her mother. There was only one choice for the caregiver, to work as the sole bread winner. She gave her mother two choices: adult day care or confined congregate care. This may sound assertive, but was motivated by necessity.

The issue of timing is also important in the caregiver's decision-making plan in adult day care. Caregivers seek out-of-home care when they have reached their limit of ability to continue care. Reasons for this are multi-dimensional, such as fear of last resort choices, financial pressures, or looking like a failure. Caregivers shared with me that they realized, after seeing the benefits of respite care at adult day services, they should have made the decision months earlier, but were afraid to trust a loved one's care to others. Grateful caregivers' comments would include testimonials, such as, "You saved my life," or "For the first time in months, I slept all night." The implication of these heartfelt comments is that it gave them their freedom and autonomy back while helping them to realize what they had given up to be a caregiver. On rare occasions, families would make a decision to move to confined congregate care after this realization.

Building Decision-Making Rapport with Caregivers and Customers

It is hard to turn daily care of a loved one over to a stranger, even though we are identified as experts. Perhaps the reason for this could be a symptom of guilt or stressors in the care relationship (Austrom, et al, 2014). Verbal reassurances cannot convince some caregivers that their mother had a wonderful time while she was at the center, and was laughing, smiling and talking throughout the day. Many times a care recipient was picked up by their caregiver and asked, "What did you do today Mom?" A usual reply: "Nothing, just sat. I was bored." This response, though inaccurate, was often believed by families. Technology, in the form of videos and mobile apps, offer adult day care centers the ability to demonstrate the engagement of the care recipient in the program to the caregivers with the added benefit of reassurance. Similar to what is used in child day care, parents/caregivers are reassured that the child/adult is safe and engaged in activities by a mobile app with a video (Tjarder, A. 2012).

Expectations were high by caregivers that the care recipient would love the center immediately, and begin to socialize with peers. Often this was not the case because an adjustment period is needed. If a family made it through the adjustment period, then chances were they would begin to see changes in their loved one. Small changes observed were more smiles, sleeping better, improved appetite, and even increases in cognitive abilities from physical and mental stimulation at the center. These changes take time, but they can happen. An example of establishing a rapport with a dementia customer occurred one day when I was in a local building supply store. I recognized one of my customers wandering around the store appearing lost. Following a short distance away, I spotted her husband as she came running up to me laughing and smiling with arms outstretched. She threw her arms around me and gave me a very big smile while hugging me and attempting to verbalize, "You're…yes… are…you….I." She could not remember my name nor engage in a conversation, but recognized me as someone who cared for her in a special way. We had established a rapport through an adult day center, as caregiver and care recipient.

To illustrate how important adult day centers can become to care recipients, I will share this story of an individual who had moderate dementia and attended the center several times a week. The caregiver was a long time spouse. One scorching summer day, on a day the customer was not scheduled, he showed up at the door of the center with a stranger who asked if the customer belonged at the center. Once confirmed by staff, the stranger proceeded to share the story that the customer was found walking alone in the street in the hot sun appearing to be lost. The stranger stopped the car and asked if he was alright. The customer was able to communicate enough information that the driver understood he was looking for someplace or someone. Worried that he was becoming overheated, the stranger decided to offer him a ride to my adult day center located several miles down the road and ask if he belonged there. Though the customer was suffering from dementia, he had left his house, walked over several miles to find the place that felt like home and where there were friends. These strong bonds can develop between center staff and customers given time to grow. Some individuals remain in care at centers for years at a time; as a provider, the longest stay I experienced was eleven years.

Caregiving Decision-Making Via Support Groups

According to the Met Life Survey, 58% of the adult day services include monthly caregiver support groups. The groups often run the gamut of emotions and can include tears and laughter in the same meeting. Caregivers share their stories, their worst days and best days. I have heard caregivers admit to feeling irritable toward their care recipients. Many times they described feeling frustrated when they were asked repetitive questions. Some responded by saying, "Don't you remember? I told you what time this morning," followed by feelings of guilt and remorse. Being able to share common experiences in a support group, offers caregivers opportunities to speak about frustrations, anger and fears of caregiving (Alzheimer's Association Support Groups, 2015).

Support groups offer a safe and secure place for caregivers to express their inner–most feelings in a supportive, "we have all been there" environment. In my center, caregivers often expressed a deep–seeded frustration with memory loss. A caregiver expressed this very emotion in a meeting once, by explaining how they were finally able to overcome this feeling by a realization that they had to change. The care recipient is unable to change, and as the disease process continues, the caregiver must become adaptable. It becomes a matter of reframing the caregiver's thought process and not that of the care recipient (Paller, et al, 2014). The revelation that your parent or spouse is no longer able to be in control, and by default, you are in control, is a big step in getting rid of the anger and frustration. Once this caregiver was able to put what needed to be done into words, the other caregivers agreed and provided support. If caregivers are annoyed by irritating behaviors, they are the ones who must reframe how they respond.

In support group, caregivers would often share helpful care tips. One creative tip was shared by a spouse caregiver trying to maintain her sense of humor. With some embarrassment, she shared her care tip for responding to repeated requests for daily aspirin from her spouse. Despite the fact that the doctor did not recommend daily aspirin, her spouse was fixated on it. She came up with her own innovative solution. She put white breath mints in an aspirin bottle and gave him his "daily" aspirin. The physician approved of this intervention which preserved the dignity of the care recipient.

In a supportive environment, it is helpful to have caregivers identify their caregiver deal–breakers. Borrowing from a business term, I would ask them in the support group what it would take for them to place their care recipient in more confined care. Answers varied, depending on the type of relationship with the care recipient. Frequent responses from the caregivers included physical aggression, incontinence or not recognizing the caregiver. By acknowledging their deal–breakers in advance, caregivers were more prepared for making the decision to move their loved one into the next level of care.

Anticipatory Transitional Decision-Making

Changing levels of care is never an easy process for the caregivers or the care recipients. Caregivers often don't want to acknowledge that the level of care required has changed because they are afraid of what the future will be. This transition is difficult for everyone concerned. The care plan process is often the perfect venue to discuss any observed changes and possible outcomes. The Met Life survey has noted that 96% of adult day centers use care plans as a tool to assess changes in the customers, and to update treatment, functional status, and medication information (Met Life Survey, 2010). Using a gradual approach is the best method to assist caregivers through the transition process. Often caregivers have said to me, "You have to be the one to tell me when mom is too much to care for." These are difficult conversations, but safety issues provide assessment tools for caregivers and professionals to use when deciding if or when to transition to confined care. I found that caregivers appreciated openness and frankness in transition discussions, and it is what I have labeled "anticipatory transitional decision-making." Everyone is a beneficiary if the process is the "anticipatory transitional" method of taking gradual steps, and having open and frank discussions along the caregiving journey.

Caregivers have taught me that caregiving is meant to be a generic term. Caregivers are not always bound by a formal relationship to the care recipient, but can be bound by simply the process of caring for another person (Zarit, 2011). However, it can also be a form of duty. At times, siblings compete to have the responsibility to control the care of their loved one. The responsibility may shift from one caregiver to another as caregivers need a break. In my experience, it was not uncommon for customers to be rotated by family members and attend one month at a time during the rotation. Caregivers would do better and be able to care longer for their care recipient while they were in an adult day care when the responsibilities were shared with others.

Though I was the professional, the customers and their caregivers in adult day services were excellent educators. In my adult day center, I could not decide who was the customer, the family or the care recipient. Assuming the role of a caregiver as an adult day services provider taught me that caregivers are very much a package deal. There are some people who come by it naturally, and those who try harder to succeed. During a support group, a spouse offered an insightful response, "People ask me, now that my wife is gone, would I do it again knowing how hard it was? I really had to think about it, but in the long run, I would. I may do some things differently, but I would do it." Reflecting on my caregiver experiences as a provider of adult day services, I agree, I would do it again. I may do things differently, because experienced caregivers are knowledgeable educators.

Recommendations for Future Research and Practice

As I reviewed the literature for this reflective article, I discovered that there are gaps in literature for adult day services. Though this service has been around in its earliest form since 1940 (National Adult Day Services Association, 2015), there is little information about how important it is in assisting families with loved ones to age in place. Another aspect which seems to be overlooked is the inherent cost effectiveness of adult day services in a nation of increasing and complicated health care costs. Since I have sold my business, I am able to look at adult day services in a more insightful and objective manner, which leads me to suggest that there are multiple areas of potential research, and opportunities for data collection in this industry. There are several quantitative surveys such as The Met Life National Study on Adult Day Services, Glenworth 2015 Cost of Care Survey, and the survey from the National Study of Long Term Care Providers.

These surveys provide statistical information, but there needs to be more exploration into qualitative studies on such topics as adult day service's role in assisting older adults to age in place, customer's adjustment to adult day care, and social engagement activities. In addition, there are multiple models of adult day services and it would be advantageous to have data about which models provide care most successfully for specific populations. I will acknowledge first–hand, that while data collection could be a challenge, providers would welcome partnering with researchers in an effort to educate the caregiving public about the wide range of therapeutic and multi-dimensional services.

As a practitioner in this industry, I found adult day center program directors to be seriously committed to providing services to their customers and families. Nevertheless, I was able to identify specific issues which may need to be addressed by the industry in the future. 39% of ADS centers are free standing, however, a majority are part of a parent company (Met Life Survey, 2010). The parent companies are from a wide variety of private, governmental, religious, and health care affiliations. This creates layers of administration between the adult center program directors and their fiscal administrators; layers that can encumber the direct delivery of services to the customer and families. While this wide variety of affiliations enhances the multi-levels of service flexibilities, it also creates frustrations and impediments to direct program delivery. As the national need for aging services increases, this market pressure may afford researchers and providers the opportunities to come together in a mutual national service plan that focuses on adult day services.

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