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Beneficial Care Approaches in Specialized Daycare Units for Persons With Dementia

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Abstract

Background: Daycare services are seen as a valuable means of helping old people to continue living in their own homes. Relatively little is known about care approaches in daycare units and how they benefit the clients themselves. This work attempts to show the way in which the care approaches in daycare units are constituted. *Methods*: Participant observation that was concluded with individual interviews with the directors of the units. *Results*: The findings show that beneficial care approaches in these daycare units establish practices and habits that give a particular structure to the course of everyday life of the patient with dementia, enhance the person's sense of normality, and allow him/her to enjoy being among others, while being appreciated as the person he or she is. *Conclusion*: Well-organized and knowledgeable daycare service not only provides relief from care for the relatives, but also supports and enriches the lives of the individuals with dementia.

Keywords

daycare, dementia, participant observation, care approaches

Introduction

Available community services are seen as valuable means of helping old people to continue living in their own homes despite varying degrees of disability, and to delay their need for residential care.[1] Daycare for the elderly has recently received increased attention both in public and in professional debate, as an important resource within community services for the disabled aged. Alteras[2] has, indeed, emphasized the economic advantages of the use of the services of adult health daycare for the elderly, as compared to institutional care

In all, 3 models of daycare are often cited, ie the medical model, the social model, and the combined model.[3] Reference may also be made to specialized models of daycare if they target a specific population such as patients with Alzheimer's.[2] Apart from the model of services, daycare tends to be discussed in terms of a remedy of some kind for elderly disabled people and their relatives. There has been some research on the effects of daycare upon the burden of caring for an elderly person,[4-6] but less is known about the elder's own experience of attending daycare.[2,7]

Definitions of daycare services appear to be quite similar in different countries. The Icelandic approach is in fact very much in line with American and German outlines of such services.[3,5,6] However, it has been pointed out that the activities offered in different daycare centres in Sweden vary widely, and it has also been maintained that there is a lack of a clear picture of the organization of daycare in that country.[8]

Daycare in Iceland is defined as follows in the Act on Services for the Elderly[9]:

> Daycare for the elderly (belongs to open services for the elderly) as a support measure for those who require constant supervision and care to be able to continue living at home. Daycare for the elderly should include nursing services and facilities for physiotherapy and medical services. It should also provide transport to and from the individual's home, health assessment, training, leisure activities, social support, education, consultation, and assistance with the activities of daily living.

A specialized model of a daycare unit for patients with dementia was first established in Iceland in the early spring of 1986, largely on the initiative of the country's Alzheimer Association.[10] In all, 2 more daycare units for patients with dementia had been established in 2003, when this study commenced. Much has changed since this study was conducted, as an additional 6 daycare units have now opened in the country, the most recent in the autumn of 2008. Thus, a total of 9 units now operate in and around the capital of the country. The first unit was administered by a social worker for a few years, but now all the units in the capital city are administered by Registered Nurses (RNs) and visited weekly by an appointed geriatrician. Fifteen clients attend the smallest unit daily, while the others serve just over 20 clients.

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The Memory Clinic of the Geriatric Services at the University Hospital now refers most of those who enter daycare units, as publicly provided treatment of patients with dementia in Iceland generally follows on from diagnosis and a followup at the Clinic. This was also the case at the time when these data gathering proceeded, but at that time, the cooperation between the Memory Clinic and the daycare services was in its development phase.

Today, all 9 units encourage their clients to attend the services for 5 consecutive weekdays, for approximately 7 to 8 hours every day, as the first unit did when it was established, and the other 2 participating in the study.

The first unit founded as a specialized daycare unit for patients with dementia has always been run under the auspices of a private organization constituted by different groups; the second unit was established and run by the City of Reykjavík (the capital of Iceland); and the third unit already operating when this study took off was run under the auspices of the Alzheimer Association. Daycare in these 3 units, targeted to care for individuals with dementia, was, like other health care services in the country, funded by National Health Insurance, while clients may have paid for transportation and some leisure activities from their own private funds.

Purpose and Methodological Background

This article reports on 1 aspect of a larger interpretive phenomenological study whose purpose was to explore collaboration between families and staff in daycare units caring for elders suffering from dementia. The design of the study comprised 3 parts: longitudinal study of the family's experience, group interviews with staff, and participant's observation. The study commenced in 2003 and data collection finished in the spring of 2009, when the last longitudinal interview with a family member took place. The premises of the study were to explore different approaches to care by family and staff, in order to gain a better understanding of how these approaches might inform and complement each other.

The study is grounded in the interpretive phenomenological approach to research. Interpretive or hermeneutical phenomenology is a practice of interpretation and understanding of human concerns and practices.[11] "This approach attempts to capture everyday skills, habits, and practices by eliciting narratives about the everyday and by observing action in meaningful contexts".[11(p.351)] Phenomenological study attempts to get hold of the richness harbored by the real, without seeking to make some specification about the real by synthesizing activity.[12] "The real has to be described, not constructed or formed."[13(p.x)]

Participant Observation

It is usually assumed that participant observation is ingrained into the interpretive phenomenological approach to the research.[14] This report focuses on the participant observation aspect of the study. Other aspects of the study will be described elsewhere. Participant observation was conducted over a period of 1 year in 2003-2004 during which the extended periods of time were spent in all the units; in addition, more intense observations were carried out in each of the units at certain periods during the year. The researcher would visit each of the units every week during the year of observation, for approximately 2 hours at a time at different hours of the day: early morning, midmorning, and late morning or midday, early, afternoon, or late afternoon. More intensive observation in each unit was planned around the time of an individual interview with a family member or a group interview with staff, focusing on the experience of caring for a particular patient with dementia, both at home and in the unit. The researcher sought at all times to blend with the guests in the daycare, sit among them, and participate in whatever activity was going on. However, the researcher visited the swimming pool only once, without going into the pool, and made only 1 attempt to ride along on a bus drive "home," as the participation in these events appeared to be perceived as an intrusion and seemed to interrupt the smooth running of the course of everyday for the guests.

More intense participant observation refers to at least 2 visits in the respective unit during the week of an individual interview with a family member or a group interview with staff. The complex interview process began when the elder participating in the study had been attending the unit for about 3 months. The aim of the extended stay in all the units was to observe "action in a meaningful context" as a way of carrying out participant observation, in terms of ethnographic research. Gerrish points out that according to Hammersley and Atkinson, ethnography involves "... participating, overtly or covertly, in people's daily lives for an extended period of time, watching what happens, listening to what is said, asking questions—in fact, collecting whatever data are available to throw light on the issues that are the focus of the research."[15(p80)] The focus of this research was care approaches in daycare units. Care approaches in nursing homes have been extensively researched by participant's observation.[16-21] Indeed, these nursing-home projects have shown that observation of staff performing their work in nursing homes can elicit important information about the kind of care provided in the particular setting at the focus of the research. Hence, in this study, ethnographic principles were applied which are similar to those used in researching care approaches in nursing homes.

Sites and Data Collection

Access to the units was granted by permission of the boards of directors of the respective units. The research was then approved by the National Bioethics Committee.

Participant observation in all 3 units was carried out overtly: staff were well-informed about the study and many of them participated in group discussions at the same time. In fact, all staff, all clients, and all clients' families were included in the participant observation. The participant observation was attuned to the working patterns of each unit, so there was no interference with the staff's way of monitoring and approaching the client

group. The researcher was permitted simply to drop in, during different hours of the day, and follow the action in different places, for about 2 hours at the time. Often, the observer would place herself or himself in the close vicinity of the particular client to be the subject of upcoming interviews. The visits happened to be very informal, as both staff and clients were used to having the researcher around in her or his role of a teacher of the students in the units. No formal tests were carried out during the observation or before the interviews, and no inquiry made about the results of the test that had been performed at the Memory Clinic before the client's entry into the unit. In fact, the staff would not in their daily work refer to Mini Mental State Examination (MMSE) scores,[22] any particular stage of the dementia process, or any measurement of functional ability of the individual client, so these aspects of the client's condition were not brought up during the observational stay. Short and often fragmentary notes were summarized immediately after each visit in the different units. Occasionally, some special comments made by staff or clients were noted in these summaries. Also, it was pointed out in these summaries that the staff did not seem to categorize their clients in any way, neither according to some former evaluation in the Memory Clinic nor their own evaluation. Initially, the observational notes were mere descriptions of the scene displayed in the 3 units, but later the observation was increasingly directed toward the clients that participated in the longitudinal interview process. By that time, individual interviews with family members were underway so it was certainly attempted during the observation process to discern whether the family's concern for any particular client informed the staff's approaches to care. Thus, it was noted in the observational notes if the staff's approaches seemed to be influenced by the family's talk about their relative enjoying the services in the unit. However, as the participant observation went on, answers to those questions were increasingly lost, as questions about the staff's way of addressing and organizing their work were evoked. Gradually, remarks made by staff about each individual response to the daily events became more prominent in the notes, especially their reference to the daily condition, capabilities, mood, and preferences of the different clients. Some more questions that emerged in reading through the notes were brought up in individual interviews with the 3 directors of the centers when the participant's observation was concluded. Many of these questions evoked in interpreting the data were clarified in these interviews. The participant observation was concluded after over a year of observation in the 3 units. By that time, all the longitudinal interviews with family members had been initiated, and the group interviews with the staff had been completed.

Observational notes generally consisted of 2 or 3 pages of double-spaced writing; sometimes, there would be a reference to an individual interview with a family member or a group interview with staff. However, it was quite clear from the beginning that the participant observation was carried out to inform the interviews and not vice versa. Nevertheless, it transpired that the participant observation in the 3 centers yielded its own insights, requiring a separate account of the culture of these care settings.

Data Analysis

The interpretive strategies of thematic analysis illuminated with exemplars gave way to interpretation, while some of the paradigms became clear.[14] The data analysis was based on the viewpoint of Zahavi that we should "let our experience decide our theories instead of letting some accepted theories decide our experience ahead."[12(p30)] Summaries of the observational notes were read continually and repeatedly, both during the observational period and afterward. As the summaries were read, they were compared within each unit and between the 3 units. This was done in order to identify the commonalities in care approaches in the different units, and to discern similarities and differences in care approaches that appeared to count as important for the client group. Often, one or more questions emerged during these readings and comparisons. For example, some of the activities appeared to be quite obvious, while others had to be inquired about. Leisure activities were particularly easy to see and observe, while assistance with personal care was given so discreetly that it was hard to detect, for example, when the staff prompted somebody to go to the toilet regularly, or persuaded another to take a shower. But grooming, especially hairdressing or varnishing nails, was most often public, and seemed to be enjoyed by everyone around, and often the setting resembled a beauty salon during this kind of grooming. These occasions reminded the researcher of her own visits to a beauty salon while enjoying looking at others being beautified. Efforts were made, both during the stay in the units and, in particular, while reading the summaries, to discern the meaning and purpose of actions of the staff [23] while interpreting their effects upon the clients.

Results

The findings show that beneficial care approaches in these daycare centers establish practices and habits that give a particular structure to the course of the everyday life of the patient with dementia, enhance the person's sense of normality, and allow him/her to enjoy being among others while being appreciated as the person he or she is.

The thematic analysis clarified that the structure of the course of everyday life indicates the relationships between different features of everyday life, as each person follows his or her schedule in accordance with his or her health, capability, preferences, and mood. Various paradigms showed that normality reflects the dignity of looking respectable and getting along with others on equal terms. Its enhancement includes, in particular, manner of conduct, personal hygiene and grooming, as well as doing things together. The third aspect of beneficial care approaches was also mostly revealed by paradigm cases when the people were observed enjoying being among others, while being appreciated as individuals. This aspect appeared to capture the feeling of sitting in a place for enjoyment of the atmosphere and the context, while sitting among others—enjoying the view, watching people, and the surrounding activity—like sitting in a café.

The trustworthiness of these findings assumes "that our common lived experience can prove with its pragmatic stance whether something is good, real, or true."[12(p33)] Merleau-Ponty maintains that "rationality is precisely proportioned to the experiences in which it is disclosed. To say there exists rationality is to say that perspectives blend, perceptions confirm each other, a meaning emerges."[13(pxix)]

The Course of the Everyday

Initially, the course of the everyday came across as being very similar for everybody in all the units. But gradually clear differences emerged, as it became ever clearer that the features of everyday life were very much adjusted to the changing health conditions, capabilities, preferences, and mood of each and every individual, during the course of the day, and from 1 day to the next. For example, a certain feature would be changed for any particular individual that felt weak or out of shape, and not up to participating in some of the activities in the unit. Clearly, each guest had personal control over the features of his or her day, for example, 1 man did not participate in any of the walking groups in his unit, as he maintained that he got enough exercise, as he always walked to daycare in the morning.

The care approach to each individual thus had to be regularly evaluated, as one of the RNs, or a unit director, described it in the following quote:

> Yes—yes—naturally—some people are just loners—some would rather not participate in this, or that—I think—indeed—you need to focus on the individual—there is once a week—in the early morning—a meeting with all the staff—then we go over all our clients and discuss—if there are any special problems—and set the course—try to get this one to be more active—or another one is not content with something—probe this and try a little bit—like that, once a week—then I just go over all the clients—[to see] if there are any problems and what the staff think—whether somebody has been down or something like that, and we just talk together—how we can handle this—what we should do—[and we] make some plans . . .

The features of everyday life appeared, however, to establish practices and habits which gave a structure to the course of the day, and this kind of schedule provided the individual with an anchor, in a sense, for being in the world.

Features of the course of the everyday include:
Get up in the morning
Get going—get lift to daycare
Follow the schedule of the day:
Meals
- Reading
- Singing

Coffee breaks
- Exercise—swimming
- Bathing—grooming
- Time at the "beauty saloon"

Rest
- Walks
- Handicrafts
- Gardening
- Leisure time, etc

Preparing to return home
Return home

Meals, coffee breaks, and rest periods were the landmarks of the daily routine, after the clients had arrived in the unit. However, the time to get ready for going to the unit in the morning, and the ride to the unit, as well as preparations for returning home and the ride back home were all critical features during the course of the day. All of them had to be very carefully planned by the staff in the units, particularly in cooperation with drivers, relatives, and sometimes the relevant home health service agency. Careful planning could, however, easily go awry, if something came up, such as changing health, change of capabilities, preference, or mood. But the staff knew that it was part of their care tasks to deal with such situations, so flexibility was embedded into their care approaches in many ways. In such situations, some features had to be adjusted, while the individual practices and habits that gave structure to the everyday life of the respective client were upheld as far as possible. For example, the staff would think of the circadian rhythm of their clients as they tried to dissuade clients from napping in the late afternoon, encouraging instead some kind of diversion for them. At the same time, a rest immediately after lunch was seen as both desirable and necessary, as otherwise clients would be very tired when they returned home and would be tempted to rest for a while before dinner, and might have trouble falling asleep later. The RNs would in fact often inform the clients and the relatives about favorable bedtime routines and individual sleep-promoting practices.

A Sense of Normality

Approaches to personal hygiene were often hard to put a finger on, except in the case of the "beauty salon." Nonetheless, this aspect of care was important to the clients, as personal hygiene and grooming enhanced their sense of normality. It appeared that the people felt that a way of being accepted in the group was to be decently groomed and dressed, and evidently the staff purposely set an example of hygiene and grooming norms in the units, by themselves being very neat and tidy at all times. All the staff in fact wore their own clothes, and blended in well with the guests. Apparently, the clients often saw the daycare unit as their workplace, and you are supposed to turn up appropriately kitted-out for work. The staff also took care to avoid referring to the place as "daycare"—they generally spoke of it as "day therapy,"—"day training," or simply used the name of the unit. The staff said that the meaning of the concept of daycare implied that the elder was being looked after or "minded," and they maintained that their clients did not like the idea of being somewhere where they were "taken care of." The way that the staff referred to the daycare reflects their

attitude to the manner of conduct in the units. People, both staff and the guests, seemed to share everything and be on the same level, for example, when sitting together during mealtimes, while it was observed during meals, how the staff made the meal accessible and the consumption of food manageable for the individual client. Sometimes, it was even hard to distinguish the staff from the clients, as there was easy, general conversation among everyone. But at times like that it could be sensed that the staff directed the conversation in a manner that made participation in the talk or any activity—kind of transparent.

Being Appreciated

According to the staff, things were often done together on an individual basis, or in a small group of 4 to 6 people, in order to minimize stressful stimuli. There were usually 1 or 2 staff members in each group that made the group cohesive, sometimes just by their presence, or at other times by directing the activity in the group, be it reminiscing, reading a newspaper, playing cards, knitting, or crocheting, etc. Each woman in 1 of the units had a little basket by her side with some handicraft they could reach for, often there would be a little piece of paper next to the handicraft saying how to proceed with the work—or there would be a staff member on hand for a guidance next to that person. In 1 unit, especially, clients did a lot of handicrafts. The director of that unit described the scene with following words:

> . . . so many of them become real craftswomen when they come here—women that have [once] done handicrafts, but have not done so for a long time. Then they just start again when they come here—when they see the others and start by trying—then there is something they can quite well do—and they do like it—just to be there [with the others].

Acceptance of individual differences colored greatly the staff's care approaches in doing things together. Interestingly, this kind of acceptance of individual differences created an atmosphere of tolerance and helpfulness; it was noticeable that the people attending the units would give each other a hand, or make sure that the next person was all right, while doing things together. Surprisingly, there would not be very much disturbance even if there was a person in the group with behavioral problems. The person would sometimes sit a little bit apart from the group, possibly occupied by some activity like drawing or just sitting nearby, or perhaps taking a walk with a staff member. A restless person could also sit in the group and rise to her or his feet repeatedly and move around the room. The guests would not say all that much, but maybe look toward each other with a meaningful expression, and at times somebody would murmur "that's the tenth time".

However, the place appeared at all times to be theirs, and everybody seemed to take it for granted that they needed to work together so things could move smoothly. In addition, there were breaks for sitting down, gossiping, and looking around, surrounded by people of all kinds. At such times, the individual would simply be appreciated in his/her own way.

Discussion

It was obvious, seen through the researcher's eyes, that the guests sensed what may be called an atmosphere of ease in all the units,[24] and they seemed to enjoy the formation of community and community roles[25] that emerged in doing things together with other clients and staff, as well as when sitting among others in the unit.

It is noteworthy that strategies used by staff in the daycare units to support activity were similar to those of the families participating in Phinney's study.[26] Her analysis revealed 3 strategies that allowed families to sustain meaning, both for the person with dementia and for the family itself. These strategies were (a) reducing demands, (b) guiding, and (c) accompanying. Strategies of this kind appeared to be part of the staff approaches in all the units, and they may certainly help the clients to assimilate the disease into their life and find ways to accept it—not least the clients learning to live with early dementia.[27] Also, the staff care approaches may lessen anxiety among the clients, as increased socialization while attending day centers and outpatient hospital care at the time of diagnosis has been shown to be highly beneficial in managing anxiety.[28]

From the researcher's perspective, the staff could be seen using a variety of theoretical knowledge to back up their work: for example, they took great care to minimize stressful factors in the surrounding environment, and to provide the appropriate stimulus and training for every single individual, apparently informed by Hall and Buckwalter's theory of progressive lowered stress threshold of persons with dementia.[29] Also, the effects of the needs-driven dementia-compromised behavior model [30,31] were evident, as the staff would often refer to the person's history and habits while interpreting all behaviors as having a meaning. Actually, the staff observed very carefully how the comportment of an individual client might convey some information about any bodily necessity of the self of the person, requiring particular attention on the part of staff. The researcher reasoned in her interpretation that the staff's conduct vis-à-vis their clients was informed not least by well-known theories about the impact of control on the institutionalized person,[32] as well as theories on procedural memory.[33] Indeed, the staff in all units emphasized an approach of doing things together, an approach that both enhanced each client's control of the situation and activated individual procedural memory.

Conclusion

Visions of nursing care approaches tend to be rather circumscribed and focus on "hands-on care." Daycare units tend to be seen more or less as a way of relieving the burden of caring for a person with dementia. However, the care approaches in these units encompassed more than "hands-on care" and respite care. Indeed, it was obvious in this study that a knowledgeable daycare service not only provides respite from care

for relatives, but can also support and enrich the lives of persons with dementia. Knowledgeable services in these 3 units appeared to be rooted in a solid educational background of the staff. Remarkably, the staff's care approaches were characterized by continual discussion of the impact of their services upon their clients. Most importantly, the staff care approaches seemed to bring about culture that inspired a feeling of being worthwhile among the clients of these 3 daycare units. As said some long time ago, ''We need more, not fewer, ways to tell of culture''.[34(p140)]

The participant observation described above was very time consuming, but the time spent in the units was very enjoyable and good, because of the warm and welcoming atmosphere in all the units. This warm and welcoming atmosphere in fact characterized all the units, but at the same time each unit had its own distinctive atmosphere. In one place, action and humor were typical, while the atmosphere in another unit was very quiet and calm, and an atmosphere of past times was evoked in the old building where the third unit is housed, with its old-fashioned furniture. But the services in all the units showed that daycare for people with dementia can be a very valuable community resource for the well-being and family life of many of the attending clients.

Author's Note

Margrét Gústafsdóttir designed the study, carried out the data collection, analyzed the data and wrote the paper.

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