ABSTRACT

WASKIEWICZ, B. A. The effects of a leisure activity visitation training program on the visitor's perceived satisfaction of visits with individuals with dementia related diseases including Alzheimer's disease. MS in Recreation, August 1994, 83pp. (N. Navar)

A leisure activity visitation training program (LAVTR Program) was developed in order to identify the effects of the visitors' perceived satisfaction of the visits with residents with dementia related diseases including Alzheimer's disease (DRD-AD). Participants (N = 11) voluntarily participated in the 3 hr training program. The visits of the participants were studied for 4 wk periods prior to and directly after the training program. Through the data collected from the Visitor Questionnaire Forms, the participant evaluation forms, and the Miller Social Intimacy Scale, the study was based on a collection of single subject designs. Several findings support that a change in the visitors' knowledge and use of leisure activities occurred during visits after participation in the LAVTR program. The percentage of visits that were identified as "a lot" of satisfaction increased after the training: 67% pretraining (10 of 15) and 75% (12 of 16) posttraining. After the training, 8 of the 11 participants used new leisure activities during visits that were not used prior to the training.
THE EFFECTS OF A LEISURE ACTIVITY VISITATION TRAINING PROGRAM ON THE VISITOR’S PERCEIVED SATISFACTION OF VISITS WITH INDIVIDUALS WITH DEMENTIA RELATED DISEASES INCLUDING ALZHEIMER’S DISEASE

A MANUSCRIPT STYLE THESIS PRESENTED TO THE GRADUATE FACULTY UNIVERSITY OF WISCONSIN-LA CROSSE

IN PARTIAL FULFILLMENT OF THE REQUIREMENTS FOR THE MASTERS OF SCIENCE DEGREE

BY

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We recommend acceptance of this thesis in partial fulfillment of this candidate's requirements for the degree:

Master of Science in Recreation

The candidate has successfully completed her final oral examination.

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INTRODUCTION

Dementia related diseases including Alzheimer's disease (DRD-AD) are some of the most disabling and life threatening disorders of older adults. According to the Diagnostic and Statistical Manual of the American Psychiatric Association (1987), the diagnostic criteria for dementia includes:

A deterioration of previously acquired intellectual abilities of sufficient severity to interfere with social or occupational functioning; memory impairment; at least one of the following: impairment of abstract thinking, judgment of impulse control, personality change; and evidence of a specific organic factor that is judged to be etiologically related to the disturbance, or, in the absence of such evidence, a reasonable presumption of an organic factor based on the exclusion of other conditions. (p. 126)

As the disease progresses, the symptoms decrease the functional independence of the individual (Alzheimer’s Disease and Related Disorders Association, 1990). As a result, an individual with DRD-AD gradually progresses to a decreased ability to interact with others. Therefore, it is probable that this disease has tremendous effects on the personal relationships with family members and friends (Blieszner & Shifflett, 1990).

Family members and friends may be apprehensive about visiting and during visiting because of a variety of issues that may be associated with the changes in the relationship. Some of these issues may include: increased disappointment
due to not being recognized or acknowledged during visiting, apprehension about the decreased memory recall, fear of the individual’s decreased verbal communication skills, or fear of behavioral outbursts by the individual. Because of the visitors’ decreased knowledge in coping with these issues during visiting, family members and friends may be dissatisfied with the visit and perceived a decreased level of social intimacy in the relationship. This study was conducted to determine if the use of leisure activities during visiting increased the visitors’ perceived satisfaction of the visits with individuals with DRD-AD.

NEED FOR THE STUDY

Although studies have been conducted that examine some aspect of the relationship of the individual with DRD-AD and the family member, none of the studies addressed the qualitative aspects of visiting. According to Lee and Ellithorpe (1982), virtually all such studies have concentrated on frequency or quantity of interaction and ignored the qualitative dimensions of relationships with family and/or friends. As a result, this study explored the qualitative aspects of satisfaction and social intimacy of relationships with family and/or friends.

Based on personal and collegial observations made at a residential group home for individuals with DRD-AD, the length and quality of the visit appeared to be limited. The interactions lacked indepth social intimacy and use of
leisure activities. Frequently, the visitors avoided intimacy by basing their conversations on impersonal topics such as the weather or activities occurring in the immediate environment. Through these observations, the need for a leisure activity visitation training program (LAVTR Program) was evident. This training program addressed the problems related to visiting as well as techniques for using leisure activities during visiting. Educational interventions which addressed these two issues were used to determine if the visitors' perceived satisfaction of the visit and the level of social intimacy of the relationship were increased.

BACKGROUND LITERATURE

The following areas of literature were reviewed in order to develop a broad understanding of the components of this study. These areas included: (1) characteristics of individuals with DRD-AD during the early to middle stages; (2) changes in a relationship with an individual with DRD-AD; (3) visiting issues; (4) the benefits of using leisure activities with individuals with DRD-AD; and (5) leisure satisfaction of visitors.

The characteristics of early to middle stages of DRD-AD for each individual are unique, even though there are some common characteristics during these stages. The individual begins to need cuing for activities such as dressing and hygiene. More complex activities, such as meal preparation or financial management require direct assistance by others.
The individual becomes less able to cope in unfamiliar settings and experiences frequent disorientation. Difficulties with communication, written and verbal, become more apparent. Frustration with these progressive losses may lead to emotional reactions, physical aggression, or paranoia. Concentration, attention, reasoning, and judgment become more difficult. The most frustrating aspects of these stages, according to Bowlby (1993), are the decreased recognition of loved ones and decreased memory recall of their names.

The occurrence of DRD-AD presents a source of change in the close relationships of married partners, parents and children, and friends. It is not easy to change the expectations or images of a person who has been the recipient in a close familial or friend relationship. However, as this disease progresses, the change of the relationship is based on the misconceived expectations of the individual by the family and friends, the emotional closeness to the individual by the family and friends, and the preexisting roles of the individual with DRD-AD with the family and friends (Gruetzner, 1988). When changes in the relationship occurs, the satisfaction of the relationship with the individual with DRD-AD may be decreased.

According to two studies (Edelson & Lyons, 1985; Greene, 1982), family and friends have reported that visits are often frustrating and painful. Very often family and
friends worry about how they are going to entertain their elderly relative when they visit (Karr, 1991). As a result, apprehension, frustration, or a decreased ability to communicate with satisfaction and intimacy occurs. According to another study (Blieszner & Shiflett, 1990), items about aspects of intimacy such as confiding in the relative or friend, enjoying time spent together, finding the relationship satisfying, and receiving encouragement and support from the individual dropped sharply after the onset of the symptoms of DRD-AD. As a result, visiting may not be viewed as satisfying. If a sense of intimacy is not developed, the visits may be decreased, of short duration, or not contain meaningful interactions. According to an earlier study (Moss & Kurland, 1979),

When subjects were judged to enjoy their visits, the visits tended to be more frequent, longer, and less upsetting, to have involved more interaction and mutual supports, and with the resident tending to have less impairment in cognition and communication. (p. 274)

As a result, if the visit is not satisfying to the visitor, the visiting patterns and frequency may be decreased.

According to Teri and Logsdon (1991), engagement in pleasant activities during a visit may enhance the patient-caregiver relationship. These pleasant activities are related to leisure, recreation, and/or social interests of the individual with DRD-AD. This may result in the improved well-being for both individuals. Identification of activities in which the individual with DRD-AD can
participate may help alleviate depression, as well as provide individual and interpersonal benefits for both the individual and the caregiver (Manning, 1992).

According to Kelly (1982), leisure is activity chosen in relative freedom for its qualities of satisfaction. Since visiting is considered a particular type of leisure activity, a perceived level of satisfaction and quality of visiting with an individual with DRD-AD is a valued component of leisure within the visitor's lifestyle. According to Kelly (1982),

If family interaction itself is considered leisure, then that interaction ranks high in importance to adults. Four kinds of interaction are in the highest ten activities in importance: marital affection and intimacy ranked first in the three towns studied, family conversation ranked third and activity as a couple ranked fourth. Family outings such as picnics were ranked fifth. (p. 157)

Based on Kelly's construct of the importance of family interaction, visiting is a valued component of leisure within the visitor's lifestyle. The satisfaction and social intimacy received from this leisure activity presumably needs to be of importance to the visitor since it is such a prevalent component of the visitor's leisure participation. As a result of the importance of visiting, this study focused on this component of leisure, visiting.

METHODOLOGY

This study examined the relationship between participation in the LAVTR Program and the perceived level of satisfaction of the visit and social intimacy of the
relationship with individuals with DRD-AD. The following research question was the focus of this study: Will the visitors’ perceived level of satisfaction of the visit and the social intimacy of the relationship increase as a result of the participation in the LAVTR Program?

The intended design of the study was a one-group pretest-posttest design. However, due to the small number of participants in the study, the actual design was a collection of single subjects.

Setting

The visits took place in either Hearten House I or Hearten House II. Both Hearten Houses provide a home-like setting with a secure, restraint-free environment. These group homes are located in a quiet, scenic setting on the Bethany-Riverside campus in La Crosse, WI.

The homes provide a variety of settings in which the visits took place. At least eight locations were available for visiting at each of the homes. They included the private bedroom, the parlor, the kitchen, the dining room, the living room, the beauty parlor area, the screened patio, or the fenced courtyard.

Participants

The participants of the study were those family members, friends, and volunteers who visited Hearten House I and/or Hearten House II and volunteered to participate in the LAVTR program. Eleven visitors, 8 female and 3 male,
participated in this study. The participants ranged from 45 to 87 years of age, with a median age of 62 years. The participants’ relationships to the residents included: five volunteers, one son, three daughters, and two sisters-in-law.

**LAVTR Program**

Educating the family members is often used as a technique to increase relationship satisfaction between an individual with DRD-AD and the family members (Dziegielewski, 1991). As a result, in order to increase relationship satisfaction, the LAVTR Program was designed. The face validity of this program was affirmed by the three thesis committee members. In addition, a pilot study was conducted with visitors from a similar group home.

The leisure activity training program was used to educate the family members and friends on the awareness and benefits of using leisure activities during visiting (see Appendix A). The use of the Peterson and Gunn (1984) systems design model enables the replicability of the LAVTR Program. Included in the program are: specific performance measures, terminal program objectives (TPOs), enabling objectives (EOs), and the content and process documentation (see Appendix A). The goal areas represented in the TPOs and EOs were based on the researcher’s perceived needs of the visitors from a therapeutic recreation perspective (see Figure 1).
TPO #1: To demonstrate an understanding of difficulties during visiting

EO #1: To identify characteristics of dementia
EO #2: To identify changes in roles of the relationships between the resident and visitor

TPO #2: To demonstrate the knowledge to utilize leisure activities during visiting

EO #1: To identify benefits of using leisure activities during visits
EO #2: To identify skills required to use leisure activities during visits

Figure 1. - TPOs and EOs of the LAVTR Program

Instruments

Miller Social Intimacy Scale

This measure was structured to assess intimacy in the context of friendship or marriage (Miller & Lefcourt, 1982). It is based on a scale that includes 17 intimacy items (6 requiring frequency and 11 requiring intensity ratings on 10-point scales) that measure the maximum level of intimacy experienced in a relationship (see Appendix B). The potential scores on the scale range from a low intimacy level of 17 to a high level of 170.

Although the development of this scale was used with undergraduate students, this scale was also used in a previous study (Blieszner & Shifflstt, 1990) that measured the effects of DRD-AD on close relationships between patients and caregivers. The results of Blieszner and
Shifflett’s study suggested that intimacy was lower in the presence of DRD-AD than it had been before the onset of the disease. Based on Blieszner and Shifflett’s results, this researcher chose to use this scale to measure the visitors’ perceived social intimacy of the relationship with the resident.

**Visitor Questionnaire Form**

In order to thoroughly study the perceived satisfaction and quality of the visits by the visitors, a qualitative method was used with the development and implementation of the Visitor Questionnaire Form (see Appendix B). The development was based on the approval of an expert panel that consisted of three Certified Therapeutic Recreation Specialists, the Program Director of Hearten House, and three thesis committee members. The purpose of this form was to identify the visitor’s perceived emotions before and after each visit as well as to identify the visitor’s perceived content, success, and satisfaction of the visit.

**Participant Evaluation**

Approximately 4 weeks after participating in the LAVTR Program, the participants completed a written evaluation form (see Appendix B). The purpose of this form was to identify the participants’ perceived usefulness of the content of this training program.
PROCEDURES

Data Collection

Pretraining

For a 4 week period, prior to the implementation of LAVTR, the participants completed the Visitor Questionnaire Form after each visit. The participants also completed a Miller Social Intimacy Scale prior to the training program.

Training

Each participant attended one session of the LAVTR Program for a length of 3 hours. The session was offered twice in order to accommodate each of the participants. LAVTR was conducted by the two researchers of this study who are Certified Therapeutic Recreation Specialists and graduate assistants in therapeutic recreation at the University of Wisconsin-La Crosse.

Posttraining

The participants completed the Visitor Questionnaire Forms after each visit for another 4 week period. After this 4 week period, the participants completed another Miller Social Intimacy Scale and an evaluation form (see Appendix B).

Data Analysis

Visitor Questionnaire Form

Based on the comparison of the pre- and posttraining Visitor Questionnaire Forms, the frequencies and percentages of the responses on the forms were analyzed. From the 11
participants in the study, 15 visits took place during the pretraining component and 16 during the posttraining component. Analysis included both the comparisons of the individual visitors and the group after participation in LAVTR.

Data were analyzed in order to answer each of the following research questions:

1. Did participating in LAVTR increase the visitors' perceived degree of satisfaction of the visit with residents with DRD-AD?

2. Was there a change in emotional response of the visitor before and after each visit before and after participation in LAVTR?

3. Did the amount of leisure activities used during visits increase after participation in LAVTR?

4. Did participation in LAVTR increase the visitors' perceived level of success with each of the leisure activities?

**Miller Social Intimacy Scale**

To determine the level of intimacy before and after participating in LAVTR, the Miller Social Intimacy Scale was administered twice. Quantitative analysis was not appropriate based on the small number of participants in study. A visual examination of the scores was performed in order to determine any patterns among the participants' responses.
Data were analyzed in order to answer the following research question: Did the level of intimacy experienced in the relationship as perceived by the visitor increase after the implementation of the LAVTR Program?

**Participant Evaluation**

To determine the usefulness of the content of LAVTR, a participant evaluation form was given. Data were analyzed in order to answer the first four research questions identified.

**RESULTS**

The purpose of this study was to identify whether the LAVTR Program influenced the visitors' perceived satisfaction of the visit with individuals with DRD-AD. In relation to the five research questions previously stated, several findings were positive.

One research question was based on the amount of satisfaction of the visit. Several findings support the belief that the use of leisure activities during visits increased visitor satisfaction. One supporting factor is based on the increased percentage of visits that were identified as "a lot" of satisfaction during the posttraining visits: 67% pretraining visits (10 of 15) and 75% posttraining visits (12 of 16). Since the program objectives of the LAVTR Program were developed in order to increase the satisfaction of visiting residents with DRD-AD,
an increase in the percentage of satisfaction was identified.

Another finding that supports this research question is based on the findings of four participants. "A lot" of satisfaction in the visits were identified when a leisure activity was utilized during the visit compared to "some" satisfaction in the visit when no leisure activities were utilized.

Another research question was based on the amount of leisure activities utilized during visits. Since an objective of LAVTR is to identify benefits of using leisure activities during visiting, several findings support the achievement of this objective by the participants. For example, 8 of the 11 visitors used new leisure activities during the posttraining visits that they did not use during the pretraining visits. Another finding is based on the increase in the percentage of physical activities used during the posttraining visits compared to the percentage used during pretraining visits: 7% pretraining (1 of 15) and 13% posttraining (2 of 16). Similar to the increase in physical activities, there was an increase in the percentage of outings during the posttraining visits: 27% pretraining (4 of 15) and 38% posttraining (6 of 16). Several written comments made by the participants also support an increase in the awareness of the benefits of using leisure activities during visits. They include the following:
"I didn’t realize there were games, etc., available (at Hearten House) and how much these do make a difference."

"... more activities. She really seems like she would appreciate more walks and outings with family" (when asked what suggestions from the training program did the visitor plan to use in the future).

Another research question was based on changes in emotional responses of the visitors after participating in LAVTR. The knowledge and awareness gained during this training program has the potential of influencing the visitors' perceptions of the residents' abilities, their skills to use leisure activities during visiting, and their knowledge of the characteristics of dementia that may cause difficulties in visiting. As a result, the visitors' emotional responses to visiting has the potential of changing. The following results support this change in emotional responses:

The percentage of visitors that identified "happy" as an emotion felt before each visit after participating in the training program increased: 53% pretraining (8 of 15) and 69% posttraining (11 of 16).

The percentage of visitors that identified "excited" as an emotion felt before each visit after participating in the training program increased: 7% pretraining (1 of 15) and 19% posttraining (3 of 16).

The percentage of visitors that identified "nervous" as an emotion felt before each visit after participating in the training program decreased: 27% pretraining (4 of 15) and 13% posttraining (2 of 16).

Another research question was based on the visitors' perceived level of success with each leisure activity used during the visits. Since a program objective of LAVTR was
to demonstrate knowledge to utilize leisure activities during visiting, the participants' skills and awareness of leisure activities were increased. As a result, their perceived level of success in using leisure activities has the potential of increasing. Two results from the data support this assumption:

The percentage of "a lot" of success in the leisure activities used during the posttraining visits increased compared to the percentage during the pretraining visits: 53% pretraining (8 of 15) and 75% posttraining (12 of 16).

Thirteen percent (2 of 16) of the pretraining written comments from the Visitor Questionnaire Form and 60% (13 of 22) of the posttraining comments related to the use and success of leisure activities during the visits.

Written comments from the participant evaluation also support this research question:

"...sometimes it isn't the frequency (of visits), it's the total success of EACH visit that matters."

"I was surprised that playing cards worked so well with the residents."

Another research question was based on the level of social intimacy experienced in the relationship as perceived by the visitor. Based on the visual examination of the scores, the results were not conclusive. The range of scores of the pretraining implementation was 78 - 143. Posttraining, the scores ranged from 88 - 143. Even though the results were not conclusive, this researcher would not reject using the scale in the future. Due to the small
sample size in this study, the scale was not sensitive enough to identify conclusive results.

Due to the small number of participants and the exploratory nature of this study, statistical analysis of the data was not utilized. However, indicators of change were evident for each of the 11 participants. The results were encouraging. The participants perceived that they benefitted from the LAVTR Program. This perceived benefit may increase the satisfaction and quality of the visits and relationships between the visitors and the residents.

DISCUSSION AND CONCLUSIONS

As evident through the background literature and the identified need of this study, visiting is difficult. As a medium to ease some of this difficulty, the LAVTR Program was developed. The use of leisure activities can provide structure, satisfaction, and success to the visits of individuals with DRD-AD.

Through the educational interventions of the LAVTR Program, the participants identified a change in their emotions. Through increased satisfaction, success, excitement, and happiness identified by the participants, the program was significant to their visiting patterns. The participants identified the usefulness, effectiveness, and appreciation of the LAVTR Program. For example, one participant stated:
"I am glad that I attended the program. I learned a lot about my mom’s illness as well as the skills that she still has. I will keep the information about leisure activities in the back of my mind when I visit her."

Three significant points of the LAVTR Program are important to the results achieved. One important component of this training program was the inclusion of dementia knowledge. Even though the purpose of the training program was the identification of using leisure activities during visits, family members and friends benefitted from an understanding of the disease. This component is important to the training program since many of the family members and friends possess limited knowledge about dementia. This knowledge helps the visitor understand the characteristic behaviors of dementia, the skills and abilities of the individual, and the challenges of the individual. This knowledge in turn, helps the visitor in the appropriate selection and successful implementation of leisure activities during visits.

Another important component of the training program was the leisure awareness element. Prior to the discussion, the majority of the participants identified with the traditional view of leisure activities as diversion or entertainment. However, after participation in discussions, role plays, and educational interventions, the participants identified a new awareness toward leisure. The education of the benefits, scope, and awareness of leisure within the lifestyles of the
residents was beneficial for the participants to understand.

The third important point utilized in the training program was providing the participants "permission" to use leisure activities during visiting. Previously, many of the participants did not use leisure activities during visiting for a variety of reasons:

"I do not want to intrude on the staff. They are the ones that do the activities."

"I didn't know that we could use the kitchen for baking with my mom." 

"I didn’t know that all of those games and activities were available for us to use."

Visitors need to feel comfortable and willing to use leisure activities when they visit. As a result, a Certified Therapeutic Recreation Specialist may need to take the responsibility to provide leisure education to more than the traditional clientele. In addition to the clients, a Certified Therapeutic Recreation Specialist may have a responsibility to enhance the visiting component of client’s lifestyles through the use of educating family members, friends, and volunteers.

RECOMMENDATIONS

Three considerations for future research emerged from the findings of this present study. One factor that was significant to this study was the participants' mixed recognition of the need for training. Through telephone and personal conversations, the researcher identified that the majority of those refusing to participate did not recognize
the need for training. Some common responses to the declination for participation were:

"I am too tired during the evenings and the weekends are the times that I spend with my family."

"I do not have time to participate in this program. I have too many things to do."

As a result of these comments, one consideration to enhance more participation from family members and friends is to develop a different format for the delivery of the training program. For example, incorporating the training with family orientation or family nights may be beneficial. This may be beneficial since a family may be more willing to learn when they first bring a resident to a group home setting.

Since limited literature is available about the content of family visits (Weiss & Thurn, 1990), this study was exploratory in nature. Consequently, one instrument utilized (Visitor Questionnaire Form) and the content and process of the LAVTR Program were developed specifically for this study. As a result, the second consideration for future research is to further validate the instrument and/or training program for other visitors. These may include visitors of individuals with mental retardation, traumatic brain injuries, or mental illnesses.

The third consideration for future research is the need to generalize the findings to broader populations of family members and friends and to a variety of health care
settings. Since visiting is often identified as frustrating and painful for visitors (Edelson & Lyons, 1985), training the visitors is crucial in order to assist in the elimination of some frustration and pain. Consequently, the need for future training in the use of leisure activities during visits may have the potential to increase the satisfaction of visits with other individuals. These could include visitors of individuals that reside in other group homes, nursing homes, or community-based residential facilities.

Given the limited number of participants trained, the success of the program was difficult to determine. However, the results are encouraging. The researcher believes that these reported successes would occur again through the implementation of the LAVTR Program.
REFERENCES


APPENDIX A

CONTENT AND PROCESS OF

LEISURE ACTIVITY VISITATION TRAINING PROGRAM
Leisure Activity Visitation Training Program

Program Objectives and Performance Measures

TPO #1: To demonstrate an awareness of difficulties during visiting

EO #1: To identify characteristics of dementia

PM: During the group discussion on dementia, the participant will verbally identify at least four of the eleven listed characteristics of dementia.

EO #2: To identify changes in roles of the relationships between the resident and visitors

PM #1: During a group discussion on role changes, the participant will verbally identify at least one change in the roles of the relationship with the resident.

PM #2: During a group discussion on the recommendations to deal with the changes in roles, the participant will identify at least two of the five recommendations to use in their next visit.

TPO #2: To demonstrate the knowledge to utilize activities during visiting

EO #1: To identify benefits of using activities during visits

PM #1: During a group discussion on the components of an activity, the participant will identify all four of the behavioral components of an activity: physical, cognitive, social, and emotional.

PM #2: After participating in the selected group activity, the participant will
PM #2: After participating in the selected group activity, the participant will identify at least one benefit for each of the four behavioral components of an activity.

EO #2: To identify skills required to use activities during visits

PM #1: During one of the two role playing activities, the participant will identify at least one of the three appropriate communication skills and one of the three inappropriate communication skills as judged by the CTRS.

PM #2: During a group discussion on challenges of dementia, the participant will identify at least one appropriate response to the behavior for one of the eight situations explained as judged by the CTRS.

PM #3: During paper and pencil activity, the participant will identify at least five current and five past leisure interests of the resident.

PM #4: During a resource awareness activity, the participant will identify at least five leisure resources located in the room within a three minute period.

PM #5: During a group skills modification activity and given an object, the group will identify at least two ways to modify an activity within a ten minute period.
LAVTR Content and Process Description

**TPO: #1** To demonstrate an understanding of difficulties during visiting

**EO: #1** To identify characteristics of dementia

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| 1. The Imagery Activity | 1. The CTRSSs lead the participants through the steps of an imagery activity. The purpose of the activity is to assist the participants in the understanding of the characteristics of dementia. The steps of this activity include:  
   a. Before beginning the session, we want you to close your eyes for a minute.  
   b. Think about the last time you visited with your resident (pause for 10 seconds).  
   c. Recall all of the behaviors that the resident displayed during that visit.  
   d. Think about how he/she greeted you.  
   e. Think about what you talked about.  
   f. Think about his/her facial expressions.  
   g. Think about how the visit ended.  
   h. Now put yourself in to his/her shoes.  
   i. How do you think you would be reacting? |
**LAVTR Content and Process Description**

**TPO:** #1  
**EO:** #1

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| j. Take a few minutes to think about this scene.  
k. Now open your eyes.  
l. We wanted you to experience this situation before we began talking about the characteristics of dementia.  
| 2. The CTRSs emphasize the importance of an understanding of the characteristics of dementia that may interfere with visiting.  |
| 2. Purpose of dementia knowledge component | 3. The CTRSs ask the participants to list some common characteristics of dementia. The CTRSs record the responses on a posterboard labeled: "Characteristics of Dementia." If the participants do not provide examples, the CTRSs write additional characteristics on the posterboard.  |
| 3. Common characteristics of dementia discussion | |
| Some of these characteristics include:  
a. Wandering  
b. Memory loss  
c. Perseveration  
d. Mood swings  
e. Aphasia  
f. Decreased attention  
g. Decreased physical skills  
h. Suspiciousness  
i. Delusions  
j. Hallucinations  
k. Hoard  
l. Decreased judgment | |
When the list is complete, the CTRSs ask the participants the following question: "How do these characteristics relate to difficulties with visiting."
LAVTR Content and Process Description

TPO: #1 To demonstrate an understanding of difficulties during visiting

EO: #2 To identify changes in the roles of the relationships between the resident and visitors

<table>
<thead>
<tr>
<th>CONTENT</th>
<th>PROCESS</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Group discussion on the changes of relationship roles because of the characteristics of dementia and how this change affects the visit. Examples of role changes:</td>
<td>1. The participants are asked to identify any changes in the roles of the relationship between the resident and him/herself. The discussion is based on the participants input. The participants are then asked how have they been coping with these changes.</td>
</tr>
<tr>
<td>a. Financial responsibilities of the parent may now be designated to the daughter/son.</td>
<td>The CTRSS continually reinforce that there are no definite techniques to cope with the changes in the relationships with the residents. The CTRSS emphasize that role changes are personal and effect each relationship differently.</td>
</tr>
<tr>
<td>b. Decrease in the social intimacy of the relationship.</td>
<td></td>
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<tr>
<td>c. Reversal of caregiver and care receiver roles.</td>
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</tbody>
</table>
**LAVTR Content and Process Description**

<table>
<thead>
<tr>
<th>CONTENT</th>
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<tbody>
<tr>
<td>2. Discussion on suggestions to deal with the role changes.</td>
<td>2. The suggestions are reviewed and the CTRSs ask for feedback from the participants.</td>
</tr>
<tr>
<td>Suggestions may include:</td>
<td>The CTRSs emphasize that because of the changes in the roles in the relationships during visiting, the primary recommendation of this session is the use of leisure activities during visits. The use of leisure activities may decrease the difficulties of visiting.</td>
</tr>
<tr>
<td>a. Be realistic about your commitment to visiting</td>
<td></td>
</tr>
<tr>
<td>b. Be prepared to deal with the difficulties of dementia</td>
<td></td>
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<tr>
<td>c. Allow enough time to visit without feeling guilty</td>
<td></td>
</tr>
<tr>
<td>d. Accept that all visits can not be perfect</td>
<td></td>
</tr>
<tr>
<td>e. Be open-minded about the resident’s abilities</td>
<td></td>
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</tbody>
</table>
# LAVTR Content and Process Description

**TPO: #2** To demonstrate the knowledge to utilize leisure activities during visiting

**EO: #1** To identify benefits of using leisure activities during visits

<table>
<thead>
<tr>
<th>CONTENT</th>
<th>PROCESS</th>
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</thead>
<tbody>
<tr>
<td>1. Behavioral components of leisure participation discussion. Definitions of each component include: a. The physical requirements of an activity are based on the identification of the body parts and their corresponding movements. The resident’s physical skills should correspond to the physical requirements of the leisure activity. b. The cognitive requirements of an activity are based on the mental functioning of an individual.</td>
<td>1. The CTRSs identify the four behavioral components: physical, cognitive, social, and emotional. A posterboard labeled for each component is used in the discussion. The CTRSs verbally provide the definitions for each component.</td>
</tr>
</tbody>
</table>
Since the mind regulates the other components of an activity, the cognitive component is essential for activity participation.

c. The social requirement of an activity is based on the interactive skills among participants. The social component is essential when interacting during a visit.

d. The emotional components of an activity are based on the affective responses of each individual. Because each individual reacts differently, there is no definite emotional requirement for each activity.

2. Potential benefits of leisure participation discussion

2. The CTRSs lead a discussion on the potential benefits of leisure participation. The information is provided through a handout.
Potential benefits of leisure participation include the following:

a. Potential physical benefits of a leisure activity
   1. Maintain coordination
   2. Maintain range of motion of joints
   3. Maintain strength
   4. Maintain hand/eye coordination
   5. Maintain endurance
   6. Maintain flexibility
   7. Maintain the use of the five senses

b. Potential cognitive benefits of a leisure activity
   1. Awareness of the rules for game play
   2. Memory recall
   3. Maintain concentration skills
   4. Maintain strategy skills
   5. Maintain the use of reading, writing, spelling, and mathematical skills
## IAVTR Content and Process Description

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<th>CONTENT</th>
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<tbody>
<tr>
<td>c. Potential social benefit of a leisure activity</td>
<td>3. The CTRSs introduce the game to the participants. The participants circle their chairs around the poster board that is on the floor. Each participant is handed a bean bag. The designated participant throws the bean bag onto the posterboard that contains the titles of six songs.</td>
</tr>
<tr>
<td>1. Maintain verbal communication skills</td>
<td></td>
</tr>
<tr>
<td>2. Maintain non-verbal communication skills</td>
<td></td>
</tr>
<tr>
<td>3. Interpersonal interactions</td>
<td></td>
</tr>
<tr>
<td>d. Potential emotional benefits of a leisure activity</td>
<td></td>
</tr>
<tr>
<td>1. Enjoyment</td>
<td></td>
</tr>
<tr>
<td>2. Contentment</td>
<td></td>
</tr>
<tr>
<td>3. Excitement</td>
<td></td>
</tr>
<tr>
<td>4. Satisfaction</td>
<td></td>
</tr>
<tr>
<td>3. Leisure benefits identification activity (Group Sing-a-Long Activity)</td>
<td></td>
</tr>
</tbody>
</table>

Sample songs include:

a. "The Little Brown Jug"

b. "God Bless America"

c. "Yankee Doodle"

d. "I've Been Working on the Railroad"

e. "You are My Sunshine"

f. "Bicycle Built for Two"
### Leisure benefits

Discussion

Possible benefits from Group Sing-a-Long Activity include:

- **Physical**
  1. Hand/eye coordination
  2. Flexibility of upper extremity

- **Cognitive**
  1. Attention
  2. Memory recall

- **Social**
  1. Turn-taking skills
  2. Communication skills

- **Emotional**
  1. Laughter
  2. Enjoyment

<table>
<thead>
<tr>
<th>CONTENT</th>
<th>PROCESS</th>
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<tbody>
<tr>
<td>The song that the bean bag lands on is the song that the group sings.</td>
<td>After the game is complete, the CTRSs identify that the residents frequently participate in this activity. The CTRSs then ask the following questions:</td>
</tr>
<tr>
<td>After the song is finished, the next participant to the right throws</td>
<td>a. What are some of the physical benefits of this activity? (The CTRSs record the responses on the posterboard labeled &quot;Physical&quot;).</td>
</tr>
<tr>
<td>his/her bean bag. Each participant takes a turn to throw the bean bag.</td>
<td>b. What are some of the cognitive benefits of this activity? (The CTRSs record the responses).</td>
</tr>
<tr>
<td>Each participant is also given a song book with the words to all six of the songs.</td>
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</table>
## LAVTR Content and Process Description

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<tr>
<th>TPO: #2</th>
<th>EO: #1</th>
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<tr>
<th>CONTENT</th>
<th>PROCESS</th>
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<tbody>
<tr>
<td>c. What are some of the social benefits of this activity? (The CTRSSs record the responses on the &quot;Social&quot; posterboard). &lt;br&gt; d. What are some of the emotional benefits of this activity? (The CTRSSs record the responses on the &quot;Emotional&quot; posterboard). &lt;br&gt; e. Have you or your resident experienced any of these benefits during your visits in the past? &lt;br&gt; f. What benefits, as a visitor, can you experience during this activity or other leisure activities during a visit? &lt;br&gt; g. Would these benefits motivate you to use other leisure activities during visits?</td>
<td></td>
</tr>
</tbody>
</table>
**LAVTR Content and Process Description**

**TPO: #2** To demonstrate knowledge to use leisure activities during visits

**EO: #2** To identify skills required to use leisure activities during visits

<table>
<thead>
<tr>
<th>CONTENT</th>
<th>PROCESS</th>
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<tbody>
<tr>
<td>1. Introduction to skills required to use leisure activities during visits. The suggested skills include the following: a. Communication skills b. Skills to deal with challenges associated with dementia c. Skills to identify the resident’s leisure interests and skills d. Skills to identify leisure resources e. Skills to modify leisure activities</td>
<td>1. The CTRSs explain that they will be discussing certain skills that are needed in order to interact with their resident through the use of leisure activities. It is important to emphasize that these skills are suggestions when using leisure activities during visits. Because each resident is individual, not all of these skills will provide success during visits.</td>
</tr>
</tbody>
</table>
## LAVTR Content and Process Description

<table>
<thead>
<tr>
<th>CONTENT</th>
<th>PROCESS</th>
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<tbody>
<tr>
<td>2. Discussion on the use of communication skills during visits</td>
<td>2. The CTRSs introduce the communication skills through the use of a handout provided for each participant.</td>
</tr>
<tr>
<td>The handout includes the following information:</td>
<td></td>
</tr>
<tr>
<td>a. Verbal Communication Skills</td>
<td></td>
</tr>
<tr>
<td>1. Speak to the resident as an adult</td>
<td></td>
</tr>
<tr>
<td>2. Validate the resident’s emotional message even if you can not understand what he/she is saying</td>
<td></td>
</tr>
<tr>
<td>3. Do not argue with your resident</td>
<td></td>
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<tr>
<td>4. Emphasize recognition, not recall</td>
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<tr>
<td>5. Always introduce yourself, state your relationship to the resident, and provide other orienting information</td>
<td></td>
</tr>
<tr>
<td>6. Speak slowly and clearly</td>
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<tr>
<td>7. Use short, simple sentences</td>
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<td>CONTENT</td>
<td>PROCESS</td>
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<tr>
<td>8. Lower your voice tone and speak loudly, but do not shout</td>
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<tr>
<td>9. Allow time for response</td>
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<tr>
<td>10. If repetition is necessary, repeat the comment using the same words</td>
<td></td>
</tr>
<tr>
<td>11. Give instructions one step at a time</td>
<td></td>
</tr>
<tr>
<td>12. Never speak in front of the resident as if he/she is not there</td>
<td></td>
</tr>
<tr>
<td>b. Nonverbal communication skills</td>
<td></td>
</tr>
<tr>
<td>1. Use gestures and demonstrations to get your message across</td>
<td></td>
</tr>
<tr>
<td>2. When touching the resident, approach him/her gradually</td>
<td></td>
</tr>
<tr>
<td>3. Use facial expressions to emphasize your message</td>
<td></td>
</tr>
<tr>
<td>4. Display a relaxed posture</td>
<td></td>
</tr>
<tr>
<td>5. Maintain direct eye contact</td>
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<tr>
<td>6. Recognize proximity during interactions</td>
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<tr>
<td>CONTENT</td>
<td>PROCESS</td>
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<td>----------------------------------------------</td>
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<tr>
<td>Role play activities for communication skills</td>
<td>The CTRSs introduce the role playing activity. They role play two different situations in which there are three appropriate and three inappropriate communication skills used in each situation. After each role play, they ask to distinguish the inappropriate and appropriate skills.</td>
</tr>
<tr>
<td></td>
<td>Role play #1: During the role play, one CTRS is the visitor and the other is a resident. The visitor correctly uses verbal communication skills a4, a10, and b1 (refer to 2a and 2b of CONTENT). The visitor will incorrectly use skills number a5, a12, and b2.</td>
</tr>
<tr>
<td></td>
<td>Role play #2: The visitor will correctly use skills a2, a7, and b3. The visitor will incorrectly use a1, a3, and b6.</td>
</tr>
</tbody>
</table>
### CONTENT

3. Skills needed to deal with challenges associated with dementia discussion

Suggested skills include the following:

a. Suggested skills to use with the resident that wanders
   1. Walk with the resident
   2. Bring an activity to the resident while he/she is walking
   3. Provide verbal and nonverbal communication cues to redirect the resident to a leisure activity

b. Suggested skills to use with the resident that demonstrates memory loss
   1. Provide visual cues and prompts during the leisure activity
   2. Provide labeled photographs for the resident
   3. Give step by step instructions

### PROCESS

3. The CTRSs discuss some challenges associated with dementia and skills to assist in dealing with these challenges. A handout is provided for each participant with the information listed under CONTENT.
### LAVTR Content and Process Description

**TPO:** #2  
**EO:** #2

<table>
<thead>
<tr>
<th>CONTENT</th>
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<tbody>
<tr>
<td>c. Suggested skills to use with the resident displaying perseveration</td>
<td></td>
</tr>
<tr>
<td>1. Acknowledge the resident’s concern after each statement is made</td>
<td></td>
</tr>
<tr>
<td>2. Ignore the statement after acknowledging it the first time</td>
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</tr>
<tr>
<td>3. Use validation techniques to verify the statement</td>
<td></td>
</tr>
<tr>
<td>d. Suggested skills to use with the resident demonstrating mood swings</td>
<td></td>
</tr>
<tr>
<td>1. Ask the resident why he/she is displaying the emotion</td>
<td></td>
</tr>
<tr>
<td>2. Identify any changes in the environment that may have caused the mood swing</td>
<td></td>
</tr>
<tr>
<td>3. Redirect the resident to a different environment</td>
<td></td>
</tr>
<tr>
<td>e. Suggested skills to use with the resident displaying aphasia</td>
<td></td>
</tr>
<tr>
<td>1. Respond to the message rather than the spoken word</td>
<td></td>
</tr>
<tr>
<td>CONTENT</td>
<td>PROCESS</td>
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<tr>
<td>2. Use many facial expressions, gestures, and eye contact to validate his/her message</td>
<td></td>
</tr>
<tr>
<td>3. Ask simple questions that can be answered with short responses</td>
<td></td>
</tr>
<tr>
<td>f. Suggested skills to use with the resident demonstrating decreased attention span</td>
<td></td>
</tr>
<tr>
<td>1. Provide leisure activities for short durations</td>
<td></td>
</tr>
<tr>
<td>2. Use leisure activities based on leisure interests</td>
<td></td>
</tr>
<tr>
<td>3. Recognize when the resident becomes distracted during a leisure activity</td>
<td></td>
</tr>
<tr>
<td>g. Suggested skills to use with the resident with decreased physical skills</td>
<td></td>
</tr>
<tr>
<td>1. Use adaptive equipment and techniques when available</td>
<td></td>
</tr>
<tr>
<td>2. Do not limit leisure activity involvement based on decreased physical skills</td>
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### LAVTR Content and Process Description

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<tr>
<th>CONTENT</th>
<th>PROCESS</th>
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<tbody>
<tr>
<td>3. Recognize environmental factors that may intensify the decreased skills</td>
<td>The CTRs ask the participants to respond to the following eight questions after learning about the skills to deal with challenges associated with dementia.</td>
</tr>
<tr>
<td>h. Suggested skills to use with the resident with suspiciousness</td>
<td>a. If your resident is wandering around the room, what would you do to get him/her involved in a leisure activity?</td>
</tr>
<tr>
<td>1. Offer assistance when searching for a lost item</td>
<td>Sample answers include:</td>
</tr>
<tr>
<td>2. Validate the resident’s suspiciousness</td>
<td>1. Go on a nature walk</td>
</tr>
<tr>
<td>3. Redirect attention toward another activity</td>
<td>2. Walk around the room observing the environment</td>
</tr>
</tbody>
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Scenarios that require identification of skills to deal with challenges associated with dementia.
<table>
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<tr>
<th>CONTENT</th>
<th>PROCESS</th>
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<tbody>
<tr>
<td>b. Your resident believes that someone has stolen her purse. What would you do in this situation?</td>
<td>Sample answers include: 1. Develop a scavenger hunt 2. Develop an activity using a different purse</td>
</tr>
<tr>
<td>c. You just came back from a trip to Texas. You visited five of your family members and would like to share this information with your resident. You are not sure if he/she will remember them. How can you share this information with him/her so he/she will know who you are talking about?</td>
<td>Sample answers include: 1. Label the photographs 2. Create a videotape of the family members you visited</td>
</tr>
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<td>CONTENT</td>
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<tr>
<td>d. Within the past five minutes, your resident has asked you at least nine times, &quot;What is the weather like?&quot; How would you respond to his/her questions?</td>
<td>Sample answers include: 1. Go to the window, look outside, and discuss the weather 2. Redirect conversation by discussing or looking at pictures to identify his/her favorite weather.</td>
</tr>
<tr>
<td>e. Within 10 minutes that you arrive at Hearten House, your resident begins to cry for no apparent reason. How would you deal with this change in emotion?</td>
<td>Sample answers include: 1. Validate the emotion 2. Participate in a sensory stimulation activity (e.g., hand massage)</td>
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<tr>
<td>CONTENT</td>
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<tr>
<td>f. Your resident wants to play horseshoes. He uses a wheelchair for mobility. Do you play the game with him? Why or why not?</td>
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<tr>
<td>Sample answer includes: 1. Adapt the game at wheelchair level by moving the target closer to his wheelchair and using lighter horseshoes</td>
<td></td>
</tr>
<tr>
<td>g. Your resident is attempting to explain what she/he had for a snack. You are unable to understand what she/he means. How do you respond to his/her statements?</td>
<td></td>
</tr>
<tr>
<td>Sample answers include: 1. Have the resident look in the refrigerator 2. Validate his/her response about the snack</td>
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LaVTR Content and Process Description

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<tr>
<td>h. You and your resident are playing a game of cards. Another person enters the room and the resident is not able to attend to the game. What would you do next?</td>
<td></td>
</tr>
<tr>
<td>Sample answers include:</td>
<td>4. The CTRSs discuss the importance of identify the skills and interests of the residents. These skills are identify through a handout for each participant. The handout includes the information listed under CONTENT.</td>
</tr>
<tr>
<td>1. Include the other person in the card game</td>
<td></td>
</tr>
<tr>
<td>2. Initiate a different leisure activity with the new person and resident</td>
<td></td>
</tr>
<tr>
<td>4. Skills needed to identify the resident’s leisure interests/skills discussion</td>
<td></td>
</tr>
<tr>
<td>The skills needed to identify the resident’s leisure interests/skills</td>
<td></td>
</tr>
<tr>
<td>a. Identify the resident’s past leisure interests</td>
<td></td>
</tr>
<tr>
<td>b. Identify the resident’s current leisure participation</td>
<td></td>
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<tr>
<td>c. Identify the resident’s current skills and abilities</td>
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### Leisure Interests Activity

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<th>CONTENT</th>
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<tr>
<td>The CTRSSs provide a paper and pencil to each participant. The paper is divided into two halves. One half is labeled &quot;Past Interests&quot; and the other half &quot;Current Interests.&quot; They are instructed to write at least three leisure interests under each column.</td>
<td></td>
</tr>
<tr>
<td>A discussion of the importance of identifying leisure interests occurs after the completion of the activity. This list provides the participants with a reference for using leisure activities during visits.</td>
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### 5. Skills needed to identify available leisure resources discussion

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<th>CONTENT</th>
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<tbody>
<tr>
<td>5. The CTRSSs discuss the skills needed to identify leisure resources for visits. The information is provided through a handout for each participant.</td>
<td></td>
</tr>
</tbody>
</table>
The skills needed to identify available leisure resources
a. Identify where supplies and equipment are located at Hearten House
b. When visiting, bring items to share with the resident
c. Use the staff as a resource to identify the resident's current interests and/or mood

Leisure resource activity

<table>
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<tr>
<th>CONTENT</th>
<th>PROCESS</th>
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<tbody>
<tr>
<td>Each participant is given a piece of paper labeled &quot;Leisure Resources.&quot; The participants are given three minutes to identify objects in the room that may be used for a leisure activity during a visit. Each participant writes the objects identified on the paper. After the three minutes, the participants voluntarily share the objects they identified.</td>
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### LAVTR Content and Process Description

**TPO:** #2  
**EO:** #2

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<tr>
<th>CONTENT</th>
<th>PROCESS</th>
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</table>
| 6. Skills needed to modify leisure activities discussion  
The skills needed to modify leisure activities  
a. Change the rules of the leisure activity  
b. Use adaptive equipment  
c. Consider the size of the group of the leisure activity  
d. Consider the environment in which the leisure activity is taking place  
e. Change the duration of the leisure activity  
Leisure activity modification activity | 6. The CTRSs discuss the importance of modifying and adapting leisure activities as necessary. The information is provided to the participants through a handout. The information is listed under CONTENT.  
The group is divided into three smaller groups. Each group is given an object (e.g., book, UNO cards, and a balloon). As a group, they need to identify a way to modify the activity for a resident. After 10 minutes, each group demonstrates the activity to the other groups and explains the modifications used. |
APPENDIX B

INSTRUMENTS
## Procedure for Implementing the Instruments

### Visitor Questionnaire Form

The visitors completed this form after each visit at Hearten House I and/or II during a four week period before participating in the training program and another four week period after the training program.

### Miller Social Intimacy Scale

The visitors completed this form at the beginning of the training program and also four weeks after participating in the training program.

### Participant Evaluation Form

The visitors completed this form four weeks after participating in the training program.
Visitor Questionnaire Form

Your name __________________ Your resident’s name ____________

Relationship to the resident ______ Length of visit ______

Date ______________ Room and/or rooms of visit ______________


1. a. Circle all emotions you felt before beginning the visit.
   anger    eager    nervous    happy    open minded
   sadness  guilty  excited  preoccupied  other ______

2. a. Circle and list all leisure activities you and your resident did during your visit.
   physical activity _______ board game _________
   crafts ________ music _________ outing ______
   cards _______ reading _______ socializing _____
   other ______________________________________

   b. Circle the level of success with each of the leisure activities.
      a lot    some    a little    none
      1        2        3          4

3. a. Circle all emotions you felt after the visit.
   anger    eager    nervous    happy    open minded
   sadness  guilty  excited  preoccupied  other _____

4. Circle the degree of satisfaction you felt during the visit.
   a lot    some    a little    none
   1        2        3          4

   Explain.

Please answer the additional questions on the back side.
5. a. Circle all emotions the resident displayed during the visit.
   anger  eager  restless  withdrawn  happy
   sad   excited  relaxed  content  aggressive
   fatigued  other ____________________________

   b. Circle the degree of emotional responsiveness of the resident.
      a lot  some  a little  none
      1       2       3    4

6. a. Circle all communication skills the resident displayed during the visit.
      eye contact  hugging  holding hands  laughing
      conversation  crying  other ____________________________

   b. Circle the degree of communication skills used by the resident.
      a lot  some  a little  none
      1       2       3    4

7. a. Circle all facial expressions the resident displayed during the visit.
      smiling  frowning  yawning  closing eyes  blank stare
      other ____________________________

   b. Circle the degree of facial expressions used by the resident.
      a lot  some  a little  none
      1       2       3    4

8. Circle the degree of social interaction between you and the resident.
      a lot  some  a little  none
      1       2       3    4

9. Circle the degree of satisfaction you believe the resident felt during the visit.
      a lot  some  a little  none
      1       2       3    4

   Explain.
Miller Social Intimacy Scale

Please circle the number that best describes your current relationship with your resident at Hearten House.

<table>
<thead>
<tr>
<th></th>
<th>Very Rarely</th>
<th>Some of the Time</th>
<th>Almost Always</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. When you have leisure time how often do you choose to spend time with him/her alone?</td>
<td>1 2 3 4 5 6 7 8 9 10</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. How often do you keep very personal information to yourself and do not share it with him/her?</td>
<td>1 2 3 4 5 6 7 8 9 10</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. How often do you show him/her affection?</td>
<td>1 2 3 4 5 6 7 8 9 10</td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. How often do you confide very personal information to him/her?</td>
<td>1 2 3 4 5 6 7 8 9 10</td>
<td></td>
<td></td>
</tr>
<tr>
<td>5. How often are you able to understand his/her feelings?</td>
<td>1 2 3 4 5 6 7 8 9 10</td>
<td></td>
<td></td>
</tr>
<tr>
<td>6. How often do you feel close to him/her?</td>
<td>1 2 3 4 5 6 7 8 9 10</td>
<td></td>
<td></td>
</tr>
<tr>
<td>7. How much do you like to spend time alone with him/her?</td>
<td>1 2 3 4 5 6 7 8 9 10</td>
<td></td>
<td></td>
</tr>
<tr>
<td>8. How much do you feel like being encouraging and supportive to him/her when he/she is unhappy?</td>
<td>1 2 3 4 5 6 7 8 9 10</td>
<td></td>
<td></td>
</tr>
<tr>
<td>9. How close do you feel to him/her when he/she is unhappy?</td>
<td>1 2 3 4 5 6 7 8 9 10</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

(CONTINUE ON THE BACK SIDE)
<table>
<thead>
<tr>
<th></th>
<th>Question</th>
<th>Scale</th>
</tr>
</thead>
<tbody>
<tr>
<td>10.</td>
<td>How important is it to you to listen to his/her very personal disclosures?</td>
<td>1 2 3 4 5 6 7 8 9 10</td>
</tr>
<tr>
<td>11.</td>
<td>How satisfying is your relationship with him/her?</td>
<td>1 2 3 4 5 6 7 8 9 10</td>
</tr>
<tr>
<td>12.</td>
<td>How affectionate do you feel towards him/her?</td>
<td>1 2 3 4 5 6 7 8 9 10</td>
</tr>
<tr>
<td>13.</td>
<td>How important is it to you that he/she understands your feelings?</td>
<td>1 2 3 4 5 6 7 8 9 10</td>
</tr>
<tr>
<td>14.</td>
<td>How much damage is caused by a typical disagreement in your relationship with him/her?</td>
<td>1 2 3 4 5 6 7 8 9 10</td>
</tr>
<tr>
<td>15.</td>
<td>How important is it to you that he/she be encouraging and supportive to you when you are unhappy?</td>
<td>1 2 3 4 5 6 7 8 9 10</td>
</tr>
<tr>
<td>16.</td>
<td>How important is it to you that he/she show you affection?</td>
<td>1 2 3 4 5 6 7 8 9 10</td>
</tr>
<tr>
<td>17.</td>
<td>How important is your relationship with him/her in your life?</td>
<td>1 2 3 4 5 6 7 8 9 10</td>
</tr>
</tbody>
</table>
Visitor Leisure Activity Training Program
Participant Evaluation Form

Please evaluate the following components of the visitor leisure activity training program. Your cooperation will assist us in the continued improvement of the program.

1. A. How useful was the information presented during the program?

<table>
<thead>
<tr>
<th></th>
<th>very useful</th>
<th>useful</th>
<th>not useful</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>3</td>
</tr>
</tbody>
</table>

B. What information was most useful?

2. A. To what extent was the dementia knowledge helpful in improving the quality of visits?

<table>
<thead>
<tr>
<th></th>
<th>very helpful</th>
<th>helpful</th>
<th>not helpful</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
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<td>1</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>3</td>
</tr>
</tbody>
</table>

B. What information was most helpful?

3. A. To what extent was the information about role reversal helpful in improving the quality of visits?

<table>
<thead>
<tr>
<th></th>
<th>very helpful</th>
<th>helpful</th>
<th>not helpful</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
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<td></td>
<td></td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>3</td>
</tr>
</tbody>
</table>

B. What information was most helpful?
4. A. To what extent was the information about the benefits of using leisure activities during visits helpful?

<table>
<thead>
<tr>
<th>very helpful</th>
<th>helpful</th>
<th>not helpful</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
</tbody>
</table>

B. What information was most helpful?

5. A. To what extent was the information about the skills needed to use leisure activities during visits helpful?

<table>
<thead>
<tr>
<th>very helpful</th>
<th>helpful</th>
<th>not helpful</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
</tbody>
</table>

B. What information was most helpful?

6. Name three things you learned at this training program.

7. A. Since the training program, which of the suggested techniques/activities/ideas have you used?

B. Which do you plan to use in the future?
APPENDIX C

LETTERS TO THE VISITORS
Time Line for Sending the Letters

February 23, 1994
A letter to all family members and friends that are visitors of Hearten House III was sent. This was an invitation to the visitors as part of the pilot study. A support letter from the Program Director and Coordinator was also sent.

March 7, 1994
An initial letter to all family members and friends that visit Hearten House I and/or II was sent. The purpose of the letter was to explain the initial four week component of the study. A support letter from the Program Director was also sent.

March 28, 1994
A second letter was sent to the list of family members and friends of Hearten House I and II. This letter explained the training program components and dates for participation.

May 13, 1994
A final letter was sent to those 11 participants in the training program. The purpose of this letter was to thank them for participating and to provide them with the evaluation form, the Miller Social Intimacy Scale, and a Visitor Questionnaire Form.
February 23, 1994

Dear Families,

I am happy to invite you to a special evening of educational information presented by Jackie and Becky, graduate students at UW - La Crosse who are presently working on a grant at Hearten House I and II.

This can also be an opportunity to get acquainted with other Hearten House III families. We would like to invite you for a soup and sandwich supper at 6:00 pm on Tuesday, March 8, 1994, with the program to start at 7:00 pm.

We will be meeting at the Holmen Lutheran Church lounge at 228 Morris Street in Holmen. Use the side door on Church Street.

Looking forward to seeing you!

Sincerely,

Linda Erickson
Program Director
Bethany Hearten House

Marge McIlnay
Program Coordinator
Hearten House III
February 21, 1994

Dear <Visitor>,

Since <your resident> has moved into Hearten House III, there have been many new and exciting opportunities. We would like to offer you another chance to learn more about issues related to dementia. Because we know that visiting with Lillie is important, we will be providing you with some suggestions and techniques to use while visiting.

We are two graduate assistants from the University of Wisconsin - La Crosse in the Therapeutic Recreation program. We have had the opportunity to interact with the family members and residents of Hearten House I and II during the past five months. Now we would like to learn more about the family members and residents of Hearten House III.

We would like to invite you to attend an informational program on Tuesday, March 8, 1994, from 7:00 to 9:00 pm. It will be held at Holmen Lutheran Church. Directions are enclosed. This program will include steps to improve your understanding and use of activities during visiting.

We will be contacting you within the next week to verify your attendance. If you have any questions, you may reach us at Hearten House II at 784-4522. We are excited to share our information with you and hope to see you that evening. Please feel free to bring a friend or family member with you.

Thank you for your time.

Sincerely,

Jackie Cords & Becky Waskiewicz
Graduate Students/Therapeutic Recreation
University of Wisconsin - La Crosse
March 7, 1994

Dear Families and Friends,

As some of you know who have been with us over the past few years, Hearten House has been privileged to have researchers come to us from Rochester, Minnesota, the University of Michigan and Dr. Pastelon from Washington, D.C.

Now we are privileged to have two researchers from the University of Wisconsin - La Crosse, Jackie Cords and Becky Waskiewicz, who are creating an exciting program to benefit families and friends when visiting their loved ones. I greatly encourage you to participate in their research and later to attend the workshop they will be presenting for visitors.

If you have any questions, please feel free to call me at 784-4534.

Sincerely,

Linda Erickson, Program Director
Bethany Hearten House
Bethany Lutheran Homes, Inc.
March 7, 1994

Dear <Visitor>,

What do you do with <Resident> at Hearten House while visiting? Are you satisfied with your visits? We all know that it is very important to make the visit as meaningful as possible for <Resident> as well as for yourself.

We know that visiting with someone with dementia and memory loss is not always an easy experience. Family members and friends may not know what to say or what to do during the visits. Visiting requires patience and understanding, can be frustrating, and not as rewarding as you would like it to be. As a result, we would like to help family members and friends have more satisfying visits.

If you are interested in learning more about visiting and how to make your visits more meaningful, we would like your help. As part of our graduate program in Therapeutic Recreation at UW-La Crosse, we are interested in learning more about visits to Hearten House. You do not need to change any aspect of your visiting style in order to help us with this project. During the weeks of March 21 through April 16 we would like to gather information about visiting at Hearten House. You will be asked to complete one questionnaire after each visit. We will conduct casual observations periodically. Enclosed is a sample copy of the questionnaire that you will be completing after each visit.

Please complete the enclosed informed consent forms for yourself and 2- and return them to Hearten House during your next visit. The informed consent forms ensure that you are in agreement with our observations of your visits.

If you would like to have more information or if you have any questions, you may contact Becky Waskiewicz or Jackie Cords at Hearten House II at 784-4522.

Thank you for your time. We look forward to your visits.

Sincerely,

Becky Waskiewicz & Jackie Cords
Graduate students/Therapeutic Recreation
University of Wisconsin - La Crosse
INFORMED CONSENT FORM

Please complete the first consent statement for yourself and the second statement for your resident.

1. FAMILY MEMBER OR FRIEND

I, ____________________________, consent Becky Waskiewicz and Jackie Cords (two graduate assistants from UW - La Crosse) to periodically observe my visits with __________________________ at Hearten House.

   (Your resident)

2. RESIDENT

As the legal guardian of __________________________,

   (Your resident)

I, ____________________________, consent

   (Your name)

Becky Waskiewicz and Jackie Cords (two graduate assistants from UW - La Crosse) to periodically observe __________________________ visit with other family members or friends at Hearten House.

   (Your resident)

(Your signature) ____________________________

(Date) ____________________________
March 7, 1994

Dear <Visitor>,

What do you do with <resident> at Hearten House while visiting? Are you satisfied with your visits? We all know that it is very important to make the visit as meaningful as possible for <resident> as well as for yourself.

We know that visiting with someone with dementia and memory loss is not always an easy experience. Family members and friends may not know what to say or what to do during the visits. Visiting requires patience and understanding, can be frustrating, and not as rewarding as you would like it to be. As a result, we would like to help family members and friends have more satisfying visits.

If you are interested in learning more about visiting and how to make your visits more meaningful, we would like your help. As part of our graduate program in Therapeutic Recreation at UW-La Crosse, we are interested in learning more about visits to Hearten House. You do not need to change any aspect of your visiting style in order to help us with this project. During the weeks of March 21 through April 16 we would like to gather information about visiting at Hearten House. You will be asked to complete one questionnaire after each visit. We will conduct casual observations periodically. Enclosed is a sample copy of the questionnaire that you will be completing after each visit.

Please complete the enclosed informed consent form and return it to Hearten House during your next visit. The informed consent forms ensure that you are in agreement with our observations of your visits.

If you would like to have more information or if you have any questions, you may contact Becky Waskiewicz or Jackie Cords at Hearten House II at 784-4522.

Thank you for your time. We look forward to your visits.

Sincerely,

Becky Waskiewicz & Jackie Cords
Graduate students/Therapeutic Recreation
University of Wisconsin - La Crosse
INFORMED CONSENT FORM

Please complete the consent statement and return it to Hearten House during your next visit.

I, ________________________________, consent Becky Waskiewicz and Jackie Cords (two graduate assistants from UW - La Crosse) to periodically observe my visits with ______________________ at Hearten House.

(Your signature) ____________________ (Date) ____________________

(Your resident)
March 28, 1994

Dear <Visitor>,

Thank you for your continuous completion of the visiting questionnaires and for allowing us to observe your visits. As a result of our observations, we noticed a variety of visiting patterns.

Because of your input, we are offering a Leisure Activity Training Program for all visitors of Hearten House I and II. If you are interested in learning more about visiting and how to make it more meaningful, we would like to invite you to attend this training program. If you decide to participate, you will attend a three hour session for one day. This session will include steps to improve your understanding and use of leisure activities during visiting.

The three options for the training program are as followed:

- Tuesday, April 19, 1994  6-9 p.m.
- Wednesday, April 20, 1994  6-9 p.m.
- Saturday, April 23, 1994  1-4 p.m.

All training programs will be held at the English Lutheran Church, 1509 King Street, La Crosse, Wisconsin.

If you choose to participate in this program, please return the enclosed form by April 11, 1994. A self-addressed, stamped envelope is enclosed for your convenience. You may also contact Becky Waskiewicz or Jackie Cords at Hearten House II at 784-4522 if you have any questions. Upon receiving your form, we will contact you about the details of the training program.

We appreciate the time and effort that you have given by completing the Visitor Questionnaire Form. This is an important component of our study. Please continue to complete a Visitor Questionnaire Form after each visit. The forms are located in the front entrance of each house. Also, please return your Consent Forms as soon as possible.

Thank you for your time. We look forward to your visits.

Sincerely,

Becky Waskiewicz & Jackie Cords
Graduate Student/Therapeutic Recreation
University of Wisconsin - La Crosse
Agreement for the Leisure Activity Training Program

Name

Resident's Name

Relationship to the Resident

The following dates and times are three options for participation in the Leisure Activity Training Program:

  Tuesday, April 19, 1994 at 6-9 p.m.
  Wednesday, April 20, 1994 at 6-9 p.m.
  Saturday, April 23, 1994 at 1-4 p.m.

Please circle the date that is most convenient for you.

If none of the dates or times are convenient for you, please indicate a date and time that you prefer.

Please include any suggestions you would like addressed during the training session.
May 13, 1994

Dear <Visitor>,

Thank you for your participation in the leisure activity training program. We appreciate all of your assistance in our project. Because of your involvement, we received additional awareness of the challenges associated with dementia.

Since the last component of our training program will be completed on May 21, your assistance in completing the final set of forms is requested. The completion of these forms are important to the overall success of our project. Please complete the Visitor Questionnaire Form and the Miller Social Intimacy Scale and return them in the enclosed self-addressed, stamped envelope by May 27, 1994.

We have also included a form for you to evaluate the leisure activity training program. Please answer the six questions and return this form along with the other forms in the self-addressed, stamped envelope.

We greatly appreciated your participation in our program. Thank you for your support.

Sincerely,

Becky Waskiewicz & Jackie Cords
Graduate Students/Therapeutic Recreation
University of Wisconsin - La Crosse
APPENDIX D

REVIEW OF LITERATURE
REVIEW OF LITERATURE

Introduction

The following areas of literature were reviewed in order to develop a broad understanding of the components of this study. These areas included: (1) characteristics of individuals with DRD-AD during the early to middle stages; (2) changes in a relationship with an individual with DRD-AD; (3) visiting issues; (4) benefits of using leisure activities with individuals with DRD-AD; and (5) leisure satisfaction of visitors.

Early to Middle Stages of DRD-AD

Alzheimer’s disease is a progressive, degenerative disease that attacks the brain and results in impaired memory, thinking, and behavior. This disease affects an estimated 4 million American adults (Alzheimer’s Disease and Related Disorders Association, 1990). Symptoms of the disease include a gradual memory loss, decline inability to perform routine tasks, disorientation in time and space, impairment of judgment, personality change, difficulty in learning, and loss of language and communication skills. Even though these symptoms are common, the rate of progression of the disease varies for each individual.
The individuals associated with this study were characterized as early to middle stages of DRD-AD. The characteristics of these stages for each individual are unique, even though there are some common characteristics. The individual begins to need cuing and prompting for activities such as dressing and hygiene. More complex activities, such as meal preparation, shopping, and financial management require direct assistance by others. The individual becomes less able to cope in unfamiliar settings and experiences frequent disorientation. Difficulties with communication, written and verbal, become more apparent. Frustration with these progressive loses may lead to emotional reactions, physical aggression, or paranoia. Cognitive functions are also impaired. Concentration, attention, reasoning, and judgment become more difficult. The most frustrating aspects of these stages, according to Bowlby (1993), are the decreased recognition of loved ones and decreased memory recall of their names.

**Changes in Relationships**

The occurrence of DRD-AD presents a source of change in the close relationships of married partners, parents and children, and friends. It is not easy to change the expectations or images of a person that has been the recipient in a close familial or friend relationship. However, as this disease progresses, the change of the
relationship is based on the misconceived expectations of the individual by the family and friends, the emotional closeness to the individual by the family and friends, and the preexisting roles of the individual with DRD-AD with the family and friends (Gruetzner, 1988). When changes in the relationship occur, the satisfaction of the relationship with the individual with DRD-AD may be decreased.

Through the progression of the disease, family members and friends may have moments of feeling emotionally withdrawn from their family member or friend. At the same time, they have memories of true connections with this person or wanting to find a way to remove the obstacles and be close again (Felder, 1990). Because of the cognitive, physical, and behavioral changes as a result of the disease, a previously close relationship may become strained. Family members and friends may find it difficult to talk to the individual with DRD-AD. They may find it hard to relax with the individual. They may become distant because they are unsure what to do. Also, they may not know how to restore the closeness once felt.

According to a previous study (George, 1984), spouses of individuals with DRD-AD had poorer health, were more likely to use psychotropic drugs, had more financial problems, and had less leisure time than adult children. However, adult children reported more stress and unhappiness than spouses of individuals with DRD-AD. Both of these
groups also had lower well-being than more distantly related caregivers such as nieces, siblings, and daughters-in-law. These findings imply that psychological and emotional closeness to the individual with DRD-AD affects the reactions to the visit.

Based on these changes in the relationships with an individual with DRD-AD, sensitivity toward these changes are necessary. Family members and friends are not only coping with the stresses and burdens of the individual’s with DRD-AD behaviors, challenges, and changes. They are also coping with the loss of the partner in one of their significant adult roles. Although this partner is physically present, he/she is no longer responding to the relationship itself (Blieszner & Shifflett, 1990).

**Visiting Issues**

Although family and friends visit their relative or friend with DRD-AD, they have reported that visits are often frustrating and painful (Edelson & Lyons, 1985; Greene, 1982). Very often family and friends worry about how they are going to entertain their elderly relative when they visit (Karr, 1991). Visiting often entails a great deal of patience and understanding because the visitors are required to accept this change in the relationship caused by the progression of the disease. As a result, apprehension, frustration, or a decreased ability to communicate with satisfaction and intimacy occurs. According to one study
(Blieszner & Shifflett, 1990), items about aspects of intimacy such as confiding in the relative or friend, enjoying time spent together, finding the relationship satisfying, and receiving encouragement and support from the individual dropped sharply after the onset of the symptoms of DRD-AD.

Satisfaction is a valued component of the visit. If a sense of intimacy is not developed, the visits may be decreased, of short duration, or not contain meaningful interactions. According to one study (Moss & Kurland, 1979),

When subjects were judged to enjoy their visits, the visits tended to be more frequent, longer, and less upsetting, to have involved more interaction and mutual supports, and with the resident tending to have less impairment in cognition and communication. (p. 274)

As a result, if the visit is not satisfying to the visitor, the visiting patterns and frequency may be decreased.

According to Hook, Sobal, and Oak (1982), visitation of residents in nursing homes helps to maintain role relationships with other individuals. This maintenance of role relationship is based on the satisfaction of the visit by the visitor and the individual with DRD-AD. According to a previous survey (Fisher & Tessler, 1986), the greater frequency of visitation was most strongly associated with the shorter distance that visitors must travel, the close relationship, and the shorter length of the individual in the nursing home. Therefore, this study supports the belief
that visiting is desirable even with the challenges associated with visiting an individual with DRD-AD.

Benefits of Leisure Activities with Individuals with DRD-AD

Much of the literature on activities and DRD-AD identifies that meaningful activity and relationships can help establish a positive self-image and sense of identity (Zgola, 1987). The purpose of using leisure activities in this context may be to accomplish improved functioning. In addition, the purpose of activities for individuals with DRD-AD has been described as preventative and enabling (Hasselkus, 1992). The emphasis on this approach is to promote the best possible experiences rather than on the functional goals of activities (Zgola, 1987). With either philosophical approach, the emphasis for leisure activity participation should be based on the basic needs of each individual with DRD-AD. According to Zgola (1987),

A calm, predictable, and accepting environment can provide the sense of security that enables a client to make full use of his/her abilities. It is the safety and security itself that enables the person with dementia to function to the best of his/her abilities. Activity programming in dementia care may provide the key means for the creation of that safe and predictable environment, which may be its primary and most important contribution. (p. 28)

Individuals with DRD-AD do not lose the basic activity component that gives a purpose and meaning to their lives, even though they are confronted with many changes (Hellen, 1992). Awareness of the individual’s abilities and identification of them within the framework of supportive
activity-focused care and participation enables a positive affirmation of the caregivers, family members, friends, and the individual with DRD-AD (Bowlby, 1992). Involvement in meaningful relationships is shared through purposeful communication expressed as verbal and nonverbal messages, gestures, and activity participation (Hellen, 1992). Activity participation includes those interests, skills, and abilities during leisure, recreation, and/or social participation.

The use of activities during visitation provides a framework to structure the relationship of the family member or friend with the individuals with DRD-AD because of the maintenance of the basic activity component of their lives. Increased activity is beneficial to individuals with DRD-AD in a variety of ways: improving the individual's mood, reducing disruptive behaviors, and providing the individual with a feeling of success and accomplishment (Teri & Logsdon, 1991).

According Teri and Logsdon (1991), engagement in pleasant activities during a visit may enhance the patient-caregiver relationship. These pleasant activities are related to leisure, recreation, and/or social interests of the individual with DRD-AD. This may result in the improved well-being for both individuals. Identification of pleasant activities in which the individual with DRD-AD can participate may help alleviate depression, as well as
provide individual and interpersonal benefits for both the individuals and the caregiver (Manning, 1992). For example, individuals who are aware of activities that are appropriate and enjoyable for the individual with DRD-AD often experience an improved sense of efficacy as well as a reduction in feelings of burden and hopelessness.

Leisure Satisfaction of Visitors

According to one definition, leisure is activity chosen in relative freedom for its qualities of satisfaction (Kelly, 1982). Since visiting is considered a particular type of leisure activity, a perceived level of satisfaction and quality of visits with an individual with DRD-AD is a valued component of leisure within a visitor’s lifestyle. According to Kelly (1982),

If family interaction itself is considered leisure, then that interaction ranks high in importance to adults. Four kinds of interaction are in the highest ten activities in importance: marital affection and intimacy ranked first in the three towns studied, family conversation ranked third, activity as a couple ranked fourth, and play with children ranked seventh. Family outings such as picnics were ranked fifth. (p. 157)

As a result, visiting by family members and friends of individuals with DRD-AD is a valued component of leisure within many visitors’ lifestyles. Therefore, visiting should remain as consistent as possible during interactions with individuals with DRD-AD. Since visiting is so valued, the satisfaction and social intimacy received from this leisure activity presumably needs to be of importance to the visitor. Otherwise, this activity would not be such a prevalent component of the visitor’s leisure lifestyle.
REFERENCES


Felder, L. (1990). When a loved one is ill: How to take better care of your loved one, your family, and yourself. New York: New American Library.


