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## The effect of facilitating increased involvement in nursing home caregiving on former caregivers' satisfaction with the care arrangement

Christine Toye  
*Edith Cowan University*

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**THE EFFECT OF FACILITATING INCREASED INVOLVEMENT IN  
NURSING HOME CAREGIVING ON FORMER CAREGIVERS'  
SATISFACTION WITH THE CARE ARRANGEMENT**

**BY**

**Christine Teye RN**

**A Thesis Submitted in Partial Fulfilment of the  
Requirements for the Award of**

**Bachelor of Nursing - Honours  
at the Faculty of Health and Human Sciences  
School of Nursing, Edith Cowan University**

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## USE OF THESIS

The Use of Thesis statement is not included in this version of the thesis.

### **Abstract**

This study examined the effect of a programme that facilitated former caregivers' increased involvement with nursing home caregiving on their satisfaction with the care provided for their relatives. It was guided by Roy's Adaptation Model of Nursing (Roy, 1984, 1989). The hypotheses stated that the programme would help former caregivers to adapt to the institutionalisation of their loved ones, as manifested by their increased satisfaction with aspects of the care arrangement (overall care, nursing care, relationships, and the environment). The convenience sample consisted of 31 former caregivers of long term residents admitted to a metropolitan nursing home 1 - 24 months prior to the study. Using an experimental design, subjects were randomly assigned to an experimental group, which received the programme, or a control group, which continued as normal. The Family Perceptions of Care Tool (Maas, Buckwalter, Kelley, & Stolley, 1991) measured aspects of satisfaction with the care arrangement in both groups, before and after the intervention. Analysis of Covariance was used to examine differences between the groups' post-test scores, while controlling for pre-test scores. Demographic data were collected and examined, as was information about possible extraneous variables. The hypotheses were not supported. However, only four people chose to have extra involvement. These were all related to recently admitted residents and tended to have become more satisfied with care by the end of the study. Comparisons were made between experimental group members with relatives admitted 1 - 6 months before the study and others in the same group, and between those with relatives admitted 1 - 6 months before the study in each of the two groups. Experimental group members with recently admitted relatives had the greatest increases in levels of satisfaction, although this finding was not shown to be statistically significant. Results of the study provide a basis for recommendations for further research with larger samples of relatives of recently admitted residents, for the education of relatives and staff about the benefits of family member input, and for providing more opportunities for input into caregiving to the family members of new residents.

"I certify that this thesis does not incorporate, without acknowledgment, any material previously submitted for a degree or diploma in any institution of higher education and that, to the best of my knowledge and belief, it does not contain any material previously published or written by another person except where due reference is made in the text".

Signature..

Date..3.2.95..

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## CHAPTER I

### Introduction

#### Background and Significance of the Study

Research has confirmed that caring for a disabled friend or relative at home is often extremely stressful (George & Gwyther, 1986; Smith, Smith, & Toseland, 1991; Zarit, Todd, & Zarit, 1986). Yet, admission of the care recipient into a nursing home may not bring relief for the former caregiver: It may, instead, precipitate a crisis in that person's life (Brody, 1985; Townsend, 1990). A variety of distressing emotions can, therefore, hinder the adaptation of such a friend or relative to a new role in an unfamiliar, institutional environment.

Feelings of helplessness are likely to be a major part of the emotional spectrum experienced at this time, since the decision to seek nursing home placement for a family member is usually made when there is perceived to be no alternative (Kasmarik & Lester, 1984). Such feelings may be compounded by the belief that nursing homes, "historically ... patterned after the model of the acute hospital" (Kasmarik & Lester, p. 181), retain absolute control over caregiving, and that, as bureaucracies, they dictate the roles of family members (Buckwalter & Hall, 1987). Unless staff make it clear that their input will be welcomed, many former caregivers who wish to have continued involvement are unlikely to pursue this.

In the absence of an explicit invitation, therefore, a valuable source of supplementary care may be lost and an opportunity for a degree of community integration missed. Moreover, those feelings known to be commonly experienced by family members around the time of placement, including inadequacy (Tobin, 1987); guilt (Matthiesen, 1989); and hostility towards the institution (Pratt, Schmall, Wright, & Hare, 1987), may be perpetuated by the perception that change cannot be achieved by collaboration. As a result, passive acceptance of the situation (Pratt et al., 1987), verbal aggression directed at staff (McLeod, 1991), and withdrawal from visiting (Tobin, 1987) remain likely scenarios.

A Commonwealth Government report (Ronalds, 1989) has urged staff to make friends and relatives aware of the importance of maintaining their links with residents, and many nursing homes (including that proposed as a setting for this study) already have a philosophical commitment to facilitating family involvement. However, formal programmes offering continued participation in caregiving are lacking. In reality, the enthusiasm of individual nursing staff and the assertiveness of interested family members determine the true extent of family input.

Friends and relatives who would be prepared to enter into such a partnership are, clearly, a neglected resource (Buckwalter & Hall, 1987). There is no doubt that their involvement has the potential to improve resident care. Former caregivers would be of particular value, since they possess detailed knowledge of residents' preferences. That it is not, already, common practice to facilitate their involvement indicates that empirical evidence of additional benefits must be compiled before this will occur.

Benefits to former caregivers of additional involvement are likely to include a greater degree of satisfaction with the care arrangement. As they become included in the caring "team" they may develop improved relationships, possibly with their family member, but especially with the staff of the home. The care that is given to their loved one is more likely to meet with their approval, and they may even find it possible to improve the environment of the nursing home. Being able to choose a new role that enables them to retain some control over caregiving is also likely to help them to cope with the situation, and, therefore, to view it more positively.

While "customer" satisfaction may be a goal in itself, there are also clear advantages to staff in having the needs of family members met: There are likely to be fewer complaints, more accolades, a more co-operative working environment, and an opportunity to develop a rapport with family members that will assist the nurse to extend his or her knowledge of the resident. There is, to date, a notable lack of objectively reported evidence of the effects of facilitating increased former caregiver involvement. This study was conducted in order to provide such evidence.

### **Purpose of the Study**

The purpose of the study was to determine whether the inclusion of former caregivers in the Programme Facilitating Increased Involvement in Caregiving (PFIIC), between 1 and 24 months after the recipients of their care were admitted to a nursing home, increased their satisfaction with the care arrangement. The hypotheses of the study are documented after the conceptual framework is explained.

### **Definition of Terms**

#### **Adaptation**

In this study, adaptation was defined as a person's adjustment to a new set of circumstances, while Roy (1989) stated that "the person is conceptualised as having four modes of adaptation: physiological needs, self-concept, role function, and interdependence relations" (p. 108). The physiological needs of former caregivers were not relevant to this study. The remaining modes of adaptation were described by Roy and are explained below:

**Self-concept.** Perceptions of self, as reflected by others, are the self-concept (Roy, 1989). People need to adapt in the self-concept mode when, for example, they receive an unexpectedly good or bad performance appraisal from their superior at work.

**Role function.** The carrying out of certain duties, expected of individuals in certain situations within communities, is called their role function (Roy, 1989). A woman needs to adapt in the role function mode when she first becomes a mother.

**Interdependence relations.** The interactions with others that are needed by people, such as the seeking of love, attention, and assistance, are their interdependence relations (Roy, 1989). Adaptation in this mode needs to occur, for example, when the death of a spouse deprives an individual of a major source of love and attention.

### **Collaborative Care**

Collaborative care was defined as the provision of care by nursing home staff and family members, or friends, in partnership.

### **Coping Mechanisms**

According to Roy (1984), the "innate or acquired ways of responding to the changing environment" are a person's coping mechanisms (p. 28).

### **Former Caregivers**

For the purpose of this study, former caregivers included only those relatives or friends who were involved in the physical or psychological care or support of the resident within the year prior to admission into the nursing home. They need not have lived with the resident.

### **Nursing Home**

A nursing home provides residential care for people who have disabilities that render them unable to meet their everyday needs either in the community, with the existing support, or in a hostel setting. In Australia, nursing home care is only available to those who have been assessed by an Aged Care Assessment Team as being in need of "professional nursing care on a daily basis" (Reid, 1992, p. 55). Such care is provided by Registered Nurses (RNs), and/or Enrolled Nurses (ENs), on a twenty-four hour basis. Nursing Assistants (NAs) also provide direct care for the resident, as do Carers, who may also assist with cleaning and catering. Other appropriately qualified personnel, such as Physiotherapists, Occupational Therapists, Speech Pathologists, Dietitians, Podiatrists, Clinical Psychologists, and Social Workers may be available to nursing home residents on the premises, and there is usually at least one General Practitioner who makes regular visits to the home.

### **Programme Facilitating Increased Involvement in Caregiving (PFIIC)**

The PFIIC, developed by the researcher, was designed to facilitate the increased involvement of former caregivers with the nursing home care of their loved ones. They could choose to have greater involvement in any, or none, of several broad categories of caregiving: planning and decision making; extra care, which would



supplement that provided by staff; or nursing care. The latter was considered to be the care that was usually provided by RNs, ENs, NAs or Carers and that could be provided by family members or friends without detriment to the residents or risk to the caregivers.

### **Proxy Consent**

For ethical reasons, it was considered that the resident, or some one acting on his or her behalf, would need to consent to a nominated former caregiver's participation before that person was formally approached. Whenever possible, the resident was asked for this consent. However, when it was clear that a resident's cognitive status precluded rational decision making, a close friend or family member, who was not going to take part in the study, acted on the resident's behalf by giving or refusing proxy consent. Where there was no such person available, the Director of the nursing home acted in this capacity.

### **Role Ambiguity**

Role ambiguity was defined as experiencing uncertainty about the role that one might play in a given situation.

### **Satisfaction with the Care Arrangement**

Conceptually, in this study, satisfaction with the care arrangement referred to the meeting of expectations related to the care of the resident. Four aspects of this were examined, as measured by the four scales of the Family Perceptions of Care Tool (FPCT) (Maas, Buckwalter, Kelley, & Stolley, 1991).

**Overall care.** Overall care was defined as the care provided for nursing home residents by all categories of staff. It was implicit in this term that the attitude of staff towards residents, as well as the available level of human and material resources, was bound to affect the quality of care.

**Physical nursing care.** Physical nursing care was defined as the care provided by nursing staff (including RNs, ENs, NAs, and Carers) for residents of the nursing home. This included helping residents to maintain their existing self-care abilities while supplying whatever care the resident could not provide for him/herself, with

input from friends and family members. It also included keeping the resident comfortable and safe from injury.

**Relationships among residents, staff, and family members.** Relationships between staff and residents, staff and relatives, residents and relatives, and between the residents themselves were assessed according to their quality. In an ideal staff/resident relationship the resident was seen to be treated as an adult human-being who was in need of care because of a disability. Relatives, ideally, were supported by staff while being invited to contribute to the care of the resident, and residents lived together harmoniously.

**The resident's environment.** The resident's environment included the degree of safety for this person, and for his or her possessions; the amount of available resources, including staff; and the role of the relative in the nursing home.

### **Stress**

In this thesis, the term "stress" has been used to refer to psychological stress, defined by Lazarus and Folkman (1984) as "a relationship between the person and the environment that is appraised by the person as taxing or exceeding his or her resources and endangering his or her well-being" (p.21).

## **CHAPTER II**

### **Review of the Literature**

This review examines accounts of previous research and other, recently published, literature that is relevant to this study. It includes sections on the impact of a relative's institutionalisation on other family members, the current role of the family in institutional care, relevant recommendations for change, and strategies that have been implemented to bring about change. The review concludes with an explication of the relevance of conducting this study at this time, with reference to the methodology used.

#### **Institutionalisation of a Relative: Its Impact on the Family**

As reflected in this review, research that has examined effects on family members of a relative's admission to a nursing home comes mainly from the United States of America (U.S.A.). Only one of the studies examined in this section is not American: that of Rosenthal and Dawson (1991), from Canada. There is, unfortunately, a lack of relevant, published Australian research. Studies that utilised samples selected solely from the family members and friends of those with Alzheimer's Disease (AD) are considered at the end of the section, since their findings cannot be widely generalised and they may, therefore, have less application to the present study, in which residents had a variety of disabilities. The smaller of the studies where samples were not biased in this way are examined first. Many of these examined the effects of having an institutionalised relative on particular groups of family members, including wives, daughters, and sons.

Rosenthal and Dawson (1991) utilised a sample of 69 wives of institutionalised husbands. They used a mixed methodology to test the first stage of a model conceptualising a wife's experience following the placement of her husband. The model suggested that such an experience is similar to widowhood, progressing through a time of ambivalence, uncertainty, depression, and loneliness to a time of improved physical and mental health and role redefinition, leading on to resolution and adaptation. Ambivalence was confirmed as a factor: wives expressed

satisfaction with the arrangement, and relief, while at the same time reporting feelings of sadness, loneliness, guilt, resentment, and anger. The incidence of depression was also found to be much higher than that in the community, while morale was lower, and physical health poorer. Feelings of uncertainty were not reported by most of the subjects, however, the exceptionally good reputation of the institution was cited as a possible reason for this.

Indeed, uncertainty as to the future progress of the resident was found to be a problem for many of the 22 family members of 10 nursing home residents in a case study conducted by Johnson, Morton, and Knox (1992). However, relationships were not specified in this instance. These relatives also experienced conflict between family values and those of the care system, and a scarcity of information both about the resident's health and care and about the role that they were to play.

The lack of knowledge that is bound to result from such a scarcity of information was also found to be a problem for 32 daughters with institutionalised mothers who were studied by Matthiesen (1989), and for 16 daughters, each having an institutionalised parent, studied by Johnson (1989). Matthiesen, using grounded theory, documented the daughters' feelings of unresolved guilt, and their sense of loss that led them to grieve. She also determined that they needed to acquire new roles, and to unburden themselves. Their coping strategies included withdrawing from their mothers and depersonalising them. In Johnson's case study, some daughters reported feeling excluded from the care process, while others found a particular nurse who they trusted to keep them informed.

Brody, Dempsey, and Pruchno (1990) used a much larger sample of 311 sons and daughters, each of whom had an institutionalised parent. They found a negative association between depression and the amount of direct involvement with caring tasks, especially in the case of daughters. There was also a correlation between lower former caregiver age and greater emotional effects of the kind that have been attributed by adult children to having an institutionalised parent, such as helplessness, frustration, anger, and guilt. This led the authors to speculate that such a crisis may

be harder to bear when it comes unusually early. In addition, they found that those with poor health and many commitments suffered to a greater degree from these emotional effects.

Two other larger studies, which investigated the experiences of a variety of family members, were both carried out at the Margaret Blenkner Research Centre. These were longitudinal panel surveys and investigated the causes and consequences of changes in care arrangements for the elderly (Townsend, 1990). The researcher studied members of 538 families that each included an elderly person. During the 5 year study period, 81 people from the two samples were admitted into institutional care. The majority of relatives reported being distressed by the placement, although some expressed relief. Family members' perceptions of the quality of care provided by the institution were found to be related to satisfaction with the care arrangement, and, inversely, to guilt.

Family members' perceptions of care were examined in more detail by Maas et al., (1991) using an instrument that measured satisfaction with care, but, in this case, the level of guilt was not assessed. This study was one of those utilising a sample of friends and relatives of those with AD, their loved ones being in two nursing homes ( $N = 16$  at the time of completion). The findings of this longitudinal study showed that satisfaction with care tended to fall over the 1 year study period, the greatest area of dissatisfaction being that concerning physical care. Subjects were found to be particularly dissatisfied with staff being too busy to provide adequate care and their failure to ask for family member assistance, as well as with the existing level of resources and the amount of resident involvement in activities.

Dellasega (1991) also selected her sample from relatives of those with AD, but these people had also all attended AD support groups or education programmes. Because of this, the generalisability of the findings was limited further: The 93 community caregivers and the 31 former caregivers of institutionalised relatives who made up the two groups in her study were only representative of those who had sought help in this way. However, Dellasega found no significant difference between

the levels of role strain, personal strain, and caregiving burden (the stress related to caregiving) in the two groups, which tended to support the findings of Townsend (1990), as it indicated that the distressing emotions experienced when a family member is institutionalised may negate any relief that is felt.

In addition, using a similar sampling frame to that of Dellasega (1991), Pratt et al. (1987) reported no significant difference between the caregiving burden of 149 community caregivers and that of 91 caregivers of institutionalised relatives. They also cited findings of a study conducted by Wright in 1986, this researcher being one of their number. These findings showed that there was no significant difference between the caregiving burden and life satisfaction scores of 155 caregivers with institutionalised relatives and those of 287 community caregivers. Furthermore, Mathew, Mattocks, and Slatt (1990) found no significant difference in caregiving burden between men directly caring for predominantly female relatives with dementia ( $n = 12$ ) and men with institutionalised, female relatives with dementia ( $n = 8$ ). Five husbands in this study reported that the inability to control institutional caregiving was a stressor, while Wright's study showed that those with institutionalised relatives had significantly higher mean scores for chance control orientations, and for avoidant-evasive and regressive coping behaviours (eating, drinking, and getting angry). These were significantly associated with caregiving burden and, negatively, with life satisfaction.

Finally, Clements (1992), an RN, presented a moving personal account of placing her father in a nursing home. She stated that it was one of the hardest things she had ever had to do, and wrote that "the worry, guilt, exasperation, and feelings of powerlessness never stopped" (p. 304).

In summary, former caregivers of institutionalised people with AD have repeatedly been shown to have levels of caregiving burden at least as high as those of community caregivers. Most participants in these studies, however, had sought support or education. This may have reflected the fact that these were people who felt more stressed, or that they were able to recognise their need and seek help. More

generalisable findings have shown that family members experience both distress and relief following the institutionalisation of their loved ones, as well as uncertainty, guilt, grief, depression, resentment, and anger. In addition, most of these emotions have been reported specifically by adult children and wives of residents. A variety of coping behaviours have been documented, including those that are regressive, and those that are avoidant-evasive. Particular problems which have been identified include a lack of knowledge about the new environment and the role of family members, a lack of information received about the resident and his or her care, conflict between family and institutional values, and an inability to control the caregiving process. In one study, more involvement in direct care was associated with lower rates of depression.

#### **The Current Role of the Family in Institutional Care**

A search of the literature yielded two recent studies that investigated the involvement of family members in acute care for the elderly, and only one examining the same phenomenon in a nursing home. However, a different author has raised a number of pertinent issues in her discussion of the role of family members of the elderly in long term care settings in the U.S.A.

This author, Brody (1985), indicates that relatives already provide emotional support and aid socialisation in such settings. However, she believes that they may also wish to continue their community role as advocates, mediators with the formal system, and collaborators in decision making: roles that are not clearly defined within institutions.

The assertion of Brody (1985) that family members already provide emotional support is corroborated by the findings of Bower's study (1988). This used grounded dimensional analysis, had a sample of 28 family members of residents with various disabilities, and was conducted in a 130-bed nursing home in the U.S.A.. As well as reporting that they provided emotional support for their loved ones, these family members tended to hold themselves responsible for monitoring the standard of care given to their relatives, and for ensuring the provision of "preservative care" (p. 362):

Preservative care was defined as the care that helps to retain the uniqueness of the individual by maintaining family relationships, allowing the resident to have some control over the environment, and preserving his or her dignity and hopes. Subjects expected that nurses would make preservative care a component of the technical care which they administered, but found that they were often disappointed in this respect.

While participants in Bower's study (1988) appeared to choose an active role, 80% of the 60 relatives surveyed by Sharp (1990) stated that the extent of their involvement was just as they would wish, this being described as "minimal" by the author (p. 70). However, 60% of the 74 RNs included in Sharp's study indicated that relatives were involved too little. By way of explanation, the setting for this study was a hospital for mentally ill, short-stay patients in the United Kingdom: Relatives, therefore, may have been reluctant to increase their involvement because they knew that they might have to re-assume a domestic caregiving role. Their feelings might have been quite different had their family member been permanently institutionalised. Finally, Collier and Schirm's study (1992), which audited patients' notes in two hospitals in the U.S.A., did not support the belief, expressed by the 60 RNs interviewed, that family members were involved in care. However, in this study, data were not obtained from relatives

There is evidence from one study, therefore, to suggest that family members of those in nursing homes hold themselves responsible for preventing their relatives' assimilation into the institution and consequent loss of individuality, as well as for monitoring the standard of the care that is given. Family involvement in hospital care has been seen to be limited, although, according to one study, it was at the level desired by relatives. It has been suggested that additional involvement as advocates, mediators, and collaborators is required by family members of those in long term care.



### **Recommendations for Change**

Morgan and Zimmerman (1990), in the U.S.A., undertook a study using in-depth interviewing and the completion of two questionnaires to discover any factors that made the transition from home care to institutionalisation less stressful for former caregivers of those with AD. From the data obtained from the 10 spousal caregivers it emerged that 5 categories eased the transition: Firstly, emotional support helped, as did receiving permission/command for the cessation of home caregiving, such as a doctor's suggestion or order. Next, finding acceptable both the proximity of the institution, and the care that it provided (compared with that given at home and at other facilities) also eased distress. Finally, acceptance of the situation helped, as did being able to retain some control. Two of the categories identified by these researchers, those of retaining control and of offering support, are of particular relevance to the current study. These have been addressed by a number of other authors who do not restrict their recommendations to applications in institutions caring only for those with AD.

Emotional support, in the form of support groups and/or counselling has been recommended (Buckwalter & Hall, 1987; Matthiesen, 1989), as have transitional programmes for families, which might help individuals to "...take charge of their own lives in ways that are maximally beneficial to their adaptation" (Stephens & Hobfoll, 1990, p.303). In addition, there are suggestions for staff education programmes that might lead to an awareness of family difficulties and of ways in which staff might aid in their resolution (Ferris, 1992; McLeod & Schwartz, 1992).

The introduction of collaborative care has been seen as one way in which relatives can retain control over the situation, and improved communication is viewed as a necessity if this is to occur (Brody et al., 1990; Kasmarik & Lester, 1984; Matthiesen, 1989). Buckwalter and Hall (1987) have specifically recommended joint care planning plus negotiation on the desired level of family involvement, with a family liaison nurse to encourage relatives to utilise rehabilitative strategies. These authors have stressed that there is an obligation for staff to help family members to

adapt "to seeing their loved one within the environment so abandonment does not occur" (p.181). In addition, Pratt et al. (1987), recognising that caregiving involves far more than physical input, suggested that caregivers should be encouraged to view their relatives' institutionalisation as "an end of the burdensome physical care but not the end of caring" (p. 209).

In summary, the need for support for relatives while they assume a new role, along with improved communication between family members and institutional staff, are themes running through much of the literature. Recommendations for collaboration in caregiving recur, as do those for the use of contact (liaison) people. At the same time, it is noted that staff need to achieve a higher level of understanding of the crisis experienced by the family when institutionalisation occurs if they are to provide the necessary assistance for family members.

#### **Effects of Programmes Supporting or Involving Family Members**

A number of reports of programmes that have been implemented in the U.S.A. are discussed in this section, but there has been little objective measurement of the effects of these. However, one study, in Iowa, used a quasi-experimental design and measured the effect of a particular intervention on the satisfaction of family members with the care arrangement (Buckwalter, Cusack, Kruckeberg, & Shoemaker, 1991).

In this Iowan study, thirty-six patients with brain damage and a diagnosis of aphasia or dysarthria were entered into a programme designed to improve their speech. The 23 patients who completed the 18 month study showed only minor speech improvements. However, family members who were involved in the programme (providing memorabilia, audio tapes, and video tapes) were significantly more satisfied with the care received by their relatives, felt that they were more involved in their care, and perceived nursing staff to be significantly more concerned about the residents, than those in the control group (Buckwalter et al., 1991). Clearly, this study has great relevance to the current research.

A study yielding less measurable data was that reported by Tobin (1987). This involved an approach at nursing home: A social worker was selected and trained to

be seen by families as all loving and caring to residents, while senior nursing staff allowed themselves to be used as targets for relatives' hostility. The reason behind the trial was to encourage continued family visiting at a time when family members felt angry at themselves for being inadequate, and at the resident for inducing these feelings. It was argued that the institution needed to be seen as "the life-sustaining all-giving other and also the life-impeding other that is the cause of the present, as well as further, deterioration" (p.50). Although there was no formal evaluation of the programme, there was a reported consensus among staff that it led to a sense of partnership between social workers and senior nurses, as well as to more family involvement.

A further programme yielding subjective data was that documented by Hansen, Patterson, and Wilson (1988). This "Resident Enrichment and Activity Program" (p. 509) was initiated by family members in a 30 bed unit of a Jewish, aged care facility in the U.S.A.. Relatives coordinated various weekend activities with residents. Benefits noted by the authors included the fact that family members were given structured opportunities to interact with residents while sharing in an extended family atmosphere, and that it led to mutual co-operation and respect between staff and relatives. The cultural aspect of the programme was not emphasised by the authors, but it may have had a bearing on the cohesiveness shown by this group of relatives, particularly since they initiated the intervention themselves.

The results of another intervention, one specifically designed to increase family involvement, were documented by Anderson, Hobson, Steiner, and Rodell (1992). Relatives of 12 of the residents of a Veterans' Nursing Home in the U.S.A. (who all had similar degrees of dementia and some family involvement), were randomly assigned to an experimental and a control group ( $N = 12$ ). Family members in the control group continued as usual, while RNs drew up care plans and individualised family involvement plans with experimental group members, each relative retaining a copy. Family members in the experimental group were also asked to bring in items of special interest for residents. It was noted that the care plans of those whose relatives

were in the experimental group placed greater emphasis on psycho-social rather than physical care, that relatives in this group were more involved in the stimulation of the resident, and that they had more communication with nursing staff, although there was no empirical measurement. The "as required" medications were also decreased for residents whose relatives were in the experimental group, when compared with those whose relatives were in the control group. In addition, letters of appreciation were received from five out of six experimental group members.

In further literature from the U.S.A., Sancier (1984) described how a family support group for those who have placed a relative in a nursing home can help them to retain some control and decision making power in the life of the resident. Also, Drysdale, Nelson, and Wineman (1993) detailed such a support group, one that had an educational perspective. No objective measurements of the effects were made, but all participants stated that they would recommend such a group to others.

Finally, McLeod (1991), from Canada, discussed one education session aimed at helping nurses' relationships with family members of residents in long term care facilities. The nurses stated that they found family members' unrealistic expectations, anger, distrust, and manipulative behaviour particularly difficult to deal with. In order to sensitise nurses to the emotions experienced by such relatives, data from a meeting of a family support group were presented.

In summary, it has been shown that the opportunity for collaboration in caregiving may lead family members to be more satisfied with care and to view the role of staff more positively, although empirical evidence is limited. Additionally, support groups have been seen to be appreciated by family members. It is clear that some staff members have difficulty dealing with the common emotional responses of family members, although, in one study, senior nurses were used as willing targets for relatives' hostility.

### **Conclusion**

The literature has shown that family members who institutionalise a relative experience a time of emotional turmoil, that may, or may not, be resolved over time. There is evidence that these relatives hold themselves responsible for maintaining the individuality of their loved ones, as well as for monitoring the standard of their care, and that they might find the transition time easier if they were able to retain some control over the situation and to receive emotional support. Various programmes have been implemented, either to provide family member support or to increase the input of these relatives into caregiving. Many have only been subjectively assessed, but one programme involving family members produced empirical evidence of their increased satisfaction. This intervention, however, was specific to the needs of residents, rather than to the needs of family members.

In view of this, it was appropriate, in the current study, to measure the impact of a programme designed specifically to meet the needs of former caregivers for increased involvement in the care of their loved ones. It was also appropriate to measure changes in their satisfaction with the care arrangement, so that comparisons might be made with the findings of Buckwalter et al. (1991). The methodology ideally suited to the purpose was an experimental design, with random selection from the population of former caregivers of nursing home residents, and random assignment to a control or an experimental group. Random selection from all the nursing homes in Western Australia was not possible for this study because of the existing constraints, instead a convenience sample from one nursing home was utilised. However, the remaining criteria were met: an experimental design was used, and there was random assignment to the two groups.

## **CHAPTER III**

### **Conceptual Framework and Hypotheses**

#### **Conceptual Framework**

The conceptual framework used to guide this study was based on Roy's Adaptation Model of Nursing (Roy, 1984, 1989). This model views the individual as an adaptive system, having coping mechanisms that respond to stimuli from the environment so that adaptation can occur in the physiological, self-concept, role function, and interdependence modes.

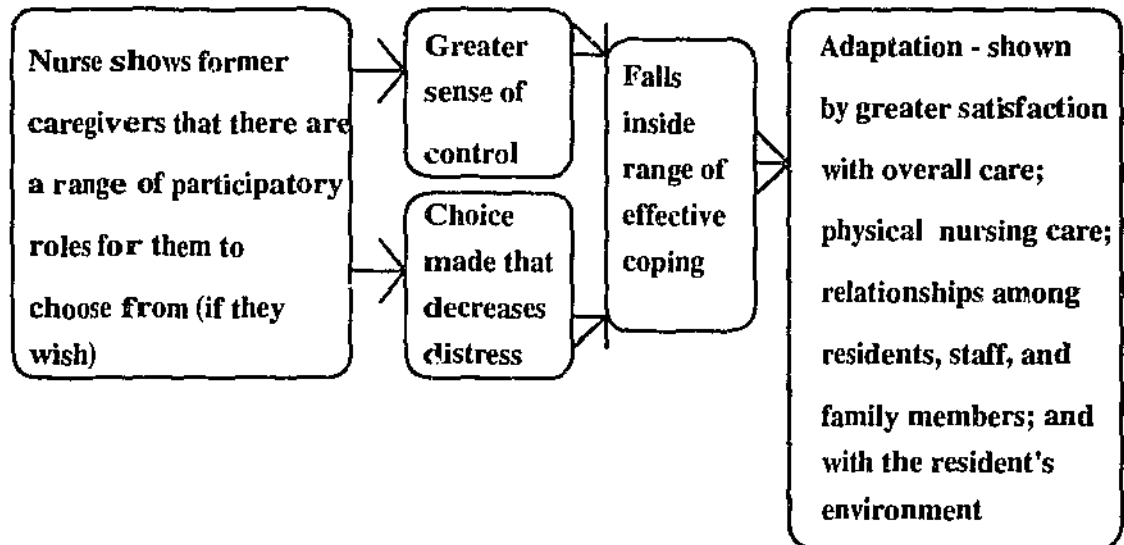
The cognator, which produces cognitive and emotional responses, and the regulator, which produces reflex responses, are mechanisms used in adaptation. Stimuli may be focal (immediately confronting the person), contextual (other environmental influences), or residual (all remaining factors). The range of effective coping is influenced by all of these. Nurses may promote an effective response either by manipulating environmental stimuli, or by encouraging clients to do this. In this study, the former caregiver whose friend or relative had been recently been admitted into a nursing home was viewed as the client.

Such clients need to adapt to an unknown role in an unfamiliar environment. Usually, they are not aware that they could continue to have some involvement in the care of their loved one. If they believe that they have no choice but to abstain from their caregiving role, they may find that their emotional turmoil is heightened to such an extent that they cannot cope effectively with the situation.

The premise of this study was that the nurse can promote effective coping by showing clients that they do have some control over the situation: As shown in Figure 1, former caregivers were informed that they could choose from a range of participatory roles, or they could elect to have no input. It was for them to select the amount and type of input that suited them best. In this way, the nurse was manipulating environmental stimuli, reducing perceptions of the controlling nature of the institution, while clients were able to address their own distressing emotions

by the choices that they made (for example, their guilt might be diminished by their choice to regain input into care).

Adaptation, resulting from effective coping, was to be evidenced by increased satisfaction with the care arrangement: with the overall care provided for residents; their physical nursing care; the relationships that were formed among staff, residents, and relatives; and the resident's environment.



**Figure 1.** How facilitating increased involvement in caregiving may assist former caregivers, whose loved one has been institutionalised, to adapt to the new care situation (adapted from Roy, 1984, 1989).

### Hypotheses

1. Former caregivers of nursing home residents who have been included in the Programme Facilitating Increased Involvement in Caregiving (PFIC) will report higher levels of satisfaction with the overall care of their friend/relative than those who have not.

2. Former caregivers of nursing home residents who have been included in the PFIC will report higher levels of satisfaction with the physical nursing care of their friend/relative than those who have not.

3. Former caregivers of nursing home residents who have been included in the PFIIC will report higher levels of satisfaction with the relationships among residents, staff, and family members than those who have not.

4. Former caregivers of nursing home residents who have been included in the PFIIC will report higher levels of satisfaction with the resident's environment than those who have not.

#### **Assumption**

It is assumed that the role of the nurse incorporates caring for the family system to which the resident belongs, since, by addressing the plight of one family member, all members of the system benefit. In this study the former caregiver was the recipient of the nursing intervention.



## **CHAPTER IV**

### **Method**

This chapter describes the design of the study; the setting; the sample, including the processes of selection and of stratified, random assignment; and the questionnaires, including their modification. Finally, the procedures undertaken to complete the study are listed, complete with details of the intervention.

#### **Design**

The study utilised an experimental, pre-test-post-test control group design, with stratified random assignment to an experimental and a control group. There were two strata: one of former caregivers of residents who had given their own consent, and the other of former caregivers of residents on behalf of whom proxy consent had been obtained. The strata, therefore, reflected the cognitive status of the residents.

The independent variable was inclusion in the intervention, the Programme Facilitating Increased Involvement in Caregiving (PFIIC), for 6 weeks. Only members of the experimental group received this intervention. Details of the intervention are given in the section detailing procedures.

The dependent variables were as follows: satisfaction with the overall care of the resident; satisfaction with physical nursing care; satisfaction with relationships among residents, staff and family members; and satisfaction with the resident's environment.

There were a number of possible, extraneous variables. Those recorded were the characteristics of former caregivers (Appendix A), changes in some of these characteristics during the study period (Appendix B), and resident characteristics (Appendix C). Random assignment to groups was carried out in order to increase the likelihood of an even spread of their effect in each group.

### Setting

The research was carried out in a government funded, suburban, Western Australian nursing home. The home has over 200 beds. It was built at the turn of the century, but has undergone some renovations. Rooms, for between one and six residents, are either arranged along long, straight corridors, or they fan out from passages encircling utility areas. There are gardens, verandahs, and lounge rooms, as well as family facilities including a library, and a kitchen area. The residents, many being elderly, have a variety of disabilities and diseases.

Physiotherapy, occupational therapy, speech pathology, dietetic, podiatry, and social work services are provided. Several General Practitioners visit, and the Nursing Division employ Clinical Nurses, RNs with recognised clinical expertise in the speciality; RNs; ENs; and NAs. Cleaning and catering are usually undertaken by staff employed for these specific tasks, although, in one area, the concept of multi-skilling is being introduced in the form of carers (who assist with direct resident care, with cleaning, and with serving food). The wearing of a uniform is not compulsory, and approximately half of the staff of the Nursing Division wear their own clothes to work.

Immediately before this study was carried out, those relatives and friends who requested increased involvement with the care of the resident were being accommodated, unless issues such as safety were a concern. Certain aspects of family involvement were actively encouraged, most notably attendances at the occasional social functions and at case conferences (multi-disciplinary meetings where the care of individual residents was discussed). However, there was no formal process in place to discover and implement the level and type of involvement desired by friends and family members.

### **Sample**

This section describes the selection of subjects, which involved obtaining consent from, or on behalf of, residents as well as the former caregivers; their assignment to groups; and the characteristics of those who completed the study.

#### **Selection of Subjects**

A convenience sample of 42 former caregivers of nursing home residents was selected in the following way: Firstly, all long-term residents who had been admitted to the nursing home more than one month before the commencement of the study, but within the previous 2 years, were identified. Then, those with no contact person in the metropolitan area were excluded, as were those whose former caregivers were in the home's support group for relatives of residents with dementia (7 people) because of a possible interaction effect. This left 77 residents with eligible former caregivers.

The next step involved two different approaches to obtain the consent of residents for their former caregivers to participate in the study. The variation in the process was necessary because of the altered cognitive state of some residents. The response rate resulting from each approach is described below and illustrated in Table 1.

**1. Residents able to give informed consent.** Thirty two residents were able to nominate a former caregiver (Appendix D). When these residents were approached by the researcher, 21 of them agreed to do this. Of the remaining 11, 3 indicated that any eligible person would be away at the time of the study, 4 stated that they did not wish a former caregiver to be involved in their care, 1 indicated that he was happy with the current situation and did not want it changed, and 2 asked that their relatives should not be troubled. From the 21 nominated former caregivers, 18 agreed to participate, signing the consent form (Appendix E).

**2. Residents unable to give informed consent.** Forty five residents could not be asked for nominations because of their cognitive impairment. Therefore, the "first contact" person for each of these residents, as identified from the case notes, was sent

a letter (Appendix F). This letter asked for one person, acting on the resident's behalf, to nominate a former caregiver (not him/herself) who could be asked to take part in the study. As a result of these 45 requests, 22 names were put forward. An additional 2 family members expressed their interest in participating but indicated that there was no other friend or relative to act on behalf of the resident. The Director of the nursing home gave the proxy consent for these people to be included. This gave a total of 24 possible participants nominated by proxy, all of whom agreed to participate. Of those who did not nominate a participant, 4 indicated that the only appropriate person would be away at the time of the study, 14 stated that there was no former caregiver who was willing and available to participate, and the remaining 3 people gave no explanation.

**Table 1**

**Summary of Response Rates of Residents and of Potential Participants**

<b>Resident characteristics</b>	<b>Eligible residents (ER)</b>	<b>Nominated potential participants (NPP)</b>	<b>Number of consenting participants</b>
<b>Residents able to give informed consent</b>	32	21	18 ( 56.3% of ER) ( 85.7% of NPP)
<b>Residents unable to give informed consent</b>	45	24 <sup>a</sup>	24 ( 53.3% of ER) (100.0% of NPP)

**Note.**

<sup>a</sup>22 (relative as proxy) + 2 (Director as proxy).

At the beginning of the study, therefore, the sample consisted of 42 former caregivers, including 22 females and 20 males. All were relatives, ranging in age from 32 to 87 years. Residents were aged between 63 and 96 years, and also included 22 females and 20 males. One male resident died prior to random assignment to groups, leaving a sample of 41 former caregivers.

### **Random Assignment**

Random assignment was carried out as soon as all written, subject consents had been obtained. The sample was stratified to ensure similar representation in each group of those who were nominated by residents and of those who were nominated by proxy consent. This was done since it was believed that they might be drawn from two different populations, each having distinct characteristics that would influence results. The process was as follows:

1. All the names of the consenting former caregivers who had been nominated by residents were listed.
2. A coin was tossed to decide whether the first name, drawn out of a box, would be assigned to the experimental or the control group. Subsequent names were then to be assigned alternately to the groups, so that the first, third, etc. names would be assigned to one group, and the second, fourth, etc. to the other.
3. Single names were drawn out and assigned as indicated, ensuring that every name was replaced after it had been drawn, and the box shaken, so that each name was equally likely to be drawn on the next occasion. This was continued until all the names had been assigned.
4. The same process was repeated with the names of those people nominated in the proxy consent process.

In this way, 21 people were assigned to the control group, and 20 to the experimental group.

### **Subjects Completing the Study**

As shown in Table 2, from the 21 subjects assigned to the control group, 16 completed the study, and from the 20 subjects assigned to the experimental group, complete data sets were obtained from 15 experimental group members. This meant that 73.8% of the original 42 participants provided the data for analysis.

**Table 2**

### **Summary of Completion Rates of Participants by Group**

<b>Numbers of participants<sup>a</sup></b>	<b>Control group</b>	<b>Experimental group</b>
<b>Assigned to groups</b>	21	20
<b>FPCT Time 1 not returned</b>	2	0
<b>FPCT Time 2 not returned</b>	0	1
<b>Resident hospitalised 3 weeks or more</b>	2	1
<b>Resident discharged</b>	1	1
<b>Resident deceased</b>	0	1
<b>High percentage of missing FPCT data</b>	0	1
<b>Completing study</b>	16 (76.2%)	15 (75%)

**Note.**

<sup>a</sup>One resident died prior to group assignment (former caregiver nominated by proxy).

Former caregivers of those residents who were hospitalised for more than 50% of the study period were excluded, but when residents were hospitalised for shorter periods of time this time was made up at the end of the study. Possible contamination was not an issue, since no members in different groups were known to communicate.

As shown in Table 3, there were 19 women and 12 men in the final sample of former caregivers, their ages varying from 32 to 84 years ( $M = 57.9$ ,  $SD = 13.2$ ). All except 2 subjects had attended secondary school, 42% continuing their education.

**Table 3**

**Demographic Characteristics of Participants**

Characteristic	Control group ( $n = 16$ )	Experimental group ( $n = 15$ )	Total sample ( $N = 31$ )
Mean age <sup>a</sup>	59 ( $SD = 13.93$ )	57 ( $SD = 12.78$ )	58 ( $SD = 13.22$ )
<b>Gender</b>			
Female	11 (68.8%)	8 (53.3%)	19 (61.3%)
Male	5 (31.2%)	7 (46.7%)	12 (38.7%)
<b>Level of education</b>			
Primary	2 (12.5%)	0 (0%)	2 (6.5%)
Secondary	8 (50%)	8 (53.3%)	16 (51.6%)
Training course	2 (12.5%)	4 (26.7%)	9 (19.4%)
Tertiary	4 (25%)	4 (20%)	7 (22.6%)

**Note.** Means displayed for interval data, frequencies/percentages for nominal data.

<sup>a</sup>Mean age expressed to nearest year.

In summary, of the 42 former caregivers recruited for the study, 41 were randomly assigned to an experimental and a control group, and 31 sets of data were obtained for analysis. Sixteen of these were from the control group (11 females and 5 males) and 15 from the experimental group (8 females and 7 males).

### **Instrumentation**

#### **Demographic Questionnaires (1) and (2)**

Both demographic questionnaires were designed by the researcher and obtained information about former caregivers (Appendix A and Appendix B). Many of the questions related to possible extraneous variables and were developed with reference to the literature. These questionnaires were piloted prior to data collection: the researcher asking each of eight relatives of residents admitted more than 2 years previously to complete a questionnaire in the researcher's presence, four completing each version of the questionnaire. As a consequence, several changes were made (Appendix G).

#### **Resident Details**

A questionnaire was designed to allow the researcher to record relevant details from the residents' notes (Appendix C). The area of residence within the home was not included as it was observed to be evenly spread throughout the two groups.

#### **Family Perceptions of Care Tool (FPCT)**

The FPCT (Appendix H), designed by Maas et al. (1991), was used to assess the satisfaction of family members with the care arrangement. The questionnaire was developed for use with families of those with Alzheimer's Disease (Maas, personal communication, October 25th, 1993). Since a large proportion of the residents of the nursing home in this study evidenced a degree of confusion and/or disorientation, the use of this instrument was appropriate. Permission for its use was obtained from Professor Buckwalter (Appendix I).

The total FPCT, measuring satisfaction with the care arrangement, has four subscales measuring the following: satisfaction with overall care; satisfaction with



physical nursing care; satisfaction with the relationships among residents, staff, and family members; and satisfaction with the resident's environment.

The latest, 51 item, FPCT was used in this study, but details of the psychometric properties of this version are not yet available. The previous, 48 item, version of the instrument had established content validity, and its internal consistency reliability co-efficients (Cronbach's Alpha), as shown in Table 5, ranged between .92 and .97 for the total instrument, and between .74 and .96 for individual scales. The "...test-retest reliability coefficients, based on data from 15 family members with a time interval of 10 days ranged from .78 to .90 ( $p < .05$ )" (Maas, unpublished report, 1993, p. 2).

With the permission of the author (Appendix J), the 51 item FPCT was adapted for use in the present study following piloting (Appendix G). The resultant instrument, which still had 51 items, was administered during the study.

The FPCT was further refined when the raw data were examined prior to analysis because certain items were, fairly consistently, not answered by participants, or marked as "not applicable" or "don't know". These responses were all classified as "missing".

When the items where more than 25% of responses were "missing" at both Time 1 and Time 2 were appraised, it appeared that former caregivers saw them to be irrelevant. For example, Items 31 (opportunity for exercise) and 41 (use of self care abilities) probably seemed inappropriate to those whose relative was severely disabled, while Item 40 (sensory stimulation) may have seemed inapplicable to participants whose family member was apparently unresponsive. Item 39 (use of restraints) was irrelevant in many cases, and a number of former caregivers may have been unaware of the work of the Social Worker (Item 20); the Speech Pathologist (Item 25); the Physiotherapist (Item 23); and the Occupational Therapist (Item 24). All the above items were, therefore, deleted from the analyses.

In addition, the five items where over 25% of responses were "missing" at either Time 1 or Time 2, but not at both times, were examined. These were retained

because there was an increase in appraising responses at Time 2 for most of them, which may have been related to the study, and because one item was highly relevant to the current study (Item 11: staff support of residents' relatives). These items had no more than 33% of "missing" responses at Time 1 or at Time 2.

Following internal consistency reliability checks on the remaining items in each scale, two more items were deleted in order to improve reliability: Item 12 (other residents' behaviour) and Item 47 (care of possessions). Table 4 shows the 41 items that were left in the FPCT following its modification.

**Table 4**

**Items in each Scale of the FPCT**

<b>Scale</b>	<b>Items in 51 item FPCT<sup>a</sup> (given to participants)</b>	<b>Items in revised, 41 item, FPCT (used for analysis)</b>
Satisfaction with overall care	1, 13-17, 19-25, 45, 48-51	1,13-17, 19, 21-22, 45, 48-51
Satisfaction with physical nursing care	18, 37-39, 41-44	18, 37, 38, 42-44
Satisfaction with relationships among residents, staff, and family members	2-12	2-11
Satisfaction with the environment	26-36, 40, 46, 47	26-30, 32-36, 46

**Note.** Information provided by Maas (personal communication, October 25th., 1993).

<sup>a</sup>Items added to the 48 item version by the authors (to make the 51 item version) were 36, 43, and 44.

As shown in Table 5, reliability coefficients of the total instrument and of all but one of the scales of this 41 item FPCT were at least as high as those previously shown to apply to the 48 item instrument. A comparison could not be made with the 51 item FPCT as the necessary data were not available. Scoring is described in Appendix K.

**Table 5**

**Cronbach's Alpha Coefficients for the FPCT**

<b>Scale of FPCT</b>	<b>Alpha: 48 items<sup>a</sup></b>	<b>Alpha: 41 items Time 1<sup>b</sup></b>	<b>Alpha: 41 items Time 2<sup>b</sup></b>
<b>Satisfaction with overall care</b>	.87 - .96	.79	.76
<b>Satisfaction with nursing care</b>	.82 - .93	.90	.90
<b>Satisfaction with relationships</b>	.74 - .92	.82	.87
<b>Satisfaction with the environment</b>	.77 - .94	.89	.88
<b>Total instrument</b>	.92 - .97	.94	.95

**Note.**

<sup>a</sup>Data provided by Maas (unpublished report, October 25th, 1993, p. 2).

<sup>b</sup>As used in this study: 41 of 51 items retained.

In summary, four questionnaires were utilised in this study, two obtained information about participants at Time 1 and Time 2, one documented resident details at Time 2, and the FPCT obtained scores used to assess the satisfaction of participants with aspects of the care arrangement at Time 1 and Time 2. Piloting

resulted in minor changes to the questionnaires, and the FPCT was further amended after data were collected, without adversely affecting the psychometric properties of the instrument.

### **Procedure**

This section addresses the pre-testing of subjects, the treatment of the control and experimental groups, and the post-testing procedure. Due to pending changes at the nursing home, the study period was limited to 6 weeks. However, it was believed that this would be long enough to demonstrate at least a trend, if not a significant effect, Buckwalter et al. (1991) having demonstrated a marked difference in satisfaction between a control and an experimental group after 3 months of a similar intervention, using an earlier version of the same instrument. In the current study, collection of all data was carried out by the researcher.

### **Pre-testing**

So that participants were not inconvenienced, appointments were made for times when they would be visiting their relatives. In order to protect their privacy and to increase the likelihood that honest answers would be given, these former caregivers were invited to a quiet spot in the home, where their responses would not be overheard by others. The researcher thanked them for attending, and conversed with them for a few moments to put them at ease. Formal, written consent was then obtained.

At the same interview, the researcher requested verbal responses to the Demographic Questionnaire (1), and marked them onto the form. This was done in full view of participants in order to increase their ability to complete the Demographic Questionnaire (2) alone, at Time 2. Completing the first questionnaire in the company of the researcher also enabled participants to become a little more familiar with her before answering the questions, some of which were on sensitive issues.

Also at this meeting, participants were given the Time 1 FPCTs. They were asked to take these home, complete them within a week, and then deposit them in

one of the sealed boxes placed on each of the wards. Although most were returned by this method, five were given, sealed, to the receptionist at the main entrance, and five were returned in the mail after follow up letters were sent out with stamped, self addressed envelopes. Before leaving, participants were asked not to discuss the study with other residents' visitors, as this might have led to contamination. The amount and type of each participant's existing involvement in caregiving was also noted at this time.

Although random assignment was carried out as soon as all formal consents had been obtained, the letters informing participants of their group assignment (Appendix L and Appendix M) were not sent out until the respective FPCT questionnaires had been completed.

#### **Treatment of the Control Group**

The control group experienced the usual conditions over the study period. Nursing staff were asked to inform the researcher of changes in involvement in caregiving of any relatives, since they were not told who was in the control group in case this affected their treatment of participants. No changes were reported. The researcher also observed for any alteration in staff attitudes towards control group members. Again, there appeared to be none. Control group members were informed of the end of the study period, by mail, 6 weeks after being notified of their group assignment.

#### **Treatment of the Experimental Group**

After experimental group members had been notified of their group assignment, the intervention (inclusion in the PFHIC) was commenced as soon as it was possible to contact them by telephone. The maximum time that elapsed between the completion of the Demographic Questionnaire (1) and the start of the intervention was 5 weeks, the delay being due to the time taken by some respondents returning the first FPCT questionnaires. The minimum time was 13 days ( $M = 27.9$ ,  $SD = 6.1$ ).

**The Programme Facilitating Increased Involvement in Caregiving.** Details of the PFIIC were as follows:

1. One RN or EN, working in the appropriate area, was appointed by the researcher as a special liaison person for each former caregiver. Only RNs and ENs were utilised since it was believed that their knowledge base and authority was essential for the programme to be implemented effectively. In a single case, one nurse was required to be a liaison person for two former caregivers (due to a shortage of trained staff in the area), otherwise there was a one to one relationship. At the beginning of the study, therefore, there were 19 nurses who had agreed to act as liaison people. All the staff who were asked to take part were given the option to refuse, but none took up this option.
2. The letters advising former caregivers of their assignment to the experimental group also offered them increased involvement in the care of their friend or relative. In attachments to these letters, three broad categories of caregiving were nominated by the researcher: planning and decision making, nursing care, and extra care. Examples were given of specific ways in which they might choose to be involved (Appendix N).
3. Within a week of posting these individual notifications, the researcher telephoned group members to learn of their decisions. Each one was given the name of the appropriate liaison person, even if he or she chose not to have increased involvement. Participants were informed that these liaison people, as well as the researcher, would be available to help facilitate their desired involvement, and/or to discuss their concerns about the care of the resident. The researcher refrained from commenting on participants' preferences unless it was necessary to point out any potential difficulties, such as times when it might be impossible to meet with staff members.

4. Liaison people were made aware of the type and level of involvement desired, and, together with the researcher and the former caregiver, planned how this would be facilitated.

5. Liaison people were also asked to introduce themselves to participants when they visited, and to make themselves available to listen to their concerns regarding the care of their friend/relative, acting on them when appropriate. In this way, even those participants who had elected not to have increased involvement would find it easier to augment their input, should they wish to do so.

6. At the end of the sixth week, letters were sent out to participants notifying them that the study period had ended. It was also made clear to them that any increased involvement could continue, being facilitated by their liaison person, who would still be available.

**Reliability checks.** To ensure that the desired involvement was being facilitated, regular, fortnightly, personal contact was made by the researcher with the liaison people. Also as a reliability check, fortnightly telephone calls were made to all except two experimental group members (these people having requested that they should not be called). One question was asked: "Are you happy with the involvement that you have with your friend/relative's care, at the moment?". Reasons for dissatisfaction were followed up immediately, so that the desired level of involvement was maintained.

### **Post-testing**

At the end of the 6 week study period the Resident Details questionnaire was completed by the researcher. The FPCT (Time 2) and the Demographic Questionnaire (2) were included with each of the letters notifying subjects of the end of the study period, along with stamped, addressed envelopes for their return. This was done in the hope of avoiding the delays experienced in the return of the FPCT at Time 1. The overall response was quicker, although reminder telephone calls had to be made to four people, and letters sent to two of these. One respondent from the experimental group, having had increased involvement, refused to complete this

FPCT, giving no reason. However, this person had informed the researcher that it took a period of 3 days to consider answers to, and to complete, the pre-test FPCT.

### **Ethical Considerations**

Sachs, Rhymes, and Cassel, discussing the ethical concerns of conducting research in long-term care settings, stated that there is "increased vulnerability of potential subjects to inattention, coercion, and abuse" (1993, p. 771). Although the authors were referring to the residents as subjects, which was not the case in the current study, resident vulnerability was still an issue. It was ethically necessary to ensure that a former caregiver should not be offered increased involvement in the care of the resident if this was not what the resident would have wished. Furthermore, residents, or those acting on their behalf, had to be reassured that there would be no repercussions if they refused permission for a former caregiver to be approached, or if friends or family members refused consent to participate. It was also essential for former caregivers to be assured of anonymity if they were not to fear victimisation of the resident should staff discover that they were dissatisfied with resident care, or that they were unwilling to participate. In addition, it was necessary to be aware that former caregivers are, themselves, particularly vulnerable at the time of the placement of their friend or relative.

The following steps were taken to ensure that this study was conducted in an ethical manner:

1. Either informed resident consent or proxy consent was sought from, or on behalf of, residents before subjects were approached (Appendix D and Appendix F). Large print copies of the "Resident Consent" forms were made available to those with impaired vision, and verbal consents, from those with an impaired ability to read or write, were always sought in the presence of a witness who was agreed to by the resident. It was made clear to residents that there would be no repercussions if they refused their consent, and that, once given, it could be freely withdrawn at any time. Residents were also assured that their relative or friend would not be told of their refusal by the researcher, nor would the researcher reveal this information to others.



2. As suggested by Sachs et al. (1993), any persistent behaviour indicating that a resident objected to their relative's increased involvement, was to be noted, as this was to be taken to indicate refusal of their consent for the purposes of the study. This did not eventuate.

3. Written, informed consent (Appendix E) was also required from eligible subjects prior to completion of the first questionnaire. Prospective subjects were made aware that their refusal would not affect the care of the resident, that the researcher would not reveal this information to any other person, and that, having consented, they were free to withdraw at any time.

4. Residents, and those giving proxy consents, were informed that any nominated former caregiver's refusal to take part would not be revealed to other staff by the researcher, and that it would have absolutely no implications for their care.

5. It was made clear to participants that questionnaires were anonymous, coded, and the code list locked away, separately, at the researcher's home. The researcher undertook not to reveal responses to questions to others in a way that might reveal the identity of the respondent.

6. The boxes placed on the wards for the receipt of completed questionnaires were sealed by the researcher, who checked them at least twice each week to ensure that they had not been tampered with.

7. No former caregivers were invited to participate within the first month after the placement of their friend or relative, in recognition of the stress experienced at this time.

8. Absolutely no pressure was brought to bear on experimental group members to increase their involvement in caregiving.

9. The intervention is to be offered to members of the control group after completion of this thesis.

10. The risk of injury to relatives or residents while former care givers were providing direct care was not an issue, since this type of increased involvement was not chosen by any subject. It was anticipated as a potential problem, and it was

believed that any risk would be minimised by careful collaborative planning, and by discouraging physically strenuous interventions.

11. The proposal was submitted to the Higher Degrees Committee of Edith Cowan University, and to the Executive of the nursing home, for approval prior to the commencement of any procedures.

12. The questionnaires and the master list will be kept locked away, separately, at the researcher's house for 5 years. They will then be destroyed by "shredding".

## **CHAPTER V**

### **Data Analysis and Results**

This chapter details the following: (a) the caregiving choices of experimental group members; (b) differences between experimental and control group members' FPCT scores, including the results of hypothesis testing; (c) characteristics of the members of both groups that had the potential to influence findings; (d) comparisons within the experimental group between those choosing extra involvement and those not (characteristics and FPCT scores), and between those with relatives admitted 1 - 6 months before the study and those not (FPCT scores only); (e) a comparison between experimental and control group members who had relatives admitted 1 - 6 months before the study (FPCT scores only); and (f) comments made by participants at the end of the FPCT. An overall summary completes the chapter. Data analysis is documented at each stage. The Statistical Package for the Social Sciences (SPSS for Windows) was utilised for analyses, and alpha was set at .05.

#### **Choices made by Experimental Group Members**

Immediately prior to the study, only 1 of the 15 experimental group members had a great deal of involvement in resident care. This person regularly participated in "physical" care and discussed care with staff almost every day. Three other people had moderate input, which included visiting daily, questioning nursing staff about care, and having a little involvement in "physical" caregiving. Another 3 had minimal input, sometimes questioning and making suggestions, and the remaining 8 subjects had no input at all apart from visiting.

From the eight people who had no input, three chose to increase their involvement when the intervention commenced. Another person, who already had a moderate degree of input, chose to increase this after 2 weeks of the intervention, despite having indicated that existing commitments filled all available time. Only these 4 subjects chose to increase their involvement during the study. The most common choice that they made was to have extra involvement in planning and decision making. Residents related to these former caregivers all lived in different areas of the home.

The remaining 11 experimental group members elected not to increase their input. They maintained their previous degree of involvement throughout the study: Six subjects stated that they were happy with the level of involvement they already had; 2 indicated that they would have preferred to have more input, but were already fully committed; and 3 stated that old age or ill health prevented them from making an additional commitment.

### **Differences Between the Groups in Satisfaction**

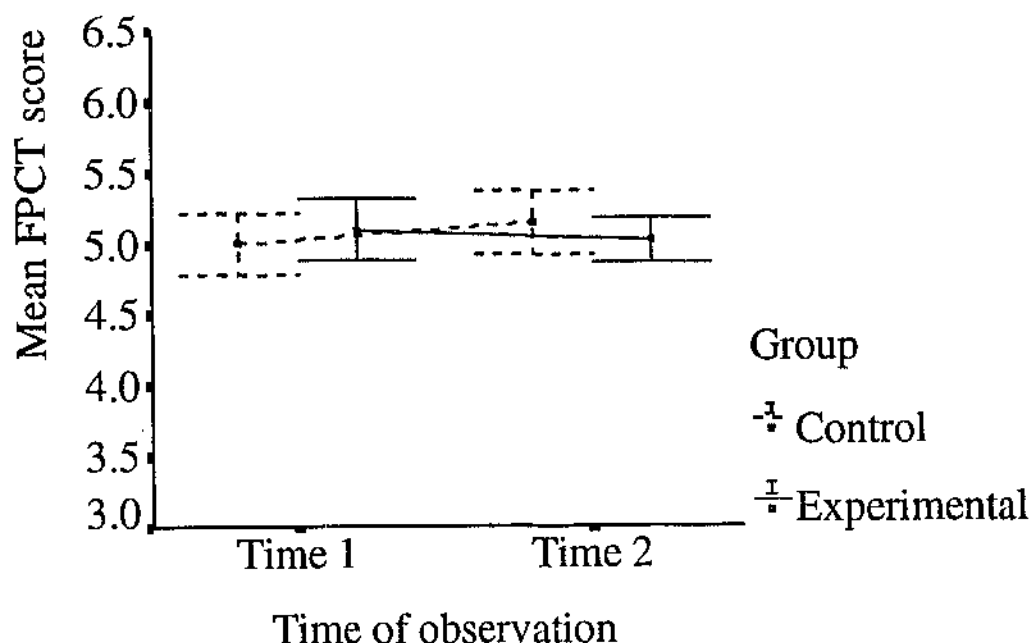
Prior to analysis, the missing data for the remaining 41 items of the FPCT were estimated using means calculated from available data, as recommended by Tabachnick and Fidell (1989). In this case, the group means for each scale were utilised (see Appendix O for a summary of missing scores that were replaced)

A visual inspection of FPCT data then revealed a ceiling effect in some scales: a number of subjects scored many items at Time 1 as "7", which meant that any increase in their satisfaction at Time 2 could not be indicated on the questionnaire. Therefore, a direct comparison of differences in scores was not used for hypothesis testing. Instead, Analysis of Covariance (ANCOVA) was used: While controlling for FPCT scores at Time 1 (the covariate), FPCT scores at Time 2 (the dependent variable) were compared between the experimental group and the control group. This procedure was carried out for each scale of the FPCT in order to test each hypothesis. It was then repeated for the total instrument. Differences between control and experimental group means at Time 1 and Time 2 were illustrated with graphs, error bars showing one standard error of the mean on each side of the mean. Although FPCT scores could range from 1 -7, scale axes of all line graphs show a range of 3.0 - 6.5 for the means, so that differences may be seen more clearly. Bar graphs show differences between mean group scores for each item. Items attracting a mean score of 4 or under at either time were especially noted, as these appeared to denote areas of particular dissatisfaction.

### Satisfaction with Overall Care

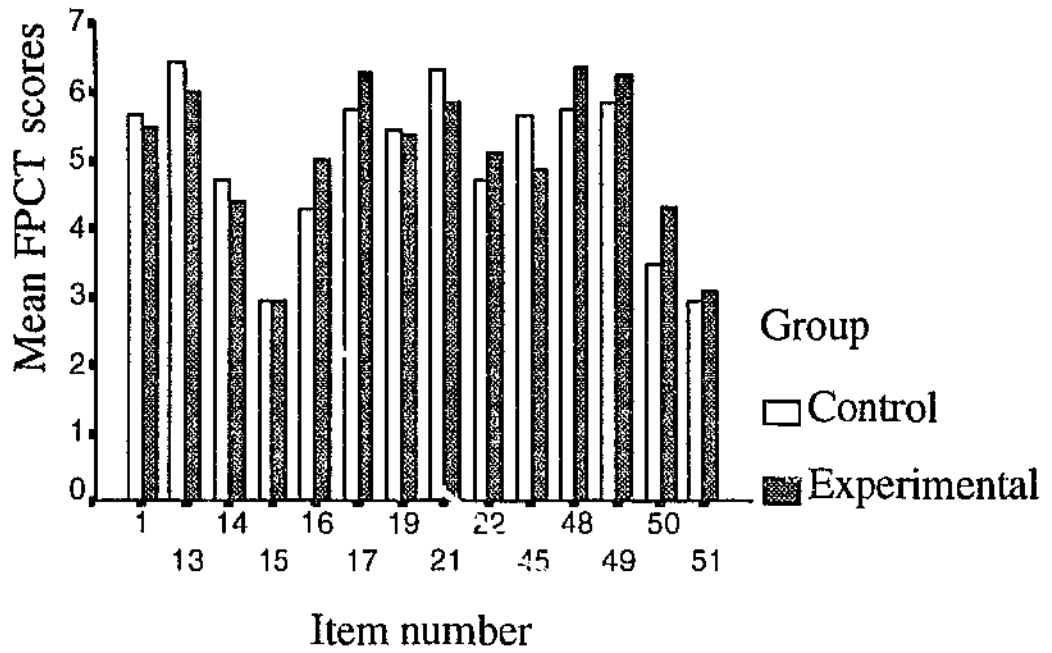
The first hypothesis was that former caregivers of nursing home residents who had been included in the Programme Facilitating Increased Involvement in Caregiving (PFIIC) would report higher levels of satisfaction with the overall care of their friend/relative than those who had not.

As shown in Figure 2, the change in mean scores was not in the predicted direction. An ANCOVA, with satisfaction with overall care at Time 2 as the dependent variable, and at Time 1 as the covariate, failed to find a significant difference between the groups,  $F(1,28) = .98$ ,  $p = .33$ .



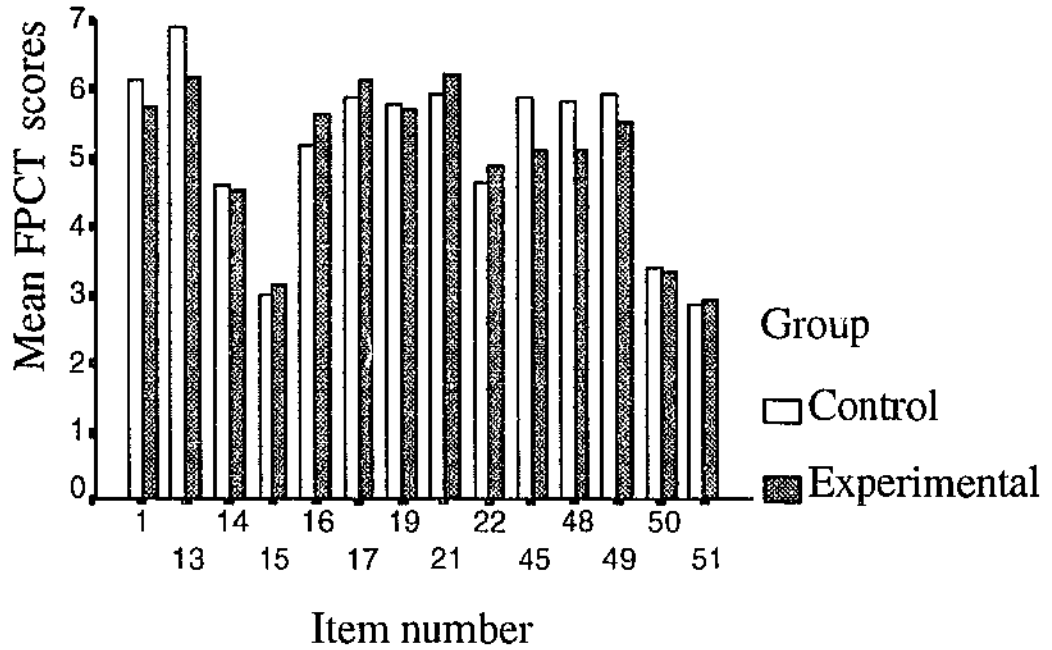
**Figure 2.** Comparison of means of "Satisfaction with Overall Care" scale, by group, at Time 1 and Time 2.

As shown in Figures 3 and 4, there were no major differences in mean scores for any item, by group, at either time. However, Items 15 (satisfaction with the encouragement of residents to participate in activities), 50 (satisfaction with the amount of staff attention for residents), and 51 (satisfaction with the amount of resources) attracted mean scores of 4 or under.



**Figure 3.** Comparison of mean FPCT scores for each item in the scale

"Satisfaction with Overall care" at Time 1.



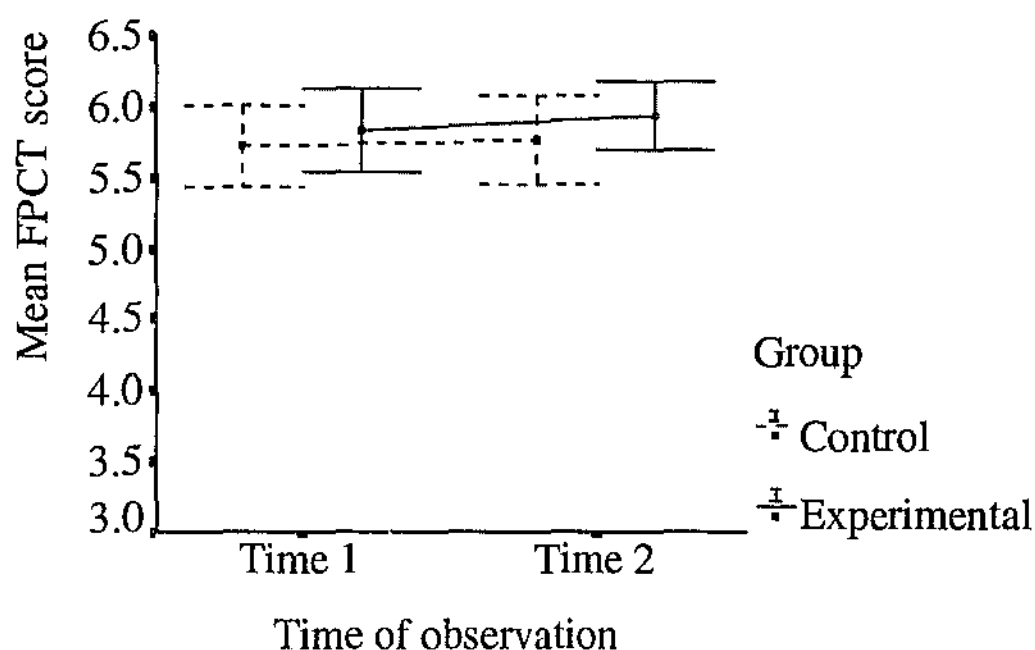
**Figure 4.** Comparison of mean FPCT scores for each item in the scale

"Satisfaction with Overall Care" at Time 2.

### Satisfaction with Physical Nursing Care

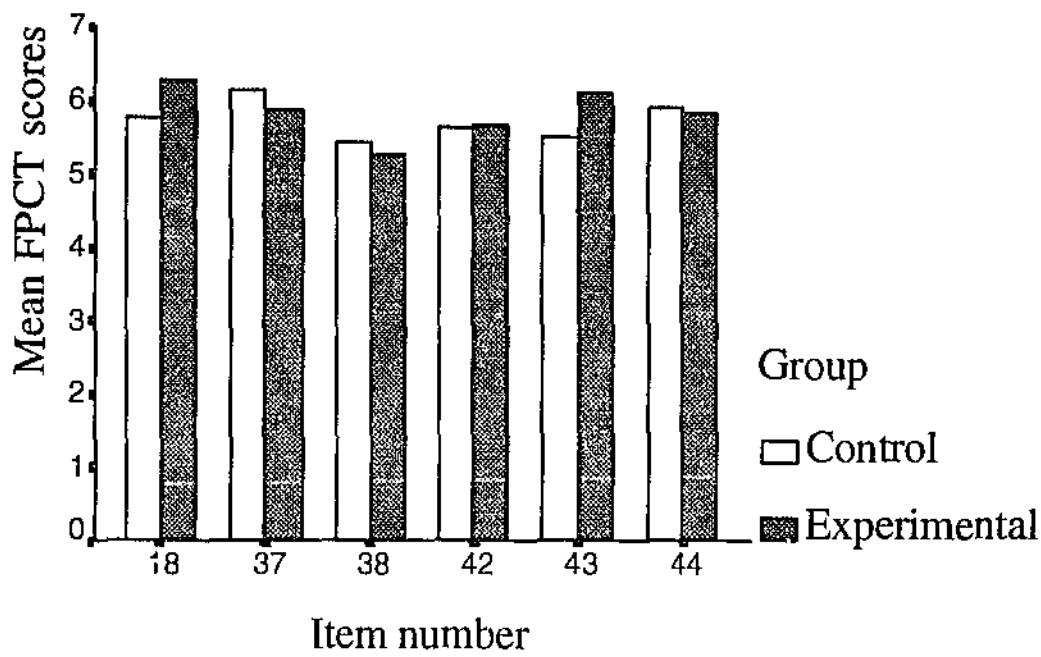
The second hypothesis was that former caregivers of nursing home residents who had been included in the PFHIC would report higher levels of satisfaction with the physical nursing care of their friend/relative than those who had not.

The change in mean scores was in the predicted direction (Figure 5). However, a similar ANCOVA, using scores from the scale "satisfaction with physical nursing care", at Time 2 as the dependent variable and at Time 1 as the covariate, again failed to find a significant difference between the groups,  $F(1,28) = .15$ ,  $p = .70$ .

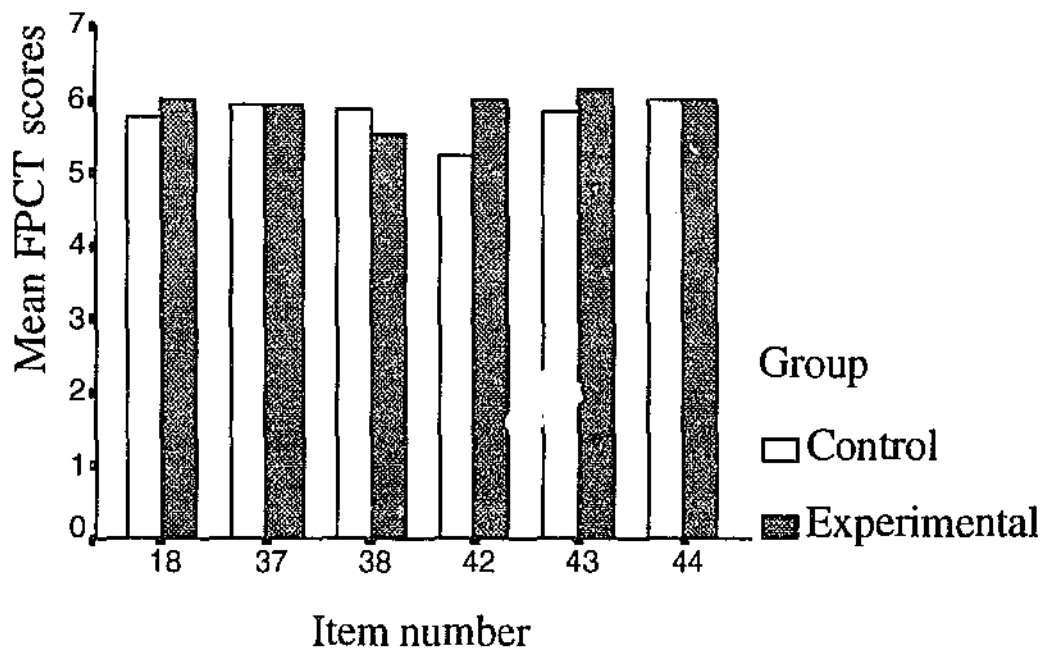


**Figure 5.** Comparison of means of "Satisfaction with Physical Nursing Care" scale, by group, at Time 1 and Time 2.

Also, there were no major differences between the groups in mean scores for any item at Time 1 or Time 2, and no mean score was 4 or under (Figures 6 and 7).



**Figure 6.** Comparison of mean FPCT scores for each item in the scale "Satisfaction with Physical Nursing Care" at Time 1.



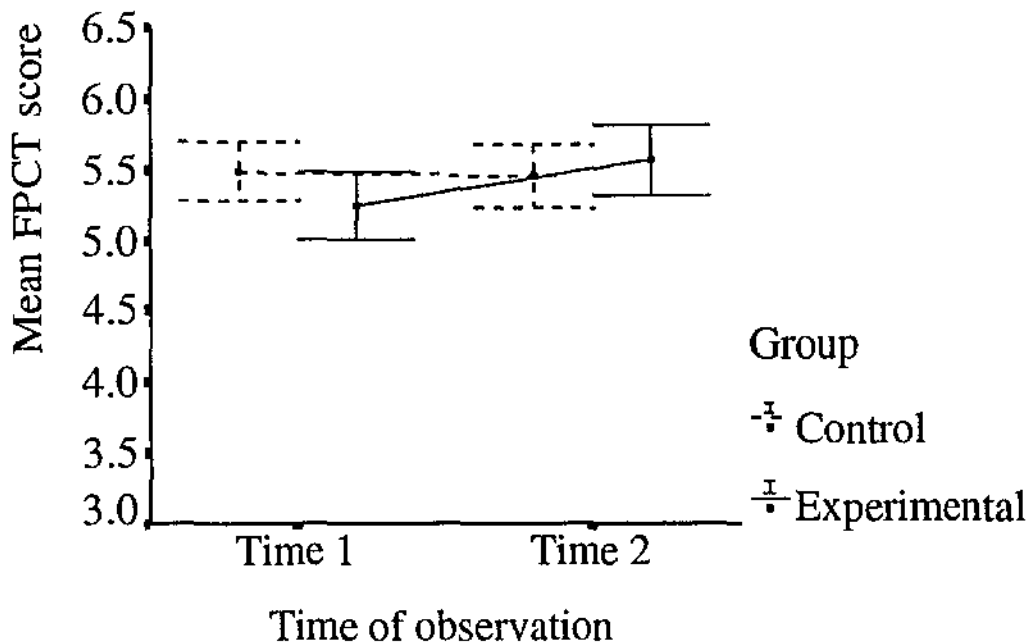
**Figure 7.** Comparison of mean FPCT scores for each item in the scale "Satisfaction with Physical Nursing Care" at Time 2.



### Satisfaction with Relationships among Residents, Staff, and Family Members

The third hypothesis was that former caregivers of nursing home residents who had been included in the PFIIC would report higher levels of satisfaction with the relationships among residents, staff, and family members than those who had not.

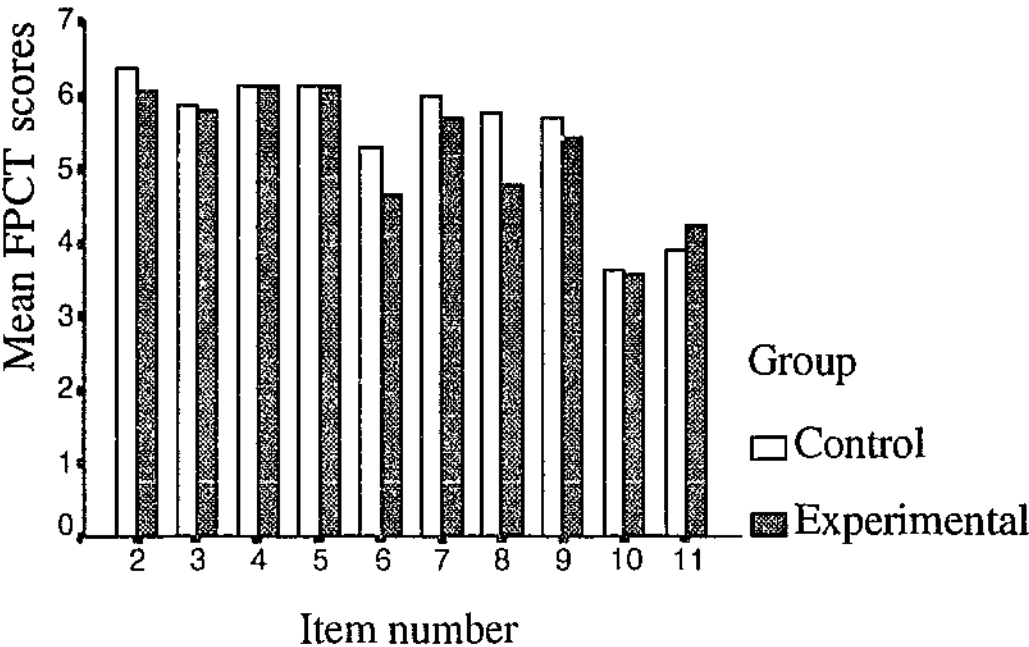
The change in mean scores was, again, in the predicted direction (Figure 8). An ANCOVA, with satisfaction with relationships at Time 2 as the dependent variable, and at Time 1 as the covariate, once more failed to find a significant difference between the groups,  $F(1,28) = .73, p = .40$ .



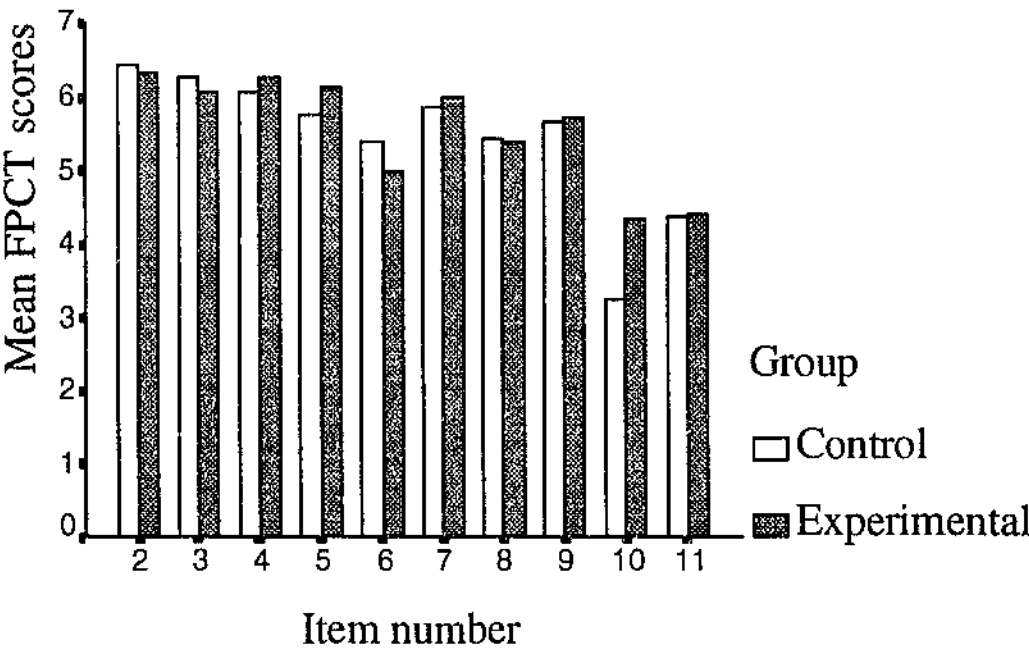
**Figure 8.** Comparison of means of "Satisfaction with Relationships among Residents, Staff, and Family Members" scale, by group, at Time 1 and Time 2.

The mean group scores for each item were very similar at Time 1 and at Time 2. However, mean scores for Item 10 (staff asking for relatives' help) were all

below 4, except for that of the experimental group at Time 2, and the mean score for Item 11 (staff providing support for former caregivers) was also under 4 at Time 1 for the control group (Figures 9 and 10).



**Figure 9.** Comparison of mean FPCT scores for each item in the scale "Satisfaction with Relationships" at Time 1.

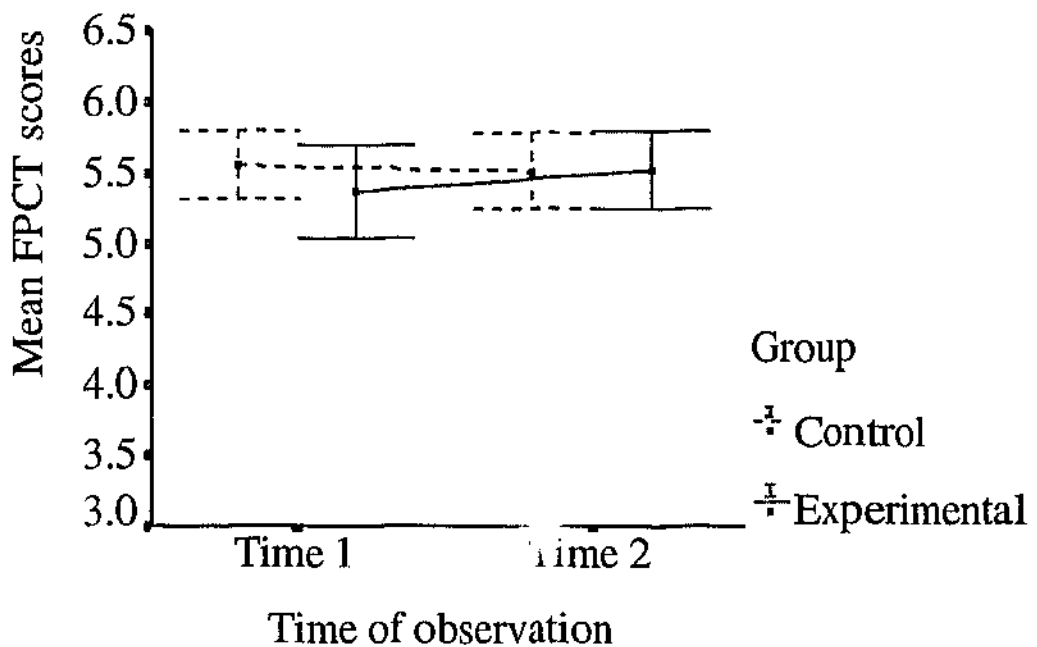


**Figure 10.** Comparison of mean FPCT scores for each item in the scale "Satisfaction with Relationships" at Time 2.

### Satisfaction with the Environment

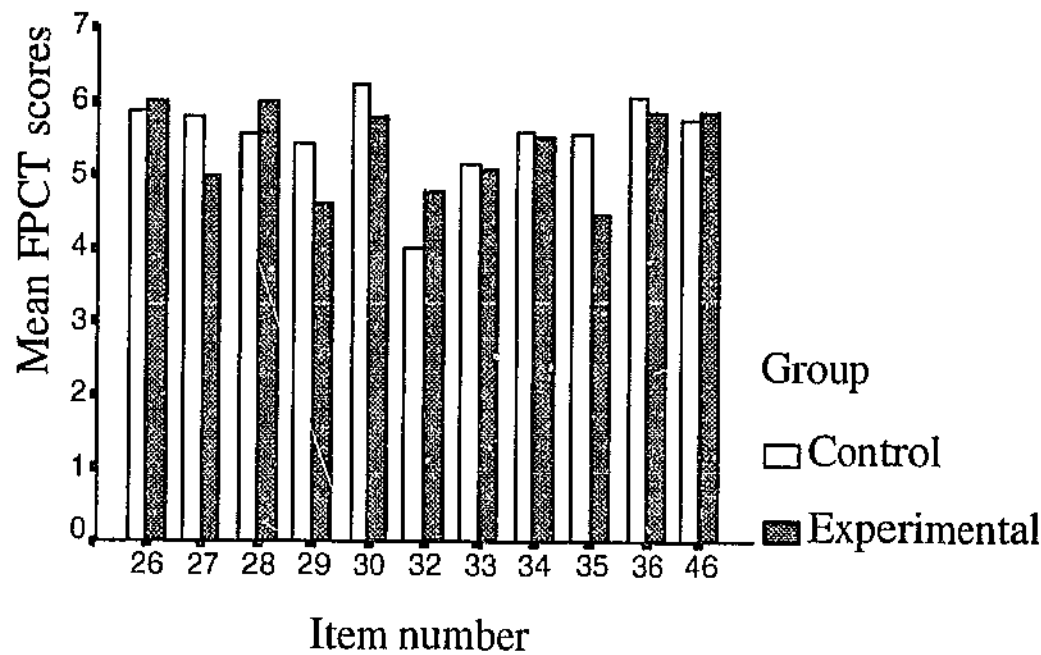
The fourth hypothesis was that former caregivers of nursing home residents who had been included in the PFIIC would report higher levels of satisfaction with the resident's environment than those who had not.

The movement in mean scores was in the predicted direction (Figure 11). In this ANCOVA satisfaction with the environment at Time 2 was the independent variable, scores at Time 1 being the covariate. As before, there was no significant difference shown between the groups,  $F(1,28) = .75, p = .39$ .

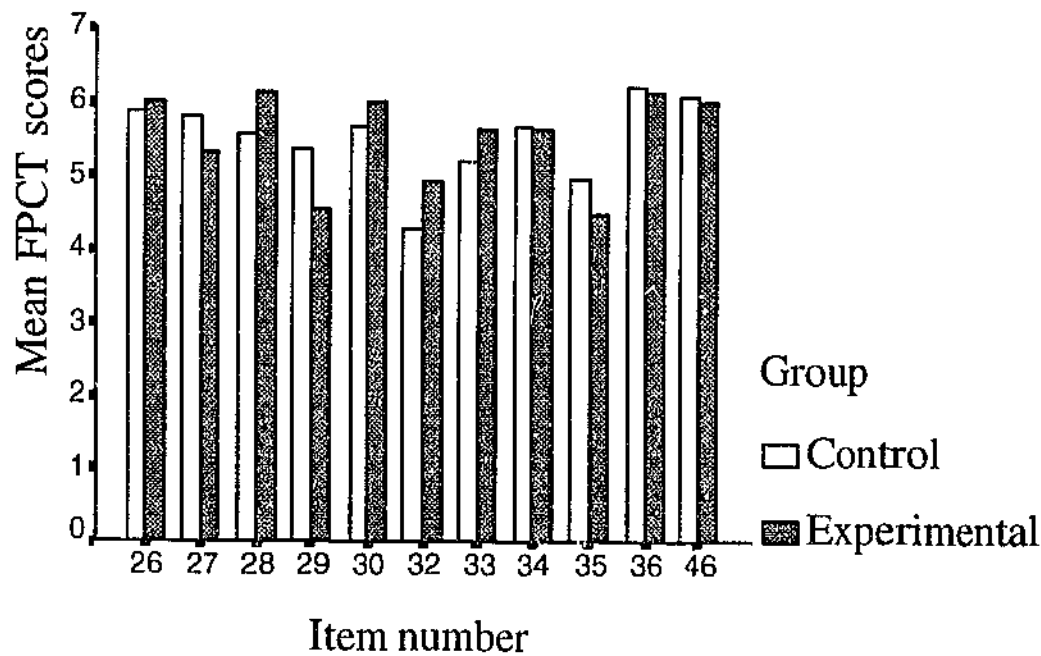


**Figure 11.** Comparison of means of "Satisfaction with the Environment" scale, by group, at Time 1 and Time 2.

Mean scores for each item remained similar in each group at Time 1 and at Time 2 (Figures 12 and 13). However, Item 32 (satisfaction with the number of staff to provide care) attracted a mean score of under 4 at one time.



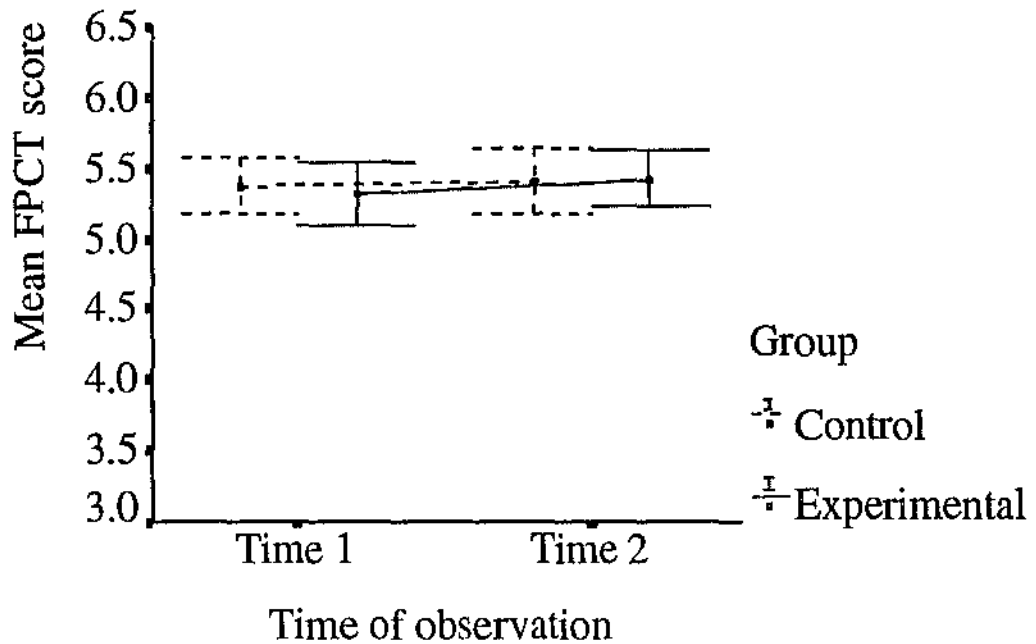
**Figure 12.** Comparison of mean FPCT scores for each item in the scale "Satisfaction with the Environment" at Time 1.



**Figure 13.** Comparison of mean FPCT scores for each item in the scale "Satisfaction with the Environment" at Time 2.

### Satisfaction with the Care Arrangement

Finally, total FPCT scores, indicating subjects' satisfaction with the care arrangement, were subjected to an ANCOVA. At Time 2 these were the dependent variable, and at Time 1 they were the covariate. Again, although the small change in total, mean scores of the FPCT was in the expected direction, no significant difference between the groups was detected,  $F(1,28) = .11$ ,  $p = .74$  (Figure 14).



**Figure 14.** Comparison of means of the total FPCT, by group, at Time 1 and Time 2.

### Summary

Using ANCOVA, no significant differences were found between the mean scores of the experimental group and of the control group for any of the dependent variables at Time 2 (controlling for scores at Time 1). Therefore, all the hypotheses were rejected. Similarly, using the total instrument, there was no significant difference found between the satisfaction with the care arrangement of the experimental group at Time 2 and that of the control group at Time 2 (controlling for scores at Time 1).

All the changes in satisfaction levels except that concerning satisfaction with overall care were in the directions predicted by the hypotheses, but, without exception, the changes were extremely small. The mean scores for each individual item in each group, at Time 1 and at Time 2, were also very similar.

### **Characteristics of the Experimental and Control Groups**

On the basis of the findings presented above, it appeared that the independent variable in this study (inclusion in the PFHC) had little impact on the dependent variables (aspects of the satisfaction of former caregivers with the care arrangement). However, levels of satisfaction may alter in response to numerous factors. For this reason, factors recognised as having the potential to act as extraneous variables were examined to see if they were distributed evenly in the two groups, as was expected since subjects had been randomly assigned.

These factors, which were also sample characteristics, were not tested for significant differences between the groups for the following reasons: the numbers of subjects in each group were low, which meant that the frequencies in many of the cells were too small for Chi Square analyses to be conducted; and at least 20 tests would have been required, so one or two would have shown significant differences by chance with an alpha level of .05. Data are displayed in tables to facilitate easy visual comparisons.

### **Participants' Relationships with Residents**

As shown in Table 6, all the former caregivers were relatives of residents, with 58.1% being sons and daughters. The most notable difference between the groups in respect of the relationships of subjects to residents was that the experimental group had 20% daughters and 40% sons, while the control group had 50% daughters and 6.3% sons. Over 90% of all participants had had contact with the care recipient at least weekly during the year prior to nursing home placement. Ninety three point five per cent of participants, at both Time 1 and Time 2, indicated that they felt either close or very close to their institutionalised relative (subjects rated their closeness to the resident on a scale of 1 = very close to 5 = not at all close).

**Table 6****Details of Participants' Relationships with Residents**

<b>Characteristic</b>	<b>Control group (<u>n</u> = 16)</b>	<b>Experimental group (<u>n</u> = 15)</b>	<b>Total sample (<u>N</u> = 31)</b>
<b>Relationship</b>			
<b>Son</b>	1 (6.3%)	6 (40%)	7 (22.6%)
<b>Daughter</b>	8 (50%)	3 (20%)	11 (35.5%)
<b>Husband</b>	4 (25%)	0 (0%)	4 (12.9%)
<b>Wife</b>	1 (6.3%)	3 (20%)	4 (12.9%)
<b>Sister</b>	1 (6.3%)	0 (0%)	1 (3.2%)
<b>Niece</b>	1 (6.3%)	2 (13.3%)	3 (9.7%)
<b>Brother-in-law</b>	0 (0%)	1 (6.7%)	1 (3.2%)
<b>Pre-placement contact</b>			
<b>Lived together</b>	8 (50%)	5 (33.3%)	13 (41.9%)
<b>Daily</b>	4 (25%)	3 (20%)	7 (22.6%)
<b>Weekly</b>	3 (18.8%)	5 (33.3%)	8 (25.8%)
<b>Fortnightly</b>	0 (0%)	2 (13.3%)	2 (6.5%)
<b>Monthly</b>	1 (3.2%)	0 (0%)	1 (3.2%)
<b>Closeness of relationship</b>			
<b>Time 1</b>	1.50 ( <u>SD</u> = .73)	1.67 ( <u>SD</u> = .49)	1.58 ( <u>SD</u> = .62)
<b>Time 2</b>	1.62 ( <u>SD</u> = .89)	1.60 ( <u>SD</u> = .51)	1.61 ( <u>SD</u> = .72)

**Note.** Means displayed for interval data, frequencies/ percentages for nominal data.

### **Caregiver Characteristics**

As seen in Table 7, experimental and control group members had about the same number of commitments. Those that were classified as "remaining" were mainly sporting activities. In the total sample only 22.6% had no other major commitments, 74.2% having from one to three. Health was reported to be good to very good in both groups (subjects rated their health on a scale of 1 = very good to 5 = very poor).

**Table 7**

### **Caregiver Characteristics of Participants**

Characteristic	Control group (n = 16)	Experimental group (n = 15)	Total sample (N = 31)
<b>Other commitments</b>			
Children	3 (18.8%)	4 (26.7%)	7 (22.6%)
Sick relative	4 (25.0%)	6 (40.0%)	10 (32.3%)
Employment	4 (25.0%)	7 (46.7%)	11 (35.5%)
Voluntary work	4 (25.0%)	4 (26.7%)	8 (25.8%)
Study	2 (12.5%)	1 (6.7%)	3 (9.7%)
Remaining	6 (37.5%)	3 (20%)	9 (29.0%)
Mean number	1.44 (SD = 1.15)	1.67 (SD = 1.23)	1.55 (SD = 1.18)
<b>Own health</b>			
Time 1	1.94 (SD = .77)	2.00 (SD = .76)	1.97 (SD = .75)
Time 2	2.00 (SD = .52)	2.00 (SD = 1.00)	2.00 (SD = .77)

**Note.** Means displayed for interval data, frequencies/percentages for nominal data.

### **Participants' Visiting Journeys**

As seen in Table 8, most subjects drove to the home with mean times of 27 minutes at Time 1 and 26 minutes at Time 2. The degree of difficulty experienced was fairly consistent (this was rated on a scale of 1 = very difficult to 5 = very easy).



Table 8

Details of Visiting Journeys of Participants

Characteristic	Control group ( <i>n</i> = 16)	Experimental group ( <i>n</i> = 15)	Total sample ( <i>N</i> = 31)
<b>Time taken<sup>a</sup></b>			
Time 1	32 ( <i>SD</i> = 34.50)	26 ( <i>SD</i> = 17.00)	27 ( <i>SD</i> = 27.16)
Time 2	25 ( <i>SD</i> = 13.95)	28 ( <i>SD</i> = 18.17)	26 ( <i>SD</i> = 15.93)
<b>Degree of difficulty</b>			
Time 1	4.13 ( <i>SD</i> = .81)	3.67 ( <i>SD</i> = .98)	3.90 ( <i>SD</i> = .91)
Time 2	3.81 ( <i>SD</i> = 1.05)	3.67 ( <i>SD</i> = .72)	3.74 ( <i>SD</i> = .89)
<b>Transport Time 1</b>			
Own car	11 (68.8%)	13 (86.7%)	24 (77.4%)
Public	2 (12.5%)	2 (13.3%)	4 (12.9%)
Walking	1 (6.3%)	0 (0%)	1 (3.2%)
Lifts	1 (6.3%)	0 (0%)	1 (3.2%)
Combined	1 (6.3%)	0 (0%)	1 (3.2%)
<b>Transport Time 2</b>			
Own car	11 (68.8%)	12 (80%)	23 (74.2%)
Public	2 (12.5%)	1 (6.7%)	3 (9.7%)
Walking	1 (6.3%)	0 (0%)	1 (3.2%)
Lifts	1 (6.3%)	0 (0%)	1 (3.2%)
Combined	1 (6.3%)	2 (13.3%)	3 (9.7%)

**Note.** Means displayed for interval data, frequencies/percentages for nominal data.

<sup>a</sup>To the nearest minute (one way).

### Resident Characteristics

Residents were aged between 62 and 96 years, were 58.1% female, and dementia affected 45.2% of them. Cerebro-vascular accidents (CVAs) had disabled 22.6% (more details in Appendix P). Some subjects could not tell residents' feelings about institutionalisation (rated from 1 = very happy to 5 = very unhappy) (Table 9).

**Table 9**

### Resident Details

Characteristic	Control group ( <i>n</i> = 16)	Experimental group ( <i>n</i> = 15)	Total sample ( <i>N</i> = 31)
Age <sup>a</sup>	79 ( <i>SD</i> = 8.85)	82 ( <i>SD</i> = 10.15)	80 ( <i>SD</i> = 9.5)
Gender			
Female	10 (62.5%)	8 (53.3%)	18 (58.1%)
Male	6 (37.5%)	7 (46.7%)	13 (41.9%)
Length of stay <sup>b</sup>	12 ( <i>SD</i> = 7.07)	10 ( <i>SD</i> = 7.26)	11 ( <i>SD</i> = 7.08)
Main disability/disease <sup>c</sup>			
Dementia	6 (37.5%)	8 (53.3%)	14 (45.2%)
CVA	4 (25.0%)	3 (20.0%)	7 (22.6%)
Other	6 (37.5%)	4 (26.7%)	10 (32.3%)
Feelings about institutionalisation			
Time 1	2.18 <sup>d</sup> ( <i>SD</i> = 1.80)	2.33 <sup>e</sup> ( <i>SD</i> = 1.35)	2.67 ( <i>SD</i> = 1.79)
Time 2	2.13 <sup>d</sup> ( <i>SD</i> = 1.50)	2.27 <sup>f</sup> ( <i>SD</i> = 1.34)	2.75 ( <i>SD</i> = 1.58)

**Note.** Means displayed for interval data, frequencies/percentages for nominal data.

<sup>a</sup>Age to nearest year. <sup>b</sup>Length of stay to nearest month. <sup>c</sup>changes in condition were evenly

distributed. <sup>d</sup>*n* = 12. <sup>e</sup>*n* = 14. <sup>f</sup>*n* = 13.

### **Summary**

Other than the distribution of sons and daughters, the overall characteristics of the experimental and control groups were similar. There were no major changes from Time 1 to Time 2. Therefore, from these data, it seems unlikely that the characteristics of the two groups had counteracted the effect of the intervention on the experimental group and accounted for the non significant findings.

#### **A Comparison: Those Choosing Extra Involvement and Those not**

All the members of the experimental group received the intervention, so they were all offered the choice of having extra input into their family members' care. However, only four of them chose to change their level of involvement. This may have impacted on the findings, and there may have been particular reasons for it occurring. Because of this, the characteristics and mean FPCT scores of subjects who chose extra involvement were compared with those of experimental group members who decided to continue with their existing level of input.

The characteristics of the two sub-groups of the experimental group, those choosing to have more involvement and those choosing not to, are detailed in Appendix Q. Tests for significant differences were not carried out on these data for the same reasons as those given when discussing sample characteristics, however, the following main points emerged: Experimental group members who chose to have more involvement had a lower mean age than that of the whole group; three of the four were sons, the other a daughter; and three had received post-secondary education. All reported having a close relationship with their family member, which became closer during the study. Their pre-admission contact had been at least weekly, they had a higher mean level of commitments than the rest of the group, and rated their health as a little better at Time 1 ( $M = 1.5$ ,  $SD = .6$ ) compared with others in the group ( $M = 2.2$ ,  $SD = .8$ ) (on a scale of 1 = very good to 5 = very poor). They tended to have the shortest and least difficult visiting journeys, and the residents related to them (three fathers and a mother, three having dementia), tended to be seen as less unhappy by Time 2. All were admitted 1 - 6 months before Time 1.

As shown in Table 10, for those in the experimental group who increased their involvement the mean satisfaction scores for every scale started lower than those of the rest of the group and increased during the study. Mean scores for the others in the group remained about the same. The significance of these changes was not tested because of the low numbers of subjects.

**Table 10**

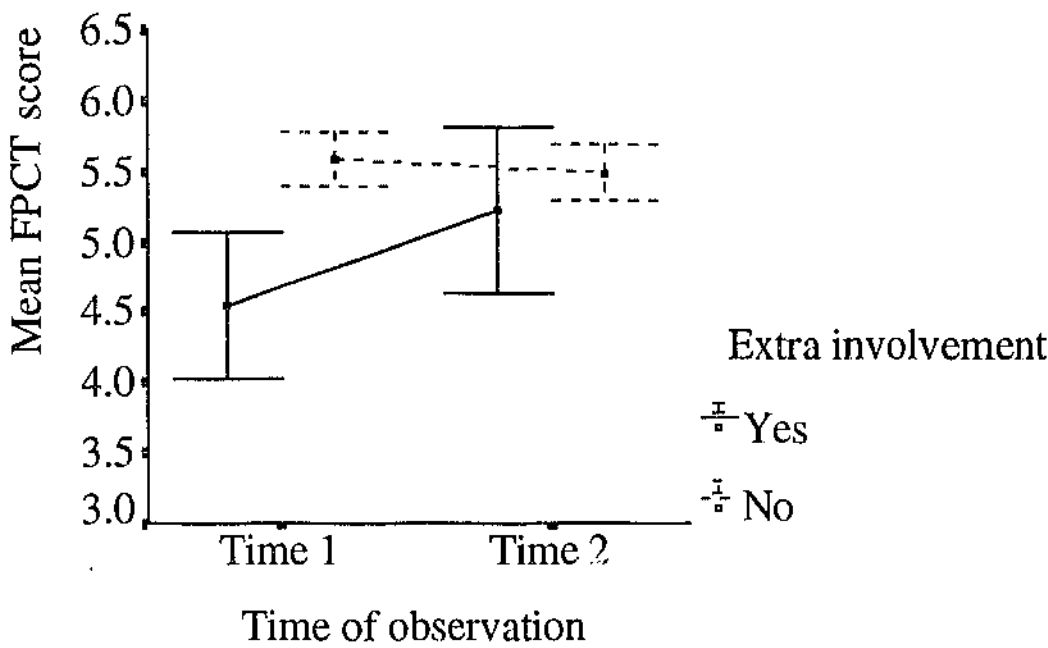
**FPCT Scores: Comparison of Those Choosing Extra Involvement with Those not**

<b>Scale</b>	<b>Those having extra involvement (n = 4)</b>	<b>Those having no extra involvement (n = 11)</b>	<b>Total experimental group (n = 15)</b>
<b>Overall care</b>			
<b>Time 1</b>	4.21 (SD = .84)	5.42 (SD = .59)	5.10 (SD = .84)
<b>Time 2</b>	4.87 (SD = .53)	5.07 (SD = .67)	5.02 (SD = .62)
<b>Nursing care</b>			
<b>Time 1</b>	5.09 (SD = 1.78)	6.11 (SD = .71)	5.84 (SD = 1.12)
<b>Time 2</b>	5.55 (SD = 1.53)	6.08 (SD = .66)	5.94 (SD = .93)
<b>Relationships</b>			
<b>Time 1</b>	4.42 (SD = .54)	5.55 (SD = .88)	5.25 (SD = .94)
<b>Time 2</b>	5.50 (SD = 1.27)	5.60 (SD = .91)	5.57 (SD = .97)
<b>Environment</b>			
<b>Time 1</b>	4.80 (SD = 1.73)	5.57 (SD = 1.05)	5.36 (SD = 1.25)
<b>Time 2</b>	5.25 (SD = 1.74)	5.63 (SD = .84)	5.53 (SD = 1.09)
<b>Total FPCT</b>			
<b>Time 1</b>	4.55 (SD = 1.05)	5.59 (SD = .63)	5.31 (SD = .86)
<b>Time 2</b>	5.23 (SD = 1.17)	5.49 (SD = .64)	5.42 (SD = .77)

In addition to the fact that three out of four people choosing to have more involvement were males, the males of the experimental group also had slightly lower FPCT scores at Time 1 ( $M = 4.9$ ,  $SD = .9$ ) than the females ( $M = 5.7$ ,  $SD = .7$ ).

The comparison of mean, total FPCT scores between those in the experimental group choosing to have extra involvement ( $n = 4$ ) and those in the same group choosing not to do so ( $n = 11$ ) is further illustrated in Figure 15. As before, error bars show one standard error of the mean on each side of the mean and the scale axis shows mean scores from 3.0 to 6.5 (FPCT questionnaire scores could range from 1 to 7). This is to aid comparisons with other figures.

Figure 15 shows that the mean, total FPCT scores of those choosing extra involvement rose from Time 1 to Time 2, but were lower than those of experimental group members not choosing more involvement at Time 1, and remained slightly lower.



**Figure 15.** Mean total FPCT scores in the experimental group: scores of those who chose extra involvement compared with scores of those who did not.

### **Summary**

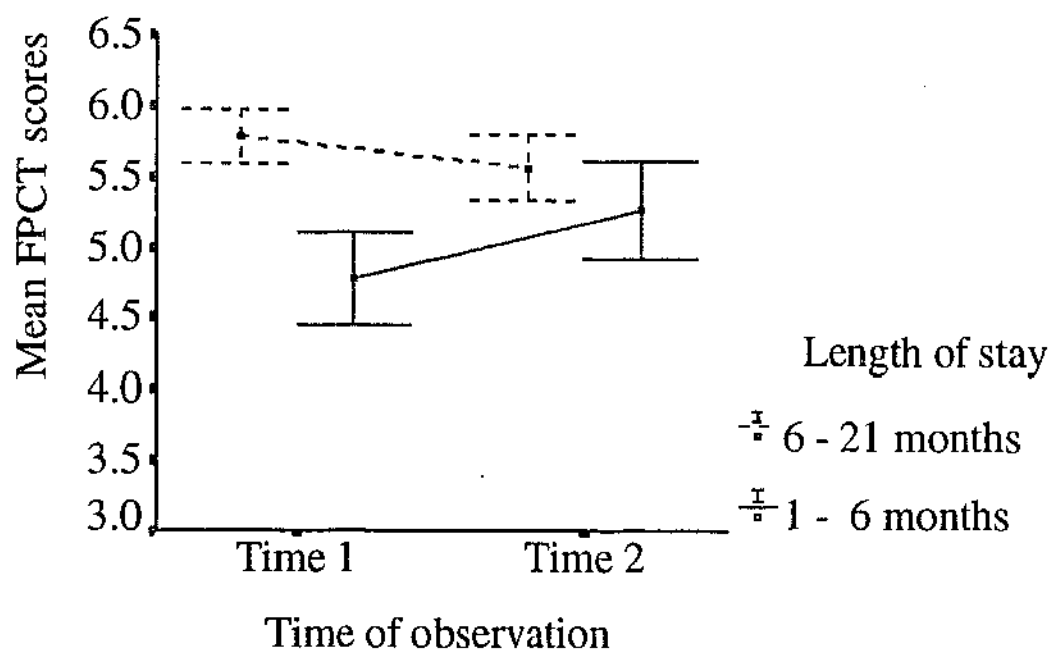
Those in the experimental group who increased their involvement with the care of the resident during the study also increased their FPCT scores, in all scales and in the total instrument, by a small amount, while those choosing to have no extra involvement did not. However, it was not appropriate to test for significance. In addition, those who chose to have extra involvement shared some common characteristics: all were sons and daughters whose family member had been admitted within the 6 months prior to the commencement of the study. They tended to have been a little better educated than others in the group, as well as younger and healthier. They also tended to have had shorter and easier visiting journeys and slightly more commitments. Moreover, they seemed to have become a little closer to the resident during the study, and to have believed that their relative had become a little less unhappy about institutionalisation.

### **The Impact of Recent Admission**

The literature suggests that relatives will need most help to adapt to the institutionalisation of their loved one in the months that follow admission (Buckwalter & Hall, 1987; Rosenthal & Dawson, 1991). In the current study, all those who chose to have extra involvement were related to residents who had been admitted within the last 6 months. These two factors suggested that the effect of the intervention may have depended upon the length of time since the placement of participants' relatives. Therefore, relevant data were examined in more detail. However, because of the varied impact of the ceiling effect, findings should be viewed with some caution: In the experimental group 45.1% of the responses of those with relatives admitted 6 to 24 months before the study were marked as "7" at Time 1, compared with 18.8% of those from participants with more recently admitted relatives. In the control group 35.2% of responses scored "7" at Time 1 when the length of stay was greater than 6 months, compared with 28.7% when the resident was placed more recently.

**Comparisons Within the Experimental Group**

Total FPCT scores of the seven experimental group members with relatives admitted within the last 6 months, including all four choosing extra involvement, were compared with those of the other group members. As shown in Figure 16, the mean score of those with recently admitted relatives rose ( $n = 7$ ), while that of the remainder of the group fell ( $n = 8$ ). The significance of this was not tested because of low numbers, but the changes were small. The mean score of those with recently admitted relatives was lower at both times.



**Figure 16.** FPCT scores (experimental group): Those whose relatives were admitted in the 6 months before the study compared with those whose relatives were admitted before this time.

It is realised that the above comparison confounds two variables, that of time since admission and that of choosing to have more involvement, since all those choosing extra involvement were in one sub group. This was felt to be appropriate in order to examine a possible effect of offering such an intervention only to those with recently admitted relatives. However, mean, total FPCT scores of experimental group

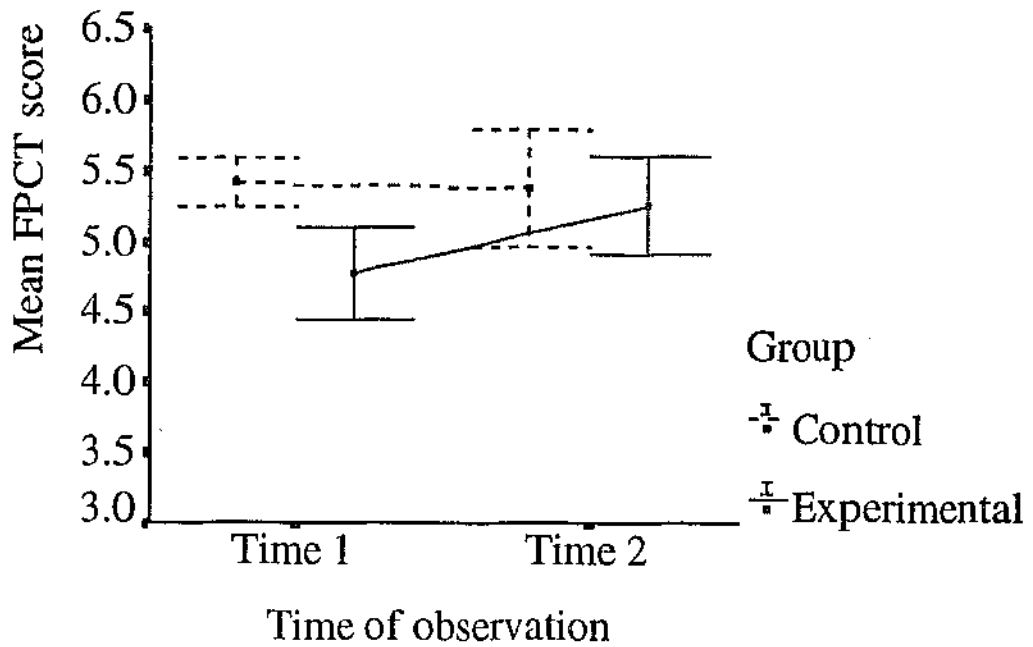
members who did not increase their involvement, but who were also related to residents admitted in the 6 months before the study, were also examined separately ( $n = 3$ ): These scores were seen to increase from Time 1 ( $M = 5.1$ ,  $SD = .7$ ) to Time 2 ( $M = 5.3$ ,  $SD = .7$ ). However, the increase for those choosing to have more input ( $n = 4$ ) was greater ( $M = 4.4$ ,  $SD = .5$  at Time 1; and  $M = 5.5$ ,  $SD = 1.3$  at Time 2).

### **Comparisons Between the Groups**

Finally, the mean, total FPCT scores of the seven experimental group members with family members admitted 1 - 6 months before the study were compared with those of the four control group members whose relatives were also admitted in that time. This last comparison was carried out in order to determine whether administering the PFHC to those with family members admitted in this timeframe had made a difference to their satisfaction levels that would not have occurred anyway, without the intervention.

As shown in Figure 17, mean total FPCT scores of participants in the experimental group whose relatives were admitted within 6 months of the commencement of the study ( $n = 7$ ) rose, while there was very little change in the mean scores of those in the control group ( $n = 4$ ). The mean score of those in the experimental group, despite rising, was the lower at both Time 1 and Time 2. The significance of the difference was again not tested because of the low subject numbers.





**Figure 17.** Mean total FPCT scores of those in the experimental and control groups whose relatives were admitted in the 6 months before the study.

### Summary

The scores of those in the experimental group whose relatives had been admitted within the past 6 months increased from Time 1 to Time 2: Of these people, those choosing not to have extra involvement ( $n = 3$ ) had very slightly increased satisfaction scores, while the scores of those choosing to increase their involvement rose more. Satisfaction scores of former caregivers in the experimental group whose relatives had been admitted from 6 to 24 months before the study had fallen very slightly, and those of control group members with relatives admitted from 1 to 6 months before the study had remained about the same. It must be noted that these results were not tested for significance, and have to be regarded with particular caution because of the varied impact of the ceiling effect.

### **Comments from FPCT Questionnaires**

With a single exception, the brief comments written on the FPCT questionnaires indicated dissatisfaction. One did state, "We are generally happy with our father's care". Only two specific topics (noted in the text) were addressed by more than one source. However, it became apparent that dissatisfaction was being expressed with three aspects of the nursing home: with the resources provided, the care of the resident, and the level of support and understanding for family members.

Regarding the quality and quantity of the resources provided for residents, three people stated that the meals were not of a sufficiently high standard, one cited a lack of cold water in the wards, and another indicated that the laundry process was too slow. Other comments were that there were too few nursing staff, and that their standard was variable. This was the comment referring to the latter issue: "There are some (few)!!! nursing staff, who, when I know they are on, I feel more assured that my mother's care and needs, and even wants are met". Two people referred to the shared rooms at the home: One stated, "There cannot be privacy in a ward, except for the pulling across of curtains for each patient at certain times", the other referred to the problem of odours in shared rooms.

Comments referring to dissatisfaction with resident care included: "Some physical defects are not noticed quickly, and relayed to the Dr hence a delay in effective physiotherapy, could be improved", and, "Few nurses give her the respect due and her dignity, as much as possible". The remaining statements referred to having to request extra input from staff (rather than it being offered) and to items going missing from the bedside, even when the resident was immobile.

Finally, the following comments concerned the way former caregivers considered themselves to be treated: One person said, "When his medication is changed we would appreciate it if this was discussed with some member of the family in the presence of the doctor and my father", and another stated both, "...sometimes incooperation of them [the staff] listening to family concerns, makes one feel very much out of control in the life of a loved one" and, "There is a quite, large degree of

lack of insight and understanding of staff in general to understand how a sudden chronic disability (ie stroke) can affect not only the patient, but family also. Stroke is very much a family illness and affects all members in varying degrees". Finally, one former caregiver, discussing the fact that relatives regularly take the resident out stated, "When we bring ... [him] back to the ward to be put to bed, we feel like we are nuisances because we have to pester the staff to do it for us".

There were two additional comments, but these referred to specific instances that might have identified the family member, so these have been omitted from this section.

### **Overall Summary**

From the 15 experimental group members included in the PFIIC, 4 chose to have additional involvement, mainly in planning and decision making, and 11 chose to continue with their present level of involvement. There was no evidence that the experimental group members, as a whole, became more satisfied with the care arrangement as a result of the intervention. There was an unequal distribution of sons and daughters in the control and experimental groups, however, other differences in the characteristics of the two groups did not appear to be so great that they might have accounted for the non significant findings. Those who chose to have more involvement had certain characteristics in common: They were younger, felt healthier, had slightly more commitments, and had shorter and less difficult visiting journeys than the others in the same group. Also, their relatives were all admitted within the 6 months before the study. The mean FPCT scores of those increasing their involvement increased from Time 1 to Time 2 in all scales, while those of others in the experimental group did not.

When the impact of recent admission was examined more closely, it was seen that the mean, total FPCT scores of all those in the experimental group with relatives admitted from 1 to 6 months before the study ( $n = 7$ ) rose, the scores of those increasing their involvement rising more than the scores of those choosing not to do this. Also, mean, total scores of experimental group members whose relatives were admitted from 6 - 24 months before the study ( $n = 8$ ) fell very slightly, and those of

control group members with relatives admitted 1 - 6 months before the study ( $n = 4$ ) remained about the same. However, these particular findings must be viewed with caution. This is because it was not appropriate to carry out tests for significance on these data, and because there was evidence of a ceiling effect (which could not be counteracted by the use of ANCOVAs), particularly in the scores of former caregivers whose relatives had been in the nursing home for more than 6 months.

Finally, comments from the FPCTs indicated that former caregivers were concerned about the provision of resources within the home, the care of residents, and the way family members were treated.

## **CHAPTER V1**

### **Discussion**

This chapter evaluates and interprets the findings of the study: Results of hypothesis testing are addressed with particular reference to the size of the sample, the possible impact of extraneous variables, and any variation in the effect of the intervention. The PFIIC is then evaluated, and, finally, the strengths and limitations of the study are summarised.

### **Introduction**

The framework, with reference to Roy (1984, 1989), proposed that nurses would show former caregivers that they could choose to play whichever role they wished in the care of their loved one: They could elect to have no involvement, or they could choose virtually any area and level of participation. Since a lack of control over the care situation has repeatedly been shown to be a problem for family members of the institutionalised (Brody et al., 1990; Johnson, 1989; Mathew et al., 1990), and those who cared for their loved ones at home may also experience this as a significant loss, inclusion in the PFIIC was aimed at restoring control to former caregivers. In addition, it allowed them to give input that might decrease other aspects of their emotional distress: They might not only feel less powerless, but less guilty and angry as well. In this way, administering the PFIIC was congruent with Roy's view of the role of the nurse, who may manipulate environmental stimuli, or may encourage clients to do this, so that such stimuli will fall within their range of effective coping. Adaptation is brought about by effective coping.

In the current study, it was anticipated that adaptation would be manifested by increased satisfaction with the care arrangement: with overall care; physical nursing care; relationships among staff, residents, and relatives; and the environment. It was, therefore, hypothesised that former caregivers included in the PFIIC would have increased satisfaction with the care of their relative, whether or not they chose to have extra involvement.

### **Results of Hypothesis Testing**

In fact, the study produced no statistically significant findings to substantiate the hypotheses. This contrasts with the results of Buckwalter et al. (1991), which showed that relatives having extra involvement in a particular programme of resident care did report increased satisfaction with the care arrangement. However, in that study, the intervention was notably different from the PFIIC (this will be discussed later); satisfaction scores were reported for a group of family members who had all increased their involvement, which was not the case in the current study; and the intervention was implemented over a longer period of time.

The fact that the hypotheses were unsupported suggests that inclusion in the PFIIC did not aid adaptation. However, before this conclusion may be drawn, the effects of the sample size, extraneous variables, and any variation in the impact of the intervention must be considered, since these factors may have contributed to the non significant findings.

### **The Size of the Sample**

The small sample size made it more likely that an existing effect on former caregivers' satisfaction of their inclusion in the PFIIC would be found to be insignificant (a Type II error). One way to augment the sample size would have been to include former caregivers of residents admitted more than 2 years before the study, however, this would have been inappropriate because the intervention was designed to aid adaptation to a relatively new situation. There were a number of other constraints that led to the use of a small sample: Firstly, the researcher could access only one nursing home, so the size of the sampling frame could not be increased. Secondly, limitations on time precluded the use of a longitudinal study, where a larger sample of family members related to recently admitted residents could have been obtained over a period of years. Finally, the unusual consent process may have impacted on sample size because it required an additional step to obtain either the consent of residents or consent given on their behalf (by proxy). This process is

discussed in more detail in order to consider whether it was essential and whether it did impact on sample size.

When obtaining resident consents, eight residents who were asked to nominate a former caregiver to take part were definite that they did not wish to do so. Some of these people may have chosen to be admitted to a nursing home specifically because they did not wish to be cared for by family members. However, a few residents may have refused their consent because they believed that their former caregiver would refuse to participate anyway, since the response rate of this group of former caregivers was unexpectedly high (85.7%). Consequently, this procedure provided essential protection for residents by ensuring that their right to freedom of choice was upheld, but it probably did not limit the sample size to any great degree.

When obtaining proxy consents, it was seen that the proxy consent process was an imperfect method of ensuring that residents' wishes would be followed. This was because it relied on family members being both aware of those wishes and prepared to act upon them. However, it did protect the resident to the extent that relatives' knowledge of particular reasons for excluding former caregivers from the care process could be acted upon without question, and, unbeknown to the researcher, this may have occurred. It was essential to have such a safeguard because a history of elder abuse may have existed that was only known to family members. The effect of the proxy consent process on the response rate is difficult to assess: All of the nominated former caregivers agreed to participate, but only 53.3% of the requested proxy consents were obtained and no refusals were said to be on behalf of the resident. The communication between family members that was a necessary part of the process may have been so difficult to achieve that some potential participants were never nominated. Therefore, the obtaining of proxy consents offered essential protection to residents, but it was likely to have limited the sample size.

In summary, the lack of access to a wider population of nursing home residents and limitations on the time available for this study definitely limited the sample size.

Also, although it was ethically essential, the use of the proxy consent process probably restricted it further.

In addition to increasing the likelihood of a Type II error, the small sample size may have accounted for the fact that the experimental and control groups were not entirely equivalent. Whether differences between the groups acted as extraneous variables will now be examined.

### **Recognised Extraneous Variables**

A number of characteristics of experimental and control group members had been recognised as having the potential to act as extraneous variables during the study. Consequently, the demographic questionnaires were designed to obtain relevant information. From this information, there was no evidence of any major change in group characteristics, from Time 1 to Time 2, that might have impacted on satisfaction. Also, the groups were seen to be similar in most respects. However, the distribution of sons and daughters varied considerably: There were more sons in the experimental group (40%) than in the control group (6%), and more daughters in the control group (50%) than in the experimental group (20%).

This difference between the groups was not one that would obviously have impacted directly on the findings, since offering extra input into caregiving is not known to affect satisfaction differently in sons and daughters. However, there may have been an indirect effect: Firstly, the imbalance might have accounted for the fact that no one chose to have extra involvement in "hands on care". In support of this, Brody et al. (1990) found that daughters, to a greater extent than sons, became less depressed when involved in the physical tasks of institutional caregiving. Secondly, since females have traditionally had the greater association with caring and nurturing in our culture, the lack of daughters in the experimental group may have impacted on the number of subjects choosing to increase their involvement in any aspect of care. This number was low, and may have had a more direct bearing on the results of the study.



In summary, therefore, there was no direct effect of recognised extraneous variables that might have accounted for the non significant findings of the study. However, the imbalance between the groups might have had a bearing on the particular type of input that was chosen, and it may have impacted on the findings of the study by influencing the number of people choosing extra involvement.

### **The Variation in the Effect of the Intervention**

A variation in the effect of the intervention was indicated by the fact that only four people chose to increase their involvement, that these people had certain characteristics in common, and that their levels of satisfaction tended to rise during the study by more than those of others in the group. Neither the lack of demand for extra involvement nor the varied impact on satisfaction of inclusion in the PFIIC was anticipated. This was because the premise of the study was that former caregivers, overall, did want more control over institutional caregiving, and that their adaptation would be promoted by the opportunity for them to have this control, rather than by the choices that they made. In an attempt to understand these findings, the characteristics held in common by those choosing more involvement are discussed. The length of time since admission appears to have been a factor of particular relevance to the variation in effect of the intervention. It is, therefore, considered separately and in detail.

**Characteristics of those choosing more involvement.** Those who chose to have extra involvement had characteristics in common that seemed to fall into three, main categories. Firstly, they were all adult children of residents, they tended to have shorter and easier visiting journeys, to be younger and feel healthier, and to have had a higher level of education. They also had more commitments, which probably reflected the level of their energy. Therefore, these appeared to be people who had reason to be confident that they had the ability to increase their involvement in their family members' care.

Secondly, those who chose to have more input tended to believe that their family members were less happy than those related to other group members. Moreover,

three out of four were males, and the males in the experimental group were less satisfied with care at Time 1 than the females. It seems, therefore, that these were people who were particularly unhappy with the existing situation.

Thirdly, three of the four residents related to those former caregivers who increased their involvement suffered from Alzheimer's Disease (AD), and all were admitted in the 6 months before the study. While the recent relinquishing of control over the care of a relative may mean that feelings of powerlessness are at their height, they are also likely to be greatest when the level of input has been high prior to admission. This is likely to occur when the care recipient has AD, since those afflicted with this disease generally require a gradually increasing level of input into care over a period of years. In contrast, former caregivers of those institutionalised as a result of a sudden, catastrophic incident (such as a CVA) may have had minimal involvement in care prior to institutionalisation, even when living with the care recipient. The people electing to have more input, therefore, seemed to be those who were likely to be feeling the most powerless.

Therefore, the number of people choosing extra involvement appeared to be limited by the perceptions of family members as to whether they were able to participate any further in care, and by the extent of their motivation to do this. Incentives appeared to relate to dissatisfaction with the existing situation and to feelings of powerlessness. Powerlessness is said to be a problem in the self-concept mode (Roy, 1984), so perhaps the PFIC promotes adaptation in this mode.

**The length of time since admission.** The variation in the impact of the intervention seems to have been particularly related to the length of time since admission, because all those who chose to have more involvement had relatives who were admitted in the 6 months before the study, and because the satisfaction levels of those choosing to have extra input rose the most. Therefore, the intervention may have tended to aid the adaptation of former caregivers in the early months after the placement. In the following discussion only those residents admitted from 1 to 6 months before the study are considered to have been "recently admitted".

The satisfaction levels of those in the experimental group with recently admitted relatives rose, while those of others in the group were already high (as indicated, particularly, by the ceiling effect in their FPCT scores at Time 1) and these fell very slightly. The fall may have reflected an unsettling effect of the intervention on those who had already adapted, some of whom may have withdrawn from the resident. However, it cannot be assumed that the increased satisfaction levels of those with recently admitted relatives indicated adaptation. This is because the increase that occurred in those increasing their involvement (four of the seven people whose relatives were recently admitted) may, instead, have been a sign that former caregivers believed their input to have improved care. Moreover, any results concerning satisfaction that are not related to hypothesis testing have to be regarded with caution in view of the low numbers, lack of significance testing, and the ceiling effect which could not be countered by the use of an ANCOVA. The change in scores, therefore, may have only been due to random fluctuation over time.

While the satisfaction scores of the three experimental group members with recently admitted relatives who chose not to increase their involvement had risen (although not by as much as the scores of those choosing extra involvement), this was only a very small indication that, perhaps, adaptation was aided by the intervention in these people.

**Sub-summary.** Therefore, in summary, it seems that the choice of extra involvement was limited to those who felt able to have more input and who had particular incentives to do this. These people tended, in particular, to have been those with recently admitted relatives. The satisfaction scores of experimental group members with recently admitted relatives rose, while those of others in the group fell by a very small amount. In addition, the satisfaction scores of control group members with recently admitted relatives remained about the same. Because of this, it seems that the intervention tended to have a varied effect on the satisfaction of former caregivers with the care situation: It only impacted on the scores of those with recently admitted relatives. However, it is not possible to be sure that the increases in

satisfaction levels (which were not shown to be significant) were due to adaptation because two variables were confounded: receipt of the intervention and the choice to increase involvement.

### **Summary**

Although the intervention did not have a significant effect on the satisfaction scores of the experimental group as a whole, this may have been influenced, in part, by the small sample size and by the fact that any effect seems to have been limited to those with recently admitted relatives. Indirectly, the non equivalence of the groups in one respect may have had an additional impact on the findings. The intervention seems to have increased the satisfaction with the care arrangement of a few people, possibly because it aided in their adaptation. There may well be changes that could be made to the PFIIC to make it more effective. Therefore, the intervention will be evaluated in the following section.

### **Evaluation of the PFIIC**

In evaluating the Programme Facilitating Increased Involvement in Caregiving it was necessary to discuss the range of choices that it offered, the need for former caregiver education, and the role of the liaison person. Finally, suggestions are made for its improvement.

### **The Range of Choices**

The PFIIC differed from the intervention offered by Buckwalter et al. (1991) in that it did not offer one particular type of involvement, but a range of choices. The authors of the former study did not indicate the response rates of family members in either of the two reports of their study (Buckwalter et al., 1991; Buckwalter, Cusack, Sidles, Wadle, & Beaver, 1989), so direct comparisons cannot be made. It is possible, however, that one reason for so few people choosing extra involvement in the current study was the daunting prospect of considering so many options. This may reflect the problem of role ambiguity that was described by Johnson (1989) and Matthiesen (1989).

In practice, the majority of those wanting extra involvement chose to have more input into planning and decision making. This ratifies the recommendation of Brody (1985), that relatives should be allowed to continue their community role as collaborators in decision making, and that of Buckwalter and Hall (1987), that joint care planning should be facilitated to allow family members to retain some control over caregiving. In the current study, offering a programme of weekly contact sessions with staff would have met most of the demonstrated demand for extra involvement, and may have generated more because of its specificity. However, owing to the dearth of empirical evidence in the area, this would not have been appropriate. Offering a range of options ensured that the preferred choice for any particular subject was likely to be included. Moreover, former caregivers' control over the situation was enhanced by their being given the right to choose.

The choices that they made from the range of options may well have been affected by the setting. In particular, the lack of people wishing to be involved in assistance with the activities of daily living may have resulted from the institutional environment: It is difficult to discover the location of bathrooms, for example, in such a setting. Furthermore, family members cannot be assured of privacy to help their relatives to wash and dress in six bedded rooms with curtains for screening, and they may be equally as concerned that they might invade the privacy of others. The trend for homelike environments in nursing homes may mean that former caregivers will become more enthusiastic about continuing their "hands on" involvement.

In summary, it was not appropriate, in this study, to limit the range of options available to former caregivers, even though this might have led to more people electing to increase their caregiving input. The fact that those who chose to have more involvement did so in the areas of planning and decision making, in preference to that of "hands on care", may have been influenced, in part, by the environment.

### **The Need for Former Caregiver Education**

Enthusiasm for increased involvement, moreover, may have been lacking in this study because former caregiver education was not included in the programme. It became evident that there was a lack of understanding about the effectiveness of the "extra care" strategies that were suggested. One response, "but it's no use doing anything extra with him - he doesn't know what is going on", was echoed by many. Education strategies about the benefits of specific interventions, such as music or touch therapy, might have led to a more realistic perception of the roles that could have been played. Interest might have been stimulated, and confirmation given that the time spent was of value to the resident.

In addition, ensuring that former caregivers were aware of the care already provided by nursing home staff might, in itself, have improved their satisfaction. Their lack of knowledge of the input of some allied health professionals, seen in this study, may have led them to believe that their family members had inadequate care.

Therefore, a lack of former caregiver education in the PFIIC may have limited the impact of the intervention on satisfaction and the numbers of those choosing more input.

### **The Liaison Person**

Liaison people were included in the programme to aid in the facilitation of extra involvement. Their use in institutional settings was suggested in the literature (Buckwalter & Hall, 1987; Matthiesen, 1989). In the current study, experimental group members were not asked to comment on the role of the liaison person. However, spontaneously, many of them told the researcher that it was a comfort to know that a specific and unchanging person was regularly available to them.

In addition, the liaison people of relatives who chose to have more involvement indicated that they found their relationship rewarding, and that knowledge was gained about resident preferences. This has implications for the personalising of resident care, and the provision of "preservative care" (that care which preserves the individuality of the resident) as described by Bowers (1988).

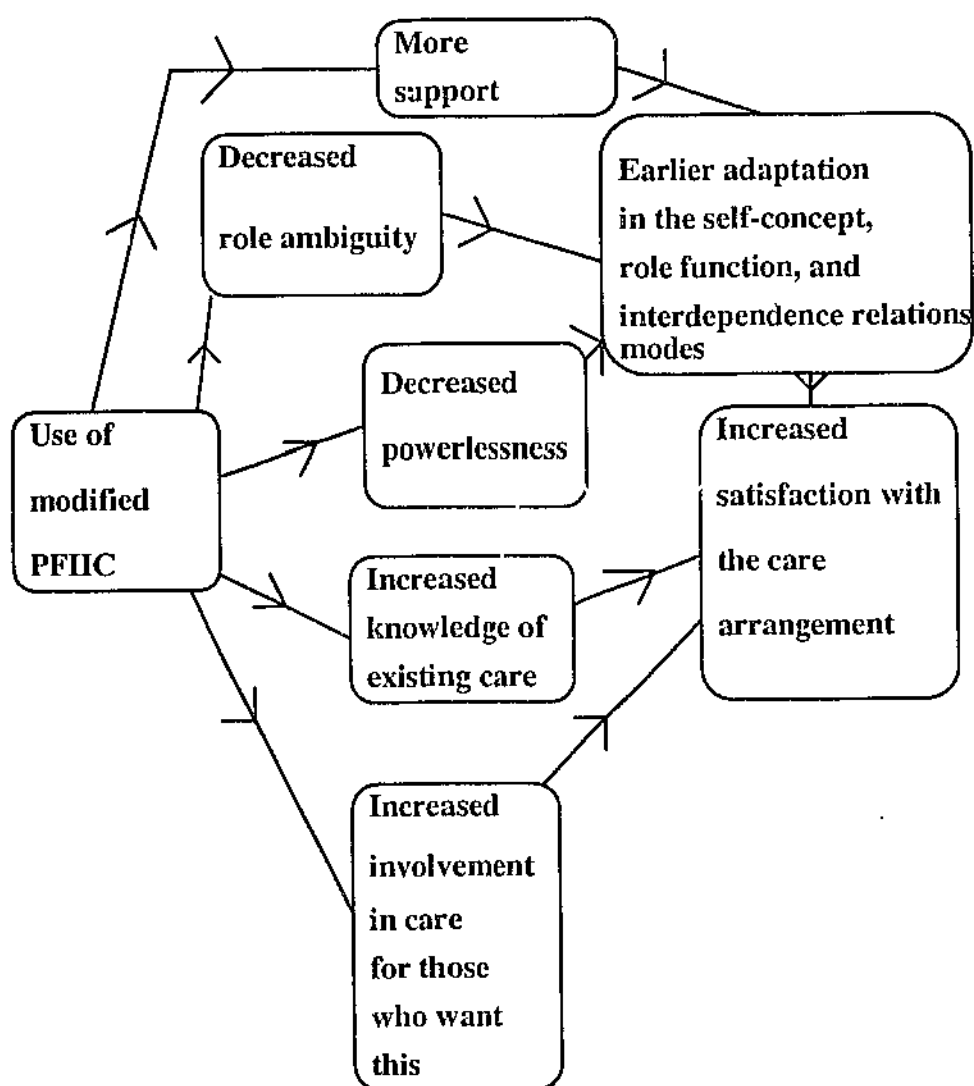
Liaison people were generally disappointed if they were not utilised by relatives, and valued the time spent communicating with them. One RN commented, "This is what we should be doing all the time, anyway. It's an important part of our job". The CNs remarked that their role often did, already, include liaising with relatives. The ENs, however, found it difficult to meet their expectations: They stated that relatives would talk things over with them, but would bypass them in favour of the RN on duty if they wanted either clinical input or a decision as to whether a certain type of involvement might be appropriate. One EN stated that she really wanted to be a good liaison person, but that more backing from senior ward staff would be needed for this to be achieved.

Therefore, in summary, anecdotal evidence indicated that the role of the liaison person was of value to former caregivers. It appears that family members were comforted by the knowledge that it would be easier to have some input into the care of the resident. Introducing the role of a liaison person also had benefits for staff (of increased job satisfaction), and for residents (because it made it more likely that personalised care would be given). Liaison people would undoubtedly be retained in an improved PFIIC, but a number of other changes could make it more effective.

### **Suggestions for Improvement of the PFIIC**

Ideally, improvements to the PFIIC would make it more effective in aiding adaptation. The existing PFIIC addressed the feelings of powerlessness of former caregivers by facilitating a chosen level and type of input into caregiving using the allocation of liaison people. It may be possible to ensure that the programme will also address role ambiguity. This could be done by only offering those choices of extra input which are of relevance to the resident in question, and by helping former caregivers to appreciate the value of "extra care" by adding an educational perspective to the programme. Furthermore, liaison people might be able to offer additional support to former caregivers if they become sensitised to the feelings of friends and family members at the time of admission. In this way, the PFIIC could aid adaptation in three of the modes described by Roy (1989): the role function mode, by

addressing role ambiguity; the interdependence relations mode, by offering support to former caregivers; and the self-concept mode, which it may address already by diminishing feelings of powerlessness. A modified PFIC also has the potential to increase satisfaction with the care arrangement as the result of providing more information about the existing care of the resident. In addition, as seen in this study, the increased involvement in care of former caregivers may result in their perceiving that care has been improved (Figure 18).



**Figure 18.** Conceptualisation of ways in which a modified PFIC may increase the satisfaction with the care arrangement of former caregivers whose relative has been institutionalised (adapted from Roy, 1989).



It is believed that the PFIIC, in this way, could aid the adaptation of former caregivers so that it occurs sooner, and includes less likelihood of their withdrawing from the resident. Adaptation will probably occur anyway over time. However, even former caregivers who have had time to adapt to the new care situation might decide that they would like to increase their involvement, or they might be unaware of some aspects of the care provided by the institution. As a result, their satisfaction might still be increased by inclusion in a modified PFIIC.

Therefore, an improved programme might aid in the adaptation of former caregivers in three of the modes described by Roy (1989): the self-concept, role function, and interdependence relations modes. It also has the potential to increase satisfaction with the care arrangement by increasing the knowledge of existing care, and by offering increased input into care that might improve that care. Its use, therefore, need not only benefit those who have not, yet, adapted.

### **Summary**

In summary, the wide range of choices and the lack of former caregiver education included in the PFIIC may have limited the number of people choosing to have more involvement in care, but the use of liaison people allowed them to increase their input easily, and was a major factor in offering these people more control over caregiving. An improved PFIIC, including only appropriate choices, as well as an educational perspective, would retain the liaison person. Such a programme has the potential to address role ambiguity and the need for support of former caregivers, in addition to powerlessness. In this way, it might be more effective in ensuring that adaptation occurs more quickly and is less likely to include withdrawing from the resident. It might also increase the satisfaction with the care arrangement of those who have already adapted.

### **Strengths of the Study**

This study utilised a design that controlled some of the effects of possible extraneous variables by random assignment to a control and an experimental group. Moreover, because of the data collected, it was possible to identify areas in which this form of control had not been successful. In addition, stratification of the random assignment process was included: This ensured that, if there were two distinctly different types of former caregivers included in the study, they would be evenly distributed between the two groups.

This study was also ethically sound: In addition to the standard procedures, such as ensuring anonymity, the consent process both recognised the vulnerability of the residents, and sought to avoid a paternalistic approach which might have assumed that all residents would want family member involvement in their care. Moreover, it was recognised that the former caregivers were also in a vulnerable situation. For this reason in particular, none were approached during the first month after the placement, and the crucial element of free choice was included in the PFIIC.

The use of the FPCT questionnaire also enabled areas of dissatisfaction with care within the nursing home to be identified, so that they might be addressed. It also revealed a widespread lack of knowledge, on the part of former caregivers, of the input into care of a number of health professionals. This can now be remedied.

### **Limitations of the Study**

The generalisability of the findings of this study is limited because it was not possible for the researcher to select the sample, randomly, from all the nursing homes in Western Australia. Instead, a convenience sample from one nursing home was used. It is also limited by the fact that the sample was small, particularly since those in the experimental group who chose to have extra involvement formed such a tiny sub-group. In addition, the small sample would have accounted for the fact that random assignment did not result in equivalent groups.

While the proxy consent process probably limited sample size, the design of the PFIIC, inclusion in which was the independent variable, may have limited the numbers

of experimental group members choosing to have more involvement. This was because it presented such a large range of choices, and offered no education about the benefits of these. In addition, it seems that the PFIC was administered to a number of people who may not have been in a position to gain the most benefit from it: those who had already adapted.

Time constraints, because of pending changes at the home, limited the study period. This made it less likely that a significant result could be obtained, although trends could still be examined. Buckwalter et al. (1991) obtained evidence of a significant increase in relatives' satisfaction, after increasing their involvement, over a 3 month period. This amount of time was not available for the current study.

Buckwalter et al. (1991) also used an earlier version of the FPCT. While the use of the updated FPCT in the current study had some benefits, it also had drawbacks: Firstly, although satisfaction was being measured as an indication of adaptation, it also measured changes in satisfaction brought about by relatives' increased involvement in care. This meant that two variables were confounded: The effect on satisfaction of increasing involvement could not be distinguished from the effect on satisfaction of being offered extra involvement. Secondly, the ceiling effect made it more difficult to evaluate any effect on satisfaction in small groups of subjects (where an ANCOVA could not be used).

There are a number of ways in which these limitations could be avoided in future, similar studies. These will be addressed in the following chapter.

## CHAPTER VI

### Conclusions, Implications, and Recommendations

Inclusion in the Programme Facilitating Increased Involvement in Caregiving was not seen to have a significant effect on the satisfaction with care of the members of the experimental group as a whole. There were, however, indications that the intervention tended to have increased satisfaction in a few participants. Had there been a longer study period or, particularly, a larger sample that included more people choosing extra involvement, the findings might have been different.

Those four experimental group members, in the current study, who elected to have more involvement appeared to have had particular incentives to resume some caregiving control, and to be those who would feel confident of their ability to do this. In addition, they appeared to have become more satisfied with the care arrangement during the study, however, significance tests were precluded because of the small number of subjects. All of these people had relatives admitted in the 6 months before the study.

When examining the impact of the intervention on all those experimental group members with relatives admitted in the 6 months before the study, two variables were confounded: the effect of inclusion in the PFIIC (on all seven people) and that of having extra involvement in caregiving (on four of them). Therefore, it was impossible to say if the intervention had aided their adaptation, even though their levels of satisfaction with the care arrangement had increased a little. Instead, some of these former caregivers might have perceived that their input had improved care. However, the satisfaction scores of the three people whose relatives were admitted within the 6 months before the study, but who did not increase their involvement, had also increased, although by a lesser amount. This was a very slight indication that adaptation might have been aided in these people.

If adaptation was aided by the programme, it was likely to have been because it addressed the feelings of powerlessness of those with recently admitted relatives. However, the PFIIC could be refined so that it would also address role ambiguity, by

offering more limited choices of input that are both appropriate to the individual and backed by educational strategies, and by utilising liaison people specifically to provide support for former caregivers. Such a modified programme, therefore, could aid former caregiver adaptation more effectively. It might also lead to greater former caregiver involvement. Although adaptation is believed to occur anyway, over time, an improved PFIIC might both hasten this, and ensure that it is less likely to include withdrawal from the resident.

The findings of the study have implications for nursing practice, education, and research. Those for education and practice mainly follow from the fact that a demand for increased input into caregiving was seen to exist, that this was almost exclusively in the area of planning and decision making, and that it came only from those former caregivers whose relatives had been recently admitted.

With reference to nursing practice, it is recommended that one change is made without waiting for the results of additional research: that of the introduction of liaison people into nursing homes. This could facilitate input into planning and decision making, and might, therefore, address the feelings of loss of control of former caregivers. In addition, the job satisfaction of the nurses chosen to fulfil the new roles would probably be increased, and resident care enhanced (if the strategy resulted in extra family member involvement).

Such liaison people could be assigned to family members on admission, since the greatest need appears to be in the early months after the placement, and remain available indefinitely. These nurses would need to be expert practitioners with a depth of knowledge about the feelings of family members, and about the types of extra input that would benefit each, individual resident. They would then have the potential to offer support to relatives, and to ensure that they were aware of the different roles that they could assume. The introduction of liaison people into nursing homes might aid the adaptation of relatives, particularly those who are former caregivers, to the altered care situation. It is certain that it would be a first step towards collaborative

care: that care which has the potential to break down the barriers between the institution and the "outside world". For this reason alone it would be worth doing.

In the area of education, there are implications for the education of former caregivers and for that of staff. Initially, it needs to be ensured that former caregivers understand the work of the various health professionals who care for their loved ones, and become aware of the potential benefits of appropriate care strategies (in which they might wish to become involved). It is clear that the ideal staff to provide this education would be liaison people. For this to occur, most of these nurses would need to further develop their own knowledge and skills. Moreover, even if liaison people did not take on an educational role, they would need to be highly skilled and educated in order to be effective in their support of former caregivers. There are existing programmes that could be utilised in order to meet the evident need for nurse education. Cost, however, is bound to be a deterrent in view of the existing funding restrictions.

Finally, because the findings of this study were not conclusive and have limited generalisability, further research is strongly indicated. The current study could best be regarded as a pilot for a further experimental study, ideally utilising a sample of former caregivers randomly selected from all the nursing homes in the region, and using a modified PFIIC. In addition, the sample should be much larger and composed of friends and relatives of more recently admitted residents, since they seem more likely to benefit from the intervention. Since the impact of the programme may increase over time, it is suggested that the ideal situation would be to conduct the pre-test about a month after admission, when relatives have had time to make an assessment of the home and to recover from the acute crisis brought about by the placement. The programme could be implemented over the next 5 months, then the post test conducted. If such studies with larger samples were to be carried out, it would also be possible to assess whether gender dictated the amount or type of extra involvement desired.

Furthermore, while, in the current study, measuring satisfaction has proved to be useful for assessing perceptions of care within the nursing home so that areas of dissatisfaction can be addressed, it has been seen to be less than ideal as an indicator of adaptation in such a study. Measuring adaptation directly would appear to be more appropriate, although this might require the development of a specific instrument. Alternatively, measurement of satisfaction with the care arrangement might be considered to be a relevant strategy to assess the effectiveness of "customer" service.

It would also be valuable to empirically measure the benefits for staff of a collaborative relationship with former caregivers, and those for residents of having input from friends or family members into their care.

In summary, because of the inconclusive findings of this study there are strong indications for further research. In addition, the study has led to a number of recommendations for education and nursing practice, the main one being for the introduction of highly skilled and educated liaison people into nursing homes.

## References

- Anderson, K. H., Hobson, A., Steiner, P. & Rodol, B. (1992). Patients with dementia: Involving families to maximize nursing care. Journal of Gerontological Nursing, 18(7), 19-25.
- Bowers, B. J. (1988). Family perceptions of care in a nursing home. The Gerontologist, 28, 361-368.
- Brody, E. M. (1985). The role of the family in nursing homes: Implications for research and public policy. In M. S. Harper & B. Lebowitz (Eds.), Mental illness in nursing homes (pp. 234-264). Washington, DC: US Government Printing Office.
- Brody, E. M., Dempsey, N. P., & Pruchno, R. A. (1990). Mental health of sons and daughters of the institutionalized aged. The Gerontologist, 30, 212- 219.
- Buckwalter, K. C., Cusack, D., Kruckeberg, T., & Shoemaker, A. (1991). Family involvement with communication-impaired residents in long-term care settings. Applied Nursing Research, 4(2), 77-84.
- Buckwalter, K. C., Cusack, D., Sidles, E., Wadle, K., & Beaver, M. (1989). Increasing communication ability in aphasic/dysarthric patients. Western Journal of Nursing Research, 11, 736-747.
- Buckwalter, K. C., & Hall, G. R. (1987). Families of the institutionalized older adult: A neglected resource. In T. H. Brubaker (Ed.), Aging, health, and family: long term care (pp. 176-195). Newbury Park, California: Sage.
- Clements, S. D. (1992). Today I placed my father... Geriatric Nursing, 13, 303-304.
- Collier, J. A. H., & Schirm, V. (1992). Family-focused nursing care of hospitalised elderly. International Journal of Nursing Studies, 29(1), 49-57.
- Dellasega, C. (1991). Caregiving stress among community caregivers for the elderly: Does institutionalization make a difference? Journal of Community Health Nursing, 8, 197-205.
- Drysdale, A. E., Nelson, C. F., & Wineman, N. M. (1993). Families need help too: Group treatment for families of nursing home residents. Clinical Nurse Specialist, 7, 130-134.
- Ferris, M. (1992). Nursing interventions for families of nursing home residents. Geriatric Nursing, 13, 37-38.
- George, L., & Gwyther, L. (1986). Caregiver well-being: A multidimensional examination of of family caregivers of demented adults. The Gerontologist, 26, 253 - 259.



- Hansen, S. S., Patterson, M. A., & Wilson, R. W. (1988). Family involvement on a dementia unit: The Resident Enrichment and Activity Program. The Gerontologist, 28, 508-510.
- Johnson, M. A. L. (1989). Adult daughters' perspectives on admission of a parent to a nursing home: Directions for nursing practice. Unpublished doctoral dissertation, University of Utah. (Dissertation Abstracts Ondisc, 1988 - 1992).
- Johnson, M. A., Morton, M. K., & Knox, S. M. (1992). The transition to a nursing home: Meeting the family's needs. Geriatric Nursing, 13, 299-302.
- Kasmarik, P. E., & Lester, V. C. (1984). A hard decision: When institutionalization is the best answer. In B. A. Hall (Ed.), Mental health and the elderly (pp. 165-184). Orlando, Florida: Grune & Stratton.
- Lazarus, R. S., & Folkman, S. (1984). Stress, appraisal, and coping. New York: Springer.
- Maas, M. (1993). Family measures. Unpublished report, The University of Iowa, College of Nursing, Iowa City, Iowa.
- Maas, M., Buckwalter, K., Kelley, K., & Stolley, J. (1991). Family members' perceptions: How they view care of Alzheimer's patients in a nursing home. Journal of Long Term Care Administration, 19(1), 21-25.
- Mathew, L. J., Mattocks, K., & Slatt, L. M. (1990). Exploring the roles of men caring for demented relatives. Journal of Gerontological Nursing, 16(10), 20-25.
- Matthiesen, V. (1989). Guilt and grief: When daughters place mothers in nursing homes. Journal of Gerontological Nursing, 15(7), 11-15.
- McLeod, E. (1991). Working with families of long term care residents. Perspectives, 15(3), 7-10.
- McLeod, E. & Schwartz, F. E. (1992). Working together: Collaboration among HCWs and families in long-term care. Journal of Gerontological Nursing, 18(8), 26-30.
- Morgan, A. & Zimmerman, M. (1990). Easing the transition to nursing homes: Identifying the needs of spousal caregivers at the time of institutionalization. In T. L. Brink (Ed.), Mental health in the nursing home (pp. 3-17). New York: The Haworth Press.
- Pratt, C., Schmall, V., Wright, S., & Hare, J. (1987). The forgotten client: Family caregivers to institutionalized dementia patients. In T. H. Brubaker (Ed.), Aging, health, and family: long term care (pp. 197-213). Newbury Park, California: Sage.

- Reid, R. (1992). Caring for older people: A resource guide for Australian carers. Sydney: Allen & Unwin.
- Ronalds, C. (1989). "I'm still an individual": A blueprint for the rights of residents in nursing homes and hostels: an issues paper. Canberra: Commonwealth Department of Community Services and Health.
- Rosenthal, C. J., & Dawson, P. (1991). Wives of institutionalized elderly men: The first stage of the transition to quasi-widowhood. Journal of Aging and Health, 3, 315-334.
- Roy, C. (1984). Introduction to nursing: An adaptation model (2nd ed.). Englewood Cliffs, New Jersey: Prentice-Hall.
- Roy, C. (1989). The Roy Adaptation Model. In J. Riehl-Sisca (Ed.), Conceptual models for nursing practice (3rd ed.). Norwalk, Connecticut: Appleton & Lange.
- Sachs, G. A., Rhymes, J., & Cassel, C. K. (1993). Biomedical and behavioural research in nursing homes: Guidelines for ethical investigations. Journal of the American Geriatric Society, 41, 771-777.
- Sancier, B. (1984). A model for linking families to their institutionalized relatives. Social Work, 29(1), 63-65.
- Sharp, T. (1990). Relatives' involvement in caring for the elderly mentally ill following long-term hospitalization. Journal of Advanced Nursing, 15, 67-73.
- Smith, G., Smith, M. F., & Toseland, R. W. (1991). Problems identified by family caregivers in counselling. The Gerontologist, 31, 15-21.
- Stephens, M. A. P., & Hobfoll, (1990). Ecological perspectives on stress and coping in later-life families. In M. A. P. Stephens, J. H. Crowther, S. E. Hobfoll, & D. L. Tennenbaum (Eds.), Stress and coping in later-life families (pp. 287-304). New York: Hemisphere.
- Tabachnick B. G., & Fidell (1989). Using multivariate statistics (2nd ed.). Northridge, California: Harper Collins.
- Tobin, S. S. (1987). A structural approach to families. In T. H. Brubaker (Ed.), Aging, health, and family: Long term care (pp. 197-213). Newbury Park, California: Sage.
- Townsend, A.. (1990). Nursing home care and family caregivers' stress. In M. A. P. Stephens, J. H. Crowther, S. E. Hobfoll, & D. L. Tennenbaum (Eds.), Stress and coping in later-life families (pp. 267-285). New York: Hemisphere.
- Zarit, S., Todd, P., & Zarit, J. (1986). Subjective burden of husbands and wives as caregivers: A longitudinal study. The Gerontologist, 26, 260-266.

Appendix A

FMID		RID	

Demographic Questionnaire (1)

Time 1

Numbers of the most appropriate response or responses (there may be more than one for some questions) are to be circled by the researcher.

1. What is your relationship to the resident?

- |                                  |    |
|----------------------------------|----|
| Son                              | 1  |
| Daughter                         | 2  |
| Daughter-in-law                  | 3  |
| Son-in-law                       | 4  |
| Husband                          | 5  |
| Wife                             | 6  |
| Sister                           | 7  |
| Brother                          | 8  |
| Male friend                      | 9  |
| Female friend                    | 10 |
| Other (please specify) . . . . . | 11 |

2. Before admission how often did you have contact with the resident?

- |                                    |   |
|------------------------------------|---|
| We lived in the same accommodation | 1 |
| Daily                              | 2 |
| At least once a week               | 3 |
| At least once a fortnight          | 4 |
| At least once a month              | 5 |
| Less often than once a month       | 6 |

3. What other commitments do you have (apart from visiting your friend/relative here)? Please circle as many as appropriate.

- Children (under 18 years) 1
- Another sick or disabled family member 2
- Paid employment 3
- Voluntary work 4
- Study 5
- None of the above 6
- Other (please specify) ..... 7

4. How do you usually travel to the home when you visit?

- Public transport 1
- Lifts 2
- Walk 3
- Own car 4
- Taxi 5
- Other (including combined methods), please specify  
..... 6
- How long does this take (one way)? .....

5. What is the highest level of education you have attained?  
.....

6. What is your age? .....

WHEN ANSWERING THE FOLLOWING QUESTIONS THE NUMBER BENEATH THE SINGLE MOST APPROPRIATE RESPONSE IS TO BE CIRCLED BY THE RESEARCHER.

EXAMPLE:

When answering this question the researcher should circle number 1 if a respondent expresses a strong liking for chocolate, number 5 if he or she expresses a strong dislike for it, or the appropriate number inbetween.

How much do you like chocolate?

Like it a lot	Like it a little	Neither like nor dislike it	Dislike it a little	Dislike it a lot
_____	_____	_____	_____	_____
1	2	3	4	5

---

1. How difficult (usually) is it for you to travel to the home when you visit?

Very difficult	Quite difficult	Not too difficult	Quite easy	Very easy
_____	_____	_____	_____	_____
1	2	3	4	5

2. How is your health?

Very good	Good	Fair	Poor	Very poor
_____	_____	_____	_____	_____
1	2	3	4	5

3. How close do you feel to your friend/relative?

Very close	Close	Uncertain	Not very close	Not at all close
_____	_____	_____	_____	_____
1	2	3	4	5

IN THE FOLLOWING QUESTION AN ADDITIONAL, SIXTH, OPTION IS OFFERED

4. How do you believe your friend/family member feels about living in the nursing home?

If the respondent is unable to tell because of the resident's condition please circle the number "6".

Very happy	Quite happy	Neither happy nor unhappy	Quite unhappy	Very unhappy
_____	_____	_____	_____	_____
1	2	3	4	5

Unable to tell 6

Appendix B

FMID		RID	

Demographic Questionnaire (2)

THERE ARE A FEW MORE QUESTIONS FOR YOU TO ANSWER THAT RELATE DIRECTLY TO YOU.  
PLEASE CIRCLE THE NUMBER BESIDE THE MOST APPROPRIATE RESPONSE IN THE FOLLOWING QUESTION.

1. How do you usually travel to the home when you visit?

- |                  |   |
|------------------|---|
| Public transport | 1 |
| Lifts            | 2 |
| Walk             | 3 |
| Own car          | 4 |
| Taxi             | 5 |

Other (including combined methods, please specify)  
..... 6

How long does this take (one way)? .....

FOR THE REMAINING QUESTIONS YOU ARE STILL ASKED TO CIRCLE A NUMBER, HOWEVER THE LAYOUT IS A LITTLE DIFFERENT.

THE FOLLOWING QUESTION IS AN EXAMPLE

In this question a person who liked chocolate a great deal would circle number 1, one who had a strong dislike for it would circle number 5.

EXAMPLE:

How much do you like chocolate?

Like it a lot	Like it a little	Neither like nor dislike it	Dislike it a little	Dislike it a lot
_____	_____	_____	_____	_____
1	2	3	4	5

The person answering the question has circled "1" - they clearly love chocolate.

\_\_\_\_\_

2. How difficult (usually) is it for you to travel to the home when you visit.

Very difficult	Quite difficult	Not too difficult	Quite easy	Very easy
<hr/>				
1	2	3	4	5

3. How is your health?

Very good	Good	Fair	Poor	Very poor
<hr/>				
1	2	3	4	5

4. How close do you feel to your friend/relative?

Very close	Close	Uncertain	Not very close	Not at all close
<hr/>				
1	2	3	4	5

FOR THE REMAINING QUESTION YOU ALSO HAVE THE OPTION OF CIRCLING THE NUMBER "6".

5. How do you believe your friend/family member feels about living in the nursing home?

If you are unable to tell because of the resident's condition please circle the number "6".

Very happy	Quite happy	Neither happy nor unhappy	Quite unhappy	Very unhappy
<hr/>				
1	2	3	4	5

Unable to tell 6

THANK YOU FOR YOUR PARTICIPATION.



Appendix C

FMID		RID	

Resident Details

For the following questions the researcher is to circle the appropriate number, or state the answer, with reference to the progress notes of the resident.

1. Age of resident . . . . .
2. Gender of resident

female 1

male 2
3. Resident's main disability . . . . .
4. Date of admission . . . . .
5. Change in resident's condition since completion of pre-test questionnaire.

Much worse	A little worse	About the same	A little better	Much better
_____	_____	_____	_____	_____
1	2	3	4	5

**Appendix D**  
**Resident Consent**

Mrs Christine Toyé  
(address supplied)

4 January 1994

Dear

I am undertaking a research project in order to complete my Honours Degree in Nursing at Edith Cowan University. This letter is to ask if you will consent to a close friend or relative of your choice being asked to take part in the project. Your consent is needed since their participation in the study might mean that they are offered increased involvement in your care. If you agree you will be helping in a project that is intended to benefit all families who have members in this nursing home.

There is no obligation at all for you to agree to this. Should you refuse, your family/friends will not be told of your refusal, and your care will not be affected in any way at all. Should you agree, you may withdraw your consent at any time.

When you have had time to consider this I will return and, if you decide to give your consent, I will witness your signature.

Yours sincerely,

(Christine Toyé R.N.)

I, ..... agree to .....  
participating in this study

Date ..... Resident's signature. ....

Date ..... Investigator's signature .....

OR

I have relayed the contents of the above letter to  
..... in front of a witness  
(.....), and he/she has given a verbal consent  
for ..... to take part in this study in  
front of the same witness.

Date ..... Investigator's signature. ....

Date ..... Signature of witness .....

Appendix E  
Subject Consent

Mrs Christine Toye  
(address supplied)

4 January 1994

Dear

I would like to invite you to participate in a research project I am undertaking in order to complete my Honours Degree in Nursing at Edith Cowan University. The study is intended to benefit families and friends of residents, as well as the residents themselves. I will be asking friends and relatives of some residents admitted to this home in the past two years to join the study.

If you decide to participate you will be asked to complete two very similar questionnaires 6 - 8 weeks apart. It is estimated that each of these will take about 20 minutes of your time. You will also be asked to provide me with some basic information about yourself and your relative or friend in the nursing home.

If you agree to participate, you will be assigned to one of two groups. It will not be possible to choose which group you are in. Members of one group will be offered increased involvement in the care of their friend or relative if they want it. Members of the other group will continue as they are for the study period, however, they will be offered the same opportunities as the first group later, if the programme is seen to be successful.

No names will be on the questionnaires, only code numbers. Completed questionnaires will be deposited in a box on the ward. The list linking names with code numbers (necessary for follow up purposes) will be kept securely at my home, away from the questionnaires, and no other person will have access to it.

There is no obligation for you to agree to participate, should you decline it will have no effect on the care of your friend or relative. Should you decide to take part, you have the option to withdraw at any time. The study entails

no risk for you or the resident. If you do participate, you will be asked not to discuss the study with any other visitors to the home until after its completion, since this might affect the results.

I will contact you again shortly to learn of your decision. Should you decide to participate I will need to witness your signature on this document. Thank you for taking the time to read this letter.

Yours sincerely

(Christine Teye, RN)

I agree to participate in this study, I have been informed that the questionnaires I complete and the information I give at interview will not be identified as mine to any other person. I have received a copy of this document.

Date . . . . . Subject's signature . . . . .

Date . . . . . Investigator's signature . . . . .

**Appendix F**  
**Proxy Consent**

Mrs Christine Toye  
(address supplied)

25.11.93

Dear

I am undertaking a research project in this nursing home in order to complete my Honours Degree in Nursing at Edith Cowan University. The study is intended to benefit all families who have members living in the home.

I am asking a friend or relative of some residents to take part. These people will be in one of two groups. Members of one group (Group 1) will continue on exactly as they are now, those of the other (Group 2) will be offered an opportunity to have extra involvement with the care of their friend or relative if they would like this. It is not possible for people to choose which group they will be in. However, the opportunity for increased involvement will be offered to those in Group 1 when the study is finished.

I now need to identify two relatives or friends of . . . . .  
Since this resident is unable to give me permission to ask a friend or relative to take part, one of these two people will be asked to do this on his/her behalf. If permission is given, the other person may be included in the study.

I would be very grateful if you will have a brief chat with other family members or friends and decide who will give or refuse consent on behalf of the resident, and who might like to be included in the study.

If you are the person who might like to take part - please complete PART A and ask another friend/relative of the resident to complete PART B.

If you are the friend or relative who has decided to give consent on behalf of the resident - please complete PART B and ask another person to complete PART A.

I can be contacted at work (. . . . .) or at home (. . . . .) with any queries. I enclose a stamped addressed envelope and would very much like to hear from you before December 6th., so the study can get under way.

Thank you for giving this your consideration.

Yours sincerely

Chris Teye R.N.

PART A

I, ..... , of .....  
 ..... (address and phone number)  
 would be interested in being involved in your study.

Signed ..... Date .....

N.B. more information will be given to you before you make a definite  
 decision.

\_\_\_\_\_

PART B

I, ..... , of .....  
 ..... (address and phone number)  
 give consent on behalf of .....  
 for ..... (friend/relative indicated in part A)  
 to be asked to take part in the study.

Signed ..... Date .....



## **Appendix G**

### **Changes to Questionnaires Following Piloting**

#### **Demographic Questionnaires (1) and (2)**

The demographic questionnaires were altered, as a result of piloting, in the following ways:

1. A question, which was to have been posed at Time 2, was omitted. This question asked the former caregiver to report perceptions of any change in the resident's condition since the start of the study. During piloting, it caused one family member some distress, since it was a reminder that there had been a decline in the resident's condition. Therefore, it was believed to be unethical to include it. Instead, the researcher obtained information about changes in residents' conditions from the progress notes, documenting this on the "Resident Details" questionnaire.

2. During piloting, several respondents found the method of marking their answers on the questionnaires confusing, because some questions involved Likert scales and some did not. As a result, it was decided that the researcher would complete the Demographic Questionnaire (1) with participants, so that they could see how to complete the Demographic Questionnaire (2). In addition, those questions involving Likert scales were set at the end of the two questionnaires, and an example preceded them in each case.

#### **FPCT**

Piloting of the FPCT, which was developed in the U.S.A., demonstrated a need to alter some of the terminology to fit it for use in the setting of the current study: In Item 10, "elicit" was changed to "ask"; in Item 15, "maintain" was changed to "keep"; and in Item 19, "physician" became "doctor". In Items 32 and 33 the word "resource" was omitted as it seemed unnecessary and caused confusion. However, in Item 40, the words "the amount of" and "etc." were added, the question then reading "...sensory stimulation (eg. the amount of artwork, music, colours, etc.)". Also, in Item 21, "recreation staff" was changed to read "cleaners and catering staff", and in Item 24 "occupational therapy" was changed to read "occupational therapy and

recreational staff" because these staff fulfilled both functions in the setting of the current study. The final change to terminology was when Item 25 was changed from "speech therapy" to "speech pathology".

During piloting, another problem emerged: Several respondents were seen to circle numbers indicating strong agreement with statements, while verbally indicating their disagreement. This occurred when there was a change in the way that the question was phrased. Because this problem could have meant that some of the data obtained would have been invalid, it was decided to rephrase these questions. In this way, Item 2 was changed from "I could feel more welcome..." to "I feel welcome...", and the heading for Items 37 to 44 was changed from "My family member's care could be better in regard to:" to "I am satisfied with the following aspects of my family member's care:". Scoring was adjusted accordingly, some scores no longer needing to be reversed.

Because some confusion about the method of completing the questionnaire became evident during piloting an example was included at the beginning of the instrument, and the directions on the front page of the FPCT were rephrased to indicate that the questions applied to friends as well as to family members, and to simplify them as much as possible. Lastly, a column marked "not applicable" was included since a number of people pointed out that certain questions were not relevant to their situation. One question that was cited frequently in this situation was that concerning the use of restraints.

Appendix H

FMID		RID	

Family Perceptions of Care Tool  
FAMILY/FRIEND  
QUESTIONNAIRE

Directions:

Each statement below asks about your family member's care. You will notice the questions refer to a "family member". If you are not a family member, but a close friend, the questions still apply to you.

You are asked to indicate your opinion about each statement, showing how much you agree or disagree.

Please circle the number for each statement that best describes how much you agree or disagree.

Highest Agreement               = 7  
Highest Disagreement         = 1

If a question doesn't apply then circle "8".

THE FOLLOWING IS AN EXAMPLE

	Strongly Disagree				Strongly Agree				Not Applicable
I like red hats.	1	2	3	4	5	6	7		8

The circling of the number 1 indicates that the respondent strongly dislikes red hats - since they strongly disagree with the statement.

Please read each question very carefully before answering it.

	Strongly Disagree							Strongly Agree	Not Applicable
1. I feel reassured about my family member's care after I visit.	1	2	3	4	5	6	7		8
2. I feel welcome when I visit my family member.	1	2	3	4	5	6	7		8
3. Staff listen to the problems or concerns I have with my family member.	1	2	3	4	5	6	7		8
4. Staff are patient with my family member.	1	2	3	4	5	6	7		8
5. Staff are caring in their interactions with my family member.	1	2	3	4	5	6	7		8
6. Staff show their affection through use of touch with my family member.	1	2	3	4	5	6	7		8
7. Staff tend to treat my family member as a child.	1	2	3	4	5	6	7		8
8. Staff provide for the privacy of my family member.	1	2	3	4	5	6	7		8
9. Staff appear to be knowledgeable about my family member's disability.	1	2	3	4	5	6	7		8

	Strongly Disagree				Strongly Agree				Not Applicable
10. Staff ask my help in providing care for my family member.	1	2	3	4	5	6	7		8
11. Staff provide support to help me deal with my feelings about my family member's situation.	1	2	3	4	5	6	7		8
12. Other residents on the unit get upset with my family member's behaviour and sometimes treat him or her with unkindness.	1	2	3	4	5	6	7		8
13. My family member is allowed to move about freely if she or he is physically able.	1	2	3	4	5	6	7		8
14. My family member gets enough exercise.	1	2	3	4	5	6	7		8
15. My family member should be encouraged to participate in more activities that may help keep his/her abilities.	1	2	3	4	5	6	7		8
16. Enough activities are provided for my family member.	1	2	3	4	5	6	7		8

**Strongly  
Disagree**

**Strongly  
Agree**

**Not  
Applicable**

**I AM SATISFIED WITH THE CARE MY FAMILY MEMBER RECEIVES:**

- |  |          |          |          |          |          |          |          |          |
|--|----------|----------|----------|----------|----------|----------|----------|----------|
| <b>17. In general.</b>   | <b>1</b> | <b>2</b> | <b>3</b> | <b>4</b> | <b>5</b> | <b>6</b> | <b>7</b> | <b>8</b> |
| <b>18. From nursing staff.</b>                                   | <b>1</b> | <b>2</b> | <b>3</b> | <b>4</b> | <b>5</b> | <b>6</b> | <b>7</b> | <b>8</b> |
| <b>19. From the doctor.</b>                                      | <b>1</b> | <b>2</b> | <b>3</b> | <b>4</b> | <b>5</b> | <b>6</b> | <b>7</b> | <b>8</b> |
| <b>20. From the social worker.</b>                               | <b>1</b> | <b>2</b> | <b>3</b> | <b>4</b> | <b>5</b> | <b>6</b> | <b>7</b> | <b>8</b> |
| <b>21. From cleaners and catering staff.</b>                     | <b>1</b> | <b>2</b> | <b>3</b> | <b>4</b> | <b>5</b> | <b>6</b> | <b>7</b> | <b>8</b> |
| <b>22. From the dietitian.</b>                                   | <b>1</b> | <b>2</b> | <b>3</b> | <b>4</b> | <b>5</b> | <b>6</b> | <b>7</b> | <b>8</b> |
| <b>23. From the physiotherapy department.</b>                    | <b>1</b> | <b>2</b> | <b>3</b> | <b>4</b> | <b>5</b> | <b>6</b> | <b>7</b> | <b>8</b> |
| <b>24. From occupational therapy and<br/>recreational staff.</b> | <b>1</b> | <b>2</b> | <b>3</b> | <b>4</b> | <b>5</b> | <b>6</b> | <b>7</b> | <b>8</b> |
| <b>25. From speech pathology.</b>                                | <b>1</b> | <b>2</b> | <b>3</b> | <b>4</b> | <b>5</b> | <b>6</b> | <b>7</b> | <b>8</b> |

	Strongly Disagree	Strongly Agree	Not Applicable
--	----------------------	-------------------	-------------------

**I AM SATISFIED WITH THE FOLLOWING ASPECTS OF MY FAMILY MEMBER'S ENVIRONMENT:**

<b>26. Cleanliness.</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>	<b>6</b>	<b>7</b>	<b>8</b>
<b>27. Freedom from unpleasant odours.</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>	<b>6</b>	<b>7</b>	<b>8</b>
<b>28. Noise level.</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>	<b>6</b>	<b>7</b>	<b>8</b>
<b>29. Attractiveness of decor.</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>	<b>6</b>	<b>7</b>	<b>8</b>
<b>30. Safety for residents.</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>	<b>6</b>	<b>7</b>	<b>8</b>
<b>31. Opportunity for physical exercise.</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>	<b>6</b>	<b>7</b>	<b>8</b>
<b>32. Number of staff to provide care.</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>	<b>6</b>	<b>7</b>	<b>8</b>
<b>33. Opportunities for my family member to enjoy the outdoors and other diversions.</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>	<b>6</b>	<b>7</b>	<b>8</b>
<b>34. Adequate equipment to provide care.</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>	<b>6</b>	<b>7</b>	<b>8</b>
<b>35. Protection of my family member's personal belongings.</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>	<b>6</b>	<b>7</b>	<b>8</b>
<b>36. My role in providing my relative's care.</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>	<b>6</b>	<b>7</b>	<b>8</b>

Strongly  
DisagreeStrongly  
AgreeNot  
Applicable

**I AM SATISFIED WITH THE FOLLOWING ASPECTS OF MY FAMILY  
MEMBER'S CARE:**

<b>37. Grooming and hygiene.</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>	<b>6</b>	<b>7</b>	<b>8</b>
<b>38. Medications used.</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>	<b>6</b>	<b>7</b>	<b>8</b>
<b>39. Use of restraints.</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>	<b>6</b>	<b>7</b>	<b>8</b>
<b>40. Sensory stimulation (eg. the amount of artwork, music, colours etc).</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>	<b>6</b>	<b>7</b>	<b>8</b>
<b>41. Use of self care abilities.</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>	<b>6</b>	<b>7</b>	<b>8</b>
<b>42. Bowel and bladder function.</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>	<b>6</b>	<b>7</b>	<b>8</b>
<b>43. Control of behaviour.</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>	<b>6</b>	<b>7</b>	<b>8</b>
<b>44. My input into the care provided.</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>	<b>6</b>	<b>7</b>	<b>8</b>



	Strongly Disagree			Strongly Agree			Not Applicable	
45. I always feel informed about my family member's condition.	1	2	3	4	5	6	7	8
46. I feel that this living arrangement is the best that it could be for my family member.	1	2	3	4	5	6	7	8
47. My family member's personal belongings are sometimes taken or used by other residents.	1	2	3	4	5	6	7	8
48. Staff sometimes talk too loudly to my family member.	1	2	3	4	5	6	7	8
49. Staff too often get angry and/or speak sharply to my family member.	1	2	3	4	5	6	7	8
50. Staff do the best they can but are often too busy to give my family member the attention he or she should have.	1	2	3	4	5	6	7	8
51. If more resources were available, staff could provide care that would be more beneficial for my family member.	1	2	3	4	5	6	7	8

If you have any other comments about the care of your friend or relative please add them on the back of the page.

## Appendix I

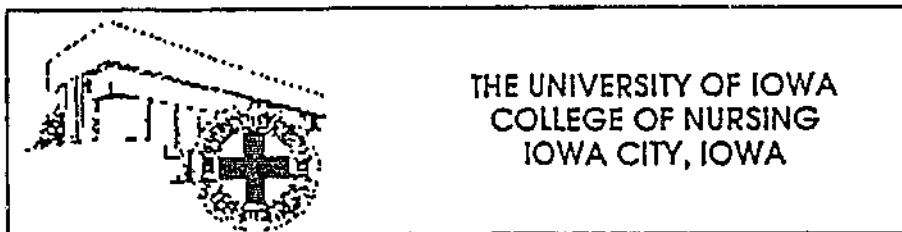
Author's Permission for use of FPCT

09/17/93 13:48

319 335 991

COLL OF NURSING

OC



College of Nursing  
13 Gleniew Avenue  
Iowa City, IA. 52242  
Phone: (319) 335-7608  
FAX: (319) 335-9990

**FAX TRANSMISSION****To:**

NAME Mrs. Christine Toye	DATE AND TIME OF TRANSMISSION 9/17/93
COMPANY / COLLEGE	FAX NUMBER 09 349 4655

**From:**

NAME Kathleen C. Buckwalter, Ph D, RN
--

**Reference:**

SUBJECT Alzheimer's Family Role Trials Study/Family Perceptions of Care Tool (FPCT)
--

**Message:**

Mrs. Toye,

You have my permission to use this questionnaire.

## Appendix J

### Author's Permission to Adapt FPCT for the Current Study

## The University of Iowa

Iowa City, Iowa 52242

College of Nursing

319/335-7018

FAX 319/335-9990

March 7, 1994



Dear Mrs. Toye:

Professor Buckwalter received your letter concerning the possibility of making modifications to the Family Perceptions of Care Tool. She has passed this request to me since I am handling all correspondence regarding the instruments we have developed.

You have our approval for making the modifications you specified in your letter. In any report of the results from using this tool, please cite our original article: Maas, M., Buckwalter, K., Kelley, K. and Stolley, J. (1991) "Family Member's Perceptions: How They View Care of Alzheimer's Patients in a Nursing Home," *Journal of Long Term Care Administration* 19(1): 21-25.

As you had concluded, item number 40 properly belongs to the "Environment" subscale alone and the item number listed under the "Overall Care" subscale should be item number 49. Thank you for pointing out this error.

*You should note that the current version has 51 items.* The three items added to the instrument are item numbers 36, 43, and 44. The psychometric properties of this version have not been determined yet, although we expect to have the data to do this within the next six months.

Sincerely,

Meridean Maas, Ph.D., RN, FAAN  
Associate Professor of Nursing

enclosures: Family Perceptions of Care Tool

## **Appendix K**

### **FPCT Scoring**

After dealing with missing data, scores for Items 7, 15, 48, 49, 50, and 51 were reversed as indicated by the authors (personal communication, Reed, May 19th, 1994). Means for each scale were then calculated by adding the scores for all the items in the scale and dividing the total by the number of scores

**Appendix L**  
**Letter of Assignment to Control Group**

Mrs Christine Teye  
(address supplied)

9 February 1994

Dear

Your continuing participation in the research project being carried out at this nursing home is much appreciated. This letter is to let you know that you have been assigned to the group that will not be offered increased involvement in resident care for the purpose of this study. You are welcome to contact me with any queries, otherwise you will not hear from me again (in this capacity) until I send out the final questionnaire in 4 - 6 weeks time. Your completion of these questionnaires is providing much valuable information. Thank you so much for giving up your time in order to complete them.

Yours sincerely

Christine Teye R.N.

**Appendix M**  
**Letter of Assignment to Experimental Group**

Mrs Christine Toye  
(address supplied)

9 February 1994

Dear

Your continuing participation in the research project being carried out at this nursing home is much appreciated. This letter is to let you know that you have been assigned to the group of people who will be offered increased involvement in the care of their family member or friend. I will be in touch with you within the next week or so in order to discuss whether or not you wish to take up this offer.

I enclose some suggestions of ways in which you might wish to increase your involvement. You may already be doing some of these things, or you may feel that they are not suited to your particular situation. You may also have your own ideas of the kind of extra involvement you would like to have.

I look forward to discussing this with you quite soon.

Yours sincerely

Christine Toye R.N.

**Appendix N**  
**Suggestions for Additional Involvement**

**1. PLANNING AND DECISION MAKING**

You might like to meet with a Registered Nurse from the relevant area, and myself, to talk about the current care arrangement. You may have suggestions for change at this stage, or may choose to give directions that you would like to have any changes discussed with you first. You might also choose to have a Registered Nurse from the ward telephone you on a regular basis (eg. weekly) to update you on your friend/family member's situation.

**2. NURSING CARE**

You might choose to assist your friend or family member with one of their meals each day. You may prefer to help settle them in the evening by assisting with a warm drink, a wash, and possibly by reading to them from a favourite book.

**3. EXTRA CARE**

- (i) If your friend or family member has a stiff or painful arm (for example) the physiotherapist may show you how to help exercise the limb to relieve the symptoms.
- (ii) If he/she has difficulty with meals, yet can still manage to eat independently with the help of special utensils and with some prompting, the occupational therapist may explain to you how you can best help your friend or relative maintain this level of independence.
- (iii) If your family member or friend has had a "stroke" that has affected his/her speech to a limited degree, then the speech pathologist may be able to draw up a programme of speech exercises that you can assist with.

- (iv) You may choose to come in each day, or once a week, and play favourite pieces of music to your friend or family member on a cassette player. It is believed that even those people who seem oblivious to everything around them are able to benefit from this.
- (v) You may prefer to massage the arms and hands of your friend or family member with oil or a moisturising cream. The need for "touch" is now widely acknowledged.
- (vii) You might like to bring in snapshots of the family, pictures drawn by grandchildren, or home videos each week. Reminiscing, as well as maintaining family links, is known to be important, so another suggestion is to bring in items that may trigger pleasurable memories (such as mementos of holidays) on a regular basis.

There are numerous other ways in which you might like to increase your involvement and you probably have many more ideas of your own. If you do decide that you would like to take up the offer, we will discuss these further in the light of the resident's needs and the amount of additional involvement you desire.



# Appendix O

## Number of Missing Cases for each Item in the 41 Item FPCT

<b>Item number</b>	<b>Number of missing cases - Time 1</b>	<b>Number of missing cases - Time 2</b>
1	2	0
2	1	0
3	1	1
4	1	0
5	1	0
6	3	3
7	2	3
8	3	2
9	1	1
10	6	6
11	7	8
13	5	7
14	6	5
15	5	8
16	6	8
17	1	0
18	1	0

Item number	Number of missing cases - Time 1	Number of missing cases - Time 2
19	7	4
21	3	0
22	9	6
26	1	0
27	0	0
28	2	0
29	0	0
30	0	1
32	4	2
33	5	7
34	6	3
35	0	0
36	1	3
37	1	0
38	7	3
42	5	3
43	10	6
44	5	4
45	1	0
46	0	0
48	1	0
49	2	0
50	1	1
51	3	1

**Appendix P**  
**Summary of Resident Disabilities by Group**

<b>Resident disability</b>	<b>Control group</b>	<b>Experimental group</b>
<b>Dementia</b>	6 (37.5%)	8 (53.3%)
<b>Post CVA</b>	4 (25.0%)	3 (20.0%)
<b>Cardiac disease</b>	1 ( 6.3%)	1 ( 6.3%)
<b>Anorexia</b>	0 ( 0.0%)	1 ( 6.7%)
<b>Chronic airway limitation</b>	1 ( 6.3%)	0 ( 0.0%)
<b>Renal failure</b>	0 ( 0.0%)	1 ( 6.7%)
<b>Paralysis</b>	0 ( 0.0%)	1 ( 6.7%)
<b>Parkinsonianism</b>	1 ( 6.3%)	0 ( 0.0%)
<b>Gastro-intestinal disorder</b>	1 ( 6.3%)	0 ( 0.0%)
<b>Depression</b>	1 ( 6.3%)	0 ( 0.0%)
<b>Coma</b>	1 ( 6.3%)	0 ( 0.0%)

### Appendix Q

#### Tables Showing the Characteristics of Those who Chose Extra Involvement Compared with the Characteristics of Others in the Experimental Group

No percentages are shown in the following tables because the numbers presented are so small.

#### Demographic Characteristics: Comparison of those Choosing Extra Involvement with Others in the Experimental Group

Characteristic	Those having extra involvement (n = 4)	Those having no extra involvement (n = 11)	Total experimental group (n = 15)
Mean age <sup>a</sup>	49 (SD = 6.70)	59 (SD = 13.60)	57 (SD = 12.78)
<b>Gender</b>			
Female	1	7	8
Male	3	4	7
<b>Level of education:</b>			
Secondary	1	7	8
Training course	2	2	4
Tertiary	1	2	3

**Note.** Means are displayed for interval data, frequencies for nominal data.

<sup>a</sup>Mean age expressed to nearest year.

**Details of Participants' Relationships with Residents: Comparison of those  
Choosing Extra Involvement with Others in the Experimental Group**

<b>Characteristic</b>	<b>Those having extra involvement (n = 4)</b>	<b>Those having no extra involvement (n = 11)</b>	<b>Total experimental group (n = 15)</b>
<b>Relationship</b>			
Son	3	3	6
Daughter	1	2	3
Wife	0	3	3
Niece	0	2	2
Brother-in-law	0	1	1
<b>Pre-placement contact</b>			
Lived together	1	4	5
Daily	1	2	3
Weekly	2	3	5
Fortnightly	0	2	2
<b>Closeness of relationship<sup>a</sup></b>			
Time 1	1.50 (SD = .58)	1.73 (SD = .47)	1.67 (SD = .49)
Time 2	1.25 (SD = .50)	1.73 (SD = .47)	1.60 (SD = .51)

**Note.** Means are displayed for interval data, frequencies for nominal data.

<sup>a</sup>Subjects rated their closeness to the resident on a scale of 1 = very close to 5 = not at all close.

**Caregiver Characteristics: Comparison of those Choosing Extra Involvement with Others in the Experimental Group**

Characteristic	Those having extra involvement ( <i>n</i> = 4)	Those having no extra involvement ( <i>n</i> = 11)	Total experimental group ( <i>n</i> = 15)
<b>Other commitments</b>			
Children	2	2	4
Sick relative	1	5	6
Employment	3	4	7
Voluntary work	2	2	4
Studying	0	1	1
Remaining	1	2	3
Mean number	2.25 ( <i>SD</i> = .96)	1.46 ( <i>SD</i> = 1.29)	1.67 ( <i>SD</i> = 1.23)
<b>Own health<sup>a</sup></b>			
Time 1	1.50 ( <i>SD</i> = .58)	2.18 ( <i>SD</i> = .75)	2.00 ( <i>SD</i> = .76)
Time 2	1.50 ( <i>SD</i> = .58)	2.18 ( <i>SD</i> = 1.08)	2.00 ( <i>SD</i> = 1.00)

**Note.** Means displayed for interval data, frequencies for nominal data.

<sup>a</sup>Health was rated by subjects on a scale of 1 = very good to 5 = very poor.

**Details of Visiting Journeys of Participants: Comparison of those Choosing Extra Involvement with Others in the Experimental Group**

Characteristic	Those having extra involvement ( <i>n</i> = 4)	Those having no extra involvement ( <i>n</i> = 11)	Total experimental group ( <i>n</i> = 15)
<b>Time taken<sup>a</sup></b>			
Time 1	19 ( <i>SD</i> = 11.09)	28 ( <i>SD</i> = 18.45)	26 ( <i>SD</i> = 17.00)
Time 2	20 ( <i>SD</i> = 11.37)	31 ( <i>SD</i> = 19.75)	28 ( <i>SD</i> = 18.17)
<b>Degree of difficulty experienced<sup>b</sup></b>			
Time 1	4 ( <i>SD</i> = .82)	3.55 ( <i>SD</i> = 1.04)	3.67 ( <i>SD</i> = .98)
Time 2	4 ( <i>SD</i> = .82)	3.55 ( <i>SD</i> = .69)	3.67 ( <i>SD</i> = .72)
<b>Transport Time 1</b>			
Own car	3	10	13
Public transport	1	1	2
<b>Transport Time 2</b>			
Own car	3	9	12
Public transport	0	1	1
Combined	1	1	2

**Note.** Means displayed for interval data, frequencies for nominal data.

<sup>a</sup>To the nearest minute (1-way). <sup>b</sup>Participants' rating of journey difficulty on scale of

1 = very difficult to 5 = very easy.

**Resident Details: Comparison of Residents Related to those Choosing Extra Involvement with Residents Related to Others in the Experimental Group**

Characteristic	Related to those having extra involvement ( <u>n</u> = 4)	Related to those not having extra involvement ( <u>n</u> = 11)	Related to any experimental group member ( <u>n</u> = 15)
Age <sup>a</sup>	87 (SD = 7.14)	80 (SD = 10.78)	82 (SD = 10.15)
Gender			
Female	1	7	8
Male	3	4	7
Length of stay <sup>b</sup>	3 (SD = 2.63)	13 (SD = 6.66)	10 (SD = 7.26)
Main disability <sup>c</sup>			
Dementia	3	5	8
CVA	0	3	3
Other	1	3	4
Feelings about institutionalisation <sup>d</sup>			
Time 1	2.25 <sup>e</sup> (SD = 2.22)	2.36 (SD = 1.03)	2.33 <sup>g</sup> (SD = 1.35)
Time 2	2.00 <sup>e</sup> (SD = 1.41)	2.36 <sup>f</sup> (SD = 1.36)	2.27 <sup>h</sup> (SD = 1.34)

**Note.** Means displayed for interval data, frequencies for nominal data.

<sup>a</sup>Age to nearest year. <sup>b</sup>Length of stay to nearest month. <sup>c</sup>Changes in residents' conditions were evenly spread throughout the two sub groups. <sup>d</sup>Subjects' perceptions of residents' feelings about living in the nursing home rated on a scale of 1 = very happy to 5 = very unhappy (a number being unable to tell). <sup>e</sup><sub>n</sub> = 3. <sup>f</sup><sub>n</sub> = 10. <sup>g</sup><sub>n</sub> = 14. <sup>h</sup><sub>n</sub> = 13.