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FAMILY TRANSITION: DEVELOPMENT, IMPLEMENTATION AND EVALUATION OF A CORRESPONDENCE PROGRAM FOR FAMILIES OF ELDERLY NURSING HOME RESIDENTS

The University of North Carolina at Greensboro PH.D. 1983

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FAMILY TRANSITION: DEVELOPMENT, IMPLEMENTATION AND EVALUATION OF A CORRESPONDENCE PROGRAM FOR FAMILIES OF ELDERLY NURSING HOME RESIDENTS

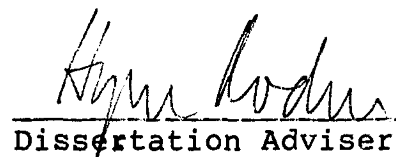
by

Ellen Strawbridge Yarborough

A Dissertation submitted to
the Faculty of the Graduate School at
The University of North Carolina at Greensboro
in Partial Fulfillment
of the Requirements for the Degree
Doctor of Philosophy

Greensboro
1983

Approved by



Dissertation Adviser

APPROVAL PAGE

This dissertation has been approved by the following committee of the Faculty of the Graduate School at the University of North Carolina at Greensboro.

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Committee Members ____________________

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30 June 1983
Date of Acceptance by Committee

30 June 1983
Date of Final Oral Examination

YARBOROUGH, ELLEN STRAWBRIDGE. Family Transition: Development, Implementation, and Evaluation of a Correspondence Program for Families of Elderly Nursing Home Residents. (1983)
Directed by: Dr. Hyman Rodman. Pp. 99.

The Family Transition Project was established in order to examine the effects of participation in a correspondence program on elements that might be expected to contribute to the satisfaction of family caregivers. It was hypothesized that participation would decrease the levels of bias and burden expressed by family caregivers and that knowledge about aging would be increased.

The subjects were caregivers of residents in seventeen licensed nursing homes in Forsyth and Guilford Counties, North Carolina. Caregivers who returned an initial survey and volunteered for the study were randomly assigned to participation and control groups.

Data were collected using the Facts on Aging Quiz (Palmore, 1977) and the Burden Interview (Zarit, Reever, and Bach-Peterson, 1980). One-way analyses of variance were performed, with significance set at .05.

The directional hypotheses were rejected; the data did not support the conclusion that the correspondence program affected the caregivers' bias, knowledge, or expressed burden.

ACKNOWLEDGEMENTS

The Family Transition Project was sponsored by the Blumenthal Jewish Home, with funding from the James G. Hanes Memorial Fund/Foundation and the Richardson Foundation. I particularly thank Executive Director A. A. Mendlovitz for his encouragement, Robert Milman for his computer instruction, and Janet Case for her drawings.

As I worked to integrate my interests in therapeutic recreation, creative drama, and family mental health maintenance, continuing support and focus were offered by members of my committee: Dr. Hyman Rodman, Chairman; Dr. Rebecca Smith; Thomas Behm; and Dr. Jesse Mann. Each has been personally and professionally helpful. Judy Lipinski, of the Statistical Consulting Center, provided aid with statistical design.

Family caregivers made the study possible through their willingness to share their time and thoughts. I am grateful for the cooperation of the caregivers and of the participating nursing homes.

Special thanks must go to my parents and to my husband and our family; my appreciative definition of "family" has been built on our shared lives.

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CHAPTER I

INTRODUCTION

Life expectancy is increasing for Americans, with one noticeable consequence being the greater proportion of elderly persons with physical or mental impairment (Brotman, 1982). Emotional support for family caregivers--those family members who bear responsibility for their impaired relatives' care--is a growing area of need (Fengler & Goodrich, 1979; Getzel, 1981). When an elderly person must enter a long-term care facility such as a nursing home, both the patient and the family caregiver require support. Factors that have made home care less feasible include greater family mobility, the trend to nuclear family households, and the growing number of households in which all adult members work outside the home (Brody, 1979; Treas, 1977, 1981). Even when institutional care is medically indicated, however, family caregivers may view long-term placement as a failure of the family system.

This study, the Family Transition Project (FTP), was established in order to develop and evaluate a correspondence program aimed at helping the family caregiver adjust to changing roles after an impaired relative had entered a nursing home. A general goal was to enhance the attitudes and habits that could contribute to caregivers' satisfaction regarding the relationship with their relatives in long-term care. Brief background accounts of the characteristics of family caregivers and of nursing home services will help to clarify why the transition program for families was developed.

Family Caregivers to the Elderly

An Issue for the 1980s

Dependence of elderly members on their families is not a new issue. As early as 1966, Brody discussed the increase in five-generation families. In 1965, Blenkner defined "filial maturity" as the capacity of an adult child to be positive and dependable, yet unenmeshed, in regard to an aging parent's needs. What may be new in the 1980s is the realization that lower birth rates are increasing the proportion of elderly people to the younger relatives who are able to care for them (Bengston & DeTerre, 1980). Members of the 1940s' "baby boom" will

be caregivers through the end of this century, but if low birth rates continue as expected, the middle generations after the year 2000 will be increasingly strained (March, 1981).

The proportion of Americans 65 and older rose from 8.9% in 1970 to 11.2% in 1980, with the group over 75 rising even more dramatically (Brotman, 1982). The majority of older persons can continue to live in their own communities; they are not seriously limited by physical or mental impairment (Palmore, 1981). Traditional expectations of the elderly and of caregivers undergird their reluctance to use institutional care, but some persons clearly need the services provided by residential nursing facilities. Commercial health care organizations, nonprofit agencies, and publicly financed programs are available for most people for whom long-term care is prescribed. The search for optimal, cost-effective care is receiving considerable attention from policy makers, health care systems, and social service providers (Shanas & Sussman, 1977; Streib & Beck, 1980; Sussman, 1983).

When impairment is emotional or mental, stress on the family caregiver may be a deciding factor in the placement (McCabe, Note 1). This situation combines the

potential for resistance in the elderly member and guilt in the caregiver. At best, the movement of a close relative into long-term care involves feelings of loss and necessitates continuing adjustment of the roles to which each member is accustomed. When the patient has deficits in memory and in the ability to maintain the self-care activities of daily living, he or she may be incapable of offering agreement or of reassuring the caregiver about the acceptability of the placement decision. The caregiver feels as if the need to make decisions is not accompanied by real authority.

Characteristics of Family Caregivers

The majority of caregivers to aged relatives are women (Brody, 1981) and many caregivers are themselves elderly (Beaulieu & Karpinski, 1981; Cicirelli, 1977; Troll, 1971). Women appear to have more difficulty than do men in finding and maintaining a comfortable emotional distance in the caregiving relationship, particularly if the recipient is also a woman (Gibson, Note 2). The impaired elderly are predominantly female (Lang & Brody, 1983) and the proportion of women to men increases as their ages increase (Brotman, 1982). Many aged mothers are caring for their own aged mothers.

Cicirelli (1977) found that women caregivers maintained a supportive relationship with male relatives but an attitude of challenge toward females. Nevertheless, Adams (1967) noted that women said they enjoyed contacts with older kindred, while men reported their contact as routine obligations. This dispassionate level of contact may function as effective protection when men bear caregiving responsibilities.

The findings of Archbold (1983) seem to confirm the effectiveness of caregivers who are unenmeshed. In a study of women who were caring for infirm parents, she described two styles of assuring care. "Providers" personally delivered most services. "Managers" arranged optimal use of public and private service resources to supplement their personal care provision. Providers reported heavier emotional costs and fewer benefits than did managers. Although managers were generally in a higher economic level, and therefore had the means to buy some services, Archbold described the major difference in the two styles as based on their attitudes rather than on their external resources.

Nursing Homes: Routine Expectations

Nursing Care in Long-term Institutions

Nursing homes provide nursing care and medical supervision for patients who are not acutely ill and do not require more specialized facilities (North Carolina State Board of Examiners for Nursing Home Administrators, 1982). In North Carolina, units licensed as Skilled Nursing Facilities must provide skilled nursing care 24 hours a day, while those units licensed as Intermediate Care Facilities are required to provide skilled nursing for only 8 hours per day (Commerce Clearing House Editorial Staff, 1980). Most nursing homes offer both these levels of care. Members of the Nursing Service staff have the most frequent and prolonged contact with residents. Other services are expected to be available in order to enhance the quality of life for residents (Joint Commission on the Accreditation of Hospitals, 1980). Rehabilitation Services may include recreation, occupational therapy, and physical therapy. Members of the Social Service staff work with individuals and with groups. Staff members from each department share the tasks of facilitating positive relationships between residents and their family members, regardless of the severity of impairment in the resident members.

Interdisciplinary Goal-setting with Residents

Assigned staff members work together to develop the quarterly Resident Care Plans that are required for each nursing home resident. Medical and dietary programs, socialization activities, personal interests and needs, and family relationships are considered by the interdisciplinary team members in setting measurable goals for the patient's care. Patients and their family members are frequently asked to take part in these planning conferences.

Orientation of the Public

Each nursing home uses many channels through which to communicate with the public. The "Patient's Bill of Rights" and the nursing home's visiting policies are posted in a prominent place. Variations in financial arrangements are based on signed agreements. Handbooks may be provided in order to familiarize patients, family members, volunteers, and community referral agencies with the services and procedures of the institution (Lincoln, 1980; Morrison, 1982). From department signs on office doors to colorful bulletin boards advertising recreational activities, each nursing home provides environmental clues to the atmosphere it attempts to create.

Social Services and the Families of Residents

Staff members see nursing home patients as their primary clients, but more and more social workers are agreeing with Lang and Brody (1983) that the whole family unit must be viewed as a client. Family interaction patterns do not end at placement, and the adjustments of residents and of their close relatives are increasingly recognized as interdependent (Fengler & Goodrich, 1979; Mancini, 1983; Silverstone, 1978; Smith & Bengston, 1979). Social workers are concerned with caregivers' own feelings, as well as with caregivers' effects on residents' attitudes and behavior. Whether the family relationship is comfortable or uneasy, it is usually a continuation of interaction styles established long before the placement. Positive and flexible styles facilitate adjustment to the new roles; negative and rigid patterns may become more pronounced as each family member faces the loss of familiar structures and feels the intrusion of the institution's power.

Professional staff members can help family members to engage in more effective communication. When caregivers appear overinvolved in decisions that properly belong to the resident, the social worker may help define areas in which the family can turn loose of some

responsibilities. Conversely, when family members seem disengaged, the worker may attempt to reduce the abandonment and loss felt on both sides. The goal is a balanced amount and intensity of interaction; all members need to recognize that the family system can still remain intact pafter the resident enters the new institutional home. Staff members try to facilitate family involvement that neither duplicates nor interferes with those services that the nursing home must provide. The resident and the caregiver are invited to maintain family ties while each is also asserting the independence that is appropriate for persons who live separately. Professional staff members also need to become known to family caregivers in order to build the mutual trust needed at times of crisis (Scanzoni, 1979).

Groups for Families of Nursing Home Residents

Groups, either task-centered or person-centered, have been used effectively by nursing homes and other community agencies concerned with problems of aging (Barnes, Raskind, Scott, & Murphy, 1981; Beaulieu & Karpinski, 1981; Helphand & Porter, 1981; Safford, 1980). Nursing home family councils are formed to deal with such issues as patient advocacy, volunteer services, and

information about special events. Group recreational and social events, which can include patients along with their families, help caregivers form alliances within the nursing home community. Other family groups are promoted as a means of emotional support for participants. For example, experience with similarly impaired relatives is the basis for caregiver groups such as the Alzheimer's Disease and Related Disorders Association.

Correspondence: A New Format

A "correspondence course" for caregivers could be a new tool for social workers--supplementing the usual individual conferences and group meetings. The Family Transition Project (FTP) correspondence program was developed in order to help caregivers view their situations from different angles and find satisfying ways of handling their changed relationships. Certain levels of knowledge, attitudes, and habits appear to contribute to satisfaction, although "satisfaction" as a concept is difficult to measure objectively. Satisfaction of a caregiver was expected to be related to the caregiver's acceptance of the real factors that affected both caregiver and patient (Lezak, 1978). Therefore the FTP program aimed to affect caregivers' subjective responses to their "objective" perceptions.

Directional Hypotheses

In order to investigate the effectiveness of the Family Transition Project correspondence program, three hypotheses were tested.

1. Caregiver participation in a personalized correspondence program will decrease the level of bias about aging expressed by caregivers of elderly nursing home residents.

2. Caregiver participation in a personalized correspondence program will increase the level of knowledge about aging demonstrated by caregivers of elderly nursing home residents.

3. Caregiver participation in a personalized correspondence program will decrease the amount of burden expressed by caregivers of elderly nursing home residents.

CHAPTER II

DEVELOPMENT OF THE CORRESPONDENCE PROGRAM

Because most of the material presently available for caregivers pertains to objective information and behavior, the FTP letter-units were purposely made subjective. Most of the exercises used a metaphorical approach, in order to communicate with caregivers at various levels of need and interest and also to assure respondents that all replies would be acceptable.

The program was designed as a set of modules that could be used in various combinations according to the needs expressed by respondents. Each module consisted of one worksheet page and a corresponding half-page response sheet; each letter-unit comprised two modules and a personal note from the author, who served as the project's Family Program Specialist (FPS). Figures 1 through 4 contain the first letter-unit and the cover letter inviting caregivers to participate in the correspondence program. (See Appendix A for the other modules.)

FAMILY
TRANSITION
PROJECT
P.O. Box 38
Clemmons, NC 27012

March 4, 1983

Dear Family Caregiver,

Thank you for completing the "Aging Americans and their Families" questionnaire. Our project includes several randomly selected groups; members of your group will receive a correspondence program for family members. Please set aside a short time to respond to our letters as they arrive over the next few weeks. If you cannot take part, use the prepaid envelope to let me know, so that someone else can be offered the opportunity.

When the study has been completed, we will print a Family Transition Manual for nursing homes to use when residents enter long-term care. No names will be used. Staff members at your relative's nursing home treat their relationship with you confidentially; by taking part in this study you allow me to join this "circle of confidentiality" and I appreciate this trust. I am not taking the place of your relative's staff members. My interest is in you -- adjustments you have had to make and concerns you have about relationships with your family member. Your satisfaction and well-being are important to the well-being of this relative and to your relationship with the personnel of the nursing home.

Over two decades of work in community education and therapeutic recreation have shown me how all of us affect each other. Families have important concerns when one member moves into long-term residential care. This family program can only be developed with the aid of people like you, so let me encourage you to participate.

Now look at the first letter-unit. The white pages are thinksheets; you keep these for your private use. The green sheet should be returned to me, with your responses and comments. Please send it in the prepaid envelope within a week if possible.

Thank you!

Ellen Yarborough

Ellen Yarborough
Family Program Specialist

PLEASE RETURN THE GREEN SHEET IN THE PREPAID ENVELOPE WITHIN 1 WEEK
Discuss the letter-unit with other family members if you like. Use the back of the sheet for comments.

Figure 1. Cover letter: Letter-unit # 1.

FAMILY
TRANSITION
PROJECT
P.O. Box 38
Clemmons, NC 27012

Letter-unit #1
Ellen Yarborough
March 4, 1983

SOMETIMES FAMILY LIFE IS LIKE A DRAMA!

You may recognize one of these scenes. What do you imagine is the next thing that will be said?

May: Your Dad was confused at the store again today, Max. He enjoyed the outing, but he picked up lots of things that the checkout clerk had to set aside -- including a jar of babyfood!

Max (her husband): Guess you got some pretty embarrassing looks!

May: Yes. Sometimes I think - - -

***

Ann (age 14): Do we have to go to the nursing home again this Sunday, Mom?

Mom: Grandmother is so cheerful that I don't see how we can complain about going to visit her every week. She can't get up out of that chair and take care of herself the way she once could, you know.

Ann: But all of us friends get together on Sundays, except for me. Can't you understand that - - -

***

Ben (a retired friend): I understand you went with your sister to see her husband.

Bob: I go out to the nursing home with her occasionally, but then I always feel so tense. He gets lost going from his room to the lobby, and we have a hard time keeping up any conversation. He recognizes me, but he never seems to remember that I've visited before. I have to work up my nerve every time I make the trip. Maybe I ought to - - -

***

Are any of these scenes familiar to you? Chances are that Max's father, Ann's grandmother, and Bob's brother-in-law seem different from the way they once were. The changes in their health affect other relatives, and some members are having to accept new family roles and relationships. When caregivers visit, write, or phone their relatives in nursing homes, some of the unspoken lines may be:

> "I love to talk over old times with you. We really feel close as we enjoy memories."
>
> "If we have never gotten along well together, how can we expect to understand each other easily now?"
>
> "Your confusion makes me sad. If I could learn what would make you feel good, even for a little while, I'd try to do it."

Figure 2. Page 1: Letter-unit # 1.
THE DRAMA OF FAMILY LIFE

Although each family's experience is unique, you may be like some of the cast members in the three scenes in regard to the feelings and decisions you face. On the green sheet you will be asked to suggest lines to complete the scenes in a fair way. Write below, for your own use, some specific activities which you have found satisfying for your relative <u>and</u> yourself when you visit, telephone, or write.

1. ____

____

2. ____

____

3. ____

____

If there are other family members living in your household or nearby, talk over this letter program with them. Perhaps you will want to plan together for the responses on the green sheet.

Please use the back of the green sheet to tell me any suggestions you have about this material. I would like to know which (if any) of the scenes are similar to those in your family:

_______________ in the past

_______________ in the present

_______________ anticipated for the future

You can see that the white pages serve as thinksheets on which you can record the replies you write on the green sheet. Each letter will focus on different ways of looking at decisions faced by caregivers. For later letters, please note two or three of the topics that interest you:

_____ Changing roles

_____ Memory-loss and confusion

_____ Independence

_____ Guilt

_____ Pressures on the caregiver

_____ Goodbyes

Now go on to the green sheet. Please fill it out and return it in the prepaid envelope within one week if possible. THANK YOU!

Figure 3. Page 2: Letter-unit # 1.
THE DRAMA OF FAMILY LIFE

(ON GREEN PAPER)

PLEASE RETURN THIS SHEET IN THE PREPAID ENVELOPE WITHIN 1 WEEK

The letter-units are to help families consider various ways of handling changing relationships and situations when members are in long-term care. There are no standard "answers." Even if you leave some responses blank, please return this green sheet. Use the back for your comments. THANK YOU!

* From your responses at the top of page 2, please share helpful ideas for other families who have relatives living in nursing homes.

  1. ______________________________

  2. ______________________________

* In the scenes on page 1, May, Ann, and Bob seem discouraged. Write what you imagine they will say next. After such scenes, often we have another thought about how to be fair to everyone. If you have suggestions, write your comments in the space left beneath each scene.

May: Your Dad was confused at the store again today, Max. He enjoyed the outing, but he picked up lots of things that the checkout clerk had to set aside -- including a jar of babyfood!

Max (her husband): Guess you got some pretty embarrassing looks!

May: Yes. Sometimes I think ______________________________

ANOTHER THOUGHT:

***

Ann (age 14): Do we have to go to the nursing home again this Sunday, Mom?

Mom: Grandmother is so cheerful that I don't see how we can complain about going to visit her every week. She can't get up out of that chair and take care of herself the way she once could, you know.

Ann: But all of us friends get together on Sundays, except for me! Can't you understand that ______________________________

ANOTHER THOUGHT:

***

Ben (a retired friend): I understand you went with your sister to visit her husband.

Bob: I go out to the nursing home with her occasionally, but then I always feel so tense. He gets lost going from his room to the lobby, and we have a hard time keeping up any conversation. He recognizes me, but he never seems to remember that I've visited before. I have to work up my nerve every time I make the trip. Maybe I ought to ______________________________

ANOTHER THOUGHT:

***

* In these scenes, whose situations (if any) resemble your experience?

  ______________ in the past

  ______________ in the present

  ______________ anticipated in the future

* Think about the topics listed at the bottom of page 2. If you would like material on any of these issues included in future letters, list the ones that interest you most.

  ______________ ______________ ______________

* Please use the back of this sheet if you need extra space for any of the responses above and for your comments and suggestions.

YOUR NAME: ______________________________

Figure 4. Green sheet: Letter-unit # 1. THE DRAMA OF FAMILY LIFE

A Framework for the Family Transition Project

The effectiveness of client education programs has some experimental support (Morisky, Levine, Green, Shapiro, Russell, & Smith, 1983). Correspondence courses are more frequently used to teach objective information and procedural skills, but Engel (1983) reported that a correspondence class in sex education for adults produced both factual learning and a high communication level. He attributed the openness in communication partially to feelings of protected privacy and confidentiality. Learning at home has been shown to be effective in other family matters such as parent education and consumer decision-making (Hennon & Peterson, 1981).

In both the content and the presentation of the FTP letter-units, characteristics of the caregivers were considered. Many of the respondents were older women. Erber, Feely, and Botwinick (1982) reported that older persons appear hesitant to reveal lack of information and therefore give a high proportion of "do not know" responses on surveys. Both the correspondence format and the permissive tone of the material helped to take pressure off respondents. Elderly persons were never described condescendingly.

In terms of counseling theory, the program was organized as a series of rational-emotive exercises (Ellis, 1974). Ellis asserted that persons can redefine their emotional states by rational awareness. Caregivers were shown possible ways to modify feelings about their experiences by reconstructing their ways of looking at those experiences and relationships, as well as by making intentional adjustments in their own behavior.

Role of the Family Program Specialist (FPS)

Participants in the Family Transition Project knew that the project's aim was development of programs to serve the families of nursing home residents. A respondent's initial role was that of enabler for the program developer; the emerging need for services to caregivers was consciously used as a means of motivating correspondents and giving them a reason to invest their time and thought in continued participation. The FPS did not assume that caregivers had problems but that everyone has needs, particularly when roles change.

Many caregivers find it hard to keep a balance between tending to their own needs, serving the nursing home resident's needs, and maintaining their responsibilities to other family members. The exercises dealt with deciding how to look at demands on one's own

resources and attention. The FPS, functioning as a friend who joined in the caregiver's interest in nursing home care, wrote a personal paragraph at the beginning of each letter-unit. These sections of each letter affirmed some suggestion from the caregiver's previous response sheet, set a nonintrusive question, or expressed empathy regarding a need described by the caregiver. The paragraphs demonstrated "reflective listening," described by Rogers in 1965. He suggested that this restatement of content confirms personal worth and helps people to trust their own capacities. In some instances, the FPS considered it helpful to deepen the affirmation to what Carkhuff (1969) called "level four," in which the feeling is reflected along with validation of content.

Rationale for Metaphorical Exercises

The metaphorical style provided protection for the correspondents (Heathcote, 1980). In each letter-unit, two introductory sheets were written so as to entice the reader into mental play and exploration. These two white pages, which were for the private and personal use of the respondent, were followed by a green response sheet that formed the basis of the return letter to the FPS. Caregivers were assured that the green sheets were not tests and were invited to omit irrelevant items and to add comments as they chose.

While not all nursing home residents are intellectually impaired, the number is high in proportion to those who have physical ailments only (Brotman, 1982). Dementia is the term used by physicians to describe a group of symptoms of functional mental impairment or memory loss (Mace & Rabins, 1981). Thomas (1981) suggested that dementia be attacked as the "disease of the century," citing its devastating effects on all those close to its victims. The wife of one sufferer described her life as "like being at a funeral that never ends" (Glaze, Note 3).

It is appropriate to offer caregivers help in becoming realistic about their relatives' conditions (Keith-Lucas, 1972; Tobin, 1978), and materials have been written to help family members communicate effectively and meet personal needs of confused elderly relatives (Carroll, 1978; Mace & Rabins, 1981; Mattson, Boyle, & Carroll, 1978). The FTP program was planned as a supplement to such direct material. Dementia in a family member, particularly a parent, adds fear about one's own future condition to the present concern for the relative (Johnson, 1978; Lee & Ellethorpe, 1982; Robinson & Thurnher, 1979). With the dementia patient, a caregiver has little hope of achieving mutual closure regarding any

leftover emotional issues. This realization may add to the caregiver's guilt and fear. An impaired parent's actual helplessness and disorientation may bring back to the caregiver's mind earlier, less reasonable, fears (Halpern, 1976).

Guilt can be described as the failure to measure up to one's own standards, while shame stems from the failure to meet others' expectations (Gerhart & Singer, 1971). Both emotions may be present, particularly if the relationship between caregiver and resident has not been positive over time or if the caregiver made the placement decision without agreement from the resident. The FTP modules aimed to unhook negative images of self or others and to find ways of building a neutral set of expectations, consistent with the demands of the real-world situation.

These emotional needs common to many caregivers suggested that metaphorical anecdotes could best introduce the new approaches promoted within the FTP exercises. The author defined indirect methods as including explicit analogies (Bandler, Grinder, & Satir, 1976; Klemer & Smith, 1975) as well as those ambiguous references that were never explained in terms of pertinent issues (Heathcote, 1980; Wagner, 1976).

Another device stimulated by the correspondence module format was mental roleplay. Working through requests, confrontations, or resolutions ahead of the actual conversation can help one see others' positions and plan one's own effective approach (Moreno, 1959). Nonverbal modes of communication can also be previewed. Contact between caregivers and their relatives in nursing homes, especially when it is irregular, tends to become a formal ritual in which roles are replayed to nobody's satisfaction (Glenn, 1982; Weinberg, 1974). The pattern can be broken by emphasizing shared values rather than current experiences and by nonverbal communication that implies low-pressure expectations (Bartol, 1979).

Metaphorical and dramatic exercises fit into the "prevention" segment of the therapeutic recreation service continuum (Avedon, 1974; Gunn & Peterson, 1978). In this relationship between recreator and client, the recreator provides materials and introduces possibilities while the behavior of the client remains independent and self-regulated. This invitational level was appropriate for FTP exercises in view of the short-term nonclinical contract. Ellis, Witt, and Aguilar (1983) suggested that the "flow" of transcendental pleasurable experiences can be facilitated by balancing an activity's difficulty with

the participant's skills and by emphasizing immediate feedback rather than rewards that are dependent on the outcome of the activity. The ambiguity of the FTP exercises made them adaptable to persons of varying conditions and functional levels, and participants were encouraged to play with the images that fit their current situations. Another implied benefit of the exercises was permission to find humor in grim circumstances--a freedom caregivers often deny themselves (LaBarge, Note 4).

Writing, in the form of letters or personal journals, can serve as an outlet for stress and as a tool for personal growth (Progoff, 1977). Compared with face-to-face conversation, correspondence has potential advantages of controlled pace and emotional distance; one may take time to deliberate about incoming messages before choosing the content and viewpoint with which one phrases a reply. Each correspondent exercises control over how intimate the exchanges become, so that there is minimal danger of being overwhelmed by another's manner or authority. In the Family Transition Project the flexibility of time requirements for respondents was expected to be an advantage in engaging participants. This time flexibility also added to the cost-effectiveness of the Family Program Specialist's schedule.

Module Topics

Eleven modules were written for the FTP correspondence program. The module titles were working descriptions. They were not used within the correspondence. Seven of the modules were standard components designed for all participants:

The Drama of Family Life

Family Strengths

"Put" in a Nursing Home

A New Look at Reality

Independence/Choice

Strength for My Responsibilities

Facts on Aging

Four were available for use in response to caregivers' individually expressed concerns:

Changing Roles

Goodbyes

Guilt

Pressures on the Caregiver

A common theme for all modules was attention to the caregivers' own needs. The majority of caregivers are women, and Gilligan (1982) reported that women seem particularly aware that high levels of moral behavior involve the networks in which each person carries responsibility. FTP materials emphasized that caregivers

themselves are due recognition as persons with the right to receive care; attention to their own needs for respite and nurture would not be disrespectful to their relatives in long-term care. Loevinger and Wessler (1970) identified a high level of ego development at which a person can admit that excessive attending to others must be moderated by the recognition of others' responsibility for their own lives. Gottman (1982) described successful relationships as consisting of the "forms people build when they are together," like verbal and nonverbal jazz, in which different players may take the lead on different occasions.

CHAPTER III

RESEARCH METHODS

Procedure

Experimental Design

Of the 27 licensed nursing homes in Guilford and Forsyth Counties, North Carolina, 17 accepted the invitation to join the Family Transition Project. Both commercial and not-for-profit homes were included, with sizes ranging from 35 to 260 residents (see Appendix B). The nursing home Administrator or a Social Worker wrote an invitation to each resident's primary caregiver (see Appendix C). A primary caregiver was defined as the person responsible for the resident's bills or the one who would be notified in case of the resident's death. These initial letters also included a short description of the study's purpose from the Family Program Specialist, along with a survey instrument. The "non-pretest" survey (see Appendix D) contained only demographic items and a space in which caregivers could give their names and addresses to indicate willingness to

participate in the study. The "pretest" version of the FTP survey (see Appendix E) included this material plus the measurement instruments--Palmore's Facts on Aging Quiz (Palmore, 1977, 1980, 1981) and Zarit's Burden Interview (Zarit, Reever, & Bach-Peterson, 1980). Also included in the pretest survey, but not analyzed for this study, was the Family Adaptability and Cohesion Evaluation Scale (FACES II), developed by Olson, Portner, and Bell (1982). With permission from the scales' creators, adaptations made each scale more suitable for caregivers of nursing home residents. The modified scales had been tested in a pilot survey of members of the Forsyth County Alzheimer's Disease and Related Disorders Association. Twenty-five responses were received in this preliminary survey.

Random assignment was assured by sending the two survey versions to alternate names on each nursing home's census list, regardless of the organization of that list (room number, length of stay, diagnosis, etc.)

The research design was based on a Solomon four-group design (Campbell & Stanley, 1966). As respondents volunteered for the project, those persons taking each of the survey versions were placed in

alternate groups. Thus four groups were identified: one tested and one untested group were controls and one tested and one untested group were offered the FTP correspondence program. No follow-up notices were sent to caregivers who did not respond to the initial mailing. The resulting selection bias toward persons who responded readily to mailed invitations was deemed desirable in view of the nature of the treatment. Participating nursing homes were also assured in this manner that their confidential relationships with their clients would be respected. Although most surveys went as one mailing from the FTP office, they were addressed by the separate institutions.

In order not to confound the interactive correspondence treatment by including persons with whom the Family Program Specialist was already acquainted, those persons were assigned to two additional "contact control" groups, one tested and one untested. These two groups received five letters--similar in content and approach to the interactive modules, but not asking for any response (see Appendix F). These one-way letters had no personalizing touches; copies were stapled and mailed

without envelopes, using metered postage. The signature of the FPS appeared only on the first and last letters, and then in copied form. The program content could thus be tested apart from the more costly personalized format.

The FTP correspondence program consisted of five letter-units, each requesting a reply within one week. The introductory letters were identical but were individually signed by the FPS. Letters two through five began with short paragraphs referring to the specific caregiver's prior responses; they were mailed from five to ten days after receipt of the caregiver's preceding letter. If a participant did not return the green sheet within three weeks, the next letter-unit was sent with a query, but this probe was not repeated if no further green sheet was returned. Caregivers were judged to have completed the program if they received the fifth letter.

Instrumentation

Palmore's Facts on Aging Quiz has been widely used to test the effectiveness of educational programs about the elderly in America (Palmore, 1980). It produces both a knowledge score and a bias score. Palmore reported the instrument's validity to be acceptable, judged on the

face validity of the items and on the research from which his true/false statements were developed. The group score reliability is high, as shown by test/retest scores in control groups.

In the initial study using the Burden Interview, Zarit et al. (1980) tested persons who were giving home care to relatives with dementia. They found the strongest predictor of low Burden scores to be regular visits to the impaired relative by family members other than the caregiver. Because tasks affect caregivers differently, Zarit and Zarit (Note 5) asserted that self-ratings on subjective scales surpass task-frequency counts as indicators of the extent to which caregivers feel burdened. The Burden Interview has produced evidence of acceptable reliability and validity, but Zarit has some question as to whether a real standard exists for validity in sensitive subjective measurements.

A search of the literature disclosed no more appropriate instruments for measuring caregivers' attitudes or adjustment regarding either the placement or

relationships between caregiver and resident. This lack of instruments reflects the fact that attention to residents' relatives has only recently come to be considered important (Quinn, 1983).

For the posttest, a "Satisfaction of Caregiver with Institutional Placement" (SCIP) scale was developed (see Appendix G). The demographic items were not repeated on the posttest, but respondents were asked to note any major changes--in health or marital status, for example. Caregivers whose relative no longer lived in a nursing home were asked to return the posttest uncompleted. This request was made mainly in order to show respect for the cooperation of caregivers even if their relative had died since the previous communication. Caregivers were not asked whether the relative had died, improved, or been transferred.

The SCIP scale contains 32 items. A "placement" subscale comprises 15 items pertaining to placement factors outside the direct control of the caregiver. A "relationship" subscale contains fifteen items that can reflect changes effected by the caregiver. There are two global items--one regarding placement satisfaction and

one regarding relationship satisfaction. Responses range from "strongly agree" to "strongly disagree" on a five-position Likert-type scale (Dillman, 1978). Some statements are phrased positively and some negatively, to control for response bias. Selection of the scale items was based on clinical experience, on consultation with several specialists on aging, and on needs cited in the literature (Lang & Brody, 1983; Quinn, 1983). The SCIP scale was developed for exploratory purposes; much additional work needs to be done to refine the instrument.

Subjects

Of the 1465 surveys mailed in February, 1983, 476 (32%) were returned, with 343 caregivers (23%) agreeing to participate in the Family Transition Project (Table 1). These responses were considered very good in view of the lack of any followup and the fact that caregivers were asked to put their names and addresses on surveys about a sensitive topic.

Table 1

Response Rates:

Family Transition Project Correspondence Program

	Number	Percentage
Surveys mailed	1465	
Surveys returned	476	32%
Volunteers for FTP study	343	23%
Posttests mailed	322[a]	
Posttests returned	201	62%

[a] Posttests were not mailed to caregivers who had withdrawn from the study for any reason (personal illness, death of resident, etc.)

Caregiver descriptions. Based on self-descriptive items in the survey, the "average" caregiver could be described as a white Protestant woman in good physical health (Table 2). Fifty-five was both the mean and the median age of caregivers. Most were married and lived in two-person households. Caregivers rated themselves as above average both in education and in financial resources.

While caregivers with fewer years of education may have selected themselves out of the study by not returning the first questionnaire, educational level did not appear to affect attrition once the caregivers were offered the correspondence program. The program-completion group and the total group were comparable in education, as well as in the other demographic variables.

Resident descriptions. The mean age of the nursing home residents was 83 (Table 3). Over half the residents were mothers of their family caregivers. Most were in poor physical health, and even more were judged to be noticeably deteriorated mentally or emotionally. Length of stay in the nursing home averaged 43 months.

Table 2

Caregiver Self-descriptions

Characteristics	Percentages[a]
SEX	
Female	73
Male	27
RELIGION	
Protestant	80
Jewish	13
Catholic	4
ETHNICITY	
White	94
Black	5
ECONOMIC RESOURCES	
I can afford anything I want to buy	3
I can maintain a comfortable lifestyle without using all my money	40
If I have only a few unexpected expenses, I can afford occasional special purchases	34
I have just enough to live, and there is rarely any extra	18
I cannot afford even the basic necessities	1

PHYSICAL HEALTH
(1 = lowest; 7 = highest)
7. . . 28%
6. . . 29%
5. . . 18%
4. . . 14%
3. . . 8%
2. . . 4%

AGE
Mean: 55
Median: 55
Range: 28 - 85

YEARS OF EDUCATION
Mode: 12
Median: 14

NUMBER IN HOUSEHOLD
2. . . 52%
1. . . 17%
Other. 30%

CONTACTS PER YEAR WITH RESIDENT
(in person or by telephone)
Mean: 137
Range: 0 - 730

N = 142

[a] Some percentages do not add up to 100 because of omitted responses.

Table 3

Caregivers' Descriptions of Residents

Characteristics	Percentages[a]
SEX	
Female	82
Male	18
KINSHIP TO CAREGIVER	
Mother	54
Father	10
Sibling	9
Aunt or Uncle	8
Parent-in law	5
Spouse	5
Other	9
MENTAL/EMOTIONAL STATUS (compared to status at age 45)	
Extreme deterioration	33
Noticeable deterioration	34
Some change, but not to a problem status	21
Very much the same	6
Improved	4

AGE	PHYSICAL HEALTH (1 = lowest; 7 = highest)
	1. . . 16%
	2. . . 34%
	3. . . 20%
	4. . . 22%
Mean: 83	5. . . 7%
	6. . . 1%

AVERAGE LENGTH OF STAY IN THE NURSING HOME: 43 months

N = 142

[a] Some percentages do not add up to 100 because of omitted responses.

Participation Analysis

Participation and completion rates compared well with those of most correspondence courses, as reported by the National Home Study Council (Lambert, Note 6). Within the limits of a modular, replicable program, the Family Program Specialist tried to personalize the appearance and style of the letter-units as much as possible. The gender of pronouns in each person's material matched his or her relative. Letters were individually signed, and colorful postage stamps were used. Addresses were typed in upper-case and lower-case letters.

The comparatively low participation rates of caregivers who responded later to the initial survey and who were invited into the program at a later date confirmed the effects of the selection process and of the attention to personalizing detail. Originally, the control groups and the program groups were randomly selected from the first 200 volunteers for the study. Fifty-nine respondents were later added to the program, after the program started, in order to insure adequate numbers for analysis (Tables 4 and 5).

The groups receiving letter-unit # 1 early in March had much higher response rates than did the groups receiving the same material three weeks later. The first

Table 4

Participation Rates:

Early-start and Late-start Groups

Group	Green sheet # 1 returned: Yes	No	N
Early-start (March 4)	84	16	100
Late-start (March 24)	28	31	59
TOTALS	112	47	159

chi square (1) = 24.31, $p < .001$
phi square = .15

Table 5

Completion Rates:

Early-start and Late-start Groups

Group	Completed correspondence program: Yes	No	N
Early-start (March 4)	51	49	100
Late-start (March 24)	5	54	59
TOTALS	56	103	159

chi square (1) = 29.41, $p < .001$
phi square = .18

green sheets were returned by 84% of the early-start group members and 51% of the early-start group completed the correspondence program. Of the late-start group members, 47% returned the first green sheets and 8% completed the program.

Three factors probably contributed to the differences in response rates. First, the early group members had responded more quickly to the original survey; the inferred bias toward written communication was part of the reason for their selection into the program groups. Second, the late-start group members received their first letter-units during the week before Easter and Passover; holiday considerations may have interfered with their responses. Third, the letters to the late-start groups looked more like bulk mail. Their letters were addressed with upper-case letters only, rather than with upper-case and lower-case letters.

Caregivers who had completed the pretest version of the initial survey consistently had slightly higher response rates than did members of the untested groups. One explanation for their response may have been the interest stimulated by the items contained in the pretest scales, or the higher response rate may provide additional evidence of selection bias toward written communicators.

CHAPTER IV

RESULTS AND ANALYSES

Results and Statistical Analyses

The research design was based on the Solomon four-group design (Campbell & Stanley, 1966). One of two survey versions--either a pretest version or a survey containing only demographic items--was mailed to each primary caregiver for the residents of the seventeen cooperating nursing homes. As respondents volunteered for the study, they were randomly placed in either the treatment or control groups. Thus four groups were formed, one tested and one untested group for controls and one tested and one untested group who were offered the FTP correspondence program. Posttest instruments were the Facts on Aging Quiz (FAQ) (Palmore, 1977) and the Burden Interview (Zarit et al., 1980). An original scale, Satisfaction of Caregiver with Institutional Placement (SCIP), was also used in the posttest.

For purposes of analysis, caregivers who received the fifth letter of the five-letter FTP program were judged to have completed the program. Posttests were returned by 54 caregivers in this completion group--33

tested and 21 untested. From the control groups, 19 tested and 50 untested respondents returned posttests. Statistical analyses were performed upon these scores only--comparing the posttest means of the program completion group and the control group.

To determine whether taking the pretest had a significant effect on posttest scores, for each of the scales a *t*-test was used to compare the posttest means of the pretested and untested control group members. There was no significant difference between the means of the two control groups on any of the three scales (Table 6). Therefore the pretested and untested groups were combined for the comparison between the completion and control groups.

One-way analyses of variance were made, using caregiver membership in the two groups as independent variables. Dependent variables were the FAQ bias and knowledge posttest scores, the Burden Interview posttest scores, and the SCIP scores.

No significant differences were found between the two groups on any of the measures (Table 7). Only the difference in the FAQ knowledge-about-aging scores approached significance ($p = .06$). The posttest scores

Table 6

Posttest Scores on Bias, Knowledge, and Burden:

Pretested and Untested Controls

Scale	Group	Mean Score	Standard Deviation	*t* Value	Degrees of Freedom	p
FAQ (bias)	pretested	-.1368	.246	1.87	67	.07
	untested	-.2663	.260			
FAQ (knowledge)	pretested	9.79	3.14	-.27	67	.79
	untested	10.04	3.48			
Burden	pretested	82.11	13.83	.05	66	.96
	untested	81.92	13.83			

N = 69

Table 7

Posttest Scores on Bias, Knowledge, Burden, and Satisfaction: Program and Control Groups

Scale	Group	Mean Score	Standard Deviation	F	Degrees of Freedom	p
FAQ (bias)	program	-.1819	.291	.95	1,121	.33
	control	-.2306	.261			
FAQ (knowledge)	program	8.84[a]	3.39	3.60	1,107	.06
	control	10.82	3.59			
Burden	program	83.83[b]	9.86	1.40	1,121	.24
	control	80.78	16.82			
SCIP	program	113.5[c]	13.04	2.27	1,121	.13
	control	109.8	13.63			

N = 123

[a]FAQ knowledge score is number of questions <u>missed</u> from a possible total of 25.

[b]Higher Burden scores indicate <u>lower</u> burden expressed.

[c]Higher SCIP scores indicate higher satisfaction expressed.

moved in the predicted directions, but by very little. Either the program had no appreciable effects or the instruments were not appropriate for measuring the changes that occurred. All three hypotheses were rejected.

Bias about Aging

The caregivers who had received the letter-units and those who were in the control group did not differ significantly on the bias scale derived from the Facts on Aging Quiz, $F(1,121) = .95$, $p = .33$.

Knowledge about Aging

On this single dimension, the difference between treated and untreated groups approached a significant level, $F(1,107) = 3.60$, $p = .06$. It is reasonable to assume that the objective material was more readily applied than the metaphorical, particularly since the Facts on Aging module had been in the final letter, which group members had received between one and three weeks before they received the posttest. There was no reference to test-taking in the Facts on Aging instructional module, and there was no green sheet associated with it.

Burden

The treatment and control groups were not significantly different in their Burden Interview scores $F(1,121) = 1.4$, $p = .24$.

Analysis of the New Scale: Satisfaction of Caregiver with Institutional Placement

Using the SCIP scores from the posttest, no significant difference was found between the the treatment and control groups' scores, F (1.121) = 2.27, p = .13. The SCIP appeared to be comparable to the Burden Interview in measuring subjective satisfaction levels. The amount of variability registered on most items suggests that the scale may be potentially useful.

SCIP responses of 184 caregivers were factor analyzed, using both quartimax and varimax rotations (Table 8). All the rotations produced similar factors that were theoretically acceptable. Factor 1 contains items related to satisfaction with the services provided by the nursing home. Factor 2 contains items related to the relationship between caregiver and resident. Items in Factor 3 pertain to the caregiver's perception of the present capability of the resident. Items related to pressures on the caregiver make Factor 4 a "countersatisfaction" Factor. Each of Factors 1 through 4 has an Eigenvalue greater than 1; together the four factors account for over 77% of the variability in the responses on the SCIP scale.

It would be useful to test the instrument further. Most of the SCIP items are suitable for any long-stay institution. With appropriate rephrasing, the scale may be used with family members of residents in such institutions as training schools or group homes.

Table 8

Satisfaction of Caregiver with Institutional Placement: Factors and Loadings

Factors (Quartimax rotation)	Loading
Factor 1: Satisfaction with the nursing home services	
54. Staff attitudes seem to have a positive effect on residents..	.41
57. Because of regulations and standards, the nursing home has difficulty providing a pleasant, homelike environment.	-.64
59. The nursing home provides attractive, nourishing food........	.53
61. There are enough staff members to care for the residents.....	.67
63. The nursing home provides a place where my relative and I can visit privately..................................	.53
66. Staff members respond helpfully to my concerns about my relative..	.70
71. The nursing home maintains a safe, secure environment for the residents and their possessions..................	.75
73. After visits, I manage to leave in a way that is satisfactory both to my relative and to me...............	.30
74. I must submit to manipulation by my relative or by the nursing home......................................	-.48
77. The nursing home does not provide care as good as was described when my relative entered long-term care.........	-.70
81. Overall, I am pleased with the care that my relative receives in the nursing home....................	.82
Factor 2: Satisfaction with the relationship	
50. I find ways in which my relative and I can have a pleasant time, even if we have to make changes in our usual activities..	.55
53. I worry about how well I play my part in caring for my relative..	-.49
55. I feel guilty about my relationship with this relative.......	-.68
58. My relative responds to me in a positive manner.............	.49
60. In addition to talking with the resident, I communicate by other attentions, such as walking together or caring for physical needs..............................	.33
64. Including personal visits, phone calls, and letters, I have the right amount of contact with this relative.......	.59
73. After visits, I manage to leave in a way that is satisfactory both to my relative and to me...............	.34
76. I feel tense after a visit with this relative...............	-.36
79. I think I do well in handling my responsibility for this relative.......................................	.67
80. Overall, I am pleased with the relationship I now have with this relative.....................................	.72
Factor 3: Present capability of the resident	
51. My relative is in excellent physical condition..............	.32
52. My relative is in excellent mental condition................	.53
56. My relative's personality style has improved since he or she entered the nursing home.......................	.58
58. My relative responds to me in a positive manner.............	.36
68. I cannot speak to this relative about money or financial matters......................................	-.55
73. After visits, I manage to leave in a way that is satisfactory both to my relative and to me...............	.31
Factor 4: Pressures on the family caregiver	
62. I feel cheated because of the time that caring for this relative takes from the time I have available for other responsibilities.................................	.33
73. After visits, I manage to leave in a way that is satisfactory both to my relative and to me...............	-.31
76. I feel tense after a visit with this relative...............	.63
78. My relative seems to need constant reassurance and attention.	.53

N = 184

CHAPTER V

DISCUSSION AND SUMMARY

Discussion

Responses of the Caregivers

Improving caregiver satisfaction through a short-term program is probably unrealistic. Feelings of emotional burden or of satisfaction are difficult to measure (Zarit & Zarit, Note 5); they are even harder to influence. Comments from the participant caregivers, however, gave evidence of their willingness to explore the requested exercises and of their appreciation for the Family Program Specialist's awareness of the pressures on caregivers. The longer respondents stayed in the program, the more quickly they returned their green sheets. On the final green sheet, several caregivers stated that they had been helped in their relationships with institutionalized relatives.

The richness of responses to the metaphorical exercises showed that caregivers were able to cope well with the levels of abstraction and ambiguity. A few

respondents did comment that the style was one to which they were not accustomed. As noted earlier, response rates were similar across all levels of education. In writing on the green sheets, participants appeared to feel free to respond in whatever ways had meaning for them. Sometimes only part of the forms would be completed; often comments or elaborations were written on the backs of green sheets. The caregivers' interest in the program did not appear related to the length of time their relatives had been in nursing care.

The relatively high completion rate suggests a need for contact between caregivers and those who can respond to their needs. The personalized messages were probably more motivating than was either the content or the style of the letter-units. In letter-unit # 3, a collection of hints from caregivers was included, so participants had evidence that their suggestions were appreciated (see Appendix H). Even on the initial surveys, many respondents volunteered comments.

Suggestions for Use of a Correspondence Program

The research requirements of concreteness and measurability imposed certain artificial restrictions on the design of the program. If the correspondence program is used as one of several services that a nursing home

can offer caregivers at the time of a relative's admission, three changes will improve the program: (1) use at time of admission, (2) correspondence between a caregiver and his or her relative's own social worker, and (3) use of both direct and metaphorical material.

Use at time of admission. Because of the time between the first identification of caregivers and the beginning of the program (five to nine weeks), all the participants had made some adjustments to their roles before the program began; many persons had years of experience. The transition program was designed for use before caregiver attitudes and behavior had become habits. Immediately after the logistical issues of entry are settled, a sensitive social worker can focus on open communication that will reassure the caregiver about his or her new role. FTP-type letters, in a limited-number series, may help ally the caregiver with the nursing home staff members in the joint service relationship to the resident family member. Such an alliance should decrease the instances of inappropriate demands that are associated with families' lack of knowledge of institutional personnel and procedures. Structured

written personal communications allow the social worker (or other assigned nursing home representative) to reinforce important messages, invite cooperative planning, and relieve some fears.

Correspondence between a caregiver and his or her relative's own social worker. The FPS, corresponding with caregivers within the study, did not claim to represent the nursing home of the caregiver's relative or to know that relative. An assigned staff member who maintains a relationship with residents and their caregivers will be able to pursue a more sensitive counseling role. The FPS wrote personal messages, but the context limited these messages to reflective responses. There were many indications that certain caregivers would have been receptive to more specific problem-solving work or interpretation of the family system dynamics. While a nursing home social worker would not be expected to provide ongoing therapy for caregivers, some family issues could appropriately be addressed because of effects on the residents.

Use of both direct and metaphorical material. The FTP modules included metaphorical exercises not only because of the usefulness of such an approach but also

because there had been little of such material written so far. A combination of metaphorical and direct communications would be more productive than either approach alone. Social workers who offer the correspondence program to caregivers at the time of a relative's admission should widen the scope of material included in the letters. After their "settling down" period, caregivers will appreciate receiving specific information about the activities, routines, and expectations of the nursing home. The optimal combination of modules would include a balance of informational, metaphorical, and direct issue-related exercises. It would still be important to develop a format that could facilitate the caregiver's response.

Summary

The Family Transition Project was established in order to develop, implement, and evaluate a correspondence program for family caregivers of nursing home residents. Caregivers who agreed to take part in the study were randomly placed in treatment and control groups. In March, 1983, the program was offered to 159 caregivers, each of whom had a relative in one of the 17 cooperating licensed nursing homes in Forsyth and Guilford Counties, North Carolina. Fifty-eight caregivers completed the five-letter program.

The Family Program Specialist conducting the study began caregivers' letters with personalized notes based on their prior correspondence. Each of the five letter-units comprised two one-page modules describing open-ended situations or questions designed to encourage looking at common experiences and relationships in a variety of ways. Themes included such issues as changing roles, dealing with loss, and maintaining self-esteem. A third page in each letter included metaphorical exercises and posed "fail-safe" questions that formed the core of the caregiver's reply to the FPS.

In a design based on the Solomon four-group design, caregivers' bias about aging, knowledge about aging, and burden scores were measured before and after the program. The posttest scores of caregivers who completed the corespondence program were compared with the scores of control group members. One-way analyses of variance revealed no significant effects of the program.

The level of participation and the comments of caregivers, however, indicated a need for structured contact between family caregivers and those who offer support. Response to the initial survey was strong. Although it was anticipated that a program focused on transition adjustment would be particularly helpful to the families of recently admitted residents, there was also a high level of participation by the caregivers of long-stay residents.

Caregivers who responded early to the survey also had high participation rates in the five-letter program. There was a significant difference between the participation rates of those who returned their initial surveys immediately and those who returned surveys later.

Correspondence similar to the Family Transition Project may show advantages as one of several services offered to caregivers by nursing home staff members. Such a program might be more effective if available soon after admission of the caregiver's relative. Correspondence could best be between the caregiver and a staff member who works directly with the nursing home resident. Letter-units which include informational, metaphorical, and direct issue-oriented exercises might also prove more effective in increasing caregivers' satisfaction.

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APPENDIX A

LETTER-UNIT MODULES

FAMILY
TRANSITION
PROJECT
P.O. Box 38
Clemmons, NC 27012

Letter-unit #2

NOTE: In letter-units 2 through 5, a personal message was typed in this space above the first exercise. Letters were signed at the bottom of the second page.

Families often share a traditional way of observing special events and holidays. When a member lives in a nursing home, this person may seem to miss out on many family occasions. Family "traditions" include not only the special days, however, but also the family's own style -- the habits of everyday roles and customs.

> Do you remember family stories that still get a laugh or give everyone a warm feeling?
>
> Is there a "Fairy Godmother" in your family? A "Big Boss?" A skeleton in the family closet? (Shhhhhhh!) A "Handsome Prince?"

Sometimes communication with the family member is so changed that we overlook memories we could share. Most folks enjoy recalling happy scenes in which we had a part.

Every family has a variety of potential strengths -- habits that can help individual members. Often we feel overcome by losses in ability to keep things unchanged, and we may not realize our own power to choose and make decisions. The Chinese character for "challenge" combines the symbols for "risk" and "opportunity." When families have members in long-term care, some opportunities quickly come to mind:

> "Now I can help him as he has helped me."
>
> "I will be sure he gets the best care I can provide."

Other positive "opportunities" in the changed situation may be just as real, but not so easy to notice:

> "If I read to him, then _I_ can enjoy the book, too."
>
> "When I realize what he needs now -- not what he used to need or what _I expect_ people to want -- then I can be free to leave off some tasks and concentrate on things that might bring pleasure, even if only for the short time we are together."

Several participants in this program have already shared helpful ways of dealing with the changed relationships with their relatives. My next letter will include some of these ideas and hints.

Page 1: Letter-unit # 2
FAMILY STRENGTHS

Are you familiar with Mark Twain's book Huckleberry Finn? From our present-day viewpoint, Huck Finn was right in his intention that the slave man Jim be allowed freedom. But what a struggle Huck had with his conscience! The moral world taught him that Jim should be only a slave and that Huck was "good" only if he helped keep Jim in bondage.

Sometimes it seems as if the world is turned upside down, when sorting out "right" and "wrong" (or even "OK!") is not as easy as we thought. Our heads determine a new course must be taken, but our hearts still feel confused. It's hard to feel right, even when we know that we have made careful, loving decisions.

Suppose Mark Twain should ask you to write some changes in Huckleberry Finn! The assignment he gives you is to make up a short, persuasive speech for Theo Strong. Mr. Strong's purpose (when we add him to the book) will be to convince Huck that having Jim be free is a decent goal. Huck wants to believe, but he just doesn't feel right about it. Could you give Mr. Strong some words to help instruct Huck's conscience?

Huck: I know he's got no right to live free!

Theo Strong: You could look at it this way, Huck. - - -

I am assuming that you are providing for your relative the long-term care you have learned is appropriate. You have been forced to weigh various needs and priorities for yourself and for her. If, twenty years ago or longer, you and she had talked about the conditions you two now face, what do you think her inner wish would show? Would some part of her true character try to bring you more satisfaction about her present life?

Just as you thought about a persuasive speech for Theo Strong, try composing the "speech" which your relative-of-twenty-years-ago might make to help you feel OK about the two of you now. Assume that she wants you to have a satisfying life of your own and that she can find positive routines and relationships in the nursing home where she is now receiving long-term care.

You: ...and now you need to have nursing care.

Your relative: Yes. And I - - -

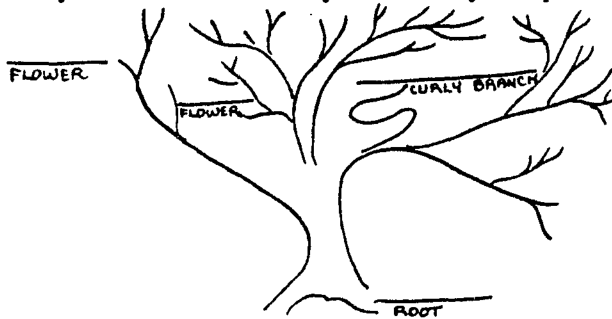
Yours truly,
Ellen Yarbrough

(ON GREEN PAPER)

PLEASE RETURN THIS SHEET IN THE PREPAID ENVELOPE WITHIN 1 WEEK

The letter-units are to help families consider various ways of handling changing relationships and situations when members are in long-term care. There are no standard "answers." Even if you leave some responses blank, please return this green sheet. Use the back for your comments. THANK YOU!

Here's one way to look at a "family tree." If you placed your family members on this diagram, who would be the Root -- the strong one members depend on? Who could be called the Flowers -- displaying special traits and capacities? Who is like a Curly Branch -- finding new ways to grow? Please fill in the illustration to describe your family. Add spaces or labels wherever you need, to show your family's special personality.



How would you describe your own place on this family tree chart?

____

____

Can you note one way in which a family value or habit affects positively your task as caregiver to your relative in the nursing home? I would appreciate an example of how you use a family strength in a way that helps both you and her feel good.

____

____

Could you carry your conversation with your relative-of-twenty-years-ago one step further? If your heart's "ear" can hear her permission to provide her with nursing care in the place where she now lives, what would you say to her (and to yourself) to assure her of your continuing concern and of your own acceptance of the different roles you each now carry?

You: ...and now you need to have nursing care.

Your relative: Yes. And I ________________________

____

You: You know that I ________________________

____

__________ I feel that you and I ____________________

____

YOUR NAME: ____________________

Green sheet: Letter-unit # 2
FAMILY STRENGTHS and "PUT" IN A NURSING HOME

HINTS FROM CAREGIVERS ON THE BACK OF THIS SHEET

FAMILY
TRANSITION
PROJECT
P.O. Box 38
Clemmons, NC 27012

Letter-unit #3

Two men are using similar phrases to describe the same woman: Which one do you think she would enjoy hearing?

Matt: When I look at her, time stands still!

Bert: Her face would stop a clock!

Sometimes we disguise unpleasantness behind nice descriptions, and sometimes we overlook true value which is delivered in strange ways. Familiar habits and judgments may keep us from thinking about our behavior and relationships. Even in our hometowns, we can hardly find the way across town with maps that were drawn when we were children. We need a realistic up-to-date view.

Try an introduction of yourself that will meet two standards:

1) Show that you are special, with a unique personality.
2) Write so fairly that the person receiving the introduction will not be biased either toward you or against you.

"Let me introduce myself. You should know that I - - -

"

Could you write such a positive, impartial introduction of your relative who lives in the nursing home? (This page is your personal thinksheet, but on the green sheet I would really like to know something about your relative, including the name I should use when I refer to this relative.)

Be sure not to gloss over uncomfortable conditions nor to neglect the positive aspects of your relative's situation as it now is. Draw on your memories, but make the introduction for now:

"Let me introduce you to my relative, who - - -

"

PLEASE RETURN THIS SHEET IN THE PREPAID ENVELOPE WITHIN 1 WEEK

The letter-units are to help families consider various ways of handling changing relationships and situations when members are in long-term care. There are no standard "answers." Even if you leave some responses blank, please return this green sheet. Use the back for your comments. THANK YOU!

Please write a short introduction to your relative, making your description as matter-of-fact as you can.

"Mrs. Yarborough, let me introduce you to

________________________________, who is
(name)

my ______________________________. You will
(kinship)

want to know that __________________________

______________________________________."

Do you find it easy to be impartial in objective introductions?

	Introductions of yourself	Introductions of your relative
YES	________	________
NO	________	________

Green sheet: Letter-unit # 3
A NEW LOOK AT REALITY

FAMILY
TRANSITION
PROJECT
P.O. Box 38
Clemmons, NC 27012

Letter-unit #4

We like to make our own choices -- to clothe ourselves in independence and individuality. Deciding what to wear, setting our own schedules, even making our own mistakes proves we are adults!

On the other hand, we generally don't like having to make decisions which rightfully belong to others; we feel weighed down, as if we are hauling someone else's baggage of responsibility. Sometimes we just feel imposed on and helpless, and other times we feel downright angry! This may be true even if we have volunteered to help another. It is as if we casually pick up a guest's suitcase and then it keeps getting heavier and heavier.

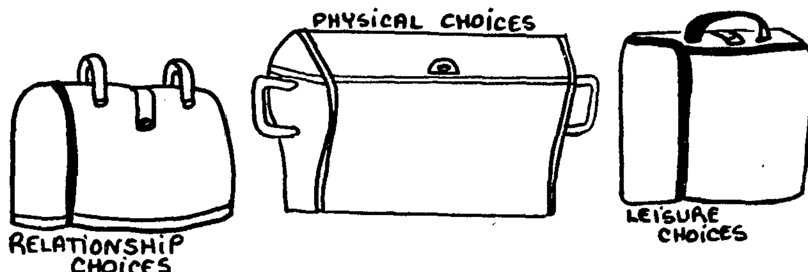
It may be helpful for you to look over some of the choices you are making on behalf of your relative in the nursing home. If you know how you started bearing various responsibilities, consider whether the original conditions and needs still apply.

Will it be appropriate for you to let go some of your power, if you can (realistically) rearrange some of the conditions or expectations? Your relative may be able to carry some of the responsibility; some services may be provided by other relatives or by nursing home staff; it is even possible that some of the burdens you carry are related to matters that actually can be left untended!

For your own consideration, look at choices you regularly make on behalf of your relative:

1) Physical choices (example: what clothes to wear)
2) Leisure choices (example: how to spend time on your visits)
3) Relationship choices (example: who deals with the Home staff)

"BAGGAGE" I CARRY FOR MY RELATIVE:



(ON GREEN PAPER)

PLEASE RETURN THIS SHEET IN THE PREPAID ENVELOPE WITHIN 1 WEEK

The letter-units are to help families consider various ways of handling changing relationships and situations when members are in long-term care. There are no standard "answers." Even if you leave some responses blank, please return this green sheet. Use the back for your comments. THANK YOU!

Even if we are unable to express the need, each of us wants to have some control over our life. On the chart below, please "clothe" your relative in the choices she presently carries for herself -- evidence of her independence.

With some adjustments of habits or standards, you may be able to offer her more choices in a way that supports her dignity. If you are thinking of ways in which you can give back some of the choices you carry for her, write those on the chart in CAPITAL LETTERS.

What will you do to make it more likely that she can take up more personal choice and self-determination?

Green sheet: Letter-unit # 4
INDEPENDENCE/CHOICE

FAMILY
TRANSITION
PROJECT
P.O. Box 38
Clemmons, NC 27012

Letter-unit #5

Say it with flowers -- you deserve a bouquet, so how about designing one for yourself! Fill in the blanks so that each statement is a true compliment. Describe some of the best things about you.

I OFTEN ________

I ALLOW ________

I KNOW ________

I SELDOM ________

I CAN ________

I EASILY ________

I AM ________

Is there an "empty pot" aspect of your life these days? Are you facing some unfinished issue or incomplete relationship, but hoping for growth? Let the label on the empty flowerpot show what you hope will grow there to make your life more pleasant.

____

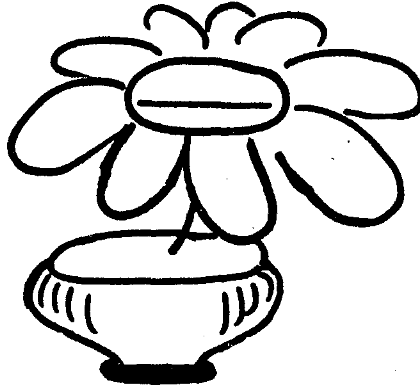
As you plan ways to maintain growth in your life, remember that the personal assets you listed above are yours to believe in and use.

Page 1: Letter-unit # 5
STRENGTH FOR MY RESPONSIBILITIES

PLEASE RETURN THIS FINAL GREEN SHEET WITHIN ONE WEEK IF POSSIBLE.

You have offered your self a "bouquet" of honest compliments, and you have identified a part of your life where growth is needed. Look over your bouquet of assets and see if you find one which can help with "the need of the empty flowerpot" -- where you can apply *a known strength to a known need.*

Please tell me about this special ability by writing it on the flower. You need not label the need on the flowerpot, but you may write it if you choose to share that with me.



Please describe (in one or two sentences) what you will do first in this matter. Make use of your personal strength!

____

____

____

YOUR NAME: ____________________

Please use the back of this final green sheet to share your comments and suggestions about this program. Many thanks for your cooperation!

Green sheet: Letter-unit # 5
STRENGTH FOR MY RESPONSIBILITIES

"Will I become like this?" It may be frightening to think about our own futures when we observe severely impaired elderly relatives. Sometimes we overlook our alert, active elders. The following positive view, however, is based on FACTS learned in recent studies of aging Americans.

A SEVENTY-YEAR-OLD JOGGER! - A HELPLESS INVALID!

Many stories about aged people highlight the dramatic extremes. Duke University's Dr. Erdman Palmore, however, has found that older Americans live very much like their neighbors do, and like they themselves lived in earlier years. Fewer than one in ten have continuing problems of mental disorientation; most elderly persons find ways to compensate for any physical limitations so that their effectiveness in tasks and relationships can be maintained.

Meet "Mary Smith" for instance -- an "average" older American. All elderly people are not alike, of course. (Think about the years in which they have been specializing in different directions!) Mary Smith's personality and lifestyle are unique to her. According to the materials reported by Dr. Palmore, though, here is what we may expect about the "average" Ms. Smith:

> Mary Smith is mentally alert, living at home, and has an income above the poverty level. She is in a small group; even by the year 2000, only around 13% of Americans will be aged 65 or older. She continues to carry out her normal activities, and she reports that she is not often angry, miserable, or bored. Religion means about the same to her as it did when she was younger. She is still able to enjoy the sexual dimension of her life.
>
> Ms. Smith wants to be doing some kind of work, whether it is paid work, volunteer work, or work with her own home and family. She can learn new skills; mastery sometimes takes her longer, but she can repeat new patterns and make new habits. Because age has brought some decline in the acuteness of Ms. Smith's five senses, in her reaction time, and in her lung capacity and physical strength, she compensates by extra carefulness, so that she can be an effective worker. In working and in driving a car, her safety record will be better than the records of younger workers and drivers.
>
> Community and family relationships are important parts of Ms. Smith's life, so that she is not isolated or lonely. At present, most health service providers give Ms. Smith and her elderly friends low priority, but the status of the older Americans is rising! By the year 2000, the gap will be much smaller between the health and socioeconomic levels of the elderly and younger members of our society.

As more attention is focused on the interests, abilities, and needs of the elderly, it is important to recognize that older Americans are themselves valuable resources. This description of the "average Mary Smith" states that the effects of aging usually do not prohibit full and satisfying life experiences and relationships.

Ellen Yarborough, 5/83

Page 2 or 3: Letter-unit # 5
FACTS ON AGING (All the FAQ answers)

On a scale from 1 (lowest satisfaction) to 10 (highest satisfaction) rate the SATISFACTION you get from the following relationships. Skip the ones that don't apply to you.

YOUR RELATIONSHIP WITH:	SCORE (1-----------10) low high
your paper carrier................	_____
your employer.....................	_____
your relative in the nursing home.	_____
your barber or hairdresser........	_____
your customers....................	_____
your family pet...................	_____
your brothers and sisters.........	_____
your closest neighbors............	_____

Now place these eight persons or groups on the COMPETENCE ladder, with the most competent on the top rung and the others placed on rungs in the order of their all-around ability.

COMPETENCE LADDER

top rung 1________________________ most competent
2________________________
3________________________
4________________________
5________________________
6________________________
7________________________
8________________________ least competent

You may find some surprises if you cross-check the two ways of looking at the relationships in your life. Is it necessary to be highly competent in order to provide satisfying relationships? Does the answer depend on what you expect from the person? When abilities change, are you able to adjust your expectations? Some times we have to struggle to recognize ways in which both persons can get real, though short-term, pleasure.

Please feel free to note any comments or suggestions you have on the back of the green sheet. Thanks!

Yours sincerely,

Ellen Yarborough
Family Program Specialist

Optional module: CHANGING ROLES

(ON GREEN PAPER)

PLEASE RETURN THIS SHEET IN THE PREPAID ENVELOPE WITHIN 1 WEEK

The letter-units are to help families consider various ways of handling changing relationships and situations when members are in long-term care. There are no standard "answers." Even if you leave some responses blank, please return this green sheet. Use the back for your comments. THANK YOU!

Most of us find satisfaction in simple and familiar activities. Think about one activity that you and your relative can share when you see one another again. Be sure to select something which can be satisfactory for both of you. In your mind, go over the way you expect the visit to be; find an expectation level with which you can be comfortable.

Decide that if she reaches this level you will be satisfied -- and if she does better, celebrate!

Please describe briefly the activity you are planning:

____

____

What will you consider a sign that your planning is successful?

____

YOUR NAME: ______________________

Green sheet: Optional module
CHANGING ROLES

When American pioneers left their friends and headed West in their covered wagons, they did not know if there would be any more face-to-face meetings. Some of them must have been careful to compose messages showing their deep feelings for those they left behind. When we face such separations, often we try to speak of our personal values as well as of our plans and hopes.

Words at parting would be treasured by our friends -- ways for them to remember our fellowship and our concern for them. What would you leave in such a message if you were heading for a very long journey, one on which you would be safe but out-of-contact with your friends?

"My Loved Ones, you know that - - -

Sometimes families could send letters to their westward-bound members, but travel was so uncertain that they never knew if the messages would be received and understood. What sort of messages do you think should be sent in such unpredictable times? Would there be any way in which careful wording might make the meaning more clear?

You probably put a great deal of thought into how you phrase the messages that you feel you <u>must</u> communicate clearly to your relative. When the message is an unwelcome one, we often have a difficult time getting it across -- even to residents who are not confused!

There are many "Goodbye" times -- at the end of visits, when we go away on trips, when we know we will not spend time together again, etc. We usually are more comfortable if we try to express our feelings as we move from one stage to another.

Yours truly,

Ellen Yarborough
Family Program Specialist

Optional module: GOODBYES

PLEASE RETURN THIS SHEET IN THE PREPAID ENVELOPE WITHIN 1 WEEK

The letter-units are to help families consider various ways of handling changing relationships and situations when members are in long-term care. There are no standard "answers." Even if you leave some responses blank, please return this green sheet. Use the back for your comments. THANK YOU!

When you talk with your relative, you want to affirm her awareness and mastery of her world. You also want her to know that you are taking care of your responsibilities, so that she can feel secure.

Have you learned useful styles of communication that satisfy both you and her? Please share some hints about ways to be clear.

A MESSAGE ON AN EVERYDAY MATTER

Subject: ______________ Message: ______________________________

____

____

____

A MESSAGE ON A MATTER OF SOME IMPORTANCE

Subject: ______________ Message: ______________________________

____

____

____

YOUR NAME: __________________________

Green sheet: Optional module
GOODBYES

THINKING IT OVER

Moe, a water skier, bought a new tow rope. Although he fastened the far end of the rope to his friend's boat, Moe did not plan to ski. As he stood in the shallow water idly talking to a fisherman, Moe tied the end of the new rope around his waist and leaned down to strap his knife into a leg-sheath. His friend mistook the action for a signal and started the motorboat — not looking back as Moe was dragged through the choppy water.

Finally the fisherman saw that Moe tugged his knife out of the sheath and cut the rope that bound him to the speeding boat. The sudden trip had left Moe bruised and faint when the fisherman rowed out to help him ashore. "Why didn't you cut the rope as soon as you realized the boat was not going to stop?" asked the fisherman.

"Well, I was hurting pretty bad, but I didn't want to ruin my rope!" Moe said.

Moe's rope; Moe's knife; Moe's decision!

Sometimes we find that we must work through one uncomfortable decision in order to relieve a worse situation. When I have to assert myself through a decision or a new habit, it often helps to "have a talk with myself." I review:

1) what my goal is
2) my right to achieve that goal (and how it affects others)
3) steps I can take toward the needed change
4) signs that will demonstrate my progress

(Moe probably went through this process, too, but he took so long!)

If you feel that your relative's needs and yours are not balanced in your relationship, you can use this outline to plan for fairness.*

My GOAL and need:

What tells me I have a RIGHT to have this need met:

STEPS I can take:

SIGNS of progress:

- -

*If I do not try to change whatever is keeping me from moving toward my goal, I have to think about another concern:

How can I get along in a HEALTHY way if I do not try this change?

And what about another natural human emotion -- ANGER?

Do I accept that anger is part of life? Can I learn from my anger, and can I forgive myself and others?

There are times when our duty is to understand that we are not able to "make everything right!"

Yours truly,

Ellen Yarborough

Ellen Yarborough
Family Program Specialist

Optional module: GUILT

PLEASE RETURN THIS SHEET IN THE PREPAID ENVELOPE WITHIN 1 WEEK

The letter-units are to help families consider various ways of handling changing relationships and situations when members are in long-term care. There are no standard "answers." Even if you leave some responses blank, please return this green sheet. Use the back for your comments. THANK YOU!

Some of the pressures on you may come from factors over which you can assert control. Consider a situation you think should be made more comfortable for you. Use the plan suggested on page 2 to decide what steps you should take to begin change.

Please describe the first step you will take which will be evident to somebody other than yourself. (You do not need to tell me what you are trying to change, but you may write that if you choose.)

My FIRST STEP toward changing my uncomfortable situation will be:

____

____

(What I want to change: ______________________________)

YOUR NAME: ______________________

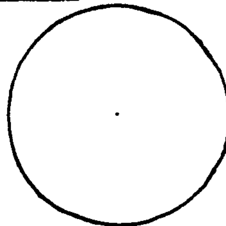
Green sheet: Optional module
GUILT

"I'm OK; you're OK." Sounds good, doesn't it? Sometimes it gets twisted around, though.

> Jack saw his wife Belle in pain and confined to a wheelchair, and he thought, "You probably don't feel OK very often, so I'm probably not OK either. In fact, I probably can't be OK, because that would feel like an insult to you."
>
> Marcia grabbed at the hands of her daughter Sophie, saying, "You mustn't leave me here. I can't eat the food, and you hardly ever visit!" Marcia felt as if she had never been able to please her mother sufficiently, and now her frequent visits weren't even remembered.

Can there be any relief? When relatives have very poor memory, or when they have little prospect for improving enough to live independently again, it may seem that there is no way for a caregiver to avoid feeling burdened or unable to measure up to expectations. Hard messages for the caregiver!! When you have other family members with legitimate demands on your attention, even more feelings of worry and strain can pile up.

The circle below represents the total of attention you can give. Draw lines to divide it up the way you want to have your priorities. How much of yourself do you owe to your family members at home? To your relative in the nursing home? To your community and religious interests? To yourself? Use any labels you choose:



The nursing home has many resources. In addition to all the people running the office and maintaining the facility, there are staff members in nursing, social work, activities, housekeeping, and food service -- all seeing her frequently. She may have more friends among the staff, residents, and visitors at the home than you have realized. This does not mean that others are taking the place of family members, but it can be reassuring to remember that the home is providing the services which she requires.

You may be able to share some of your responsibilities for her. Note some ways she could receive attention from others if you could not continue in your present role.

When we can reduce the pressure we feel on ourselves, it usually seems to help those around us feel better also.

Yours sincerely,

Ellen Yarborough

Ellen Yarborough
Family Program Specialist

Optional module: PRESSURES ON THE CAREGIVER

PLEASE RETURN THIS SHEET IN THE PREPAID ENVELOPE WITHIN 1 WEEK

The letter-units are to help families consider various ways of handling changing relationships and situations when members are in long-term care. There are no standard "answers." Even if you leave some responses blank, please return this green sheet. Use the back for your comments. THANK YOU!

Recall the strengths that you know are in your family and yourself -- the values, habits, and roles that family members count on. Consider also the resources available to you from your community and from the nursing home itself. If you feel overwhelmed by your responsibility for your relative, perhaps it is possible to see the demands in a different context.

You considered what she could receive from others besides you. Now think about your own needs. Sometimes we keep asking for what we are unlikely to receive from another person; if that person has a long-term impairment we are even more trapped! When we recognize that our burdens are left over from old misunderstandings or conflicts, we may as well realize that these burdens will be lightened only if we allow ourselves to clear up the unfinished business. This power does not mean that we lack faith or kindness; taking care of our own emotional needs is part of the way we show our respect for the unique worth of all persons, including ourselves.

If you need to give yourself permission to take care of your own needs -- without domination by your relative's needs -- try writing a clear, fair explanation for any of the "audiences" listed below. (If you decide actually to deliver the "speeches" you may be surprised by the agreement you receive!)

You must take care of your own needs. Explain this to:

Your relative -- ____________________

____

The nursing home staff -- ____________________

____

Your family and neighbors -- ____________________

____

YOUR NAME: ____________________

Green sheet: Optional module
PRESSURES ON THE CAREGIVER

APPENDIX B

LICENSED NURSING HOMES PARTICIPATING IN FTP

Forsyth County	Number of beds
Blumenthal Jewish HOme	130
Knollwood Hall	105
Lamb's Nursing Home	90
Meadowbrook Manor	115
Moravian Home	70
North Carolina Baptist Home	75
Oakwood Knoll Nursing Home	35
Silas Creek Manor	100
Willowbrook Care Center	55
Guilford County	
Clapp's Nursing Home	35
Countryside Manor	65
Evergreens I	260
Evergreens II	95
Greenhaven Nursing Center	115
Maryfield Nursing Home	115
St. James Nursing Center	90
Wesleyan Arms	100

The 17 nursing homes were licensed for 1650 beds.

(ON IVORY PAPER)

APPENDIX C

COVER LETTERS FOR INITIAL SURVEY

Moravian Home, Inc.

HARVEY B JOHNSON
ADMINISTRATOR

5401 INDIANA AVENUE
WINSTON-SALEM NC 27106
(919) 767-8130

Dear Family Member,

The Moravian Home is pleased with the increasing public interest in helping elderly persons and their families. The educational study described below is an example of that growing concern. Your participation in this project is, of course, voluntary. Personally, I welcome this opportunity for the families of our residents to share their insights and observations in this useful study. The Moravian Home will benefit from your participation in that the program workbook developed through this project will be available for the Home's future use.

Thank you for your concern for your loved one at the Moravian Home and for your consideration of this worthy project.

Sincerely yours,

Harvey B. Johnson
Administrator

FAMILY RESEARCH CENTER

Department of Child Development and Family Relations
University of North Carolina
GREENSBORO, N C 27412

February 7, 1983

Dear Friend,

We ask for your help because you have first-hand experience with a relative in a nursing home. "Aging Americans and their Families" is a survey of families in your situation. Your contribution will be treated confidentially; no names will be used. Participants will be offered a summary when the Family Transition Project is completed in the Spring.

Some persons will be randomly selected and asked to participate in a later survey or correspondence program. If you are invited, you will be under no obligation to take part, but I think you will find that participation will be interesting and will not take undue time or effort.

This survey form should be completed by the family member who has the most contact with your relative who lives in the nursing home. Whether the relationship is currently inactive or active, try to answer as accurately as possible. Please return the completed form in the prepaid envelope -- within one week if possible.

Thank you!

Ellen Yarborough
Family Program Specialist

Cover letter from the Administrator of a nursing home participating in the Family Transition Project

February 7, 1983

Dear Family Member,

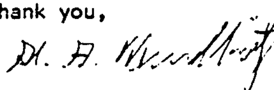
In the next few months, the Blumenthal Jewish Home will sponsor a Family Transition Project, in cooperation with the Family Research Center of the University of North Carolina at Greensboro. Sixteen other licensed nursing homes in Forsyth and Guilford Counties will join us in this study of services for the families of nursing home residents.

We ask for your help because you have first-hand experience with a relative in a nursing home. "Aging Americans and their Families" is a survey of families in your situation. Your contribution will be treated confidentially; no names will be used. Participants will be offered a summary when the Family Transition Project is completed in the Spring.

Some persons will be randomly selected and asked to participate in a later survey or correspondence program. If you are invited, you will be under no obligation to take part, but I think you will find that participation will be interesting and will not take undue time or effort.

This survey form should be completed by the family member who has the most contact with your relative who lives in the nursing home. Whether the relationship is currently inactive or active, try to answer as accurately as possible. Please return the completed form in the prepaid envelope within one week if possible.

Thank you,



Al. A. Mendlovitz, NHA, ACSW
Executive Director

Ellen Yarborough
Family Program Specialist

/rw

Enclosures

7870 Fair Oaks Drive • P. O. Box 38 • Clemmons, North Carolina 27012-0038 • 919/766-6401

Cover letter from the nursing home sponsoring the Family Transition Project

APPENDIX D

NON-PRETEST SURVEY

AGING AMERICANS AND THEIR FAMILIES

Because a member of your family lives in a nursing home, your participation can help us in this study. The survey form should be completed by the family member who is most often in touch with your relative who lives in the nursing home, regardless of how you are related to this person. Your replies will be treated confidentially. Please take a few minutes to fill out this form and return it in the prepaid envelope.

THANK YOU!

The following information will be helpful to us. If you prefer not to answer any item, go on to the next.

1. Please circle the number of the phrase that best describes your own employment status.
   1 RETIRED
   2 FULL-TIME HOMEMAKER
   3 NOT EMPLOYED BUT SEEKING WORK
   4 EMPLOYED PART-TIME
   5 EMPLOYED FULL-TIME

2. Please circle the number of the phrase describing your religious identification.
   1 CATHOLIC
   2 JEWISH
   3 PROTESTANT
   4 OTHER________________
   5 NO RELIGIOUS IDENTIFICATION

3. Please circle the number of the phrase describing your current marital status.
   1 NEVER MARRIED
   2 WIDOWED
   3 SEPARATED OR DIVORCED
   4 CO-HABITING
   5 MARRIED

4. Please circle the number of the phrase describing your racial or ethnic identification.
   1 ASIAN-AMERICAN
   2 BLACK
   3 HISPANIC
   4 NATIVE AMERICAN INDIAN
   5 WHITE
   6 OTHER________________

5. Please circle the number of the phrase best describing your current financial status.
   1 I CAN AFFORD ANYTHING I WANT TO BUY.
   2 I CAN MAINTAIN A COMFORTABLE LIFESTYLE WITHOUT USING ALL MY MONEY.
   3 IF I HAVE ONLY A FEW UNEXPECTED EXPENSES, I CAN AFFORD OCCASIONAL SPECIAL PURCHASES.
   4 I HAVE JUST ENOUGH TO LIVE, AND THERE IS RARELY ANY EXTRA.
   5 I CANNOT AFFORD EVEN THE BASIC NECESSITIES.

6. Please circle the number of the highest year of education you have completed.

Grade School								High School				Vocational School or College				Graduate Study			
1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	19+

7. All things considered, how would you rate your own physical health on the following scale? Please circle one number.

(HIGHER NUMBERS INDICATE BETTER HEALTH.)

VERY POOR HEALTH >						VERY GOOD > HEALTH
1	2	3	4	5	6	7

8. On the chart below, please list the relationships, sex, and approximate age of the persons who live in your present household, along with your sex and age. (Example: Cousin, female, 42)

RELATIONSHIP TO YOU	SEX	APPROXIMATE AGE
YOURSELF:		
OTHERS:		

The next section is about the relative for whom you are a caregiver – your family member who lives in a nursing home. Think about this person now. (If you have more than one relative in a nursing home, think about one specific person for this section.)

9. On the chart below, please state how this person is related to you, along with this relative's sex and approximate age. (Example: Father-in-law, male, 81)

RELATIONSHIP TO YOU	SEX	APPROXIMATE AGE

10. All things considered, where would you rate the physical health of this relative? Please circle one number.

(HIGHER NUMBERS INDICATE BETTER HEALTH.)

VERY POOR HEALTH .... VERY GOOD HEALTH

1 2 3 4 5 6 7

11. How does this relative's mental/emotional status compare with his or her earlier adult personality? For instance, how does he or she seem compared with the personality you observed when the same person was age 45? Please circle the number which best applies.
   1 IMPROVED
   2 VERY MUCH THE SAME
   3 SOME CHANGE, BUT NOT TO A PROBLEM STATUS
   4 NOTICEABLE DETERIORATION
   5 EXTREME MENTAL OR EMOTIONAL DETERIORATION
   6 DOES NOT APPLY

12. How long has this relative been in nursing care where he or she now lives?

*Length of stay:*____________________ *(name of the nursing home:*____________________)

13. Do you expect that this relative will need to live permanently in this or a similar place?
   1 YES
   2 DON'T KNOW
   3 PROBABLY NOT

14. Do you meet with a group especially planned for the families of nursing home residents?
   1 YES
   2 NO

15. How frequently do you have direct contact with your relative (in person or by phone)?

Approximate number of contacts per year:____________________

16. Please mention any particular issues of concern about your relationship with the family member who lives in a nursing home. Are there services you would like to see available for caregivers and other interested family members?

In order to learn useful ways of helping families adjust when an elderly member moves into a nursing home, we need the ideas and observations of many families with similar experiences. If you are willing to participate in this study, you may be contacted about taking part in a later survey or correspondence program. Any other questionnaires sent to you should be shorter than this one. Postage will be prepaid, so that there will be no cost to you if you take part. At the end of the Family Transition Project, participants will be offered a summary of what we have learned.

17. Are you willing to help us in this study of programs for the families of nursing home residents?

______YES ______NO *(If NO, please do return this survey. We will not write to you again.)*

If YES, please fill in the information requested below so that we may write to you. THANK YOU for this cooperation.

I would like to help with this Family Transition Project. Date:____________________

Please Print below:

NAME:____

STREET:________________ CITY:________________ STATE:_____ ZIP:________

Your name will be used for no purpose other than our correspondence for this project. THANK YOU.

Comments:

Please return the completed survey immediately in the prepaid envelope. Address any questions to:
Ellen Yarborough, Family Transition Project, P.O. Box 38, Clemmons, North Carolina 27012-0038

18. Do you want a Family Transition Project summary mailed to you in the Spring? _____Yes. _____No.

APPENDIX E

PRETEST SURVEY

AGING AMERICANS AND THEIR FAMILIES

Because a member of your family lives in a nursing home, your participation can help us in this study. The survey form should be completed by the family member who is most often in touch with your relative who lives in the nursing home, regardless of how you are related to this person. Your replies will be treated confidentially. Please take a few minutes to fill out this form and return it in the prepaid envelope.

THANK YOU!

We are trying to learn more about aging. You may sometimes hear these statements. Please circle the number which shows whether you consider each statement to be TRUE or FALSE.

Answer each item to the best of your knowledge.

	TRUE	FALSE
1. Over 15% of the U.S. population are now age 65 or older	1	2
2. Lung vital capacity tends to decline in old age.	1	2
3. Aged drivers have fewer accidents per person than do drivers under 65	1	2
4. Old people tend to become more religious as they age	1	2
5. All five senses tend to decline in old age.	1	2
6. The majority of old people feel miserable most of the time	1	2
7. At least 10% of the aged are living in long-stay institutions (rest homes, medical facilities, etc.)	1	2
8. Physical strength tends to decline in old age	1	2
9. Most old persons have no interest in, or capacity for, sexual relations	1	2
10. In general, old people are pretty much alike	1	2
11. About 80% of the aged are healthy enough to carry out their normal activities	1	2
12. Most old people are set in their ways and unable to change	1	2
13. The reaction time of old people is usually slower than the reaction time of younger people	1	2
14. The majority of old people are isolated and lonely	1	2
15. Old people usually take longer to learn something new	1	2
16. The majority of old persons report that they are seldom bored.	1	2
17. In the year 2000, the health and socio-economic status of older people will probably be worse than or about the same as the health and socio-economic status of younger people	1	2
18. It is almost impossible for most old people to learn new things.	1	2
19. Most older workers cannot work as effectively as younger workers can	1	2
20. Older workers have fewer accidents than younger workers do	1	2
21. Most medical practitioners tend to give low priority to the aged	1	2
22. The majority of old people have incomes below the poverty level (as defined by the Federal government)	1	2
23. The majority of old people are senile (demented or disoriented).	1	2
24. The majority of old people are working or would like to have some kind of work to do (including housework and volunteer work).	1	2
25. The majority of old people report that they are seldom irritated or angry.	1	2

The following information will be helpful to us. If you prefer not to answer any item, go on to the next.

26. Please circle the number of the phrase that best describes your own employment status.
    1 RETIRED
    2 FULL-TIME HOMEMAKER
    3 NOT EMPLOYED BUT SEEKING WORK
    4 EMPLOYED PART-TIME
    5 EMPLOYED FULL-TIME

27. Please circle the number of the phrase describing your religious identification.
    1 CATHOLIC
    2 JEWISH
    3 PROTESTANT
    4 OTHER____________
    5 NO RELIGIOUS IDENTIFICATION

28. Please circle the number of the phrase describing your current marital status.
    1 NEVER MARRIED
    2 WIDOWED
    3 SEPARATED OR DIVORCED
    4 CO-HABITING
    5 MARRIED

Page 1: Facts on Aging Quiz

29. Please circle the number of the phrase describing your racial or ethnic identification.
    1 ASIAN-AMERICAN
    2 BLACK
    3 HISPANIC
    4 NATIVE AMERICAN INDIAN
    5 WHITE
    6 OTHER___________________________

30. Please circle the number of the phrase best describing your current financial status.
    1 I CAN AFFORD ANYTHING I WANT TO BUY.
    2 I CAN MAINTAIN A COMFORTABLE LIFESTYLE WITHOUT USING ALL MY MONEY.
    3 IF I HAVE ONLY A FEW UNEXPECTED EXPENSES, I CAN AFFORD OCCASIONAL SPECIAL PURCHASES.
    4 I HAVE JUST ENOUGH TO LIVE, AND THERE IS RARELY ANY EXTRA.
    5 I CANNOT AFFORD EVEN THE BASIC NECESSITIES.

31. Please circle the number of the highest year of education you have completed.

Grade School								High School				Vocational School or College				Graduate Study			
1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	19+

32. All things considered, how would you rate your own physical health on the following scale? Please circle one number.

(HIGHER NUMBERS INDICATE BETTER HEALTH.)

VERY POOR HEALTH >						VERY GOOD > HEALTH
1	2	3	4	5	6	7

33. On the chart below, please list the relationships, sex, and approximate age of the persons who live in your present household, along with your sex and age. (Example: Cousin, female, 42)

RELATIONSHIP TO YOU	SEX	APPROXIMATE AGE
YOURSELF:		
OTHERS:		

The next section is about the relative for whom you are a caregiver – your family member who lives in a nursing home. Think about this person now. (If you have more than one relative in a nursing home, think about one specific person for this section.)

34. On the chart below, please state how this person is related to you, along with this relative's sex and approximate age. (Example: Father-in-law, male, 81)

RELATIONSHIP TO YOU	SEX	APPROXIMATE AGE

35. All things considered, where would you rate the physical health of this relative? Please circle one number.

(HIGHER NUMBERS INDICATE BETTER HEALTH.)

VERY POOR HEALTH >						VERY GOOD > HEALTH
1	2	3	4	5	6	7

36. How does this relative's mental/emotional status compare with his or her earlier adult personality? For instance, how does he or she seem compared with the personality you observed when the same person was age 45? Please circle the number which best applies.
    1 IMPROVED
    2 VERY MUCH THE SAME
    3 SOME CHANGE, BUT NOT TO A PROBLEM STATUS
    4 NOTICEABLE DETERIORATION
    5 EXTREME MENTAL OR EMOTIONAL DETERIORATION
    6 DOES NOT APPLY

37. How long has this relative been in nursing care where he or she now lives?

Length of stay:__________________(name of the nursing home:__________________)

38. Do you expect that this relative will need to live permanently in this or a similar place?
    1 YES
    2 DON'T KNOW
    3 PROBABLY NOT

39. Do you meet with a group especially planned for the families of nursing home residents?
    1 YES
    2 NO

40. How frequently do you have direct contact with your relative (in person or by phone)?

Approximate number of contacts per year:__________________

We would like to understand your feelings about being a caregiver for an elderly person. The following statements have been used by some caregivers to describe their emotions regarding relations with their relatives in nursing homes.
Please circle the number which shows your present amount of agreement with each statement.

	Strongly Agree	Agree	Neither Agree Nor Disagree	Disagree	Strongly Disagree
41. I feel strained in my interactions with this person	1	2	3	4	5
42. I feel useful in my interactions with this relative	1	2	3	4	5
43. I feel resentful of other relatives who could but who do not do things for or with this relative	1	2	3	4	5
44. I feel irritated when this relative makes requests over and above what he or she needs	1	2	3	4	5
45. Because of my involvement with this relative, I do not take enough time for my own needs	1	2	3	4	5
46. I feel frustrated about trying to give attention to this person as well as to other family responsibilities, job, interests, etc.	1	2	3	4	5
47. I feel embarrassed by this relative's behavior	1	2	3	4	5
48. I feel guilty about my interactions with this relative	1	2	3	4	5
49. I feel angry about my interactions with this person	1	2	3	4	5
50. I feel that this person currently affects my relationships with other family members or friends in a negative way	1	2	3	4	5
51. I feel nervous or depressed about my interactions with this person	1	2	3	4	5
52. I feel that I don't do as much for this person as I should	1	2	3	4	5
53. I am resentful about my relations with this relative	1	2	3	4	5
54. I brood over what the future holds for this relative	1	2	3	4	5
55. I feel pleased about my interactions with this relative	1	2	3	4	5
56. I feel that my own health suffers because of my involvement with this relative	1	2	3	4	5
57. My relative does not show me as much pleasure and appreciation as I feel I have a right to expect	1	2	3	4	5
58. I am confident about my ability to maintain a healthy relationship with this person	1	2	3	4	5
59. I feel resentful that this relative tries to manipulate me	1	2	3	4	5
60. I feel that my social life suffers because of my involvement with this person	1	2	3	4	5
61. I feel overburdened because I seem to be the only one this relative can depend on	1	2	3	4	5
62. I feel that I am contributing to the well-being of this relative	1	2	3	4	5

63. Please mention any particular issues of concern about your relationship with the family member who lives in a nursing home. Are there services you would like to see available for caregivers and other interested family members?

Page 3: The Burden Interview

Finally we would like to know something about how you do things in your present household. The following statements describe some ways in which persons behave together. Please circle the number which best indicates how frequently your family acts in the manner described in the statement. (If you live alone, please skip to the arrow below.)

	Almost Never	Seldom	Sometimes	Frequently	Almost Always
64. Family members know each other's close friends	1	2	3	4	5
65. Family members are supportive of each other during difficult times	1	2	3	4	5
66. In our family, it is easy for everyone to express opinions	1	2	3	4	5
67. It is easier to discuss problems with people outside the family than with other family members	1	2	3	4	5
68. Each family member has input in major household decisions	1	2	3	4	5
69. Our family gathers together in the same room	1	2	3	4	5
70. Family members discuss problems and feel good about the solutions	1	2	3	4	5
72. It is hard to know what the rules are in our family	1	2	3	4	5
73. Family members consult each other on decisions	1	2	3	4	5
74. Family members freely say what we want	1	2	3	4	5
75. We have difficulty thinking of things to do as a family	1	2	3	4	5
76. We have a good balance of leadership in our family	1	2	3	4	5
77. Household members feel very close to each other	1	2	3	4	5
78. Our family operates on the principle of fairness	1	2	3	4	5
79. Family members feel closer to people outside the family than to other family members	1	2	3	4	5
80. We are flexible in how we handle differences	1	2	3	4	5
81. Family members go along with what the family decides to do	1	2	3	4	5
82. Our family tries new ways of dealing with problems	1	2	3	4	5
83. In our family everybody shares responsibilities	1	2	3	4	5
84. Family members like to spend spare time with each other	1	2	3	4	5
85. It is difficult to get a rule changed in our family	1	2	3	4	5
86. Family members avoid each other at home	1	2	3	4	5
87. When problems arise, we compromise	1	2	3	4	5
88. In our family, everyone goes his or her own way	1	2	3	4	5
89. We approve of each other's friends	1	2	3	4	5
90. We shift household responsibilities from person to person	1	2	3	4	5
91. Family members are afraid to say what is on their minds	1	2	3	4	5
92. We tend to do things separately	1	2	3	4	5
↘93. Family members share hobbies and interests with each other	1	2	3	4	5

In order to learn useful ways of helping families adjust when an elderly member moves into a nursing home, we need the ideas and observations of many families with similar experiences. If you are willing to participate in this study, you may be contacted about taking part in a later survey or correspondence program. Any other questionnaires sent to you should be shorter than this one. Postage will be prepaid, so that there will be no cost to you if you take part. At the end of the Family Transition Project, participants will be offered a summary of what we have learned.

94. Are you willing to help us in this study of programs for the families of nursing home residents?

_____YES _____NO (If NO, please do return this survey. We will not write to you again.)
If YES, please fill in the information requested below so that we may write to you. THANK YOU for this cooperation.

I would like to help with this Family Transition Project. Date:_____

Please Print below:

NAME:_____

STREET:_____ CITY:_____ STATE:_____ ZIP:_____

Your name will be used for no purpose other than our correspondence for this project. THANK YOU.

Comments:

Please return the completed survey immediately in the prepaid envelope. Address any questions to:
Ellen Yarborough, Family Transition Project, P.O. Box 38, Clemmons, North Carolina 27012-0038

95. Do you want a Family Transition Project summary mailed to you in the Spring? _____Yes. _____No.

Page 4: FACES II

APPENDIX F

ONE-WAY LETTERS

March 22, 1983

Dear Family Caregiver,

Thank you for completing the "Aging Americans and their Families" questionnaire. Our project includes several groups; for the next few weeks your group will receive materials suggesting various ways of looking at the feelings which surround the caregiver role. I hope these exercises will interest you.

Yours truly,

Ellen Yarborough
Family Program Specialist

1. STRENGTHS

Families often share a traditional way of observing special events and holidays. When a member lives in a nursing home, this person may seem to miss out on many family occasions. Family "traditions" include not only the special days, however, but also the family's own style -- the habits of everyday roles and customs.

> Do you remember family stories that still get a laugh or give everyone a warm feeling?
>
> Is there a "Fairy Godmother" in your family? A "Big Boss?" A skeleton in the family closet? (Shhhhhhh!) A "Handsome Prince?"

Sometimes communication with the family member is so changed that we overlook memories we could share. Most folks enjoy recalling happy scenes in which we had a part.

Every family has a variety of potential strengths -- habits that can help individual members. Often we feel overcome by losses in ability to keep things unchanged, and we may not realize our own power to choose and make decisions. The Chinese character for "challenge" combines the symbols for "risk" and "opportunity." When families have members in long-term care, some opportunities quickly come to mind:

> "Now I can help him as he has helped me."
>
> "I will be sure she gets the best care I can provide."

Other positive "opportunities" in the changed situation may be just as real, but not so easy to notice:

> "If I read to her, then I can enjoy the book, too."
>
> "When I realize what he needs now -- not what he used to need or what I expect people to want -- then I can be free to leave off some tasks and concentrate on things that might bring pleasure, even if only for the short time we are together."

Think about ways in which your family's habits and values affect positively your task as caregiver. Try to identify an example of how you use a family strength in a way that helps both you and your relative feel good.

FAMILY
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P.O. Box 38
Clemmons, NC 27012

2. DECISION

Are you familiar with Mark Twain's book Huckleberry Finn? From our present-day viewpoint, Huck Finn was right in his intention that the slave man Jim be allowed freedom. But what a struggle he had with his conscience! The moral world taught him that Jim should be only a slave and that Huck was "good" only if he helped keep Jim in bondage.

Sometimes it seems as if the world is turned upside down, when sorting out "right" and "wrong" (or even "OK!") is not as easy as we thought. Our heads determine a new course must be taken, but our hearts still feel confused. It's hard to feel right, even when we know that we have made careful, loving decisions.

Suppose Mark Twain should ask you to write some changes in Huckleberry Finn! The assignment he gives you is to make up a short, persuasive speech for Theo Strong. Mr. Strong's purpose (when we add him to the book) will be to convince Huck that having Jim be free is a decent goal. Huck wants to believe, but he just doesn't feel right about it. Could you give Mr. Strong some words to help instruct Huck's conscience?

Huck: I know he's got no right to live free!

T. Strong: You could look at it this way, Huck. - - -

You have made decisions about providing for your relative the long-term care you have learned is appropriate. You have been forced to weigh various needs and priorities in both of your lives. If, twenty years ago or longer, you two had talked about the conditions you now face, what do you think your relative's inner wish would show? Would some part of this person's true character try to bring you more satisfaction about his or her present life?

Just as you thought about a persuasive speech for Theo Strong, try composing the "speech" which your relative-of-twenty-years-ago might make to help you feel OK about the two of you now.

Assume that your relative wants you to have a satisfying life of your own and that there are positive routines and relationships in the nursing home currently providing long-term care.

You: ...and now you need to have nursing care.

Your relative: Yes. And I - - -

Consider accepting the message you want to receive from this relative!

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3. INDEPENDENCE

We like to make our own choices -- to clothe ourselves in independence and individuality. Deciding what to wear, setting our own schedules, even making our own mistakes proves we are adults!

On the other hand, we generally don't like having to make decisions which rightfully belong to others; we feel weighed down, as if we are hauling someone else's baggage of responsibility. Sometimes we just feel imposed on and helpless, and other times we feel downright angry! This may be true even if we have volunteered to help another. It is as if we casually pick up a guest's suitcase and then it keeps getting heavier and heavier.

It may be helpful for you to look over some of the choices you are making on behalf of your relative in the nursing home. If you know how you started bearing various responsibilities, consider whether the original conditions and needs still apply.

Will it be appropriate for you to let go some of your power, if you can (realistically) rearrange some of the conditions or expectations? Your relative may be able to carry some of the responsibility; some services may be provided by other relatives or by nursing home staff; it is even possible that some of the burdens you carry are related to matters that actually can be left untended!

For your own consideration, look at choices you regularly make on behalf of your relative:

1) Physical choices (example: what clothes to wear)
2) Leisure choices (example: how to spend time on your visits)
3) Relationship choices (example: who deals with the Home staff)

With some adjustment of habits or standards, you may find ways in which your relative's dignity can be supported in making such decisions for himself or herself.

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4. RESOURCES

"I'm OK; you're OK." Sounds good, doesn't it? Sometimes it gets twisted around, though.

> Jack saw his wife Belle in pain and confined to a wheelchair, and he thought, "You probably don't feel OK very often, so I'm probably not OK either. In fact, I probably can't be OK, because that would feel like an insult to you."

> Marcia grabbed at the hands of her daughter Sophie, saying, "You mustn't leave me here. I can't eat the food, and you hardly ever visit!" Marcia felt as if she had never been able to please her mother sufficiently, and now her frequent visits weren't even remembered.

Can there be any relief? When relatives have very poor memory, or when they have little prospect for improving enough to live independently again, it may seem that there is no way for a caregiver to avoid feeling burdened or unable to measure up to expectations. Hard messages for the caregiver!! When you have other family members with legitimate demands on your attention, even more feelings of worry and strain can pile up.

Draw a circle to represent the total amount of attention you can give. Draw lines to divide it up the way you _want_ to have your priorities. How much of yourself do you owe to your family members at home? To your relative in the nursing home? To your community and religious interests? To _yourself_? Use any labels you choose.

The nursing home has many resources. In addition to all the people running the office and maintaining the facility, there are staff members in nursing, social work, activities, housekeeping, and food service -- all seeing your relative frequently. This person may have more friends among the staff, residents, and visitors at the home than you have realized. This does _not_ mean that others are taking the place of family members, but it can be reassuring to remember that the home is providing the _services_ your relative requires.

You may be able to share some of your responsibilities. Consider ways your relative could receive attention from others if you could not continue in your present role.

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P.O. Box 38
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April 28, 1983

Dear Family Caregiver,

"Will I become like this?" It may be frightening to think about our own futures when we observe severely impaired elderly relatives. Sometimes we overlook our alert, active elders. The enclosed positive description, however, is based on FACTS learned in recent studies of aging Americans.

Over the past weeks you have received materials suggesting various ways of looking at the feelings which surround the caregiver role. This is the final program letter; I hope that the exercises have been of use to you. If you have any comments or suggestions about the five letters, please use the enclosed prepaid envelope to send me your recommendations. Thank you for this cooperation.

Yours truly,

Ellen Yarborough
Family Program Specialist

Cover letter for last of five one-way letters

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P.O. Box 38
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5. FACTS

A SEVENTY-YEAR-OLD JOGGER!

A HELPLESS INVALID!

Many stories about aged people highlight the dramatic extremes. Duke University's Dr. Erdman Palmore, however, has found that older Americans live very much like their neighbors do, and like they themselves lived in earlier years. Fewer than one in ten have continuing problems of mental disorientation; most elderly persons find ways to compensate for any physical limitations so that their effectiveness in tasks and relationships can be maintained.

Meet "Mary Smith" for instance -- an "average" older American. All elderly people are not alike, of course. (Think about the years in which they have been specializing in different directions!) Mary Smith's personality and lifestyle are unique to her. According to the materials reported by Dr. Palmore, though, here is what we may expect about the "average" Ms. Smith:

> Mary Smith is mentally alert, living at home, and has an income above the poverty level. She is in a small group; even by the year 2000, only around 13% of Americans will be aged 65 or older. She continues to carry out her normal activities, and she reports that she is not often angry, miserable, or bored. Religion means about the same to her as it did when she was younger. She is still able to enjoy the sexual dimension of her life.
>
> Ms. Smith wants to be doing some kind of work, whether it is paid work, volunteer work, or work with her own home and family. She can learn new skills; mastery sometimes takes her longer, but she can repeat new patterns and make new habits. Because age has brought some decline in the acuteness of Ms. Smith's five senses, in her reaction time, and in her lung capacity and physical strength, she compensates by extra carefulness, so that she can be an effective worker. In working and in driving a car, her safety record will be better than the records of younger workers and drivers.
>
> Community and family relationships are important parts of Ms. Smith's life, so that she is not isolated or lonely. At present, most health service providers give Ms. Smith and her elderly friends low priority, but the status of the older Americans is rising! By the year 2000, the gap will be much smaller between the health and socioeconomic levels of the elderly and younger members of our society.

As more attention is focused on the interests, abilities, and needs of the elderly, it is important to recognize that older Americans are themselves valuable resources. This description of the "average Mary Smith" states that the effects of aging usually do not prohibit full and satisfying life experiences and relationships.

(ON IVORY PAPER)

APPENDIX G

POSTTEST

FAMILY
TRANSITION
PROJECT
P.O. Box 38
Clemmons, NC 27012

May 19, 1983

Dear Family Caregiver,

Early this year you completed a questionnaire and agreed to be a part of a study of services to families of nursing home residents. Whether or not you have received material since you returned the first survey, it is important that you complete and return this final questionnaire.

If you have already requested a project summary, or if you request one when you return this survey, it will be mailed to you in a few weeks. No names will be used in the summary and all your replies will be treated confidentially.

Whether or not your relative is still living in a nursing home, please return this survey in the prepaid envelope within one week.

Thank you for this cooperation. Each caregiver's response is needed, and I truly appreciate the time and thought you put into participating.

Yours truly,

Ellen Yarborough
Family Program Specialist

Page 1: Posttest

AGING AMERICANS AND THEIR FAMILIES

Please fill in the box below. Your replies will be confidential. Thank you for this help.

NAME______________________________

STREET______________________ CITY______________ STATE____ ZIP______

Do you want a Family Transition Project summary mailed to you? _____YES _____NO

Please note any important changes in your self-description since you returned our first survey. (Examples: major changes in your health level or your marital status.)

1. In January, you had a relative in a nursing home. What kin is this person to you?

____

2. Is this relative still living in a nursing home? Please circle the appropriate number.

1 YES
2 NO → Our study concerns both caregivers and their relatives. If your relative is no longer living in a nursing home, you do not need to reply to the rest of the questions, but PLEASE DO RETURN THIS SURVEY FORM IN THE PREPAID ENVELOPE WITHIN ONE WEEK. THANK YOU!

If your relative still lives in a nursing home, please complete the survey. We are trying to learn more about aging. You may sometimes hear these statements. Please circle the number which shows whether you consider each statement to be true or false. Answer each item to the best of your knowledge.

	TRUE	FALSE
3. Over 15% of the U. S. population are now age 65 or older	1	2
4. Lung vital capacity tends to decline in old age	1	2
5. Aged drivers have fewer accidents per person than do drivers under 65	1	2
6. Old people tend to become more religious as they age	1	2
7. All five senses tend to decline in old age	1	2
8. The majority of old people feel miserable most of the time	1	2
9. At least 10% of the aged are living in long-stay institutions (rest homes, medical facilities, etc.)	1	2
10. Physical strength tends to decline in old age	1	2
11. Most old people have no interest in, or capacity for, sexual relations	1	2
12. In general, old people are pretty much alike	1	2
13. About 80% of the aged are healthy enough to carry out their normal activities.	1	2
14. Most old people are set in their ways and unable to change	1	2
15. The reaction time of older people is usually slower than the reaction time of younger people	1	2
16. The majority of old people are isolated and lonely	1	2
17. Old people usually take longer to learn something new	1	2
18. The majority of old persons report that they are seldom bored	1	2
19. In the year 2000, the health and socio-economic status of older people will probably be worse than or about the same as the health and socio-economic status of younger people	1	2
20. It is almost impossible for most old people to learn something new	1	2
21. Most older workers cannot work as effectively as younger workers can	1	2
22. Older workers have fewer accidents than younger workers do	1	2
23. Most medical practitioners tend to give low priority to the aged	1	2
24. The majority of old people have incomes below the poverty level (as defined by the Federal government)	1	2
25. The majority of old people are senile (demented or disoriented)	1	2
26. The majority of old people are working or would like to have some kind of work to do (including housework and volunteer work)	1	2
27. The majority of old people report that they are seldom irritated or angry	1	2

Page 2: Posttest. Facts on Aging Quiz

(ON IVORY PAPER)

We would like to understand your feelings about being a caregiver for an elderly person. The following statements have been used by some caregivers to describe their emotions regarding relations with their relatives in nursing homes. Please circle the number which shows your present amount of AGREEMENT or DISAGREEMENT with each statement.

	Strongly Agree	Agree	Neither Agree Nor Disagree	Disagree	Strongly Disagree
28. I feel strained in my interactions with this person	1	2	3	4	5
29. I feel useful in my interactions with this relative	1	2	3	4	5
30. I feel resentful of other relatives who could but who do not do things for or with this relative	1	2	3	4	5
31. I feel irritated when this relative makes requests over and above what he or she needs	1	2	3	4	5
32. Because of my involvement with this relative, I do not take enough time for my own needs	1	2	3	4	5
33. I feel frustrated about trying to give attention to this person as well as to other family responsibilities, job, interests, etc.	1	2	3	4	5
34. I feel embarrassed by this relative's behavior	1	2	3	4	5.
35. I feel guilty about my interactions with this relative	1	2	3	4	5
36. I feel angry about my interactions with this person	1	2	3	4	5
37. I feel that this person currently affects my relationships with other family members or friends in a negative way	1	2	3	4	5
38. I feel nervous or depressed about my interactions with this person	1	2	3	4	5
39. I feel that I don't do as much for this person as I should	1	2	3	4	5
40. I am resentful about my relations with this relative	1	2	3	4	5
41. I brood over what the future holds for this relative	1	2	3	4	5
42. I feel pleased about my interactions with this relative	1	2	3	4	5
43. I feel that my own health suffers because of my involvement with this relative	1	2	3	4	5
44. My relative does not show me as much pleasure and appreciation as I feel I have a right to expect	1	2	3	4	5
45. I am confident about my ability to maintain a healthy relationship with this person	1	2	3	4	5
46. I feel resentful that this relative tries to manipulate me	1	2	3	4	5
47. I feel that my social life suffers because of my involvement with this person	1	2	3	4	5
48. I feel overburdened because I seem to be the only one this relative can depend on	1	2	3	4	5
49. I feel that I am contributing to the well-being of this relative	1	2	3	4	5

WE WOULD APPRECIATE YOUR COMMENTS.

Please complete the back page and return within 1 week.
THANK YOU. →

Page 3: Posttest. The Burden Interview

LONG-TERM CARE: THE CAREGIVER'S VIEW

Finally, we would like to understand how satisfactory you consider your relative's nursing home placement. Here are some statements about you, the nursing home, and your relative who lives in long-term care. Please circle the number which shows your present amount of AGREEMENT or DISAGREEMENT with each statement.

	Statement	Strongly Agree	Agree	Neither Agree Nor Disagree	Disagree	Strongly Disagree
– 50.	I find ways in which my relative and I can have a pleasant time, even if we have to make changes in our usual activities	1	2	3	4	5
51.	My relative is in excellent physical condition	1	2	3	4	5
52.	My relative is in excellent mental condition	1	2	3	4	5
– 53.	I worry about how well I play my part in caring for my relative	1	2	3	4	5
54.	Staff attitudes seem to have a positive effect on residents	1	2	3	4	5
– 55.	I feel guilty about my relationship with this relative	1	2	3	4	5
56.	My relative's personality style has improved since he or she entered the nursing home	1	2	3	4	5
57.	Because of regulations and standards, the nursing home has difficulty providing a pleasant, homelike environment	1	2	3	4	5
58.	My relative responds to me in a positive manner	1	2	3	4	5
59.	The nursing home provides attractive, nourishing food	1	2	3	4	5
– 60.	In addition to talking with the resident, I communicate by other attentions, such as walking together or caring for physical needs	1	2	3	4	5
61.	There are enough staff members to care for the residents	1	2	3	4	5
– 62.	I feel cheated because of the time that caring for this relative takes from the time I have available for other responsibilities	1	2	3	4	5
63.	The nursing home provides a place where my relative and I can visit privately	1	2	3	4	5
– 64.	Including personal visits, phone calls, and letters, I have the right amount of contact with this relative	1	2	3	4	5
– 65.	I feel angry about being the main family member who gives attention to this relative	1	2	3	4	5
66.	Staff members respond helpfully to my concerns about my relative	1	2	3	4	5
67.	Throughout our lives, my relative and I have had a poor relationship	1	2	3	4	5
– 68.	I cannot speak to this relative about money or financial matters	1	2	3	4	5
– 69.	I am acquainted with the staff members responsible for my relative	1	2	3	4	5
– 70.	I am bound by promises I made to my relative, whether or not they fit the present situation	1	2	3	4	5
71.	The nursing home maintains a safe, secure environment for the residents and their possessions	1	2	3	4	5
72.	My present costs for this relative's care can be paid without financial strain	1	2	3	4	5
– 73.	After visits, I manage to leave in a way that is satisfactory both to my relative and to me	1	2	3	4	5
– 74.	I must submit to manipulation by my relative or by the nursing home	1	2	3	4	5
– 75.	It is not right to talk to my relative about what I need for myself	1	2	3	4	5
– 76.	I feel tense after a visit with this relative	1	2	3	4	5
77.	The nursing home does not provide care as good as was described when my relative entered long-term care	1	2	3	4	5
78.	My relative seems to need constant reassurance and attention	1	2	3	4	5
– 79.	I think I do well in handling my responsibility for this relative	1	2	3	4	5
– 80.	Overall, I am pleased with the relationship I now have with this relative	1	2	3	4	5
81.	Overall, I am pleased with the care that my relative receives in the nursing home	1	2	3	4	5

THANK YOU for your cooperation in this project concerning services to the families of nursing home residents. Please return this survey in the enclosed prepaid envelope -- within one week if possible.

Page 4: Posttest. Satisfaction of Caregiver with Institutional Placement. NOTE: Items marked with "-" are in the Relationship subscale; others are in the Placement subscale.

APPENDIX H

HINTS FOR CAREGIVERS FROM CAREGIVERS

FAMILY TRANSITION PROJECT
P.O. Box 38
Clemmons, NC 27012

HINTS FOR CAREGIVERS FROM CAREGIVERS
April, 1983

So many useful ideas came from the participants in the Family Transition Project! The following outline probably contains insights or activities which are already familiar to you; perhaps you will also be alerted to some new approaches which other family caregivers recommend.

1. THE RESIDENT IS STILL A MEMBER OF THE FAMILY.
   A. Have various members of the family visit.
   B. Use letter-writing and reading to keep up family ties.
   C. Show family photographs and reminisce.
   D. Take special-day celebrations to the Home.
   E. Consider a personal telephone to maintain contact.
2. "HOME" IS NOW THE NURSING HOME.
   A. Show your approval (not envy) of the Home environment.
   B. Ask the Resident for a tour of the Home.
   C. Respect Home staff members, and expect their cooperation.
      (1) Meet the staff and learn their duties.
      (2) Learn who handles requests and suggestions.
      (3) Meet workers on all shifts.
      (4) Help workers asssociate you with your relative.
   D. Provide some tangible reminders of the former home.
      (1) Help Resident select favorite accessories.
      (2) Give room gifts, as you once gave home gifts.
3. A ROUTINE HELPS MAKE OUR SURROUNDINGS COMFORTABLE.
   A. Learn the Home's service schedule, and support that.
   B. Join Home groups for recreation -- trips, meals, etc.
   C. Walk with Resident on the usual routes (to eat, etc.)
   D. People may prefer predictable visit or phone times.
4. SOME INDEPENDENCE IS POSSIBLE FOR EVERYONE.
   A. Some posssessions are treasured and handled a lot.
   B. Encourage the Resident in making personal decisions.
   C. When confused residents ask for impossible things, respond to their feelings instead of worrying about the accuracy of their facts.
   D. Plan some trips away from the Home. Even confused residents can enjoy driving past flowering trees and familiar scenes. Have a meal away from the Home.
   E. Exercise (physical and mental) preserves ability ! !
5. COMMUNICATION TAKES MORE THAN WORDS.
   A. Listen
   B. Smile, laugh, joke when it's appropriate.
   C. Act unhurried.
   D. Touch. Hug, sit close, take a hand, put an arm around, comb hair, give manicure, rub sore places, massage neck and shoulders, ask to have your back rubbed!
   E. Focus on giving uncomplicated caring messages, and do not fret about getting a particular response.
6. YOU ALSO HAVE A RIGHT TO A LIFE OF YOUR OWN.

NOTE: These hints were printed on the back of page 1 of Letter-unit # 3.