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Consumer Perspectives on Quality in Adult Day Care

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Abstract

Purpose: The purpose of this project was to gain insight into the quality of care and services provided through adult day care from the user's perspective. **Design and Methods:** The project utilized 13 focus groups to explore aspects associated with user needs, preferences, and satisfaction with adult day care centers. **Results:** Focus group participants described aspects of adult day care that are important in delivering quality care, program features that are effective, and key areas in need of improvement. Ensuring the safety of clients; having caring, friendly, and compassionate staff available to provide one-on-one attention; engaging clients in stimulating activities; and providing the opportunity for clients to socialize with others were the most salient features of care. Potential areas of improvement for specific centers included enhanced communication with caregivers regarding clients' well being and program events and activities, modifications to the physical environment, improving the quality of food, and ensuring consistent transportation services. In addition, focus group respondents noted that adult day care programs need to be better publicized and made known to the community. **Implications:** Findings identify dimensions useful for provider organizations and regulatory agencies to use in their quality improvement efforts.

INTRODUCTION

Assuring quality in the provision of care has become a pivotal aspect of health service delivery. Quality assurance takes on heightened relevance at a time when there is a growing movement to empower consumers in long-term care and to embrace self-determination and autonomy. A focus on quality of care is particularly important in a climate that emphasizes cost-containment, efficiency, and profit margins. Concern about the quality of care in the long-term care segment has typically focused on the nursing home and home care environments. Other types of long-term care facilities and community-based programs have received less attention. In particular, quality and satisfaction measurement in adult day care (ADC) have not been adequately addressed by previous and current research. Given that adult day care centers do not routinely collect quality and user satisfaction information, this information is seldom used in care planning or efforts to ensure quality assurance and improvement. At the same time, because there is limited practice in identifying what is important to consumers in their care, to date, there are no known measurement tools that have been developed with input from users of ADC. For the limited number of adult day care facilities that have used satisfaction surveys, mostly in response to statewide initiatives that include those facilities as part of their overall home and community-based waiver programs, the instruments used have relied on providers and policymakers to generate quality and satisfaction questions with little or no inclusion of user-defined dimensions of care.

ADC has become an important option in the array of long-term care. Adult day services represent an alternative to current modes of institutional and community-based long-term care delivery that are both costly and highly regulated. In addition, through provision of community-based health, social, and support services to both physically and mentally impaired older adults, ADC offers respite and reductions in caregiver stress to often overburdened informal caregivers (Conrad & Guttman, 1991; Lawton et al., 1989; Panella et al., 1984; Rathbone-McCuan, 1990; Strang & Neufeld, 1990; Zarit et al., 1998). Despite the apparent benefits of ADC, coupled with the anticipated continued growth of such care as the number of disabled elderly rises, there has been little systematic research on the quality of adult day services. Previous studies have examined the organization, structure, financing, and service utilization of adult day care, and most evaluations of day care programs have focused on financial costs, risk of

institutionalization, and changes in functional status (Harder et al., 1986). Very few studies have examined client satisfaction and quality of care. Those that have indicate that consumer satisfaction with ADC is generally high (Rothman et al., 1993; Strain et al., 1988; Weissert et al., 1990). While some investigations have modeled the associations between client characteristics and program elements with satisfaction, these studies failed to use measures of satisfaction that were derived from the consumer's viewpoint. In all of this research, the experiences of the participants themselves and their definitions of quality have been largely overlooked. While most findings have been based on the reports of caregivers and providers, consumers' viewpoints may be quite different from the quality judgments of professionals or informal caregivers. Another limitation of the current research is that conceptualization of satisfaction is typically based on a single-item measure or items that are factor-analyzed and summed into scales, and in some cases, general health satisfaction scales or proxy measures are employed (Buelow & Conrad, 1992; Henry & Capitman, 1995; Strain et al., 1988; Weissert et al., 1990). In one exceptional study, Beisecker et al. (1996) explored caregivers' perceptions of benefits and barriers regarding the use of ADC. While this study did not apply an explicit conceptual framework, it incorporated several elements that parallel major components of the Andersen behavioral model of health care utilization (Andersen & Newman, 1973). This examination, however, was specific to caregivers of individuals with Alzheimer's disease.

Consumers need information on quality in order to make informed decisions about facilities that are most fitting to their needs. In addition, consumers' perceptions of what they need and what makes for high-quality service can provide a basis for setting standards and improving care. Moreover, data that provide evidence of the benefits of ADC, as evidenced by consumer satisfaction, can inform policy and funding decisions that could expand access to services. As Weissert et al. (1990) note, the success of ADC truly depends on factors that determine satisfaction and contribute to continued utilization.

Conceptual Framework

The conceptualization of quality and consumer satisfaction in a variety of fields including management, marketing, and social psychology provides the basis for the conceptualization of quality and consumer satisfaction in adult day care.

The quality perspective. The work of Martin and Kettner (1996) addresses the issues of quality and customer satisfaction as they relate to measuring the performance of human service programs. As these researchers note, service quality is a salient element of the total quality management (TQM) movement. The TQM approach has extended the classical definition of productivity to include quality considerations. In this regard, productivity is increased when programs provide high-quality services and is reduced when programs offer low-quality services. TQM focuses on promoting quality in programs by emphasizing the development, use, and reporting of performance measures. Performance measurement is a valuable management tool in that it provides for the regular collection and reporting of information about the efficiency, quality, and effectiveness of programs. Quality performance measures typically focus on two assessments: 1) outputs related to quality dimensions and 2) consumer (client) satisfaction. Output performance measures provide information on how well a program is doing in terms of the types and amounts of services provided. Within this broader spectrum lie various dimensions of quality that constitute service quality. To implement and use quality measures to evaluate performance, one must select those quality dimensions to be used and then relate the dimensions to specific characteristics of the program. One quality dimension used in many programs is reliability or consistency. An example of translating this to an ADC setting is examination of how consistently transportation is provided within expected pick-up and drop-off times. Another related quality dimension is responsiveness to consumers. In ADC, this aspect would be characterized by whether staff responds to clients when needs must be met such as toileting or assistance with eating. Selecting appropriate quality performance measures that relate to a program's mission, goals, and objectives is essential if evaluations are to be useful. Similarly, client input is critical for the selection of quality performance measures in order to truly maximize program improvements. Therefore, performance measures must represent those dimensions of quality that reflect a program's goals and are also meaningful to service recipients.

Conceptualizations of consumer satisfaction with services. Consumer satisfaction has often been used as an indicator of service quality. There are various conceptualizations of satisfaction that are germane to depicting this association. For example, consumer satisfaction is typically conceptualized as the result of an evaluative process, reflecting either an emotional response or cognitive evaluation of the consumer's experience of the service compared to his or her expectations about the service (e.g., expectations have been met or exceeded) or an affective

response that incorporates a consumer's comparison of performance to some pre-service encounter standard (Oliver, 1997; Yi, 1990). Thus, satisfaction may be a function of expectations, perceived performance, and disconfirmation. Models of consumer satisfaction and service quality argue that discrepancies between *ex ante* expectations of a service or good and the product's *ex post* performance are the best predictors of the satisfaction or quality perceived by the customer (Oliver, 1977; 1980; Parasuraman, Zeithaml, & Berry, 1985; 1988). Often times, there is a gap between what an individual expects and what services are offered. According to the gaps model, reducing this gap typically results in greater satisfaction (Linder-Pelz, 1982; Oliver, 1997).

Models of care. The present study was guided by the conceptual frameworks of Andersen's health behavioral model, Donabedian's quality of care paradigm, and Green and Kreuter's PRECEDE/PROCEED model, which is also based on the former two models. Drawing on the works of Andersen (1968) and his colleagues (Andersen & Aday, 1978; Aday, Andersen, & Fleming, 1980; Andersen et al., 1983; Andersen & Newman, 1973), Donabedian (1980), and Green and Kreuter (1991), a conceptualization including elements from models for assessment of quality of care and for investigation of factors associated with consumer satisfaction formed the basis for the study.

Andersen's behavioral model of health care and social services posits three categories of variables that have impacts on service utilization and other outcomes measured by perceived and evaluated health status and consumer satisfaction (Andersen, 1968; 1995). These include predisposing characteristics, enabling, and need factors. Predisposing factors characterize an individual's propensity to use services. Enabling characteristics describe the means that individuals have to access services. Need characteristics identify the level of illness experienced by an individual. Green and Kreuter (1991) developed the PRECEDE/PROCEED model, which is founded in the social/behavioral sciences, epidemiology, administration, and education. Applicable to various settings such as community health education, school health education, and direct patient care settings this model provides a framework to assess an intervention in terms of process, impact, and outcome. Building on the Andersen behavioral model and Donabedian's quality of care model, components of PRECEDE/PROCEED incorporate predisposing, enabling, and reinforcing factors to evaluate outcomes such as process, access, utilization, and health.

Donabedian's classic model of quality of care (Donabedian, 1980) has been applied extensively to medical care quality in general (Donabedian, 1988). In this model formulation, Donabedian specifies three major components of care: structure, process, and outcome. Structure of care includes the physical structure, facilities, and equipment, as well as the administrative and staff organization, including staff-client ratios. Processes of care include behaviors and practices of health care providers, behaviors and practices of patients, staff-patient interactions, and services provided. Outcomes of care include clinical outcomes, as well as patient attitudes, satisfaction, and health-related knowledge. All three components of care – structure, process, and outcome – can be assessed using a variety of approaches, including direct observation, review of medical records, clinical reports, and feedback from consumers. In other words, consumers can express satisfaction with aspects of structure, process, and outcome.

As a body of literature has demonstrated, consumers can play a central role in assessing and defining quality. Quality indicators can be identified and defined by consumers. One of the most effective ways to identify what is important to consumers is to ask them directly. Understanding their perspectives of the care they receive and incorporating these perspectives into the actual development of instruments to measure care are critical to ensuring that measurement tools are designed to be reliable and valid. For a survey to produce accurate and useful results, the questions must be rooted in what users identify as important to them. Therefore, a first step in identifying aspects of care that are of particular importance to a specific setting or population is to collect user feedback. One effective way to gather user feedback is through focus groups. The purpose of focus groups is to collect spontaneous feedback from consumers, to focus on their meaning and experience, and to provide a background for follow-up with quantitative strategies. An effective consumer-centered approach assumes that consumers freely comment on the care delivery process. To do this, consumers must be given the opportunity to voice their opinions about the care that they are receiving, and a focus group is a suitable forum for this. This methodology is an effective vehicle for understanding the participants' perspectives as the recipients of services. The use of focus groups to identify aspects of care represents a methodological improvement over other quality surveys that have relied on a priori identification and classification by researchers. This methodology is the best means of collecting information where the exchange of thoughts and experiences is a fundamental part in exploring and identifying viewpoints of what constitutes quality. Gathering

information in this manner as opposed to collecting a series of responses to pre-defined questions about care experiences supports the development of a user-driven instrument to evaluate care.

DESIGN AND METHODS

The purpose of this research was to identify the important dimensions of quality in adult day care from the perspective of users and caregivers. This pilot project utilized 13 focus groups (seven with clients and six with caregivers) to explore aspects associated with user needs, preferences, and satisfaction with adult day care centers. Four main questions guided the focus group discussions:

1. How do users perceive quality of care in adult day care settings?
2. What elements or aspects of adult day care support their experiences and help them meet their own needs?
3. What aspects of adult day care contribute most to the outcomes that participants hope to achieve through use of adult day care?
4. Why are these particular aspects of service delivery important to its recipients?

A qualitative research technique known as focus-group methodology served as the primary method of obtaining consumer feedback. A focus group is a structured discussion with multiple participants about a certain topic (Kreuger, 1998). An impartial moderator guides the discussion following a predetermined list of key questions. Data from focus groups can help identify and clarify underlying attitudes and beliefs around a given issue. Focus groups increase understanding about the meaning of experiences and events from the consumer's perspective. Further, information from focus groups provides a foundation for determining which aspects of care should be included in a quantitative study. The research team developed and used two written focus-group moderator's guides for clients and caregivers, respectively. All groups met for approximately 1-1.5 hours and were facilitated by the first author. The discussions were recorded on audiotape and transcribed verbatim. Within two weeks of the group, an executive summary was sent to the director of each participating facility.

Recruitment

A list of adult day care facilities in the state of Massachusetts was obtained from the Massachusetts Executive Office of Elder Affairs. Selection of centers focused on capturing a range of variability across sites in terms of for-profit/nonprofit status, medical/social philosophy, and the type of clientele. Specifically, sampling criteria included targeting an equitable number of for-profit and not-for-profit centers, programs that reflect social as well as medical approaches, and dementia-specific and non-dementia-specific centers. The principal investigator (PI) contacted the directors of facilities, explaining the project and sent interested and appropriate facilities a full description of the project, the focus group protocol, and recruitment flyers. The PI developed a plan for the recruitment of care recipients and informal caregivers with each facility director. The plan for recruiting participants was determined by the nature of the facility and protocol determined by the executive director of each site. For example, in some cases, facility staff first contacted potential participants and with their approval, provided names, addresses, and telephone numbers of participants to the PI directly. The PI then telephoned participants and followed up by sending recruitment materials to these persons. At other sites, staff disseminated flyers to care recipients and family members and provided the PI with a list of participants who agreed to attend the session. In a few instances, the PI made a site visit and presented the information to potential participants. In general, almost all of the centers contacted agreed to participate and were extremely interested in obtaining feedback about their individual sites and the services and care provided within their facilities.

Participants

A total of 13 focus groups were held; they were composed of one group with elderly participants with early-stage dementia, two groups with caregivers of participants who receive care in facilities explicitly equipped to serve elders with dementia, four groups at facilities that serve predominantly individuals of diverse minority backgrounds, and six groups held at facilities that were geographically diverse. The focus groups took place from December 2001 to April 2002 in several different cities and towns in the state of Massachusetts. Groups were arranged to suit the convenience of the participants. Each participant received an honorarium of \$20 cash for his or her participation. Before the group began, participants were required to

complete a brief demographic survey and sign an informed consent. Table 1 depicts a demographic profile of the participants.

Table 1. Demographic Profile of Focus Group Participants

	Total Client Sample (%) (n=54)	Total Caregiver Sample (%) (n=36)
Gender		
Female	76	64
Client Age		
65+	67	
Caregiver Age (mean)		59
Educational status		
Less than high school	41	17
Completed high school	32	11
Completed some college	11	33
College degree or more	15	33
Marital status		
Married	24	72
Race		
White	54	81
Health status		
Excellent/very good/good	55	86
Relationship to client		
Spouse		22
Child		33
Client reports on length of time receiving ADC services		
> 6 years	18	
Caregiver reports on length of time care recipient enrolled in adult day care program		
5 or more years		39
Caregiver reports on length of time providing care		
>6 years		25
Employment status		
Full-time		39

Content Analysis

Following detailed reviews of audiotaped focus groups and transcripts and identification of emerging themes and issues, the research team developed a set of measurement domains, coded the group interview responses, and sorted the coded responses into the measurement domains. This analysis used the constant comparative method and the principles of grounded theory as described by Glaser & Strauss (1967). Analysis began by coding each incident in the data into as many categories as possible. Categories were then refined through comparison of new incidents with earlier ones. This process subsequently led to identification of concepts and themes and explanations of how they are related. To ensure agreement of categorization, coding and sorting were conducted independently by two research team members, with discrepancies reviewed, reconciled, and documented. Seven categories were operationally defined and were used to code focus group data. All statements were placed into the category that best reflected the focus of the statement.

RESULTS

Both clients and caregivers were actively engaged in discussions that focused on what they deem as important to the care they receive and how various aspects of the program impacted them. Participants were able to respond to focus group questions in a meaningful way, eliciting information that provided insights on specific program aspects or areas of care that can be used for quality monitoring and evaluation. Focus group participants discussed features of ADC that can be classified into one of seven categories or dimensions of adult day care:

- Staff
- Medical care
- Socialization
- Activities
- Safety
- Transportation
- Caregiver benefits

There was also substantial discussion on other particular aspects of adult day care such as meals, the physical environment, caregiver involvement and awareness, hours of operation, and

program costs. While many of these issues are integral to the care and services that clients receive in adult day care facilities, respondents themselves did not deem them to be the most salient aspects of care that facilitated high quality or contributed to user satisfaction.

Staff

Throughout the discussions, participants continuously reflected on their interactions with staff, particularly the compassion, genuine concern, and respect that staff exemplify in their care for clients. Having supportive and caring staff and enough staff available to provide personal assistance and respond to individual needs and circumstances were viewed as essential factors in the delivery of quality care. Participants also felt that staff should, and in most cases do, exemplify effective communication with family members by keeping caregivers informed of the client's status and any problems that arise, as well as keeping caregivers abreast of events and activities. Suggestions were made on how better to inform caregivers such as issuing a client evaluation or "progress report" on a monthly or quarterly basis, having a scheduled conference with staff to discuss the client's progress or status, developing an individual care plan that sets forth goals, improved coordination in disseminating printed schedules of meals and activities, and dissemination of literature on medical issues and available resources.

Client:

I feel very good and very well cared for and very happy. They [staff] do everything for me, they help me, they make me smile and they do everything to make you happy. They talk with you; they sing with you; they're right there beside you with whatever you need.

Client:

Although I am blind, I have no problem walking around the house. If any changes are made, the staff will inform me before they take place. Then the staff will take me around so that I can become familiar with what has changed. I walk around; I touch things; I ask questions. All this helps me be part of the family. I am quite independent at the center. I like this kind of feeling. It makes me feel I am important. In addition, I can handle my daily living activities by myself. I was very depressed in the beginning when my eyesight was getting worse, but now with the care that [facility] provides, I feel much happier.

Client:

They [staff] constantly encourage me to do the things that I can do and things that I can't do, and I find that some things that I thought I couldn't do, I can do and I just love them for that. They give me a lot of love and respect and I love that.

Client:

The staff here is very helpful. You need help, they're right there to help you and I love this place because the staff here are so loving and nice and helpful to us. When you need help, you get it. I am a diabetic and need help at times, and they are right there to help me. They give me my insulin; they test my blood sugar, and all the help is very good to me.

Caregiver:

I think communication has been a big thing — the staff here communicating with me. If there is something wrong with your parent, they'd call you through voicemails, cell phones, or what have you. They'd keep the patient stable and comfortable until they were able to contact you.

Caregiver:

My mother has a lot of complicated medications and sometimes it amazes me when they call me and they say can you call the doctor and make sure these [pills] are the ones she's supposed to take with these [pills]. That for me is going the extra mile. ...They have a pretty good size group and I think everybody gets that special attention.

Caregiver:

My husband has to go to the bathroom very often and at first felt uncomfortable about asking for help. The staff put him at ease. They expressed their eagerness to assist him. He was relieved.

Medical Care

Both clients and caregivers alike noted the importance of having medical needs attended to, especially for elders who are increasingly frail and disabled. In particular, the availability of nurses to administer medications, take clients' blood pressure, and monitor clients' conditions as well as the provision of medical services and care focused on daily living such as grooming are paramount. In a number of instances, staff alerted caregivers of medical problems, which then prevented severe deterioration and harmful effects.

Client:

They [nurses] take your pressure and they help you out with your medicines and they fill your prescriptions that are sent to you here. They make appointments for you and they'll arrange for transportation. Whatever kind of medical appointment you might have, they'll make sure you get there.

Client:

They take our blood pressure, our temperature and make sure everything is good with us and keep us in good health.

Client:

I can discuss my health condition and my concerns with the nurse anytime. If I am at home, I have no one with whom to talk. My children are all living apart from me. They have their own business to deal with. We can't meet all the time. I consider [facility] staff to be my family.

Caregiver:

They get involved with my mother's problems with the doctor. My mother has to see a heart doctor, a lung doctor, a diabetes doctor. I mean my mother has to see a doctor every other week, and they get so involved. ...and it's my responsibility to call the doctors which I do and I take her, but sometimes if I can't make it to an appointment, they take her and they call me [and tell me] what happened in the appointment and how many prescriptions she's going home with and make sure she follows through. They're so on top of it.

Caregiver:

One of the things for me is that when my mother doesn't speak a lot it's very hard to know if there's anything wrong with her and they are so in tuned to her every need. I drop my mother off in the morning and I pick her up in the afternoon so I get a daily report every single day. I remember one day I picked her up and [staff member] said you know, her urine has a real foul odor to it so she said you might want to have her checked for a urinary tract infection. So I went home and called the doctor, I took her there. Sure enough, she had a urinary tract infection. But that to me is someone that's right on top of things. She picked up on that right away. It's not something my mother could have told me.

Caregiver:

I remember that one time my mother had a stomach pain and couldn't stand it. The ADH nurse tried to contact me, but I wasn't available. The nurse arranged for an ambulance to take my mother to the nearest hospital, which is just across the street. Also, the social worker contacted me and reported about the current situation and my mother's health condition. I was thankful and appreciated what they had done. After my mother returned home, the social worker arranged physical therapy and made other services for my mother's recovery.

Caregiver:

Another fact that I respect about them [staff] is that every patient counts. No matter who you are or what you look like, everybody is beautiful on the inside, and they take the time to search for that person, and I just think that's really remarkable. Even her medical needs have been extremely well taken care of. One morning I brought her in here she was perfectly fine. Two hours afterwards, she started vomiting; she was so sick, it was incredible. She ended up in the hospital for five days because her liver functions were way off. She had no fever, no nothing and [staff member] immediately picked up on that. She called me on my cell phone and said your mother's sick. ... She was being poisoned by the medication she was taking. Now if she had not caught that here, my mother could have died during the night. If I had given her one more dose... but when [staff member] saw her, she just knew something was off.

Socialization

One of the major benefits of ADC is that it provides participants the opportunity to interact with others, make friends, and socialize. Adult day care centers provide a place for elders to go during the day, to be with friends and others like themselves, to prevent boredom, and in some instances, to curtail depression. Respondents described adult day care facilities as their extended families, a place where they and their loved ones felt at home.

Client:

Before I came here, my wife had to go to work and she put my chair by the window and that's where I was when she came home. I owe it all to this center. If I didn't come here, I'd be by myself, here I'm not. I have a hundred friends.

Client:

I was home feeling sorry for myself, and then I came here where it lifted me a lot because here you have other people.

Client:

But I've enjoyed it because I've made a lot of friends since I've been here. I never used to have to get up at 6:00 in the morning. I used to get up, make the coffee, and then go back to bed. Now I get up with ease. I don't even have to have an alarm clock go on. I don't care if it rains or snows, as long as I know I can get here.

Client:

I was alone all the time and I was very depressed. [But coming to the center] it's like a big ray of sunshine because it's so bright and people are so cheerful and everybody talks to you.

Client:

I enjoy being here. I enjoy every time I come in. When I get home and I open my kitchen door to go in my house, I start getting that sick feeling because I live alone, it's very depressing. And then when I come here, the minute I open the door, oh my god, it seems like god is right next to me, and I'm inspired and I love it.

Caregiver:

She's just so happy when she comes home from here; she's been stimulated all day long, she's talked to people. Saturdays and Sundays are very difficult because even though I know she's resting a little bit, she's bored.

Caregiver:

Although my husband is in a wheelchair, he likes the social life. He told me that he has friends to talk to and he enjoys seeing them.

Caregiver:

Socializing I think is another important one because my mother has always been involved with communication with people so I think having the communication with other individuals with the same disease really helps because she can relate with them better than with us at home. They're more on her level on being able to talk and focus. Here, they can relate with her on things that she says.

Caregiver:

Their happiness, their contentment and that's what they seem to be. Mine anyway. She likes the idea that she's with people; no one comes to visit her anymore. It's just she and I against the world so whenever she's here, she's with people, she's communicating, she's being hugged, that's what she loves. She tells them all these stories and she's very happy.

Caregiver:

I think it's the most important thing — meeting other people like herself who are willing to communicate as well as they can and are content with the presence of one another.

Activities

Engaging clients in activities that provide mental stimulation and increase functional capacities is a significant feature of care. Among many facilities, caregivers indicated that there were discernible positive changes in their relatives' behaviors, which was attributable in many cases to the focus on client interaction and participation. For example, some noted that their relatives appeared to be less agitated and more enlivened and communicative after attending the program.

Client:

They motivate you a lot. When you're home, not doing anything, and when you get up and get dressed to come here you know it helps a lot. It gives you something to look forward to and it makes you not be so lazy because when you're home, you're just sitting but when you're here, they make you walk, do exercises and that's good because you wouldn't do that at home.

Client:

The facility helps get the best out of us. The staff and activity coordinator will demonstrate a new activity to let us know that the activity is safe and suitable for elderly people. I have good flexibility, and I am a person who likes to try new things. Besides participating in the exercise classes, I go to English classes five times per week and to Cantonese classes two times a week. Never stop learning is many people's philosophy, and it is also mine. I think it is the secret to keeping healthy and youthful.

Client:

I came here paralyzed, I came here I couldn't move, I couldn't walk. They started making me doing things and they reminded me that if I did things here, I wouldn't be home sitting by myself

so at the time they started doing crafts and things and I started using my hands. I became good at ceramics.

Client:

One day we play bingo, the next day we crochet, the next day we have puzzle words. You know it just keeps your mind going.

Caregiver:

And they get exercise and they get stimulated by activities, game activities, jewelry making, walking, things like that. I think that goes a long way rather than being at home watching television or reading the newspaper.

Caregiver:

I think she's improved quite a bit because she's more active, and before she used to just sit and fall asleep in the recliner and wasn't interested in doing anything. Now when she comes home she wants to go out, go to the store, go take a walk through the mall or something like that. She just wants to be active now where before all she wanted to do was just sit in that recliner and sleep.

Caregiver:

I think it's given her another outlet instead of just being at the house. ... It keeps her mentally stimulated and with a purpose for something to do.

Caregiver:

My wife likes to sing. She learned songs at the Center and even taught me. I was amazed since she has forgotten so much of what she's done. I can see my wife enjoys the activities there.

Caregiver:

There's a big effort to try to stimulate some kind of memory of some function: physical function, singing, artwork, baking. They have simple projects that try to bring people back to something they had done.

Caregiver:

And some of the things are just remarkably imaginative. The thing that you brought up about working on a magazine and finding a picture. It creates some kind of meaning. Here they found things that allow her to look at something and identify something in the real world.

Caregiver:

I can just see a total difference in my mother when she comes here because for one thing, she is around people and at home all she's got is pictures she looks at of her family that she doesn't see, and here she stays occupied; there are so many activities to do. It keeps her mind more active and not thinking of missing her loved ones or not being able to see them. It has helped, me, too, so it really is a benefit for both of us.

Caregiver:

I feel relieved because I feel that our sisters are in a safe environment, and we really don't have to worry constantly about them, and I'm very grateful that they have a chance to have stimulation here, to participate in different activities rather than just sit back in their room and sleep.

Caregiver:

My mother does a lot of arts and crafts and that's really important to her. She brings things home, she shows the family. These are the things that make her happy here.

The timing and scheduling of activities seemed to be problematic for some of the respondents. Specifically, not having activities well planned out, lack of variety in the types of activities, and straying from the schedule were viewed as problematic. Clients expressed that they would like to be aware of what was planned for the day, perhaps by having a monthly or weekly calendar printed and disseminated. They also suggested offering more varied types of activities and activities that were outside of the facility. Some participants noted that keeping to a set schedule for each activity would eliminate the need to cut short other activities.

Client:

I don't think that the organization is as organized as well as it should be. Sometimes they don't know what they're going to do in the day, that they have to tell you later on what they're going to do. They're not ahead of themselves and have the day planned out.

Client:

The only thing that I could think of is hoping that they'd come up with something different instead of the same things we have all the time. They repeat the same things over and over; that's when we start getting really bored.

In some instances, clients expressed the need for more age-appropriate activities and activities that offered more mobility. One facility offered the opportunity for clients to work in a store that was part of the adult day care center. Clients enjoyed working in the store and found it very helpful to be able to buy goods at the facility because they can purchase household necessities and not have to go out to make these purchases.

Client:

The exercise we do here is fine, except that it's very little. The time spent here is sedentary – we don't move around very much except for that few minutes of exercise in the morning. Sometimes that's very short. I'd like to see a walking group.

Client:

I don't think it's enough activities, for so many do nothing but sit. You can get tired of doing that all day.

Client:

I like paint but I don't like the paint that they have because I'm an adult, and the paint that they have is mostly childish, like kindergarten, they paint by numbers and this is aggravating sometimes because you're an adult. They give us kindergarten materials and everybody is not in kindergarten.

Contrary to these clients' frustrations, some caregivers were impressed with the variety of creative activities that are appropriate for clients' levels of cognitive functioning.

Caregiver:

Activities are changed on every half hour so that if someone is not interested, they do not have to wait an hour and a half to move on to something else. They change and rotate their activities every half-hour; most people who are here have short attention spans, so they need to change the activities on a regular basis.

Caregiver:

I also think that the activity at the level that they're capable of is very important. I know yesterday my father was saying, we played bingo and there was some people that they had to give them instructions many times. He apparently caught on quickly, but there were other people who were having difficulties with it. And it also showed me that the staff was taking the time with the people who couldn't grasp the concept — that it wasn't just that you walk in and it's a hug and a smile and it's a comforting place to go. People really care about their clients that are here.

Caregiver:

All the things they have here are about the capability level of what my mother can do. I can't think of anything else that she could participate in that she really would be able to do.

Caregiver:

I think they give them a purpose to live; that's the way I look at it. And every person in here is challenged to his or her own abilities. They make them want to get up in the morning and say okay well I'm going to do this, this, and this. And even though my mother doesn't speak, I know that's the way she feels inside because she looks forward to coming here. And the days that she was sick, she was getting depressed being at home. As soon as she came here that first day, she was all excited. She came home; she was smiling and back to laughing again.

Caregiver:

Absolutely they treat her like an adult. Some of the activities that they do, some of the paper things at first struck me as very childish. But to be quite honest, I think it's about what my mother can do.

Caregiver:

I think it [activities] probably covers 75% of the people real well. Your imagination with the physical limitations can only go so far, and I think they do pretty well and if someone wants to work off the norm, you can bring knitting needles and you can knit scarves.

Caregiver:

My mother has never said to me that she is ever bored or that she's doing childish things.

Caregiver:

I think that they give them things that are more appropriate for mental stimulation as to what a patient is at. You could have one table over here that is doing work for a project, the next table over here where my mother is sitting is probably coloring pieces to go with that project, and the next table is probably just putting on glitter. So they're all doing the same project but they're just working on different levels that they're capable of doing.

Safety

One of the most critical aspects of ADC programs is having a physically and emotionally safe environment. Focus group participants concurred that ensuring client safety was an essential factor in the delivery of care, and this encompassed both the physical and emotional well being of individual clients. Integral to emotional safety was the exhibition of staff respect and trust as well as caregivers' knowledge that their relatives were being treated with kindness and were content during the day. In terms of physical safety, all participants felt that the center in which they participated maintained a secure environment in which doors were locked, ensuring that outsiders could not randomly walk in and that clients could not wander off. Centers specializing in care for individuals with dementia and Alzheimer's had alarm systems in place that alerted staff if a client wandered and attempted to leave the facility. The vast majority of respondents felt that the physical surroundings were clean, safe, and provided a home-like environment with a sense of security.

Client:

They keep it safe and look after us the way we feel about things. They worry about our attitudes and this means that we get looked after. Not only physically are we safe, but emotionally we're supported and that's a good thing. If a person looks very downcast and sad, they're right on him and try to find out what the matter is and try to support him.

Client:

They have a buzzer on all the doors, and nobody can get in unless they buzz.

Client:

I think it's safe because of the fact that not just anybody can walk in. It's almost like being at home. The door is not locked but it's closed. Somebody can't just walk in off the street without ringing the bell. They know who's ringing the bell before they'll open the door.

Caregiver:

I think it is important that you know that they're safe, that they're being stimulated, and being well cared for physically as well as mentally.

Caregiver:

Clients are safe. My wife has Alzheimer's disease and is disoriented in terms of time and space. When my wife wants to go to the bathroom, the staff assists her.

Caregiver:

Mostly I feel assured of her safety and security. It sounds platitudinous but I think that that's what I'm most happy with — the fact that she's protected here, too. On the safety issue, there are times my mother would like to flee from anywhere she is, so she has tended at home at times to try and get out of the house and just walk away. She has attempted to here, but they've got an alarm that goes off, and I have seen staff run when they hear that sound.

Caregiver:

Safety. Because they're always right there for the patients. With my mother, she has a problem with getting up and down, up and down, and they're right there for her all the time. I've seen it. I've come in different hours during the day, and I know the care that she's getting. I've just popped in here to see what is going on so I know that she's being well taken care of and she's always very clean. She's incontinent and she's always, always clean and that's very important to me, too.

Caregiver:

I'd like to comment on the safety. That's a major concern obviously for an elderly parent and they're right on top. There's a good ratio of staff to clients. They keep track of everybody because I know with my mother who has some diet concerns, who would wander and visit everybody, they know, they're always right on top of everybody.

Transportation

For many individuals, transportation is necessary to be able to attend the program. In some cases, transportation services were exemplary; however, in others, problems with transportation were a main concern. The major problems identified with transportation services were the lack of consistent pickup times, the length of time required to wait to be picked up, and the duration of time spent on the vans before arriving at the facility or back home at the end of the day. The most noteworthy aspect of transportation services related to the drivers.

Specifically, caregivers regarded the drivers as caring, safe, attentive, and genial. Respondents

indicated that clients always receive help getting in and out of their homes and into and out of the vans, and in some cases, the drivers even go so far as to report client illness or negative behavior.

Client:

Sometimes they come early and sometimes they come late. One time they came to my house at 9:00, and they tell you to be ready at 8:00.

Client:

It is getting much better since we have the 15-passenger new van. It's accessible and I can easily walk to my seat everyday. I feel the drivers are doing a very good job. They respect the elderly, and they care for our safety, and never speed. The van driver escorts me from my house to the van. By the time the van arrives at the center, one of the staff will escort me into the center. I think this is called door- to-door service.

Client:

They'll [drivers] come and take them right to the door and make sure that they're in their house safely.

Client:

The driver is very intelligent and trustworthy so you feel safe around him. You feel that he will actually come get you in the morning and will take you back. He knows where you live, and you're just in very good hands. He's very congenial. He's a very fine person. He's a sweetheart.

Caregiver:

One of the things that I'm very impressed with is that there have been many times when I've been in there and the drivers will come in and will say so and so didn't answer his or her door today. Immediately, boom, they're on the phone, "Why didn't this person come; you better go check on your mother." It's like a constant alert. Those patients could be there for days if they didn't do that. They [drivers] come in and report everything. If the patient is in the van and they're not feeling too well, they'll come in and report it right to the director. They're on top of it immediately.

Caregiver:

The [facility] driver picks her up on time every day, and she returns home safely. She doesn't have to wait for hours for the driver like she would with public transportation.

Caregiver:

Also the transportation service available is a big help to family members since they all work. Therefore, none of us could provide transportation on a daily basis. Also, the transportation comes on time. It is greatly appreciated.

Caregiver:

I was having her picked up by the van in the afternoons but it was taking an hour and a half to two hours to get her home for a 15- minute ride by me, so she was worn out by the time she got home. I decided the heck with that and I would pick her up.

Caregiver Benefits

A major issue raised throughout the discussions in both client and caregiver groups was that there are substantial benefits for caregivers in having their relatives attend adult day care programs. Clients' attendance serves as a respite for caregivers and enables caregivers to detach themselves from the constant duties and worries of providing care. Other significant advantages for caregivers are that they are able to maintain other familial responsibilities such as child rearing and continue their employment as well as educational responsibilities. A number of respondents indicated that attendance at day care has prevented nursing home placement for their relative, primarily because the break from caring helps reduce the physical and emotional toll that caregiving takes.

Client:

It keeps you going. It gives me an incentive because I can see other people, I talk to people and then my family is very pleased when I do that because otherwise they'd have to have more care for them and this way I'm on my own when I come here because I get to talk to people and the staff if I have a problem.

Client:

Being here I enjoy it very much. I like the company. At home there's my wife and I; she's 88 and I'm 92 and anything that happens there if I need help I have to keep asking her and she's elderly now. It gets me out of the house and out of her hair for three days a week, which I find is very important; it helps her too.

Client:

It's also good for families you know that got maybe mothers or fathers or you know someone that can't get out- that they have to go to work- to have them come to the center and at least at the same time they're enjoying themselves and they're with people, and it gives the family a chance to do the things that they have to do.

Caregiver:

Because I don't worry about him when he's here. It gives me peace of mind. I can go to work and I know he's taken care of. I don't have to worry if he's out somewhere or walking away from the house and I know he's getting good care so it gives me a lot of peace of mind. It gives me that feeling that I have a life because at home I don't. You come home and that's your life.

Caregiver:

I need to take care of my house and my husband and my work and sometimes I feel like just to get out of work, go home and relax and not have to worry that I have to rush home because mom hasn't had lunch or something like that and I don't know whether she ate what I've left her or that type of thing. One of the things that has benefited me a lot is that my mother has to see a lot of different doctors and she went from day care and that is like a major benefit for me because

before I was taking her two or three days a week and going in two hours late, three hours late. How many times can you go to your manager and say I'm coming in late or I want to leave early?

Caregiver:

This is like a comfort zone to me. It gives me time to regroup while she's here so that I can give her good quality of care at night and the weekends.

Caregiver:

It's kept my mother out of one [nursing home] and has enabled me as a caregiver to work, to raise a family.

Caregiver:

I just went back to work this year full-time. I couldn't have done that if it wasn't for the day care. I have no doubt in my mind that if it wasn't for this facility... and I'll be honest with you it's because I don't have a world of patience, I have four children, the repetition can drive you crazy sometimes. If it weren't for this facility, my mother would probably be in a nursing home because I just don't think I could handle it all. She's so much happier now. It's a benefit both ways.

Caregiver:

Because I don't worry about him when he's here. It gives me peace of mind. I can go to work and I know he's taken care of. I don't have to worry if he's out somewhere or walking away from the house and I know he's getting good care so it gives me a lot of peace of mind. It gives me that feeling that I have a life because at home I don't. You come home and that's your life.

Caregiver:

I feel like it's really benefited me because before I found out about this place, I was going crazy. I didn't know what to do with her because she was wandering all over the place, she was wanting to jump out the windows and do this and do that and I was really ready to put her in a nursing home because I thought I can't do this anymore. When I found this place, it was like wow, what a blessing because she would come home, she was livelier, she was happier, she was more content. It was like she made a whole new life for herself too. It really just calmed me down and I was really content and I was really happy with the place. And it helped me as far as my job too so that's a big plus. I work from 8 to 4 and it works out beautiful so the hours are perfect.

Caregiver:

I also think that when you're not with them all day you can tolerate them for those hours when they are home in the evening until the time they go to bed and then you have your rest during the night and you get up in the morning, and most people are fresh in the morning, and you can take care of them and give them the extra attention that they need whereas if you're with them all day long, it's exhausting and you don't have the patience, and you get very frustrated, resentful, why do I have to do this? "He should be taking care of me," as my mother would say.

Caregiver:

It gives me a chance to do things around the house when she's here. I do the cooking and the cleaning and so forth at home.

Caregiver:

I feel fortunate because I have a place like this to go for my wife, and if I didn't have this place she might be in a nursing home and I know that's pretty expensive and would wipe away everything I have.

Caregiver:

It gives my grandfather a chance to do things during the day, catch up on sleep that he loses.

Caregiver:

It's given me peace for myself and helped me to have a little life of my own and I feel he's well taken care of.

Caregiver:

I feel peace of mind because she's getting wonderful care over here and it gives me peace of mind knowing that my wife is more content and she has peace of mind.

Caregiver:

Giving us space. Everybody needs space. Too much togetherness especially where family members have impairments and are not independent it could be very trying. I know myself I don't have a lot of patience at times with my dad. And him coming here is great because it gives me the space to complete my education and do things when I don't have school and he's busy and I know he's safe and I feel very secure with him being here than someplace else.

Caregiver:

It always gives me a chance to regroup and do what I need to do. And I think I give her better quality of care when I get her in the evening. I have more patience with her.

Caregiver:

I need to take care of my house and my husband and my work and sometimes I feel like just to get out of work, go home and relax and not have to worry that I have to rush home because mom hasn't had lunch or something like that and I don't know whether she ate what I've left her or that type of thing. Monday, Wednesday and Friday when she's in day care, if I can sneak out a little bit I can go to Demoulas or I can go pick up a prescription or I can do something special for her and not have to rush home because I know that she's there alone. One of the things that has benefited me a lot is that my mother has to see a lot of different doctors and she went from day care and that is like a major benefit for me because before I was taking her two or three days a week and going in two hours late, three hours late. There are appointments that I refused to have them take her to because I want to know what's going on, but the checkup appointments, the blood ones, that type of thing... physical therapy they will take her. How many times can you go to your manager and say I'm coming in late or I want to leave early?

Caregiver:

This is like a comfort zone to me. It gives me time to regroup while she's here so that I can give her good quality of care at night and the weekends.

Caregiver:

It's kept my mother out of one [nursing home] and has enabled me as a caregiver to work, to raise a family.

DISCUSSION

The user-centered approach used in this qualitative study to elicit aspects of the ADC experience that are most salient to clients and caregivers identified seven dimensions of care: staff, medical care, socialization, activities, safety, transportation, and caregiver benefits. Ensuring the safety of clients, having caring, friendly, and compassionate staff available to provide one-on-one attention, engaging clients in stimulating activities, and the opportunity for clients to socialize with others were salient features of care. A key factor in the delivery of high quality care centered on the way staff attends to clients, with a primary emphasis on being aware of and highly responsive to clients' needs. Overall, both clients and caregivers were satisfied with the care received. They attributed the majority of their satisfaction to the staff, particularly the medical attention and care that is given to clients, the way clients are treated, the opportunities for clients to feel like they are worthwhile, and having a safe environment in which to partake in stimulating activities and interact with others like themselves.

Potential areas of improvement for specific centers included enhanced communication with caregivers regarding clients' well being and program events and activities, modifications to the physical environment, improving the quality of food, and ensuring consistent transportation services. In addition, focus group respondents noted that adult day care programs need to be better publicized and made known to the community.

Another important finding of the project is that persons with cognitive impairment, when appropriately screened and selected, are able to communicate and voice their concerns and needs regarding the care they receive. The research team conducted one focus group composed of elderly participants with early-stage dementia. The intent was to ensure that the demented patient's perspective regarding care experiences was included. The conduct of this group indicates that obtaining information from elderly clients with early stage dementia is in fact feasible.

This qualitative research indicates that ADC users are able to identify which aspects of care are important to them. The domains described in this study resemble those found in other investigations that focus on long-term care quality and satisfaction but are unique to the adult day care arena. The concept of consumer-focused or -centered care is increasingly regarded as a fundamental dimension of the quality improvement framework. The recent work of Kane (2000)

on quality assurance in home care and nursing home care (Kane et al., 2003) addresses the importance of employing a consumer-centered approach in defining and measuring quality of care. Geron, Smith, Tennstedt, Jette, Chassler, & Kasten, (2000) measured quality in home care, using focus groups with clients as a basis for developing item content for an interviewer-administered survey. The findings of the current project lay the ground work for development of a survey instrument specific to adult day care that can measure the consumer's perspective on quality.

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