

NEEDING HELP AND WAITING: SYMBOLIC THREATS TO
INDEPENDENCE IN THE NURSING HOME

Evelyn Jane Driver
Goshen, Indiana

B.S.N. Eastern Mennonite College, 1967
M.S. University of Maryland at Baltimore, 1974

A Dissertation Presented to the Graduate
Faculty of the University of Virginia
in Candidacy for the Degree of
Doctor of Philosophy

Department of Nursing

University of Virginia
May 1997

UNIVERSITY OF VIRGINIA
SCHOOL OF NURSING

Doctoral Program

DISSERTATION APPROVAL SHEET

Formal approval is hereby given to this submitted dissertation by

Evelyn Jane Driver on Needing Help and Waiting:
(Your name) (Title of Dissertation)

Symbolic Threats To Independence
in The Nursing Home

April 30, 1997
(Date)

[Redacted Signature]

Signature, Chair of Committee

[Redacted Signature]

Signature, Member

[Redacted Signature]

Signature, Member

[Redacted Signature]

Signature, Member

Signature, Member

[Redacted Signature]

Signature

Dean, School of Nursing

©Copyright by
Evelyn Jane Driver
All rights reserved
May 1997

ABSTRACT

The meanings of independence for nursing home residents were explored using qualitative research methods within the constructivist paradigm. Purposive sampling was used for selection of the interview site (church related, not-for profit nursing home, admitting Medicaid eligible residents) as well as selection of participants.. Eleven residents (eight women, three men, mean age 86.5) thoughtfully participated in the study. Functional ability of these participants ranged from ambulatory without assistance (n=2) through the need for assistance of two persons for all transfers (n=2). Seven required at least one person assist in transfers from bed to chair or toilet. Chart data and researcher observations were used to place the interviews within the context of nursing care that was required.

Multiple tape recorded interviews were conducted using “Independence” as a surrogate term for “autonomy”. Participants responded to open ended questions that included requests for examples of times they did and did not feel independent within this context. Transcripts of interviews were analyzed first for ways in which the word “independence” was used, then for identification of themes present within the examples. Data strips were then analyzed for interpretation of meanings within the context of nursing home life as experienced by the residents. The need for assistance with toileting was linked to feelings of a lack of independence, particularly for persons who had problems with urinary

incontinence. A uniting theme of waiting functioned as a symbol for limited independence. The “Self-Imposed Behavioral Expectations” brought to the nursing home by the resident is suggested as important to the meanings that person assigns to issues such as waiting for assistance. The findings raise theoretical concerns not only about autonomy, but also the role that trust of caregivers plays in the residents’ perceptions of autonomy within the long-term care setting. Additional research is needed particularly to explore ways in which the timeliness of direct care-giving actions is related to the resident’s feelings of independence within the nursing home.

TABLE OF CONTENTS

CHAPTER ONE – INTRODUCTION	1
Problem Statement	2
Significance	4
Conceptual Framework	6
Purposes and Research Questions	10
CHAPTER TWO – REVIEW OF LITERATURE	12
Nursing Homes as Institutions	12
Choices and Control	15
Functional Ability and Control	17
Interventions Providing Choice and/or Control	22
Effects of Institutional Life	26
Summary	28
CHAPTER THREE – METHOD	30
Constructivist Inquiry as Methodology	30
Ethical Considerations	32
Researcher as Also Clinician	37

Research Setting as Context	39
Selection of Participants	44
Criteria for Inclusion	44
Panel of Experts	45
Purposive Sampling Process	46
Sample Description	47
Procedures	48
Orientation to Setting	48
Data Generation	49
Data Management	52
Data Reduction and Analysis	53
Word Use	55
Identification of Topics	55
Identification of Themes and Dimensions	55
Functional Ability Themes	56
Uniting Themes	56
Trustworthiness Of Research Process	
Introduction	57
Credibility	
Prolonged and Persistent Observation	57
Peer Debriefing	59
Member Checks	59
Transferability	60
Dependability	61
Confirmability	63
Summary of Methods	64

CHAPTER FOUR -- RESULTS - DESCRIPTION OF MEANINGS	
Introduction	66
Research Question One	67
Word Use - Definitions	69
Word Use - Examples of Independence	70
Current Abilities	71
Current Limits on Abilities	73
Examples of Not Independent	73
Themes within Examples	75
Figure 1 Five Dimensions of Independence	76
Uniting Themes:	
Doing Things and Having Preferences Honored ...	77
Metaphor of Independence as Fiber Art	77
Dimensions of Independence	79
Moving About the Environment	79
Caring for the Body	82
Having Resources	87
Being Oneself	90
Interacting with the Social Environment	94
Summary for Research Question One	114

CHAPTER FIVE -- RESULTS - INTERPRETATION OF MEANINGS

Introduction	116
Research Question Two	117
Decisional versus Executional Autonomy	118
Needing Help as Vehicle for the Move into the Nursing Home	119
Description of Functional Ability of Sample	122
Nursing Home as a Different Social Environment	128
Needing Help as Vehicle for Daily Waiting	130
Waiting as Symbol	138
Summary for Research Question Two	141

CHAPTER SIX -- DISCUSSION

Introduction	143
Research Question Three	143
Erikson on Advanced Old Age	144
Reconceptualizing Independence	146
Theoretical Support for Dual Strands of Meanings	147
Theoretical Support for "Self-Imposed Behavioral Expectations" as Important to Interactions	148

Needing Help and Waiting as Symbolic Threats	153
Toileting and Independence	156
Pain Control and Independence	157
The Call Bell and Independence	158
Summary for Research Question Three	159
 CHAPTER SEVEN- IMPLICATIONS and RECOMMENDATIONS	
Introduction	162
Major Findings	163
Implications Related to Waiting	164
Implications Related to Self-Imposed Behavioral Expectations	165
Reconceptualizing Independence	167
Trust as Supportive of Independence	167
Limitations to Applications	168
Conclusion - Summary of Major Findings	168
 CHAPTER EIGHT - EPILOGUE	
:	
“Just Do It” - Interdependence while Exploring Independence	170
REFERENCES	186
APPENDIX Codes for Categories	197

Chapter One - Introduction

An octogenarian living in an institution after several significant losses remarked that "losing my independence was the hardest part" of all the losses. The comment, though striking, is not unique to this individual and can be found in common wisdom which associates institutional living with loss of independence for the elderly. That comment led to the exploration of the meaning of independence for several older adults through a small qualitative research study. Two distinct themes emerged that represented two different uses of the term *independence*. One reference was to the ability of the person to function without physical assistance, while the second reference was to freedom and self-determination. The environmental context was an important factor associated with the referential concept. References to the functional ability type of independence were associated with comments from a community based context, while the freedom and self-determination themes were more commonly raised as important in the institutional context (Driver, 1986).

The above mentioned preliminary study provides clues that the term *independence* has multiple meanings to older adults. Some of those meanings may be similar to terms also present in the gerontology and research literature. The persons in the preliminary study were describing institutional settings that included nursing homes but the participants were not specifically addressing that type of setting. However, the themes raised by those participants do suggest that *independence* may include elements of some broader concept such as that of autonomy as used in psychosocial developmental theory (Erikson, 1963). Theoretically, the elderly person is at risk for problems with autonomy when

living in an institution such as a nursing home (Erikson, Erikson, & Kivnick, 1986). The risk is related to decline in physical ability coupled with the residence in an environment in which certain freedoms are thought to be restricted. The research literature provides little evidence that the residents' views on this issue have been addressed.

Problem Statement

Persons within nursing homes and in the community use language that implies that life in a nursing home is somehow associated with limits on the independence of the resident. However, little attention has been directed toward exploration of the residents' meanings of the term *independence* when used within the nursing home context. Additionally, lay persons and possibly nursing home residents use one set of terms, while the researchers use another more varied set. Yet both the lay and professional groups seem to overlook one reality of nursing home life, namely that the persons living in this type of group situation are those who do need assistance with some aspects of their daily care. We do not know what independence means to the residents when they are living in this type of circumstance and need the type of assistance provided by the persons available within the institution.

Researchers have examined a variety of concepts each considered to be problematic within the institutionalized long term care setting. The concepts are operationalized in a variety of ways such as dependency (Baltes, Honn, Barton, Orzech & Lago, 1983; Barton, Baltes & Orzech, 1980; Lester & Baltes, 1978), locus of control (Felton & Kahana, 1974; Lachman, 1986; Mullins, 1985; Reid,

Haas & Hawkings, 1977; Shewchuck, Foelker & Niedereke, 1990; Wolk, 1976), perceived latitude of choice (Hulicka, Morganti, & Cataldo, 1975), perceived situational control of daily activities, (Chang 1978a, 1979; Ryden, 1984), perceived personal control (Arling, Harkins, & Capitman, 1986), choices (National Citizens' Coalition for Nursing Home Reform [NCCNHR], 1985; Pohl & Fuller, 1980) and autonomy (Collopy, 1988; Hofland, 1988a, 1988b; Jameton, 1988). A number of these concepts may be related to what the residents' mean when they refer to *independence*. While labeling of the entity varies, there seems to be agreement that there are difficulties of some type for nursing home residents.

Additional researchers suggest that doing something may have a desirable impact on the situation (Banzinger & Roush, 1983; Byrd, 1983; Langer & Rodin, 1976; Rodin, Bohm & Wack, 1982; Rodin & Langer, 1977; Schulz, 1976). However, the nature of the suggested interventions demonstrates a variety of approaches to the difficulties for residents. Furthermore, researcher bias is evident in the assumption that the residents do not have control but do wish to control various aspects of their lives in the ways that younger adults operationalize control. Little attention has been directed toward the residents' perception of the situation.

A few studies that have included the residents' views related to aspects of "independence" are discussed in a later section. However, none of the studies has started with the residents' meanings of the term when used within the context of life in the nursing home. We do not know what independence means to residents within the context of the nursing home setting. Because we do not know what residents mean by the term "independence", we also do not know whether the

functional ability of the resident in any way influences those meanings.

Significance

There is fairly good agreement that nursing home settings are less than ideal environments for older adults. Agreement exists among lay wisdom, casual comments of persons who equate nursing home life with loss of independence, as well as in the gerontology literature. A variety of terms are used, but writers and researchers have identified life in the nursing home as one characterized by the need for the individual to conform to a structure imposed by the institutional setting (Bennett, 1963; Goffman, 1961; Gubrium, 1975; Kayser-Jones, 1981; Tisdale, 1987). The less than ideal nature of the institutional life is further evident in a sampling of literature ranging from the journal of a nursing home resident (Horner, 1982) to reports prepared by a citizens' group (National Citizens' Coalition for Nursing Home Reform [NCCNHR], 1985), a public policy researcher (Vladeck, 1980), and national agencies (Institute of Medicine Committee on an Aging Society and National Research Council, 1985; Institute of Medicine, Committee on Nursing Home Regulation, 1986). While there does seem to be agreement that difficulties of some sort exist for nursing home residents, there is less agreement as to either the nature of the problems or appropriate ways by which to address them.

In an attempt to improve life for nursing home residents, areas are identified within the nursing home in which residents can be given some control over their lives. Several interventions have been shown to be related to desirable health outcomes (Banzinger & Roush, 1983; Byrd, 1983; Langer & Rodin, 1976;

Schulz, 1976), although either the permanence or the value of these benefits is debatable (Curley, 1983; Schulz & Hanusa, 1978). However, the interventions selected were not those that recognize a fundamental factor underlying the admission to the particular facility, specifically that of the need for assistance with some aspect of daily life. Furthermore, criticism of the interventions suggests that the observed improvement on the assorted outcome variables was attributable to either multiple other factors (Kane & Kane, 1987) or to the cognitive activity inherent in the research participation (Beck, 1982).

Among the residents of the nursing home are those who can be divided into three general categories: 1) admitted for rehabilitation, usually directly from a hospital and expecting to return to living outside of the institution, 2) admitted for terminal care in this setting because the more complex technology of the hospital setting is not needed, and 3) admitted for nursing care, but also requiring personal care of a more custodial nature because the person is not able to manage living safely at home with community resources. It is this latter group for whom the nursing home stay is likely to be long (Tisdale, 1987). For these people, too, the nursing home essentially *is* home, not some institution designed for care of the sick who will return to a previous level of function in a less structured environment. *Home* carries with it the connotation of doing as one pleases (Ford, 1989), yet an institutional image complete with restrictions on freedom and self-determination is the predominant image relayed relative to nursing homes (Bennett, 1963; Goffman, 1961; Gubrium, 1975; Horner, 1982; Johnson & Grant 1985)

The question of the residents' views of independence and its meaning within the nursing home setting is an important one to address because a sizable number of persons is affected. Approximately 1.5 million persons, or between 4.7 and 5.3 percent of the population age 65 and above reside in nursing homes (National Center for Health Statistics, 1989; U. S. Bureau of the Census, 1989). About two-thirds of these residents can be expected to remain in the nursing home until death. (Spence & Wiener, 1990). While there has been a shift toward utilization of home health care as a replacement for institutionalization for some of the impaired older adults in our society, this effort does not seem likely to totally replace the need for institutional based long-term care in the near future.

Before any additional intervention studies are attempted, further exploration is needed regarding what residents mean when they refer to "independence" in the context of the nursing home. It is also valuable to know how they believe "independence" to be related to whatever level of functional ability precipitated the need for that placement.

Conceptual Framework

The residents' meanings of the term *independence* within the context of the nursing home is an area for exploration. Therefore, the research design did not include a priori use of a specific conceptual framework around which to organize the study. However, because the themes identified by the participants in the preliminary study (Driver, 1986) included those of functional ability, freedom, and self-determination, it is possible that the term *independence* within the nursing home context would also have several elements. These elements might be

similar to components of the concept of autonomy as used in the Erikson developmental theory.

The Erikson developmental theory (Erikson, 1963, 1968, 1982) was selected for several reasons. The theory specifies autonomy as one of the core issues with which humans must deal in the course of normal development. Throughout life, there is an underlying assumption that the person develops within a context that includes and is responsive to the environment of that person. Additionally, the theory has been recently re-examined for relevance in old age with the resulting conclusion that there may be a re-working of previously mastered stages if or when the life circumstances of the person change (Erikson, Erikson & Kivnick, 1986).

The Erikson framework (1963, 1968, 1986) was used as one point from which to analyze the data, because the 1986 re-examination of that framework does suggest that older persons in nursing homes are at risk for developing problems with autonomy. These autonomy problems may correspond in part with what residents and lay persons call "independence". However, because of the desire to first hear what the residents say about "independence" in the nursing home, the Erikson theory was not initially used as the basis for either the research questions or the initial interview questions.

The Erik Erikson developmental approach identifies a stage of autonomy as the second of eight stages that are developed sequentially. The theory proposes that persons progress through the stages by struggling to balance opposing tendencies. Resolution of this struggle at one level provides a foundation from which to develop the next stage. A re-working of the issues from previous stages

is part of the process by which the issues at the next stage are resolved. In the final stage as originally defined, the person struggles to balance a sense of ego integrity in the face of possible despair. The strength of wisdom can be developed as the desirable outcome. This final stage has been generally equated with old age, and precedes death, but is not defined specifically with respect to chronological age (Erikson, 1963).

In their 1986 work, Erikson, Erikson, and Kivnick suggest that in advanced old age there is not an additional stage beyond that of integrity versus despair. Rather, as the individual encounters new life situations, a re-working of all previous stages is required with respect to the new situation (Erikson, Erikson, & Kivnick, 1986). Neither the direction nor any sequence of this reworking was addressed. Erikson, Erikson, and Kivnick suggest that older adults might change what they think is important as they change in their abilities to function without assistance. They also suggest that as physical ability declines autonomy may become problematic, particularly in the institutional setting.

Residents of nursing homes typically are persons of the age where they are likely to be re-working developmental tasks as part of the normal development of the wisdom outcome resulting from the integrity versus despair struggle. This re-working is being done in a context in which independence and/or autonomy is thought to be restricted and with health conditions that alter the ability of the person to express certain types of autonomy (Erikson, Erikson, & Kivnick, 1986). Little is known regarding the residents' perception of this situation. Since the theme of autonomy is thought to be re-worked both in advanced age and in the presence of impaired bodily function, and since residents of nursing homes

typically have both of these conditions, it is important to obtain the residents' perspective on this issue. However, the term selected as the beginning point of this investigation was that of *independence* because residents and lay persons have used this term when referring to the nursing home setting.

Erikson recognizes that both the environment and the context of interactions within this environment have an impact on the development of the person (Erikson, 1968; Wright, 1982). The Erikson model addresses autonomy within an environmental perspective. The individual must learn to be autonomous within the constraints of that environment, balancing the desire to be autonomous with the limits imposed by the needs and wishes of others. The model is relevant for a nursing home setting because it recognizes that both context and environment are important to the development of the person in accord with culturally prescribed norms. The nursing home resident brings an individual set of meanings and interpretations to this new context and those meanings may affect how the resident experiences the setting. Part of that set of meanings may be influenced by the decline in functional ability that has in some way led to the need for the placement of the person within the nursing home.

The nursing home resident essentially needs to learn the rules of the nursing home environment, particularly those involving the ways in which physical care is delivered. This learning may be occurring at a time in which the person is also re-evaluating previous life stages as part of working with the stage of integrity versus despair. The resident may also be experiencing age changes and/or disease conditions that affect the body ability to function in ways that seem age appropriate for a given cultural group. From both theoretical and common

sense perspectives, then, it would appear that some phenomenon akin to autonomy or independence would be developmentally salient to nursing home residents. It is important to understand how they perceive this phenomenon and what meanings are ascribed by those residents.

Purposes and Research Questions

There were three purposes for this study. They are:

- 1). To determine the residents' meanings of the term "independence" when used within the context of a nursing home.
- 2). To explore how residents' meanings of independence may be influenced by functional ability.
- 3). To formulate questions for investigation in future nursing studies.

The research questions addressed by this study are as follows:

- 1). Within the context of a nursing home, what are selected residents' meanings of independence?
- 2). What do these meanings reveal about the influence of functional ability on independence within the context of a nursing home?
- 3). Can those meanings be analyzed productively from the perspective of Erikson's developmental theory?

It is by intent that *independence* was not defined prior to data analysis in this study. However, for clarity in the remaining discussion, the following distinctions are used. "Independence" is designated in quotation marks when the

reference is to the term as the object of this investigation. Use of the term *independence* without quotes indicates usual dictionary definitions of the term.

The definition of *nursing home* used in the 1986 Institute of Medicine (IOM) study of quality of care in nursing homes is used in this study when referring to a particular type of institution providing long-term care. The IOM definition specifies a nursing home as "a residential long-term-care facility that provides 24-hour care, skilled nursing care, and personal care on an inpatient basis" (IOM, 1986, p. 400). Specifically excluded in this researcher's use of the term *nursing home* are institutions commonly referred to as retirement homes, residential facilities, and board and care homes for the elderly.

Chapter Two - Review of Selected Literature

The literature review is focused on studies addressing some aspect of control, choices, dependence, or autonomy specifically for elderly persons in an institutional setting. This literature review covers the studies most directly related to the general topic of interest that were available at the start of the investigation. A few additional studies, published in the 1990s are included as part of the Discussion Chapter.

The literature on issues related to "independence" for nursing home residents does not address the residents' meanings of the term. There are clues that something in the area of "independence", control, and/or choice is important but consensus is lacking as to definition(s) or appropriate intervention(s). Common sense suggests that nursing home residents would benefit from being in control of aspects of their lives, yet the literature is limited with respect to the residents' perspective on the issue.

Nursing Homes as Institutions

The nursing home in the United States of today is a different entity than that of years ago yet, residual images persist that are less than optimal. One image is that of life as restrictive to the independence of the residents. This image is in part covered by Goffman's (1961) conceptualization of a total institution. Current researchers frequently cite Goffman as they build their case for why issues within the nursing home need to be addressed and the situation changed.

Goffman (1961) used homes for the aged as one example of total institutions. According to Goffman, within total institutions, "inmates" eat, sleep,

work, and play within the physical boundaries of an institutional and live in accord with the authoritarian structure associated with that setting. The picture presented is one in which persons are consigned to drab institutions, and are required to conform to group schedules, appearances, and activities in keeping with whatever norms have been established for that setting. Images similar to those of regimented life in a mental hospital, correctional institution or military service barracks are common in the work, and by inference, apply to the homes for the aged. However, the setting for the research for Goffman's work was that of a federal psychiatric hospital in the mid 1950's, and before the creation of Medicare and Medicaid programs. Despite the perhaps limited applicability of Goffman's concept of "total institutions" to the nursing home of today, it appears to serve as an assumption undergirding a number of subsequent publications related to the institutional care of the elderly.

Bennett (1963) expanded on Goffman's work with a specific focus on the development of criteria for degree of totality. These criteria reflect the degree of constraint and control by staff that reappear as themes in the writings critical of nursing homes. The images are reinforced by writings such as those of Townsend (1971), Mendelson (1974), Moss & Halamandaris (1977), and Vladeck (1980) as they address deplorable continued problems within the nursing home system in the United States.

Changes over the decades have affected the nursing home along with society in general. Growth in the number of nursing homes, societal focus on consumer rights, public awareness of abuses, as well as state and federal regulations to attempt to lessen the abuses have all had an impact on the life of the

nursing home resident. Recent attention has been directed toward the effectiveness of governmental regulations and inspections. There has been official recognition of the need for and ability of some residents to provide input into evaluations of nursing homes (Institute of Medicine [IOM], 1986; National Citizens' Coalition for Nursing Home Reform [NCCNHR], 1985). Further changes are evident in nursing homes as a result of the change in Medicare reimbursement payment for hospital care. This has resulted in a different mix of abilities of residents within nursing homes today.

While there have been a number of changes in nursing homes, some things have not changed. A major factor that has not changed is that nursing homes still are institutions in which elderly people receive care in a group setting. Additionally, those institutions are inhabited by individuals who are older than most of the policies and regulations that govern their care, and older than most of the researchers that address the problems inherent in the setting. By virtue of the life experience attendant with that advanced age, these residents likely have a perspective on those problems that is broader than that currently presented in the literature. Erikson (1982) identifies old age as a time in which wisdom is normally developed. There may be something in the wisdom of the residents of a nursing home that can provide a valuable perspective on the issue of "independence" within that setting.

There are descriptions of life in the nursing home available in the form of participant observation studies and journals of nursing home life. The literature from the inside does portray nursing homes with a variety of challenges. (Gubrium, 1975; Horner, 1982; Tisdale, 1987; O'Brien, 1989; Savishinsky, 1991;

Gubruim, 1993). One challenge is that of running an institution designed for group living that can accommodate individual persons with a wide variety of needs and abilities. This challenge comes with some attendant restrictions in choices, control, and independence such as those conceptualized by Goffman (1961) as totality of an institution.

Choices and Control

Researchers have addressed the restrictive environment of institutions for the elderly in various ways. Aspects of independence such as choice (Langer & Rodin, 1976), perceived choice (Hulicka, Morganti & Cataldo, 1975; Pohl & Fuller, 1980), control (Schulz, 1976; Banzinger & Roush, 1983; Byrd, 1983), perceived control (Chang, 1977; Ryden, 1982) and resident constraint (Wolk & Telleen, 1976) have been addressed. These aspects were associated with desirable outcomes such as happiness, activity, and alertness (Langer & Rodin, 1976); well-being (Schulz, 1976; Banzinger & Roush 1983); life satisfaction (Hulicka, Morganti & Cataldo, 1975; Wolk & Telleen, 1976; Banzinger & Roush 1983; Byrd, 1983); and morale (Chang, 1977, Pohl & Fuller, 1980; Ryden, 1982).

The perception of either choices or control has been compared between groups in several research studies (Hulicka, Morganti & Cataldo, 1975; Wolk & Telleen, 1976; Ryden, 1984; Arling, Harkins, & Capitman, 1986). In each study, the setting defined as having the lower amount of constraint was associated with greater scores on choice or control for the resident.

The general consensus among the researchers cited above is that some degree of control or choice is associated with desirable outcomes for residents,

and that those in less restrictive environments have more control and therefore the higher level of desirable outcomes. However, three of these studies also contained curious added findings (Hulicka, Morganti & Cataldo, 1975; Ryden, 1984; Arling, Harkins, & Capitman, 1986). These studies are discussed in the following pages.

Selected research literature related to the general issue of independence for nursing home residents is presented in this section. Research that has most directly shaped the focus of this research is presented first, followed by that in which control or choice related interventions were tested with elderly institutionalized persons.

Hulicka, Morganti, & Cataldo designed an instrument to measure "perceived latitude of choice" (1975, p. 27) then administered it to 25 elderly women residing in the community and 25 residing in "church related homes for the elderly" (p. 31). All were able to move about independently, although several used canes for assistance. Although the focus of this study was on instrument development, one finding supports the view of institutional life as restrictive with respect to choices. Perceived latitude of choice was lower in the home for the aged on some but not all items. However, this finding calls into question the almost automatic assumption that persons in nursing homes have lost all choice.

The institutionalized group had lower scores on the perceived latitude of choice for 31 out of 37 items (Hulicka, Morganti, & Cataldo, 1975). However, this same finding also suggests a need to explore how additional factors related to institutionalization might affect choices for elderly persons. The persons needing the protected environment of an institution may not have been capable of

participating in all the options for which choices were listed. Included in the list of 37 items were at least eleven for which choice could be affected by factors such as functional ability or financial resources of the person (e.g. "what to spend money on... where to shop...whether to work ...what type work to do" (p. 34).

It is not apparent that the researchers (Hulicka, Morganti, & Cataldo, 1975) accounted for different reasons that the person might have said they did not have a choice on the various items. Additionally, for the following items the institutionalized group had higher choice scores: "...with whom and where to have a snack, when and where to see visitors, when to watch TV, what hobbies to have, whether to associate with others, and whether to participate in certain recreational activities" (p. 35). An added interpretation could be that the institutional setting provided the resident with more "independence" in some areas of life. It is also possible that some factor such as the functional ability of the person might at least in part account for the perceived latitude of choices. The role of functional ability in perceived choices was one of the questions addressed in a subsequent study by another group of researchers.

Functional Ability and Control

Arling, Harkins, & Capitman (1986) conceptualized the "independence" issue as one of personal control for functionally impaired older people. A panel study was designed in which 151 persons at risk for nursing home placement were followed for six months using a number of measures, including a modified version of the Hulicka, Morganti, & Cataldo (1975) instrument. Data related to personal control were then analyzed based on whether the persons were

institutionalized at the time of the six month follow-up measures. Persons who were institutionalized "were far more likely to experience a decline in perceived control even when their impairment level, negative life events, social contacts and other factors were taken into account." (p. 53).

Several interesting factors are also evident in the Arling, Harkins, & Capitman (1986) study: "Those who remained in the community experienced no declines, but instead improved somewhat in functional status and perception of personal control" (p. 49); and "The more functionally impaired and those who had experienced more negative life events, both in the community and the institution experienced a greater decline in perceived control" with this being interpreted as reflective of the possibility that they were "more vulnerable to the loss of perceived control" (p. 53). There is no indication that the persons' views on this issue were pursued. This finding suggests that, while the institutional setting does adversely affect personal control, the functional ability also is a factor to consider. The findings do add support to the premise that functional ability is a factor that may be worth exploring in other research dealing with the issue of "independence" for nursing home residents.

An examination of perceived control with respect to the direct care-giving situation was undertaken by Chang (1977, 1978a, 1978b) in a study that focused on morale as a desirable outcome. Based on participant observation and resident interviews, an instrument was designed that addressed the residents' perception of situational control of several types of daily activities within the nursing home. Factor analysis disclosed that the activities could be reduced to two dimensions. These dimensions were "Control of Socializing and Privacy, and the other the

Control of Physical Care. It is worth noting that the question of who determines physical care may be an issue meriting separate attention from control of socializing and privacy" (1978b, p. 185). It seems to this researcher that, since the amount of physical care the resident needs is normally related to their functional ability, there would be value in exploring how this ability is related to their control of activities or to their meanings of "independence".

Chang then used the instrument (1978b) to explore relationships involving locus of control, perceived situational control of daily activities (SCDA), and morale. Chang reported "...the tentative finding that self-determined SCDA resulted in higher morale regardless of locus of control orientation." (1978a, p. 323). There was also the unexpected finding that persons who scored high on chance orientation to control also were among those who scored high on SCDA and had high morale scores. It was suggested that the resident may have recently needed to deal with the impact of an unpredictable sudden illness, or an accident which they attributed to chance, but in other areas felt in control of their lives (1978a). However, an additional factor may be related to the situation, and was not addressed in Chang's discussion. If, following that sudden illness or accident, the person required care in a nursing home, it seems obvious that the perceived control and the functional ability would be related.

Support for the premise of a relationship between independence and functional ability is provided in a study reported by Ryden. Ryden (1982, 1984) utilized the Chang (1978b) SCDA instrument to also examine the relationship between SCDA and morale for nursing home residents but expanded the study to compare residents on skilled care units with those on intermediate care units.

Perceived SCDA was an important factor in morale for residents of both skilled and intermediate care units, with this association being stronger for those on the skilled care units. The perceived SCDA also directly affected morale for residents of the intermediate care units, but "functional dependency" was among other factors also contributing to morale for this group of residents. The functional dependency measure was added to the study during data collection because Ryden thought that the level of function might be influencing the morale scores.

The measure of functional dependency was constructed from responses to five items that were intended as prompts in the interviews on the Chang SCDA scale. Ryden (1984) speculates as to reasons for the differences between the residents on skilled and intermediate care units with respect to the impact of functional dependency on their morale. The lack of data to support these speculations suggests that there may be value in exploring how the functional ability of residents is related to their meanings of "independence" within the nursing home context.

A less clear connection between functional ability and control is suggested by a more recent study. Reich and Zautra (1989) designed an exploratory study in which cognitive control education was used as the intervention for 98 older, community residing adults. One group contained recently bereaved (spouse) but not disabled persons, another recently disabled but not bereaved, and matched controls whom were neither recently bereaved nor disabled. The intervention consisted of a series of four visits spread over 10 weeks in which subjects were individually instructed in relevant ways to exert cognitive control in their daily lives. The placebo group received visits but no planned instruction.

Results were mixed with respect to the particular measure on which change was observed and all effects were short-lived. However, the disabled group showed a temporary increase in perceived control that was not found in the other groups. Additionally, Reich and Zautra reported but did not expand on the observation that they received much information in the course of the study that was not quantifiable. Their observation suggests possible value in specifically focusing on the residents' perceptions on related issues such as that of "independence" for nursing home residents.

Findings from other studies suggest that something akin to "independence" is important to institutionalized elderly residents. However, these studies fail to address a possible impact of functional ability on the findings. One such example is that reported by Wolk & Telleen.

Using a different approach to the general issue of independence for institutionalized elderly persons, Wolk & Telleen (1976) compared residents of two types of environments with respect to a number of variables. Ambulatory residents in a "high constraint" setting (a "retirement home" with rules, a daily schedule, and implied to also include group meals and staff organized procedures for daily care) were compared to those in a "low constraint" setting (a "retirement-type village" in which homes were owned by the resident and in which residents were responsible for meeting all their own needs independently but with options for group activities). Residents in the "low constraint" environment had higher scores on life satisfaction. However, the "low constraint" environment was also associated with higher scores on variables such as education and health levels that also may have affected the life satisfaction scores. This finding adds support to

the premise that some form of "independence" is related to desirable outcomes for elderly persons. However, it also fails to address the possible influence that a decline in the health status (or functional ability) of a person who is institutionalized might have on the "independence" of that person.

Interventions Providing Control and/or Choice

Several groups of researchers have not attempted to measure the amount of control that institutionalized persons have, but instead have designed interventions assumed to provide the resident with control or choice. The interventions were then reported as having desirable outcomes, with mixed reports as to the permanence and value of these outcomes.

The research by Langer & Rodin (1976) is one frequently cited in the gerontology literature on choices and/or control for the elderly. The study was conducted on two floors of a nursing home in which residents were considered to have equivalent levels of ability. Residents on one floor received the experimental intervention in the form of a message from a young, friendly, male administrator.

The administrator focused on the responsibility of the residents to decide about circumstances and events affecting their lives in the nursing home. He also stated that they should continue to control their lives as they did before entering the nursing home. He also informed them of the channels to use for any complaints they might have and the willingness of the staff to be of assistance if they so requested. The responsibility for self was symbolized by several choices including whether to have and care for a potted plant.

The experimental group (n=24) was reported as scoring higher than the control group (n=28) on levels of resident reported happiness, activity, and alertness, and on nurse rated general improvement and time spent interacting with others. Beneficial effects of the intervention were reported as still present on an 18 month follow-up study in which approximately one-half the persons from each group were compared using some of the same outcome measures (Rodin & Langer, 1977). An additional group was designated as a "control group". This group consisted of persons who resided on the two floors of the nursing home at the time of the intervention, but who for various reasons, were not present for the initial administrator's talks.

The results of the Langer & Rodin study (1976) are less convincing when some of the limitations are examined. They seem to present an overly simplistic view of life within the nursing home, and in particular ignore the potential effects of the resident "grapevine" for information about events and expectations. They also do not clearly account for the influence of an intervening variable (move to a new wing in which resident groups were re-arranged). Additional factors that may have contributed to the reported positive effects of the intervention include those of social interaction that could be a secondary effect of the intervention.

Langer & Rodin are not convincing in their discussion of the validity issues related to nurse objectivity on the outcome measures. While they assert that the nurses were not aware of the intervention, they report that a "nurse" (type unspecified) assisted with distribution of the plants to the residents. Also apparently ignored is the potential impact of the staff grapevine in relaying information about the activities of others within the nursing home system.

Additionally, they overlook the potential impact on the outcomes of resident desire to please a friendly authority figure (the 33 year old administrator) who might have the power to send them away if they fail to conform to expectations.

A parallel study that cites but does not appear to build on the Langer & Rodin work is reported by another researcher. Schulz (1976) designed an experimental study in which four groups (n=10 per group) of retirement home residents were randomly assigned to differing combinations of conditions in which visits by college students could be predicted and/or controlled. The findings of positive effects from the intervention were attributed primarily to the predictableness and secondarily to the controllability of the visits. However, the value of the intervention was then called into question by the results of follow-up measures at 24, 30 and 42 months after the intervention.

In the follow-up (Schulz & Hanusa, 1978), most of the same persons were still alive, but the only available measures were from secondary sources. The reason that the researcher did not have direct access to the residents was not addressed. The positive effects observed in the 1976 study were reported to be temporary. Furthermore, the "Persons who had previously improved in psychological and health status when an important positive event was made either predictable or controllable for them exhibited significant declines after the study was terminated." (Schulz & Hanusa, 1978, p. 1198). These declines were speculated to be related to loss of the relationship with the visitors. This finding adds a note of caution to the enthusiasm for intervention studies. However, it should be noted that the intervention in that particular study was not one directly related to the normal daily routines within the nursing home. In this respect, the

Schulz study differs from those of Langer & Rodin (1976) and of Banzinger & Roush (1983).

Banzinger & Roush (1983) expanded upon the previous intervention studies (Langer & Rodin, 1976; Schulz, 1976) in a design that involved resident responsibility. A group of 39 volunteer, semi-ambulatory residents of an intermediate care level nursing home were divided into three groups. The control-relevant group was given a message about resident self-responsibility and informed of problems the birds were having with obtaining food. Residents were then given the chance to supervise the food level in a bird feeder placed within view of the resident's window. Each resident selected the preferred type of feeder from several available models. A second group received a dependency message about how much the staff could and would do for residents, while a third comparison group received neither message. Neither the dependency group nor the comparison group received bird feeders.

Banzinger & Roush reported improvement for the control-relevant group on a variety of measures. The authors concluded that effects of the intervention were desirable, but recognized that there are multiple issues related to this type of study design. One unrecognized issue is that of the limited relevance of interventions of this type in the nursing home. The intervention may represent a replacement for lost control, but it does not address circumstances within the nursing home that have the potential to restrict the control or "independence" of the residents.

Effects of Institutional Life

The previously cited intervention studies suggest that there may be some aspects of life within the nursing home in which residents can be helped to feel more "independent". However, a problem with these intervention studies is that, while they are related to life within the nursing home, they do not address an issue that is of primary importance when one considers the fundamental circumstances responsible for the placement in the nursing home. Specifically, if the person did not have some limit in their functional ability for which they needed some type of human assistance, they would, in all probability, not be residing in a nursing home. This somewhat obvious relationship between circumstances is one that has generally not been addressed directly in other studies related to "independence" for elderly persons within institutions. An exception is the work of Baltes and associates who addressed staff responsibility for fostering dependency in residents.

The need for assistance that is associated with placement in a nursing home is thought by some to set the stage for interactions with staff that foster dependency for elderly persons. Several studies highlight this view. Lester & Baltes (1978) found that the staff (type not specified) of a skilled nursing facility rewarded dependency in the elderly residents and tended to give no response to resident independent behaviors. This finding was supported by findings from a subsequent larger study (Barton, Baltes & Orzech, 1980). In a replication and extension of the 1980 study, social partners of nursing home residents (staff, visitors and volunteers) were found to demonstrate supportive behavior in response to resident dependency and failed to reward resident independent

behavior (Baltes, Honn, Barton, Orzech & Lago, 1983).

In a more theoretical discussion, Baltes (1982) suggests that resident dependency is possibly one way by which the resident maintains control over the situation. Just such subtle rewards for dependency are suggested in one of the books providing a view from within a nursing home (Tisdale, 1987). Even though the staff might seem at fault in these dependency inducing interactions, staff represent only one side of the interaction. The residents' views regarding the reasons for their actions are omitted from the discussions of dependency yet these also seems to be an essential element.

One research project designed specifically to obtain the consumers' perspective on nursing home care is that reported by the National Citizens' Coalition for Nursing Home Reform (NCCNHR). The intent of the study was to add the residents' voices to national discussions focused on defining quality of care and identifying ways to measure that quality as part of nursing home inspections.

The project (NCCNHR, 1985) was reported as a descriptive study using a series of three group meetings and open-ended questions to focus on the quality of care and quality of life in the nursing home. The sample consisted of 457 residents from 105 nursing homes in 15 cities across the United States meeting in groups of four to eighteen persons to respond to the questions.

Among the indicators of quality were: choices about food and activities, inclusion in decision making, staff answering calls promptly, staff respect for the rights and self-determination of the resident, and staff allowing residents independence and autonomy (NCCNHR, 1985). The last two items in this list are

not easily quantified and apparently were not explored in the discussions. However, these are also the two items that, because they initially seem so illusive, are perhaps the most important ones to explore in individual discussions with residents. The presence of these themes in a discussion of quality of care supports the common wisdom that "independence" may be a problem for residents of nursing homes.

The applicability of the NCCNHR study to a question regarding the meanings of independence is limited because of the group nature of the discussions, and the focus on identification of specific factors that could be evaluated during inspections. The fact that residents raised issues related to independence, choices, and autonomy within the context of a discussion about quality care suggests that there may be additional wisdom that could and would be shared if the data collection were structured in a different manner and focused particularly on the topic of "independence".

Summary

The literature related to the question of "independence" for nursing home residents is diverse and does not lend itself to easy identification of logical next steps in the orderly building of knowledge from research. Researchers have used a variety of terms from an assortment of theoretical bases and operationalized in multiple ways to address topics possibly related to what elderly persons mean when they refer to *independence* within the nursing home. Only a handful of these persons have attempted to address the residents' perspective on the issue, and none of these have looked at what "independence" means to the resident of a

nursing home. Furthermore, the type of institutional settings have ranged from community private homes and retirement villages for active, healthy persons to the skilled nursing care units of nursing homes.

The difference in settings across the studies likely also is associated with differences in the functional ability of the study subjects. Few of the researchers have addressed the functional ability of the participants in anything more than a passing manner. However, given the variety of settings used in the studies, it is likely that the abilities of the participants varied considerably. In the studies that did address function, there is a suggestion that functional ability may in some way be related to the particular variable being studied, though the nature of the relationships are not clear (Ryden, 1984; Arling, Harkins, & Capitman, 1986).

Because nursing home residents typically do have some impairment in function, and because that impairment is among the factors typically leading to the placement in a nursing home, two things seem essential. First, we need to know what residents mean when they refer to *independence* within the context of the nursing home. Second, any discussion of the meaning of independence to the nursing home resident needs to include their explanations of any relationships between the two issues. Therefore, it is important to ask the residents what "independence" means within the context of the nursing home. Furthermore, there may be added value in exploring what those meanings reveal about the influence of functional ability on "independence" within the nursing home.

Chapter Three - Methods

Introduction

An exploratory, descriptive, interpretative study was conducted to investigate the research problem through the use of methods consistent with the constructivist (naturalistic inquiry) paradigm. The constructivist approach (Guba & Lincoln, 1994), formerly labeled "naturalistic inquiry" (Lincoln & Guba, 1985) and assumptions of that paradigm were utilized. Emergent design expectations shaped the sample selection, interview process, and category formation. Purposive sampling shaped both site selection and selection of participants. This chapter describes the methods used during the investigation and the rationale for the selection of those methods.

Constructivist Inquiry as Methodology

The constructivist paradigm is grounded in a set of beliefs that view reality as multiple and relative. These realities represent mental constructions formulated by persons in specific social situations. Knowledge about these realities is created as the investigator and participants interact to gain an understanding of/about the object of the inquiry. Methods used by the researcher working within this paradigm include those of dialogue with participants as a means by which to gain understanding of the realities as perceived at a specific point in time (Guba & Lincoln, 1994, Lincoln & Guba, 1985).

The constructivist approach is viewed as particularly relevant for health related research that involves issues affecting the interaction of persons within social environments that are context dependent. This approach is also useful for

inquiries that go beyond a focus on direct cause and effect links, especially when there is emphasis on interactions between the mind and body (Lincoln, 1992).

The constructivist (naturalistic inquiry) approach was selected because the topic of "independence" within the context of the nursing home is one about which there is little consensus. Research studies investigating a variety of conceptually related topics have typically neglected examination of the views of the residents living in those nursing homes. These residents, each as a uniquely complex individual, are living within and must interact with an environment that is also complex. Compounding the complexities is the situation in which older adults (age 65 and above) as a population group are more heterogeneous than are other age groupings within society. The heterogeneity represented by this group of persons is brought together within the context of living in a nursing home; such homes typically structured around very specific federal and state rules and regulations guiding the day-to-day operations.

The design for this study was built on the assumption that meanings of independence would be multiple yet would also contain some similar themes around which the meanings could or would cluster. Several assumptions within the constructivist paradigm, are particularly pertinent to and compatible with this study design. These assumptions include:

- 1) the existence of multiple realities that are constructed both by the researcher and the participants;
- 2) the constructed realities can only be studied holistically;
- 3) there is an interaction between the researcher and the participants in which each is influenced by the other;

4) values of the researcher and of the participants affect the decisions that are made during the inquiry process; and

5) working hypotheses rather than generalizations are the intended outcomes of the inquiry (Lincoln & Guba, 1985).

The sequence in which discussion of the methods occurs is also influenced by the constructivist paradigm. Guba and Lincoln view ethical issues as intrinsic to the inquiry when working within the constructivist paradigm. They state that "the close personal interactions required by the methodology may produce special and often sticky problems of confidentiality and anonymity" (1994, p. 115). Compatible with that view, the ethical issues related to this research study are reported next.

Ethical Considerations

The research was conducted in a manner that provided the normally expected protection of human rights of the participants, with specific added steps taken in consideration of the vulnerability of institutionalized older adults. Additionally, because the researcher is also an experienced clinician and nurse educator accustomed to evaluating delivery of nursing care, several actions were taken to facilitate improved care for residents. Presented in the following section is the description of ways in which the rights of self-determination, privacy, anonymity and confidentiality, and protection from discomfort and harm (Burns & Grove, 1993) were addressed. Appendix B contains a copy of the consent form.

Approval to conduct the study was obtained from the University of Virginia Human Investigation Committee as well as from the Research Committee within the nursing home. The individual verbal and written consent process is described with specific attention to considerations taken because of the vulnerable nature of nursing home residents. Coded pseudonyms were created and assigned to each participant as well as to the nursing home. These pseudonyms are used throughout the text whenever names are used with participants' quotes.

The researcher met with the potential participant to explain the study in simple terms, allow for and encourage questions, and obtain verbal permission. Consent of the resident alone was sought rather than from both resident and family. This approach was compatible with the suggestion by Alt-White (1995) that elderly persons may retain the ability to give informed consent for "an uncomplicated, low-risk decision" (1995, p. 702) such as participating in an interview, while being compromised in capacity to make an informed decision regarding participation in research involving a new medication.

An additional reason for seeking only the consent of the resident was the anticipation that some resident might want to participate in the interviews, but would not want the family to know they are talking to someone about the issue of independence. The researcher discussed with each resident the issue of family knowledge of the research, offered to inform the family member of the study, explain as needed, and answer questions if the resident so desired. However, none requested that the researcher contact the family.

For the potential participants who desired it, a copy of the consent form was left with the person for examination prior to deciding to participate. The potential participant was informed that the researcher would return at a later time with the consent form for the participant to sign. The time between obtaining the verbal permission and the signed consent was separated either a meal, a nap, or activity outside of the resident's room. This strategy was used as a way to allow time for the resident to reconsider and/or consult with family, thereby decreasing the potential for the request to be viewed as coercion. Additionally, the strategy provided an added opportunity to assess memory of recent events. If the resident did not remember the initial conversation in which he or she gave verbal consent, this was assumed to be an indication that the person did not meet the inclusion criteria for the study. In one case, a potential participant declined to sign the form, preferring not to participate in the study. The contact with that resident was diplomatically terminated.

The researcher read aloud the consent narrative for each participant, then asked the participant to repeat back to the researcher the essence of that consent. The charge nurse for the shift witnessed the resident's signature and verified that the resident was in his or her usual mental state. A photocopy of the signed consent form (based on Grunder, 1986) was then given to the resident on a subsequent visit. Each potential participant was also informed that they have the right to withdraw from the study at any time.

Privacy was protected by use of several strategies. The interviews were conducted in the participant's room or some other place away from hearing of other people. Participants were informed that they could decline to answer any

question that they preferred not to answer and that they could request that the tape recorder be turned off at any time during the interview. During interviews with three of the participants, the recorder was turned off for varying amounts of time and for a variety of reasons. As an additional measure to protect privacy, only a limited amount of "demographic" information was obtained.

Anonymity of the participants with respect to persons outside of the clinical setting was protected in two ways. Coded pseudonyms were assigned to each participant and are used throughout reports involving the research. The researcher did not disclose information regarding who participated in the interviews. Total anonymity could not be provided because the face to face interactions of the interview process as well as the consent process precluded such anonymity.

Confidentiality of information was protected in the following ways. The researcher avoided verbal disclosure of any content from the charts and protected written work sheets and other data from view by unauthorized persons. Each participant was assigned a coded pseudonym according to a scheme devised by the researcher. Coding sheets containing the participant's actual name and other specific identifying information were protected from unauthorized access. Persons assisting with the transcription of interviews were instructed regarding the need for confidentiality of the information and did not have access to information about the participant other than that contained in the specific interview being transcribed.

In a study such as the one reported here, the issues of possible discomfort or harm are less clearly identifiable than would be the case in an intervention

study. May (1989) suggests that interviewing carries the same risks as does any human interaction. While there are no known discomforts or harms in the usual physical sense of the term, it is impossible to know in advance of an interview whether the conversation may involve a topic that is emotionally distressing to a particular person.

Ramos (1989) takes the discussion of potential harm an additional step in the identification of one underestimated risk of qualitative research interviews. The researcher is admonished by Ramos to be aware of the possibility of the uncovering of problems that require long-term therapeutic interaction in order to resolve. This may be particularly problematic in studies in which the research focus involves topics that once were emotionally painful for the participant.

The topic of independence within the nursing home was considered to be one such topic. Therefore, one criterion for the selection of a site for the research was the availability of channels for referrals by which to handle such situations. No such new referrals were needed. Rather than being emotionally upsetting, there was some suggestion that residents found the interviews beneficial in a variety of ways

Hutchinson, Wilson & Wilson, (1994) describe several benefits that participants may receive as a result of the interview process. Among the benefits discussed are those of self-acknowledgment, sense of purpose, and self-awareness. Several participants in this study relayed a sense of pride in being selected, and implied that their selection provided affirmation that they were still "of sound mind". It was not uncommon for a participant to express surprise upon learning that ten other persons "had their wits about them" enough to participate

in similar interviews as part of this study.

One resident clearly implied that participating in this research study provided a sense of purpose in his life. He remarked on several occasions that participation was one remaining way for him to continue making a contribution to society by helping others.

Researcher as also Clinician

Krefting identified several distinct roles that were assumed by the researcher in the course of the data collection for a dissertation (cited in Lamb & Huttlinger, 1989). The discussion addressed the inevitable dilemmas that are likely to be inherent in the circumstance where an experienced clinician is functioning as a novice researcher in a clinical setting. A similar situation was anticipated with this study. Specifically, it was anticipated that in the course of talking with participants, issues might be raised which, in the researcher's clinical judgment, needed to be brought to the attention of some professional within the nursing home system. The role conflict provides an example of the "special and often sticky problems of confidentiality and anonymity" mentioned by Guba and Lincoln (1994, p. 115)

Issues were encountered that related to possible inadequate care as well as to the need for advocacy on behalf of the resident. This situation brought into conflict the researcher role expectation of confidentiality and anonymity versus the clinician role expectation of action in the best interest of the client. The approach used in addressing the concerns is presented here.

In the researcher's perception, the need for someone to fulfill an advocacy role arose with two residents. One resident expressed concern about always being

made to wait until last for help with her bath, a situation that she interpreted as meaning she was not important to the staff. Discussion focused on the need to let the staff know her wishes. The resident agreed to raise the issue with staff, and later reported that the situation improved after she talked with the nurse.

Another situation in which advocacy was used involved one resident who was experiencing chronic pain, and more recently also having problems with fatigue, anorexia, and weight loss. This resident seemed distressed by these symptoms but was quite reluctant to register her "complaint" with staff. She did, however, give permission for the researcher to relay the concerns in her behalf. By coincidence, the person designated as the agency contact person for the research project was also a part of the professional staff providing care for this resident. Discussion revealed that the concerns were being actively explored in conversations between the physician and the agency professional staff.

Within the context of interviewing in a nursing home setting, the potential exists for the researcher to hear reports of inadequate care, abuse, or maltreatment of residents. One resident did report, as an historical event, a situation in which she experienced verbal abuse from a staff member. However, the resident also reported that the worker's employment was terminated after the Director of Nursing was informed about the incident.

An additional situation related to possible inadequate care was observed by the researcher on one particular unit. There were delays in answering the call bells, a circumstance that was present on several different days, on two different shifts, and had been the subject of several comments in the interviews. Since these delays were occurring on the unit housing the persons experiencing the other

three situations just described, the decision was made to talk with the Director of Nursing about the care provided on that unit. The Director of Nursing expressed appreciation for the observations and information, adding that the researcher's comments were compatible with her awareness of and actions toward improving the quality of care on that specific unit.

Research Setting as Context

Maplewood Retirement Community is a private, non-profit, church related organization located in a scenic area on the outskirts of a town of approximately 40,000 persons. The town serves as the county seat for a large county within a mid-Atlantic state. The geographical area, predominantly rural for generations, is part of a region recently experiencing rapid growth and urbanization. The setting is picturesque, depending upon the perspective from which one views the surrounding landscape. Facing one direction, the view includes green rolling hills, a large church, the campus of an academic institution, and a variety of well-groomed, middle class houses. The buildings are interspersed with many trees, and located on quiet streets. The view from the opposite direction overlooks the town with a mountain range visible in the distance. The foreground includes multiple signs of the recent growth in this once quiet, rural town. A newly widened, five lane highway, and a variety of buildings housing businesses, commercial, and light industry activities provide visual contrasts with memories of a recent past in which this view contained rolling hills, trees, scattered houses, and large farms.

Maplewood Retirement Community is located on a large campus that contains a variety of housing options for older adults. These housing options include an adult home providing residential care for assisted living, federally subsidized apartment living for persons with low incomes, as well as single story townhouses and a newly constructed condominium complex. Persons living within the campus typically have made application for the waiting list for the nursing care facility in the event that they should need that type of assistance. The nursing facility, hereafter referred to simply as Maplewood, contains 120 intermediate care beds including a special Alzheimer's unit.

The structure housing Maplewood is a light brown brick, two level building that contains four nursing units. It is constructed on a grassy hillside in a manner that provides each floor with a direct exit to the outside without the need for a person to climb stairs. Each of the four nursing units carries the name of a geographical landmark representative of this region of the country. The surrounding grounds are carefully landscaped with numerous trees, shrubs, and colorful flower beds. Persons living within the broader campus of the retirement community have easy access to the main entrance to Maplewood.

Upon entering the main lobby of Maplewood, a visitor views a sitting area much like a large living room. The area is well lit, carpeted, contains several groupings of color coordinated chairs and sofas, and a large grandfather clock, as well as realistic looking, artificial floral arrangements and live potted plants positioned on tables. From the entry way, a clockwise examination of the view shows a large window, doors leading to public restrooms, a public telephone, the elevators, hallways to two of the nursing units, several large windows, and a

conference room. The final quadrant of this clockwise journey brings into view a wing containing administrative offices and the receptionist's desk.

The receptionist is easily accessible but off to one side in an area that separates resident areas from staff offices. The receptionist notices persons who come and go, relays helpful interest, but does not attempt to restrict visitors. Overall, there is a feel of quiet, friendly, respectful interaction among the residents, visitors, staff, and administrators that use this area. Most of the "top staff" (Gubrium, 1975) administrative positions are held by persons who are members of the denominational group that operates this retirement community. All persons seem to relate with one another on a first name basis.

The nursing units are designed with 15 to 18 rooms each, divided into three wings on each of these units. A nurses' station, utility and bathing areas, dining room and a small resident lounge form the hub from which these carpeted, short wings extend. Most resident rooms house two persons, but are designed so that each person has a large window for his or her half of the room. Each resident room has individual closet space and a half-bath room shared by the two residents. An emergency call bell system is located near the toilet within the bathroom.

The typical resident's room is furnished with a hospital style bed, call bell system, bedside stand, and overbed table, but also with a wide variety of individualized added items. The individually owned items include any combination that can comfortably fit within the allotted space. Typical items include a chest of drawers, upholstered chair, bulletin boards, pictures, televisions, and radios, as well as items displayed on the wide window sills. Overall, the rooms provide a very clean, home-like atmosphere that seems reflective of the

preferences of the person residing in that half of the room.

By contrast, the small and crowded dining room on each unit has a feel much more like that of an institutional setting. Residents who are being fed by staff are grouped together, while others able to feed themselves with only minimal assistance from staff are seated at tables accommodating four to six persons. Some residents are talking, at times loudly, and at times with words that are not clearly understandable. The more oriented persons are seated together at tables nearest to the door. Although there typically is some talking while waiting for the food to arrive, these oriented residents were not observed to be engaging in social conversation while eating.

Residents are assembled in the dining room before the arrival of the food cart. Those residents able to propel their own wheelchairs tend to enter the room last, just in time for the arrival of the cart. There is generally an "institutional" feel to the serving process. The food arrives in a closed, insulated cart from a central kitchen and is served on trays prepared for the individual resident's dietary needs. For the persons who need only minimal assistance in "setting up" the tray, staff provide that assistance in a quietly efficient manner, asking residents if they need anything else. Although there is an "institutional feel" to the process, it seems that staff know the unique eating preferences of each resident.

The general tone of interaction between staff and residents on the nursing units is polite and respectful, at times also friendly and cheerful with a feel of mutual liking for one another. Staff and residents address one another by first name. The noise level varies by time of day, but usually is reasonably quiet. Unscheduled assistance from staff is obtained in several ways, including but not

limited to the call bell system.

Each resident room is equipped with a call system whereby the resident can press the call button on the cord near the bed to summon staff. When the button is pressed, a light is displayed above the door of the resident's room as well as on a wall panel at the nurses' station. In addition a bell rings at periodic intervals until the call is answered. This bell can be heard in the hallways and usually also from inside any of the residents' rooms. The residents' call bells are attached at the bed and easily accessible when the person is in bed. The bell also can be accessible if the person is seated within about one foot of the bed.

An emergency call bell is located in the bathroom near the commode. This emergency bell activates the same call system, with the added features of a flashing light in the hallway above the resident's room door and a persistent, faster paced ringing of the bell. The emergency bell can be deactivated only from within the resident's bathroom.

Another way in which residents contact staff for assistance is through verbal contact in the hallway to request help. Some residents roll their wheelchairs to the nurses' station to make a request. Others who are seated in the areas near the station make their request of staff persons as they passed by in the hallway.

On one unit in particular, requesting assistance of staff as they walked by in the hallway did not seem immediately effective. Residents seated in wheelchairs at nurses' station would "call out" in general with requests such as to be taken to their rooms. They did not seem to be addressing anyone in particular, and generally addressed visitors as well as staff. When a visitor relayed a resident

request to staff, it was received politely, but with an explanation for their delay in responding. Such explanations typically relayed the message that the staff person knew what the resident wanted but had not yet had the time to honor that request.

Selection of Participants

Sample selection had two components; one focused on uniformity with respect to several characteristics, followed by sampling for maximum variation of views related to specific aspects of independence within the nursing home. This process resulted in a sample whose demographic characteristics generally approximated that of the population within Maplewood.

A purposive sampling strategy was used that included use of a panel of experts, participant nomination, and selection focused toward obtaining maximum variation with respect to several emergent characteristics. The panel of experts was used to compile a list of possible participants with similar characteristics from which to begin purposive sampling for maximum variation on selected other characteristics. The characteristics deemed important for the purposive sampling were emergent and are described in a separate paragraph.

Criteria for Inclusion

The parameters on which the panel of experts was asked to comment included length of residence in this nursing home and the ability to communicate with the researcher about the topic of interest. The specific criteria included (*indicates criterion that were added after the first three residents were interviewed):

Age 65 or above;

Residency of two months or more in this nursing home (Brooke, 1987);

Admitted for long-term care with the expectation of permanent residence in this nursing home;

Able to recall a reason for admission and the approximate date or length of stay;

Able to state opinions about daily life events;

Usually oriented to time, place and person;

Able to communicate verbally in English with the researcher speaking at a reasonable volume;

Not assigned to the special unit for care of persons with Alzheimer's Disease;

* Unable to walk or needing assistance with walking;

* Having at least occasional urinary incontinence.

Additionally, specific aspects of life in the nursing home as related to functional ability of the resident formed the basis for the purposive sampling (see details in later section).

Panel of Experts

The purposive sample was obtained through a combination of recommendations from a panel of experts, nominations by participants, and researcher judgment all guided by the purposes of the research and respect for residents' rights. The use of a panel of experts is suggested as particularly useful when the researcher does not yet know the possible participants in a population (Brink, 1989). A list of specific residents who met the desired criteria was created in consultation with three professional staff persons who functioned as the panel of experts. Each of the three experts functioned in a different role as described below.

The director of nursing provided a roster of all residents for three of the units in the home and indicated the ones that in her judgment met the criteria for inclusion in the study. The social worker reviewed the roster and made comments with respect to inclusion criteria based on her knowledge of the psychosocial situations of the residents. The activities director likewise made comments with respect to the inclusion criteria and, additionally, gave specific information regarding the usual response of the resident to the options of attendance at scheduled activities. If two of the three professional staff persons concurred with respect to eligibility for participation in the study, that resident's name was added to the list from which purposive sampling was performed.

Purposive Sampling Process

Purposive sampling was used with a focus on selection of persons who could present a variety of views regarding issues of autonomy and of independence within the nursing home. Within the gerontology literature focused on autonomy, writers have addressed the importance of choices in general, and the importance of social and diversional activities in particular. Therefore, the first three residents were selected based on their typical responses to available choices of activities to attend within the nursing home.

The first participant rarely attended the scheduled activities and events, preferring to occupy himself with activities suited for "an educated person with a mind" and to walk around the nursing home visiting with staff. The second participant regularly attended and actively participated in many of the activities, walking from her unit to wherever the event was scheduled. The third participant

was selected because she was almost totally confined to her bed, but engaged in many self-selected activities from that bed.

Following the initial interviews with these first three participants, data were reviewed and participant characteristics compared to the physical ability level of other residents on the list of possible participants from the panel of experts. Because it was unusual in that setting to have residents who were both able to walk unassisted and who met the selection criteria related to cognition, the decision was made to add "unable to walk or needing assistance with walking" to the selection criteria. Additionally, because the third participant identified the need to have assistance with toileting as the most notable example of feeling "not independent", an attempt was made to include in the remaining sample persons identified in staff charting as having at least occasional problems with urinary incontinence.

At the end of the first interview with each participant, a request was made for names of other residents who might provide a different view on the topic of independence in the nursing home. The names of any nominated persons were checked against the list of residents determined by the panel to be able to participate. Sampling decisions were then made so as to include residents from each of the three Intermediate Care units, with a mix on characteristics such as gender, social background and religious affiliation.

Sample Description

Eleven residents, eight women and three men, participated in the study. These persons ranged in age from 78 to 96 with a mean age of 86.5 years. Length

of time in residence in this nursing home at the first interview ranged from six months to four years and three months with a mean length of stay of two years and four months. Four of the participants had resided in this building from the time it opened approximately four years before the start of the data collection.

One-third of the participants were of the same denominational affiliation as that of the Maplewood sponsorship and management, a mix representative of that typically found within the population of Maplewood. Educational background ranged from grammar school through college. Work experiences included that of elementary school teacher, news reporter, farm owner, homemaker, factory worker, retirement home worker, business manager, and skilled tradesperson. The sample included both private pay residents and ones receiving Medicaid assistance with the costs of their care. All but one of the participants were either natives who returned to this geographical area in retirement or persons who lived in the area for a major part of their adult lives.

Procedures

Orientation of Researcher to the Setting

A member of the professional staff employed by Maplewood was designated by the Administrator as the contact person for any questions regarding the project. This professional staff person served as resource person to the researcher, providing a tour of the facilities as well as introductions to key staff persons and to the first three participants. When interviews were conducted during the evening shift, the researcher introduced herself to the evening shift charge nurse for the specific unit.

The researcher was provided with a name pin identifying the researcher as "student". Private space for use as needed while on location was provided in one of two places, the facility library or at times a temporarily empty office. Self-orientation to the setting included attendance at a variety of resident group activities and observation of "traffic flow" and interactions while seated in several different lounge areas. Additional time was spent in informal observation of resident and staff interactions while seated in each of three nurses' stations reviewing chart data.

The researcher was an outsider to the Maplewood system in that she had no professional working contacts with this nursing home and did not know any of the participants prior to the first contact. However, the nursing home was located in a geographical area in which the researcher has social network and extended family connections. Three participants made reference to these connections in the context of the get-acquainted interviews. For two of these participants, the "connections" seemed to facilitate their comfort with the interviews. The third participant was quite guarded in her comments, a factor that may have been attributable to the information about "connections".

Data Generation

The interview sequence consisted of an introductory visit followed by two visits in which tape recorded interviews were conducted. A third tape recorded interview for the purpose of member check was conducted with six of the participants.

Residents who met the criteria for the study were contacted, provided with a verbal explanation of the study, invited to participate and if interested, provided with a copy of the consent form for examination. Time was spent engaging in informal conversation during this introductory visit. An appointment was scheduled for later in the same day for the researcher to return to obtain the written consent if the resident was still interested in participating in the study. The consent form was read to the resident, then a nurse staff member was called to witness the signing of the consent. A photocopy of the signed consent was given to the resident.

Interviews were conducted at times selected by the participant, typically with a scheduled meal used as the reference point for the appointment. A small battery powered tape recorder was positioned between the researcher and the participant, usually within the participant's line of vision. Added verbal consent to record was obtained prior to each taped interview. Typical interviews were 30 to 45 minutes in length and were conducted in the participant's room with the roommate absent. Three participants judged their roommates to be unable to understand the conversation and specifically declined the offer to arrange a more private setting. One interview was conducted in an outside garden patio area at the participant's request. Another was conducted in a lounge with a view of the traffic in two halls as a specific strategy to facilitate participant comments about nursing home life.

Brief staff interruptions occurred during the interviews, particularly on one of the nursing units and involving the interviews with the least mobile participants. These interruptions included but were not limited to the

administration of medications and the serving of meals.

The interviews were conducted using a topical interview guide with unstructured questions. Specific topics addressed with all participants focused on four areas:

- 1) general information about their current life events in this nursing home,
- 2) inquiry as to what independence means to them,
- 3) request for examples of times they felt independent in the nursing home, and
- 4) request for examples of times they did not feel independent in the nursing home.

Prior to the second interview, the researcher reviewed the tape recorded first interview and/or read the typed transcript of that first interview. Notes were made of specific topics to explore further with the resident on the second interview. Residents were again asked for examples of "independence" on the second interviews.

As a final step in the data collection, a third interview was conducted with six of the residents for the purpose of a member check regarding the preliminary findings regarding major themes. These six residents were selected because they were the ones still alive and feeling well enough to participate in an interview where the focus was that of a member check. Except for one interview that took place almost eight seven months after the first interview, these third interviews occurred between two and four months following the initial interview with the resident.

Data Management

Reflective notes were written following each interview. Additionally, the tape was checked immediately following each interview to verify that the conversation had been successfully recorded. The tape recorded interviews were transcribed using a computer word processing program, checked against the tape for accuracy, corrected when necessary, and printed with 4 inch right margins to facilitate recording of notes during early steps of data analysis. The 22 interviews (2 each from the eleven participants) yielded 579 pages, ranging in length from 7 to 39 pages with a mean length of 26.3 pages per interview. Content analysis of themes involved several steps.

Each interview contained content that addressed the research questions as well as content that helped provide a description of the context from which this participant was viewing independence within the nursing home. The first step to coding involved identification of the content pertinent to the research questions. Sections of transcripts thought to be related to the research questions were marked on paper, then the computer file containing the complete transcript was used to copy relevant sections into a second computer file for further handling. A peer debriefer selectively evaluated these transcripts to determine that all essential material was included in the sections judged to contain content pertinent to the research questions.

Agar (1986), in writing about ways in which the social world can be studied, identifies the term "strip" as useful to the exploration of meaning. A "strip" can be any variety of data types from which the researcher attempts to understand the phenomenon under study. In this study, the term "strip" refers to a

portion of the interview transcript generally addressing a specific topic.

Sections of data addressing the research questions were separated into strips (Agar, 1986) containing one or more sentences that addressed a specific topic. In several of the interviews, the participants would abruptly shift the topic or thought within a sentence or paragraph. In these cases, the strip was separated in accord with the topics as addressed by the researcher. Care was taken to include enough of the interview segment to preserve the meaning. This process resulted in strips that typically contained more than one theme.

Each strip was coded to reflect the location in the original interview transcript from which it was taken. The strips were printed out on 5 x 8 card stock, paged to accommodate placement of one strip per card, and labeled with code to indicate participant name and interview number as well as card number. The cards were separated in preparation for the content analysis of themes evident in each strip. This process resulted in a total of 612 strips from the 22 interviews, ranging from 11 to 45 strips per interview with a mean of 28 strips per interview. Since the third interviews were used primarily as member checks, the cards containing strips from those interviews were kept separate during the data analysis.

Data Reduction and Analysis

The process of data reduction and analysis for this study involved a number of tactics comparable to the ones presented by Miles & Huberman (1994) as they address the issue of making meaning from narrative data. Themes and patterns were noted, then clustered into dimensions of independence as described

in this section. Miles & Huberman also address the use of metaphor as a device that can be particularly useful when trying to relay complex meanings. The use of metaphor is employed in reporting the results of this research (See Chapters Four and Five).

Several specific questions were used as a focus to guide the analysis of the data. The questions that were asked of the data were as follows:

1. How do the residents use the word "independence"?
2. What are the topics mentioned by the residents as they talk about independence?
3. What meanings of independence are implied from the examples provided by the residents?
4. What information about the functional ability of this resident is evident in his or her comments?

Throughout the process of data reduction and analysis, the following assumptions were used:

1. Topics mentioned by residents in the context of these interviews that addressed life in the nursing home are in some way related to independence for this resident.
2. Resident's comments reflected their opinion at that point in time.
3. Researcher interpretation of and decisions about the data also reflected the thoughts of the researcher at a particular point in time.
4. Researcher interpretation is inherently linked to all aspects of the data analysis process.

The cards containing strips of data were read multiple times and reflective notes written as insights and questions emerged. Many strips contained within the same paragraph references to meanings of independence as well as to functional ability. Therefore a multi-step approach was taken to handle the coding of the data.

Word Use

Content specific to meanings of independence was marked on each card then separated by type of word use. This step was taken to separate textbook or dictionary type use of the term from use of the term to give an example. Added explanation of this step is included in the "Chapter Four - Results - Description of Meanings".

Identification of Topics

Strips were read multiple times, each time noting the topics that the resident was addressing. Topics were written on the cards with any changes on subsequent readings being noted in a different color of ink. The topics were sorted into themes as described below.

Identification of Themes and Dimensions

Themes were identified using the following steps. The cards containing strips of data were examined for themes indicating meanings of independence. These strips were sorted into piles representing categories of related topics. Definitions for the themes were written and used to guide decisions during the

sorting process. The process of sorting the cards into related categories was repeated on multiple occasions until no further revisions were needed.

The resulting themes were clustered into DIMENSIONS OF INDEPENDENCE. These dimensions were developed from the categories of themes that residents mentioned while discussing independence in the context of the nursing home. The Erikson (Erikson, Erikson, & Kivnick, 1986) concept of autonomy was used to guide the formation of these dimensions. The themes and dimensions are discussed in detail in the Chapter Four -- Results - Description of Meanings.

Functional Ability Themes

Strips were again read and marked to identify content addressing the functional ability of the participant. Field notes, in the form of researcher observations and data from resident charts, were used when needed as an added source of data regarding functional ability. Following the identification of themes (described above), a grid was created to better visualize the relationships between each residents' functional ability and the themes they mentioned in talking about independence. The cells of the grid contained coded notes indicating the circumstances associated with needing help with the specific function. Circumstances referred to the predictability of scheduling the assistance, and the urgency of the need for which help was required.

The broad theme of waiting for assistance seemed to be relevant to the interaction between functional ability and participant's meanings of independence. Cards were read again and marked for comments about the process of getting help and of waiting for assistance. Sorting of the data in this manner provided the

primary basis for obtaining the results relative to the second research question (see Chapter Five).

Uniting Themes

"Independence" as used by these residents, was conceptualized within the dual themes of DOING THINGS and HAVING PREFERENCES HONORED, but in light of the functional ability changes that precede the placement in the nursing home setting, the issues become those of NEEDING HELP and WAITING. These broad themes provided a focus for the reporting of results.

Trustworthiness Of Research Process

Introduction

Guba and Lincoln (1989) address the issue of rigor for research within the constructivist paradigm by using parallel criteria for the concepts of reliability and validity in traditional research. For research within the constructivist paradigm, the concepts of credibility, transferability, dependability, and confirmability become the salient ones to describe. Credibility, an approximate analogue to internal validity, was obtained in this study by a combination of prolonged engagement, persistent observation, peer debriefing, and modified member checks.

Credibility

Prolonged and Persistent Observation

The data generation occurred over a time span of eight months. Orientation to the setting consisted of the researcher meeting with a variety of

administrative persons within Maplewood, then spending time in self-orientation attending a wide variety of group activities in which residents participated. Additional time was spent informally observing a variety of interactions between residents and staff. Although the time period spent within the setting covered a span of eight months, the researcher's involvement in data generation was interrupted for several weeks on two occasions because of personal life events. On each occasion, as part of the return to the setting, re-orientation included re-reading of field notes, talking with the social worker for an update on events and conditions of residents, observing resident group activities, and observing resident and staff interactions.

The effectiveness of the observation in obtaining information about characteristics of the setting that were relevant to the study is illustrated by two situations. As discussed in the section regarding ethical considerations, the researcher scheduled an exit interview with the Director of Nursing to discuss a particular concern about quality of care being provided on one unit. The director's comments indicated that she, too, was aware of those issues, in effect confirming the accuracy of the researcher's interpretation.

The second situation that adds to the creditability of this study was much more one of serendipity. Another researcher, apparently using a clinical setting much like the one used in this study, reported findings quite supportive of a major finding in this study. Brubaker (1996) used observational methods to explore the nature of self-care in nursing home residents. Brubaker identified waiting as a theme that was problematic for residents, a finding that parallels one of this researcher's findings. The theme of waiting is discussed in detail in Chapter Five.

Peer Debriefing

Peer debriefing was used in several ways to facilitate credibility. An experienced nurse clinician was asked to selectively review and comment on several aspects of the interviews. The first comments related to the interview style of the researcher as recorded on the transcripts while the second review addressed the process of "first cut coding" of the transcripts. The interview style was reported as facilitating of resident expression of opinions. The reviewer also validated the researcher's decisions about separation of the transcripts into contextual information and that information possibly pertinent to the research questions.

Decisions about coding of themes were also validated by a peer debriefer. The reviewer was given sets of cards containing the final designation of themes as well as the pages listing the definitions of those themes. The reviewer was asked to comment on the degree to which those themes were relevant in light of the definitions provided. There were few cards in which the reviewer did not agree with the coding. In each case, upon discussion, it was determined that the researcher's decision about the assigned code was based on contextual information about that resident, to which the reviewer did not have access.

Member Checks

A limited and modified form of member check was used as part of establishing credibility. During each interview, clarification and re-phrasing were used when needed to gain an understanding of the resident's views. Additionally,

six of the residents participated in a third interview. In each of these interviews, the researcher informed the resident of the preliminary theme of waiting as the major concern that had been expressed and that waiting seemed related to the process of getting the help that they needed. Resident's comments were invited. The comments generally took the form of agreement that the theme was relevant, followed by further discussion of various aspects of nursing home life. Information from these third interviews was not used as part of the category formation. However, in reporting the results, several quotes are included from those interviews because they provided clearer examples of some theme that had been identified in previous interviews.

Transferability

Transferability, as the parallel to external validity and generalizability (Guba & Lincoln, 1989), was not the intent of this research. Description of the setting in which the research was conducted as well as brief description of the group of participants is presented to help readers determine the degree to which this research setting is similar to ones with which they may be familiar. The detailed description of Maplewood is presented in this Chapter (see Research Setting as Context). Additional descriptive information about the participants with respect to their functional abilities is presented in Chapter Five.

It should be noted that both the purposive nature of the sampling process as well as the purposive selection of the setting limit generalizability of the findings. The researcher intentionally selected a nursing home with a long established reputation for high quality care of residents. This strategy was used to

lessen the chance of obtaining meanings of independence that were shaped by concerns over inadequate or improper care.

Dependability

Dependability is described by Guba & Lincoln (1989) as stability of the data over time and analogous to reliability. They caution that sources of data instability can be inquirer boredom, exhaustion, or psychological stress. Data instability of this undesirable type is specifically differentiated from the shifts in method and in interpretation that are a strength of the constructivist research design (p. 242). The issue of dependability as it relates to both potential sources of data change was encountered. The processes by which dependability was addressed are discussed below.

Stability of the data over time presented the researcher with a challenge because the data analysis phase of the research was interspersed with several personal life events that interrupted and extended the inquiry schedule. Several strategies were used to address this potential threat to accurate representation of the residents' views. These strategies included repeated review of data at specific points during the inquiry process, use of a method log and reflective notes, and extended discussions with a peer debriefer.

The detailed descriptions of each resident that were compiled from field notes and from information within the transcripts of the interviews were used as the primary method for re-acquainting the researcher with the participants and their contexts each time that data analysis was interrupted for longer than a few weeks. Additionally, selected sections of the audiotapes were reviewed to refresh

the researcher's memory of speech patterns of the residents. This process allowed the researcher to once again visualize the person whose comments were being analyzed, thereby linking the printed transcript strips with the context from which that resident was speaking.

A method log was maintained for recording specific decisions and changes in researcher thinking throughout the inquiry process. The method log, field notes, and strips of interviews for each participant were reviewed at the start of each block of time spent in data analysis. During such reviews, additional reflective notes were written.

Concurrent experiences in the personal life of the researcher included extensive involvement with family members and a friend, each of whom were facing major issues related to their independence, interdependence, and autonomy. It is recognized that these experiences likely shaped the thinking of the researcher in ways that are not easily recognized or documented. Possible shifts in researcher thinking that resulted from involvement in those activities that were interspersed with the data analysis are addressed in the Epilogue.

Throughout the data analysis phase of the inquiry, one person functioned as the consistent peer debriefer. The debriefer possessed qualifications of doctorally prepared nurse researcher, experience in using the constructivist paradigm during a research course and project, experience as a nurse clinician, and willingness to challenge the thinking of this researcher. The researcher and peer debriefer discussed various aspects of the shifts in thinking that were evolving as the data analysis continued. Although a formal audit of the research process by an external evaluator was not part of this study, the peer debriefer did

examine many of the paper products produced as the research process evolved into the final interpretation of findings.

Confirmability

A final criterion for judging the adequacy of research within the constructivist paradigm is that of confirmability, analogous to objectivity within other research traditions (Guba & Lincoln, 1989). Described in this section are the steps taken to ensure that the findings are rooted within the contexts of the participants at Maplewood.

Materials containing data about each specific participant were coded with pseudonym, date, and description of the context in which the interaction or observation took place. These materials were maintained in paper files bearing the code name of each of the 11 participants. The complete transcripts of each interview, the resident descriptions, pages containing notes from review of the resident's chart, and added field notes specific for that participant were included in the files.

The strips of data that were printed on cards for use in the data analysis process were labeled with code to indicate the exact pages and lines from which the strip was taken on the complete transcript. This coding of the strips was particularly useful as a means by which to track quotes to the original transcript, thereby enabling the researcher to interpret the quote within the context in which it occurred.

Two strategies were used to ensure that the interpretations and outcomes of this inquiry are grounded in sources beyond the researcher's biases. Meetings

with the peer debriefer included specific discussions about the existence and handling of biases held by the researcher. The modified member checks also served as a limited verification that the general findings were compatible with the resident's views of independence within the context of the nursing home. Both of these strategies were addressed in an earlier section of this chapter.

Informal confirmation of the relevancy of the findings for older adults was obtained from a retired Registered Nurse experienced in the care of older adults in a nursing home setting. In response to discussion of the themes and dimensions of independence, this expert reported that the researcher seemed "to be on to something important". Additionally, when presented with the examples of needing help with toileting as an important symbol of limits in independence, the nurse expert immediately confirmed the finding by adding similar examples from her practice setting.

Summary of Methods

This research was conducted within the assumptions of constructivist inquiry using methods of unstructured interviews with selected nursing home residents. The residents were purposively selected for their abilities to provide multiple and varied perspectives on the topic of independence within the nursing home context. Data analysis of themes is presented in the next two chapters.

Chapter Four reports the descriptive findings, while Chapter Five covers the interpretative findings from this research. Each of these chapters incorporates use of the metaphor of meanings of independence as a piece of fiber art. The idea for this specific metaphor was, in part, inspired by writings of Joan Erikson

(1988) in which she describes the life cycle and stages using images of weaving strands of specific colors into a rectangular picture representing an individual's unique life history.

Chapter Four Results

Description of Meanings

Introduction

The meanings of independence in the nursing home present polarities that are framed by divergent views. These views range from that of Bertha who insists that living in the nursing home allows, even helps, her be independent to that of Frank who considers independence to be an irrelevant concept because this is "a different world" with its own rules and values. This polarity is linked to functional ability in that Bertha and Frank represent the extremes of the sample with respect to their physical ability to move about and care for themselves. The polarity of meanings is additionally linked to individual identities and life histories. Bertha has a long history of needing the support of institutional life so that she can function in ways that she considers important. Frank has a long history of running corporations and using formal and informal political power to change undesirable situations. Frank's history included assembling resources and equipment so that he could continue to be politically active even when he could no longer walk. The intertwining of functional ability with the unique personal style of the individual results in highly individualized meanings of independence within the nursing home.

These differences are apparent in the residents' responses related to each of the research questions. Each response becomes part of the colored glass of a kaleidoscope that, when viewed as a whole, reflects the meanings of independence to this group of nursing home residents at a particular point in time.

Research Question One

Research Question One for this study is: Within The Context Of A Nursing Home, What Are Selected Residents' Meanings Of Independence? Residents were asked to talk about what independence means and to give examples of times they felt independent in the nursing home. The researcher specifically asked residents what independence means to them now within the nursing home setting. Residents were also specifically asked for examples of feeling not independent. When necessary to facilitate discussion, this inquiry was presented within the context of the common lay public association of "loss of independence" with living in a nursing home. Additional questions about daily life were posed as a way to help residents start talking on the general topic of independence in the nursing home.

Residents responded to the inquiries by using words for independence in different ways. The responses took the form of both definitions and examples. Examples included those from both the residents' present and past experiences as well as occasional references to independence in some other person. All these references to the term *independence* mentioned by the residents were assumed to be in some way important to their meaning of the concept and were included as data.

All (n=11) residents gave examples to illustrate what they meant by independence. In all there were 193 references to independence. Residents' references to independence ranged from 8 to 25 with a mean of 17.5 per person. Within each example, there were at least one, and typically several, themes represented.

The topic was of sufficient interest to 10 of the 11 residents that they were willing to discuss it freely and thoughtfully. One resident, who was particularly guarded in all her comments, answered direct questions but did not readily give specific examples. She possibly considered the topic irrelevant in view of her definition of independence "it means that you can help yourself" (k1*11) and her references to herself as "helpless". This response, coded as a definition, was one of only three definitions obtained in the interviews.

The three persons who responded by initially attempting to give a definition of independence expanded on those definitions (one with some coaxing) with examples that were compatible with their definition. They also commented on the topic with a more personalized use of the term. All participants gave examples of independence that included situations and/or activities within their current capabilities as well as ones for which they currently experience limits. These examples included spontaneous statements about what independence is not and/or examples of times in which they felt not independent.

When asked directly about feeling “not independent”, eight (8) persons gave examples reflecting some current situation affecting them. The resident who guarded her responses gave examples from the distant past. Another resident who was having problems with short-term memory, gave only examples of “not independent” from her past and from the experiences of others. The remaining person who viewed herself as more independent now that she is in the nursing home gave examples only from her past experiences with illnesses and injuries.

The findings of the study related to Research Question One - (Within the Context of a Nursing Home, what are Selected Residents' Meanings of Independence?) are presented by first discussing the pattern of word use, with quotes selected to provide an overview of the variety of responses obtained. Then the emergent themes are presented, clustered into dimensions of independence. The examples are presented both to compile a composite of meanings of independence within the nursing home context and to give voice to the residents. The quotes are followed by bracketed code that indicates the location of that quote in the interview transcript. Discussion of the pattern of word use follows.

Word Use - Definitions

Statements were examined for type of verbal data in order to ascertain that residents were not simply giving word use or "dictionary type" information

(Steeves, 1992). Additionally, this approach to data analysis was taken initially as a way to guard against the tendency for response bias, particularly in older adults who sometimes become overly concerned about giving "the right" response.

"Dictionary type" definitions of the term were given by three persons.

Bertha "Independence, to me it means you don't have to have help with your activities. That you can go on your own, and go when you feel like it". (b2*2).

Katie "well, it means that you can help yourself." (comment followed by a long pause) (k1*11).

Arthur "Another word for independence? It's loss of the things you had before, the loss of your faculties, it's loss of independence is what it is. It's not independence.... Yes, I think it's more of a loss of your faculties ... the ability to see, to write, to talk, to do all the things that you could." (a2*20,21)

Word Use Examples Of Independence

By far, the residents' meanings were expressed most vividly in the examples they used as they talked about independence and life in the nursing home. The balance of the comments is interesting with respect to the frequency of themes reflecting current abilities versus those reflecting current limits in ability.

The responses from six (6) persons gave more items covering current abilities than they did covering limits. Five persons displayed an opposite pattern in which they had more themes reflecting areas in which they are currently experiencing limits. Of these five (5) persons, three (Dora, Elsie, and Irene) responded with some variant of "I cannot think of any example of independence

in the nursing home." Another resident (Katie) avoided the question several times, and the fifth resident (Frank) shifted the discussion to a focus on the nursing home as a "different world" to which one must simply "adjust themselves" difficult though this adjustment may be.

Selected quotes are presented as examples of the residents' responses. These quotes are separated into two groups representing current abilities, then those representing current limits to that person's ability.

Current Abilities.

Residents talked about independence, using examples of activities that they currently can do. In response to the question "What do you consider being independent?" Arthur responds "being able to pay my bills is the first thing.... I don't have to worry (about) money" (a1*7) This theme is echoed by Elsie who expands it to also mean control of that money "Yes, Independence, have your own way - money - and don't put your lock box (where others have access to it)." (e1*17). Clara identifies independence to include:

Clara - "they tell me I can settle down for the night anytime that I want to. I'm usually the last one to bed." (c1*7) and "they have no objections at all to my knitting. And I enjoy that. Well, I have freedom to do some things here in bed. Have company. Of course the visitors are not supposed to come just any time of the day or night." (c1*9).

Harry suggests that independence includes an element of control.

Harry - "Well, you have (independence to) the extent that you are the manager of your own affairs. You direct when you want to go and where you want to go. They don't just come and grab you and take you wherever they want to take you. You are using them as helpers. ... They take you where you want to go." (h1*4).

Grace implies several meanings but also provides hints to her cognitive functioning in her response to being independent here.

Grace - "It seems I can just about do as I please in anything. I don't know if I am exactly independent or not because I haven't signed - I am not signed up to them. I guess I'm signed up that I am here. But that's all, I think. I'm free from any of the work, and I have been for a number of months." (g1*3)

Irene commenting on a time she felt independent, implies both a meaning and her view of appropriate limits on her independence.

Irene - "They don't force you to do anything. They will make suggestions to you sometimes, but they don't force you. You are pretty much independent here, in a way. But then if there is things that is not good for your health, that's another thing that they won't - say for instance, if I want something that's not good for me, they will tell me `you are not allowed to have that'" (i1*2).

Joanna mentions privacy and freedom from worry about future lodging.

Joanna - "Well, here in the room, you see, we are alone, by ourselves, separated. We got this little room here, and that makes us independent. And if I would run out of money, you see, then they go with some other organization which they have to pay it - they pay it. ...I can stay here as long as I live. See, that makes you independent, in a way." (j1*2,3)

Joanna further describes her independence in the nursing home as being involved in caretaking of her roommate.

"I help them (the staff), I read her (the bedfast roommate) stories, ...and I come in here and sit and talk to her about different things. ... Then at night if she gets sick or anything I'd call the nurses if I was awake." (j2*2).

Joanna when asked about the importance of being independent in the nursing home added:

"Well, I think its right smart important to be that way. They (staff) never

have got after me about anything yet, anything I do. That way, I feel like we got a good bit of independence." (j2*22).

Current Limits On Abilities

In their attempt to explain what they meant by independence, residents also used examples and mentioned activities that they once could do, but cannot do currently. A sampling of these follows.

Katie provides concrete examples from her life experiences and abilities prior to moving to the nursing home. She then addresses independence in terms of what has changed for her.

"Well, naturally, you have to give up driving and of course, I was handicapped and can't walk. And so I feel very - oh, the girls that wait on me try to tell me that I'm not - helpless. I do a lot with my one hand." (k1*10).

Dora implies added meanings in her examples of ways in which her illness has affected her independence.

"I can't write much any more, I can't play the piano or organ like I used to. I can't entertain friends, can't get meals for them. (d1*3).

Irene in discussing her housekeeping activities prior to the move to the nursing home -

"I call that being independent. You don't need someone to help you. You don't have to depend on somebody else." (i2*17).

Examples of "Not Independent"

The researcher specifically asked for examples of times the resident felt "not independent". All but one (n=10) gave some specific example of feeling "not independent" though the references came from both current nursing home

experiences and events prior to admission. Two examples are given here, each example reflecting several themes within the segment of conversation.

In response to the researcher's question - "Can you think of a time or an example of feeling not independent?" Clara replies:

Clara "Oh, (pause) - [laughs] when I need to sit on the commode, and I ring the bell, and nobody comes for so long. [laughs, almost chuckles]. That's one time. [laughs]

Researcher - "so its the getting out onto the commode, that's when you don't feel very independent?"

Clara - yeah. [laughs]. I have to have help for that.

Researcher - "is it the needing to wait? or is it the needing to have somebody help you out?"

Clara - "well, its both. The discomfort of waiting and it depends on - I mean that's caused by the waiting for help. Sometimes they are just awful busy. They say they are short of help nearly always on weekends. And then I think there have been times that the bell was cut off without being answered {this said in a softer voice, as if to insure that she was not being overheard by staff}. I've been told that that's happened. And it seemed like it. Well, I - lets see, was it Sunday - I came back from the chapel service, somebody brought me back - it wasn't a worker here and they couldn't put me to bed. I rang the bell and they said they were busy with meals now, they couldn't help me. So I sat up and I ate my dinner sitting up and - see how did I get - Oh, the one that brought me in the wheelchair helped me from the wheelchair into that chair you're in. And I ate my dinner there. Anyway, sometimes they just can't seem to come and help you."

Researcher "Umm, that would be hard."

Clara "Yeah, that's when I'm not independent. Yeah, I am dependent."
(c1*11,12)

Frank - when asked for an example of a time he did not feel independent referred to a period in which his electric wheelchair was not working.

"Well, for instance, if I wanted to move around, I would have to wait. For instance, sometimes you can't get anyone for one-half hour. And that's not generally - they answer the call very readily. But you get the feeling you are helpless when you can't move and are stuck here (in the room)."
(f2*22).

Themes within Examples

The statements initially examined for type of word use provided an initial list of topics indicating these residents' meanings of independence. The analysis of statements was then expanded to include all topics mentioned by the residents in the context of talking about independence within the nursing home. The focus of this re-examination was to identify additional topics used indirectly within the context of the general discussion about independence. This approach was based on the assumption that any topic raised by the resident was in some way related to independence from the perspective of the participant. Following repeated readings, the topics were sorted into 23 themes, then clustered into five (5) dimensions of independence.

Figure 1 lists, in outline format, these themes with their corresponding dimensions of independence. Appendix A contains the descriptions of these themes and dimensions that were used to guide the sorting of topics into categories.

FIGURE 1
FIVE (5) DIMENSIONS OF INDEPENDENCE

Each dimension contains themes that relate to that dimension in a variety of ways. Additionally, the strands “DOING THINGS” and “HAVING PREFERENCES HONORED” are represented respectively by the ink and paper on which these themes are printed.

MOVING ABOUT THE ENVIRONMENT

- Handling Things & Reaching
- Positioning & Turning
- Getting Up
- Walking
- Traveling

CARING FOR THE BODY

- Bathing
- Grooming & Dressing
- Eating
- Toileting
- Managing Physical Conditions

HAVING RESOURCES

- Vision & Hearing Ability
- Ability to Think & Talk
- Material Resources
- Adaptive Equipment

BEING ONESELF

- Having Wishes & Preferences
- Staying Connected
- Staying Occupied
- Managing Own Affairs

INTERACTING WITH THE SOCIAL ENVIRONMENT

- Living Space (Physical Circumstances of Living)
- Institutional Rules & Policies
- Schedules
- Choices
- Self-imposed Behavioral Expectations

Uniting Themes: Doing Things and Having Preferences Honored

Presented in the section that follows are the descriptions of dimensions and themes of independence that are evident in the statements of these residents. However, fundamental to the understanding of meanings of independence as described is a conceptualization of independence as also having two interwoven general meanings - oversimplified in the labels of "DOING THINGS" and "HAVING PREFERENCES HONORED".

The two strands of general meanings, "DOING THINGS" and "HAVING PREFERENCES HONORED" representing ability and self-determination, both support and permeate each theme of independence. Each example presented as part of a theme contains not only a topic, but also an implied meaning that involves both ability and self-determination, labeled "DOING THINGS" and "HAVING PREFERENCES HONORED". An understanding of the existence of these two strands is central to the discussion of the relationship between functional ability and meanings of independence within the nursing home context that are addressed in Research Question TWO. Within the nursing home context the general meanings of independence as "DOING THINGS" and "HAVING PREFERENCES HONORED" become distorted by threats to independence. Those symbolic threats are presented as the circumstances of "NEEDING HELP" and "WAITING".

Metaphor of Independence As Fiber Art

An analogy of independence as a piece of fiber art is useful in visualizing the overlapping and interwoven meanings of independence as expressed by these

residents. The inter-relatedness of the two strands with the five dimensions made up of the twenty-three themes, can be viewed as a loosely woven, three dimensional creation made up of a variety of fiber types woven into a variety of shapes.

The fiber art piece is designed from a base of loosely woven strands of material. "DOING THINGS" and "HAVING PREFERENCES HONORED" represent the warp and woof of the cloth base, made from strands of fibers such as wool and elastic. From that base are interwoven five types of yarns, representing the five "dimensions" of independence. Each type of yarn (dimension of independence) is multicolored, with colors representing the four or five themes present within each dimension. The three dimensional shapes that are created by the process of weaving and braiding the yarns and fabric are as varied as are the meanings of independence held by these nursing home residents.

There is considerable overlap between and among the five dimensions as well as among the themes representing meanings of independence. Likewise, there is considerable overlap between the strands of "DOING THINGS" and "HAVING PREFERENCES HONORED". The following distinction is made to facilitate clarity. "DOING THINGS" represents activities and implies presence of ability to perform those activities. "HAVING PREFERENCES HONORED" represents the quality of those activities and the circumstances surrounding the activity. These preferences serve as expressions of the "self-determination" aspect of independence.

Although the two strands are only occasionally addressed throughout the presentation of the dimensions and themes, the existence of "DOING THINGS"

and "HAVING PREFERENCES HONORED" within the examples is an essential part of each meaning. The overlap between and among the strands, dimensions, and themes illustrates the dynamic nature of individuals who live within a social context.

Dimensions of Independence - Descriptions

Moving About the Environment

The first dimension of independence, labeled MOVING ABOUT THE ENVIRONMENT, contains themes of physical abilities that are needed in order to carry out the second dimension, CARING FOR THE BODY. In this respect, these two dimensions are quite intertwined. The distinction between the two dimensions is as follows: MOVING ABOUT THE ENVIRONMENT represents the processes by which the person performs the tasks of CARING FOR THE BODY. MOVING ABOUT THE ENVIRONMENT implies the use of the musculoskeletal system, and any needed equipment, in the process of completing a task. CARING FOR THE BODY represents themes that are somewhat analogous to the specific tasks within Activities of Daily Living (ADLs) that are typically provided by caregivers in nursing home settings.

Themes within the dimension of MOVING ABOUT THE ENVIRONMENT and the associated examples are presented below. HANDLING THINGS AND REACHING represents the ability to use the hands and arms to manipulate and obtain objects within arms reach of the person. Bertha and Dora provide examples of this theme.

Bertha - "Independent? Well, making an afghan is something - that is using my fingers" [b1*12]

In response to a question about what it would take for her to feel more independent, Dora responded "You mean besides getting my hands and feet back to normal?" [d1*29] then at another time "Well, I can't walk and I can't use my hands hardly. I can't use the telephone". [d2*3]

POSITIONING AND TURNING refers to activities in which the person purposefully moves the body in bed or in a chair into desired positions. Clara, Frank, and Irene illustrate this theme.

Clara, after linking limits to independence with the theme of needing help, added an example "I can't turn myself, I can't really lie on either side." [c1*6]

Frank illustrated this link by directly asking the researcher for assistance "Would you raise those pedals up?" [f2*2]

Irene provided an illustration of her attempts to be independent by using her cane to pull up the footrest to her wheelchair "You know, day for instance, I want to elevate my foot. See, I take this cane here and hook in on to the bottom - take it like this - hook it here." [i2*35]

GETTING UP refers to the ability to move the self from the bed or chair, and to transfer to a wheelchair or other chair by supporting one's body weight. Clara and Frank, both of whom need help with transferring, provide examples for this theme.

Clara in talking about how she could feel more independent here replied "if I could wait on myself more. If I could get up out of bed when I wanted to and go to the bathroom when I wanted to - I'd naturally feel more independent". [c1*13]

Within a context of talking about freedom, Frank comments "I think it's

important that you reserve the right to eat things that you enjoy eating. And I think freedom to get up out of bed into the wheelchair to go as far as you possibly can". [f3*6]

WALKING refers to the ability to move about the room and within the nursing home by using muscle strength of the feet and legs, and including the use of assistive devices such as a walker or cane.

Dora's example of feeling not independent includes "Well, sometimes they take a bus load of us to the mall or some place and I have to just sit in the wheelchair, I can't get out and walk around or anything". [d1*7]

Harry responds to a question about how physical ability might affect a resident's independence with "It does. Quite considerably, because if - take my condition, I have polio - the result of polio, my entire left side - I can't use my left leg as well. I'm physically handicapped (laughs) not so mentally". [h2*16]

Arthur is talking more generally about independence for persons in the nursing home when he identifies walking as an example, but also expresses some of the complexity involved in separating the concept into specific discrete parts - "These people here, there are so few of them that could do anything - can't do anything for themselves, so what does independence mean to them? There are very few who aren't in wheelchairs. Most of them are these - oh, what's this name of this crazy disease they have? (points to head). Alzheimer's, yes. Most of them have that or they are extremely senile, or they have had strokes. Some of them can hear but they can't speak. They can't walk. So I don't quite follow just what you mean by independence". [a1*6]

TRAVELING refers to the ability to move about outside of the nursing home, including around the campus, into other buildings, and travel off campus.

Elsie comments on what it would take for person to be more independent "Well, for them to have a car and go out. I can't drive or nothing." [e2*16]

Katie attempts to define independence in terms of driving "Well, naturally, you have to give up driving and of course, I was handicapped and can't walk." [k1*10]

Irene "Say for instance, maybe if I had a car and was able to drive. But if I had a car and was able to drive, I would have to be somewhere else. I wouldn't be in a nursing home." [i1*10]

In summary, the dimension of MOVING ABOUT THE ENVIRONMENT represents the ability to use the musculoskeletal system in the process of performing tasks that the resident considers important to his or her life.

Caring For The Body

The dimension of CARING FOR THE BODY is closely intertwined with the themes associated with MOVING THE BODY WITHIN THE ENVIRONMENT presented above. The relationship is akin to that of outcomes and processes requisite to achieving those outcomes. The categories of activities within the dimension CARING FOR THE BODY represent aspects of daily life which adults typically expect to perform unaided. Except for the theme MANAGING PHYSICAL CONDITIONS, the themes within the dimension of CARING FOR THE BODY are similar to Activities of Daily Living (ADL) commonly used within gerontology literature. Themes within the dimension of CARING FOR THE BODY and the associated examples are illustrated in the section that follows. Closely related themes are evident in the overlap within these statements.

BATHING refers to activities associated with the daily hygienic function of "washing up" at bedside or in the bathroom. Examples are provided by Clara and

Harry, with both comment demonstrating the overlap of themes within statements.

Clara "I don't know what you - hardly what you would call independence here.... Well, I'm just so handicapped - I can't even get on the potty by myself. And I have to have - my bath, they give me my bath and everything else I need." (c2*2,3).

Harry "Well, see, I'm dependent. I'm dependent when I can't get up and get dressed and cleaned up and dressed." (h1*29).

GROOMING AND DRESSING refers to the activities associated with getting dressed and undressed as well as the daily care of the hair and teeth. Harry in the above comment addresses this topic as an example of independence. Joanna provides added detail.

Joanna, in response to the interviewer request for her opinion, "For a person in the nursing home, if their body doesn't work good for then, then how do they stay independent?" replied with this statement.

Joanna - "well - that's it. They will take care of you themselves if you need it. And they help me often times - with different things that I can't do, and like that. Now today, they made up my bed ... I had a tub bath this morning. They got me up, took me up and give me a tub bath. And helped - uh, dressed me and everything - and brought me back, and I waited for breakfast then." (j2*5).

Eating refers to the activity of consuming meals at the scheduled times.

Joanna and Frank provide examples linking this theme to independence. Joanna comments within the context of describing absence of independence for her bedfast roommate.

Joanna - "she wants help all the time. And she wants this, and she wants that ... She is pretty sick, I think ... But she may just go any time, I think. That's the way she is, the condition she is in now. They ... take her down

to the dining room and feed her down there. Or sometimes they come in here and feed her..." (j2*12).

Frank, in the context of talking about the process of adjusting to this "different world" of the nursing home (the terms he substitutes for the interviewer's language of "independence") comments about eating in a manner suggesting that needing help in this area is particularly difficult to accept.

Frank - "well, I thought about taking my life, a couple months after I came in here. I stopped eating. I found out that to commit suicide I could just stop eating, and didn't eat any more after that for a few days. If anybody wants to end their life, that's the way to do it, just stop eating. And then I got so that I couldn't feed myself - and that's when they came to the same conclusion and then from now on, they feed me. (inaudible) so I have to accept it. If anything is any more (inaudible) it's somebody that can't do it - feed themselves." (f2*15).

TOILETING refers to activities related to the handling of bowel and bladder functions, including any cleaning that is needed. The theme that seemed the most difficult for residents to raise was that of linking the need for assistance with toileting to feeling not independent. Clara, who needed the assistance of at least one person to transfer to and from bed, clearly identified this theme. However, Dora and Frank, the two participants who were the most limited in their mobility, requiring two persons for transfers, were less clear in their references to this theme.

Clara, in response to a query about feeling not independent replied: "Oh, (pause) - [laughs] - when I need to sit on the commode, and I ring the bell, and nobody comes for so long. [laughs, almost chuckles]. That's one time." (c1*11).

Dora, after a 25 second pause following the researcher question of "What other kinds of things can you think of that you don't feel very independent

here in the nursing home?" responded: "Well, sometimes I have to go half a day without having my - my clothes changed [motions slightly toward crotch]. Maybe I shouldn't say that here. The nurses are too busy or something. And that makes you feel awful." (d1*12).

Frank had been talking about being helpless and needing to depend entirely on another person, when he responded to the researcher question of "A couple of other people have commented about times that they did not feel independent were when they needed to go to the bathroom but couldn't get there by themselves. Is that - I would just like to see what your response it to that."

Frank - "That's just one of the adjustments that you have to make. It's pretty tough, pretty tough adjustment to make. ... but it's one of the worst adjustments there is, one of the tough ones - it is." (f2*24).

The linking of waiting with the need for assistance with toileting will be addressed in a later section. It is noteworthy that Clara, Dora, and Frank all resided on the same nursing unit and were the only ones that gave this specific example for not independent. The researcher also observed that, on this unit in particular, the "call bells" rang for noticeable lengths of time (up to 5 or 10 minutes) before they were answered. This delay in responding to the bells was observed to correspond to times when all staff seemed to be engaged in assisting other residents.

MANAGING PHYSICAL CONDITIONS was an unexpected theme that emerged during data analysis and placed within the dimension of CARING FOR THE BODY. Topics within this theme represent activities on the part of the person to achieve a desired end (such as control of symptoms). This theme also overlaps several themes within the dimension of INTERACTION WITH THE SOCIAL ENVIRONMENT. Arthur and Dora illustrate this theme.

Researcher - "Can you think of some examples of times you did not feel independent here? Like things that happened or times that you didn't feel independent."

Arthur - "Yes, like times the pain is so intense that it would be nice if I had a doctor here. Or if I had a doctor, it was a good doctor. I have got the doctor I have because you've got to pick from a list of 16 doctors one that they will okay. They have to agree to accept an assigned amount of money. Well, you don't find many doctors that will do that now days. And in picking that doctor, the man hasn't seen you more than a few minutes. He doesn't know you from Adam. My regular doctor would refer - I asked him to send me to the most lenient man he could find because I need a lot of Percodan - to tell the truth. And if I expect to have any reasonable amount of comfort, this doctor is very lenient that way. The other doctors, if you say Percodan, it's almost like you wanted a shot of 10 milligrams of morphine ten times a day. They'd put their hands up - they only think of how that affects them. I miss being able to find a good doctor." (a2*10).

Dora, after talking about how her arthritis limits her ability to walk or move easily, mentioned a home remedy (vinegar, honey and warm water) that had provided relief prior to her admission here. She then comments:

Dora - "That little finger would get a knot on it sometimes and if I would go take a dose of that, it would clear in an hour. It would go down, not hurt. (pause) And I've told a lot of people about it, and they tried it and it's helped them. I don't know here - I don't know - that's one thing that I don't feel independent about - I can't take that. I don't have no place to keep it here. Unless I would put it out in the refrigerator. I don't know if they would want to be bothered with it on not." (d1*9).

In summary, the dimension of CARING FOR THE BODY represents aspects of daily life which adults typically expect to perform unaided. When the adult needs help with these activities, the condition or circumstance of needing help becomes symbolic of a limit to the independence of the individual (i.e. they

must now depend on someone else for the assistance). The fact that they must rely or depend on another person for assistance places in jeopardy (at risk) the degree to which one can "HAVE PREFERENCES HONORED". The risk is present because there are qualitative factors within the conditions of receiving the help which can negatively impact the extent to which the person retains a degree of self-determination within the circumstance of needing help to "DO THINGS".

Having Resources

The dimension of HAVING RESOURCES covers both tangible resources and personal abilities that the residents use to facilitate their involvement in desired activities. Possession of such resources can function to inform others of one's preferences as well as compensate for limits that are present in ability with MOVING ABOUT THE ENVIRONMENT and/or to CARE FOR THE BODY. Personal ability resources that affect how a resident interacts with the environment include vision, hearing, and the ability to think and talk. The theme of VISION AND HEARING represents comments about either of these senses within the context of talking about any activity that the resident considered important to their life. Irene and Arthur provide examples of VISION AND HEARING as resources to facilitate independence.

Irene, after linking independence to having friends with whom one can talk, identifies resources of vision and hearing as essential to this independence.

Irene - "Some people, I could talk to (because they share my interests) but I can't hear what they are saying ... and then my eyesight, I had to have a cataract removed from one of my eyes. The other one has a cataract on it and they can't take it off because it has deterioration of the retinas. So my

problems and their problems, together is just too much!" (i1*26).

Later in response to a question about what it would take for her to feel more independent, Irene responds

Irene - "being able to converse plainly with people that I could understand them. And my eyesight good enough - that's my problems." (i1*28)

Arthur, who prides himself in being widely read and who enjoys calculating his most recent net worth, described several activities, then adds this comment.

Arthur - "But what I miss is my being able to read. Even watching TV is terrible. I can't see it... (especially football) .. I miss all that independence. I did so very many things that I'm no longer able to do. (a2*6).

ABILITY TO THINK AND TALK is another theme within the dimension of HAVING RESOURCES. Eight residents implied this theme linking independence to cognitive abilities such as thinking and talking as they attempted to explain what independence means. Arthur most clearly articulated this link.

Arthur, in reference to other residents with Alzheimers' Disease, strokes, and senility, provides this comment.

Arthur - "So what does independence mean to them? ... Some of them can hear but they can't speak. They can't walk. so I don't quite follow just what you mean by independence." (a 1*6). and later responds - "Another word for independence? It's loss of the things you had before, the loss of your faculties. It's loss of independence is what it is. It's not independence." (a2*20).

MATERIAL RESOURCES constitute another theme within the dimension of HAVING RESOURCES. Resources within this theme are tangible ones such as money and a variety of adaptive equipment. With respect to MATERIAL RESOURCES, having money was linked to being independent by Arthur, Irene, Elsie, Joanna, and Katie as they talked of ways in which money was used to obtain some desired service or item.

The theme of ADAPTIVE EQUIPMENT, also placed within the dimension of HAVING RESOURCES, is closely related to that of MATERIAL RESOURCES but differs in that the equipment is somewhat a tangible "extension" of the person as they interact with their environment. The possession and use of equipment such as Frank's electric wheelchair, Irene's cane used to reach and pull items, Joanna's hearing aides, and Harry's improvised stick used to control the light switch enabled the resident to feel independent. Bertha also mentioned objects such as a wheelchair, cane, and back brace but for her the connotation was one of lack of independence because she associated their use with times in which she was either ill or recovering from an injury.

In summary, the dimension of HAVING RESOURCES represents personal abilities as well as tangible possessions that can function to inform others of one's preferences as well as compensate for limits that are present in ability to MOVE THE BODY and/or CARE FOR THE BODY. Lack of resources, such as lack of adequate communication ability can create problems in expression of preferences, thereby placing at risk self-determination with respect to

individualization of care. The material resources and adaptive equipment can function to compensate to some extent for losses in the ability to DO THINGS, as illustrated by Harry and his "reacher", Irene's cane, and Frank's electric wheelchair. An additional way in which material resources can facilitate feelings of independence are evident in the ability to purchase goods and services (as mentioned by Arthur, Joanna, and Elsie) that one desires, or that help one achieve desired ends.

Being Oneself

Being Oneself is a fourth dimension of independence. This dimension represents activities which are expressions of unique individual ways of being in the social environment. There are four themes within the dimension of BEING ONESELF that reflect a variety of activities by which persons express their uniqueness and individuality. HAVING WISHES AND PREFERENCES is a theme that includes general comments about self-determination, and/or acting as one desires. Examples within the theme of HAVING WISHES AND PREFERENCES are provided by several residents.

Grace, in reference to independence for persons around her - "Well, they are making things. They can do whatever they want to, as far as I know." (g2*3).

Bertha relays a theme of preferences in her example "I think independence, for me it means being able to go to the different units to do this and to do that." (b1*18).

Elsie comments with respect to independence in the nursing home "Well, I don't know exactly. When you got money you have a car - and you got a

car you can go around - and go when you want to and come when you want. And here I got to wait on everything!" (e2*4).

STAYING CONNECTED with other significant persons is another theme within the dimension of BEING ONESELF and therefore part of being independent as explained by Irene, Elsie, and Dora.

Irene - "well, you know, one thing that happens too - there is a lot of people here that has strokes, and passed away. You know that bothers too - your feeling independence - because they're gone and you can't talk with them." (i1*24).

Elsie mentions telephone calls in a context of having to depend on other people "All the morning nurses are wonderful, every one of them, they are awful nice. Then the afternoon nurses was kind of hateful, but I - I don't ask them for nothing. I can't phone if I have a phone call. I have to get them. I can answer it, but if I want to call out, they have to help me with that." (e2*12).

Following a brief dialogue about inability to talk with friends, and then making reference to dining room table companions Dora remarked "There is just one man that comes to our table that talks with any intelligence at all. And he hasn't been coming for about a month - he hasn't been well." (d2*7).

STAYING OCCUPIED by engaging in a variety of hobbies and activities was another theme representing independence. This theme is placed within the dimension of BEING ONESELF because it reflects the diversional and recreational activities with which the person expresses some of their individuality. The theme is illustrated by three examples.

Clara, in response to a query about her independence replies "Well, they

have no objections at all to my knitting. And I enjoy that. Well, I have freedom to do some things here in bed" (c1*9).

Bertha uses her previous days in the adjoining adult home as her frame of reference "We had right much independence over there. They had different activities that we would go to. Exercise, and we would go to music, and have different things planned for us. And they would take us on trips..." (b2*4).

Grace uses language of "dependent" for her example. "You have people here that don't do anything. M. is one that I mentioned awhile ago, she thinks she is busy - she talks about working hard. But when I asked her, 'M. what did you do between such and such a time' well, she doesn't know - or remember what she did. Gets hard, I know for her, because she doesn't do anything." (g2*5).

The theme MANAGING OWN AFFAIRS is the final theme within the dimension of BEING ONESELF that provides examples of independence. The topics within this theme are analogous to activities typically listed as Instrumental Activities of Daily Living (IADLs) within gerontology literature. Harry, Elsie, and Joanna provide examples to illustrate the link to independence.

Harry - "(independence) Well, you have the extent that you are the manager of your own affairs..." (h1*4). and later "Yes, I like to shop for the kind of clothes I want - the things I need - and there are lots of things I would rather do for myself than someone else do them." (h1*14).

Elsie illustrates her independence by her description of how she dealt with a relative whom she considered to be getting out of line in the attempt to control Elsie's property.

Elsie - "She (the relative) even tried to get in my lock box. But there was a (unclear) - and I said to her "no". She asked me if she could go in the box and I said "no". I knew right then and there was some trouble. But I

taken it as long as I could stand it. - so I just told my niece I got a power of attorney (POA) and I'll work on that now.... Ya I got it changed - and my checks will come in and my bills will come in - this month now. This month and (name of new POA) will come up and (unclear). She's (the new POA) very very good to me. But now, I don't know if (name of relative) likes it or not.." (e2*7,8).

Joanna also illustrates this theme dramatically as she describes the actions of an aide who, without permission, sorted and then discarded Joanna's "everyday hose".

Researcher (clarifying a previous comment) "you said - let's see - she went through the hose and was throwing out the ones with the runs in - was that it?"

Joanna - "she took out every one that I had. And if there was a run in it, she threwed it away. And the ones that didn't have runs, she left. Then I had them. But the ones she threwed away in the trash can, she took with her. She took them along, instead of leaving them in the trash can, she took them out and took them with her. And so I just reported it in. Cause she did all of that... I wrote them a note and laid it down there, you know (points to her bedside stand)" (j1*5)

Then in regard to some missing magazines Joanna continues:

Joanna - "I don't know who took them magazines. I don't know who did that. So I have wrote a note and put it up there (pointing toward the nurses' station). I told them whoever took my Maturity Magazines please return them. and I said, I think I had the new one. I wanted that one - June and July. I think I had just received it - and hadn't used it at all!... I had asked them to return the ones they had." (researcher - did you get them back yet?) "No. They took the letter up there to the office, and they have been checking." (j1*6).

In summary, the dimension of BEING ONESELF represents activities which are expressions of unique individual ways of staying connected with the social environment. The nursing home resident who is able to "DO THINGS" (such as move about and care for the body) likely also retains the abilities that are requisite for specific social and recreational activities. It is through such activities that the resident expresses the self-determination aspect of independence. Limits in specific physical abilities impact the BEING ONESELF dimension of independence because the resident must obtain help with activities that an adult typically does unassisted. When the assistance is secured within the context of a nursing home, "HAVING PREFERENCES HONORED" takes on new meanings because of the interactions that are required. While the above examples illustrate a way of managing one's own affairs, they also serve to illustrate the need for the resident to interact with persons in the social environment of the nursing home. The interactions with that environment are inherent in "DOING THINGS" and in "HAVING PREFERENCES HONORED" within the nursing home context. Interactions such as this are evident in specific examples of the themes placed within the final dimension of independence.

Interacting With The Social Environment

Interacting With The Social Environment is the final dimension of independence identified in this study. The themes within this dimension illustrate the fact that the resident must now attempt to "DO THINGS" within the

constraints of the nursing home rules, policies, schedules, choices, and living space. Examples of comments that represented five separate themes within this dimension follow. The themes within this dimension are related to the "HAVING PREFERENCES HONORED" aspect of independence because each theme is related to some part of the environment of the nursing home with which the resident must interact.

A theme of RULES AND POLICIES was addressed by each resident, although the variety of topics and the nature of the residents' responses to those RULES AND POLICIES varied considerably. The existence of the rules has a connotation of limits on independence, but such limits were deemed acceptable (even necessary) in group living situations. Frank makes the following observation in reference to rules.

Frank - "I think it's a matter of whether you like it or not, we have to do it anyway. Take speeding. The order is not to speed in a car... I think you are victim of that (rules and regulations) all through life." (f3*23)

Specific policies were viewed as restrictive to independence, though a problem only to the extent that some desired entity was denied. Topics upon which residents commented were a desire for selection of specific physicians, rules prohibiting use of alcohol, and limits on the number and nature of items that could be placed within the resident's room. The residents speak through their examples.

For Elsie, it seemed that "rules" somehow became the focus for everything that was not to her liking. She commented critically about food options (e1*8), limits on salt and fat intake (e2*3), and closet space too small to accommodate her

three wardrobes full of clothes from home (e2*9). This theme is summarized in her response to a question about the kinds of freedoms she has in the nursing home:

Elsie - "That's a question now I tell you! You have to obey - be under the rules" [e2*14].

For Joanna, at least some aspects of the rules and policies help her to feel independent, particularly because she has been assured that she can stay in this nursing home even if/when she runs out of money.

Joanna - "yes, (even if I run out of money) I can stay here as long as I live. See, that makes you independent in a way." [j1*3]

Irene mentions rules in the context of talking about the fact that the nursing home just does not feel like being at home.

Irene - "Well, because when you are at home you can do what you want to do and what you don't want to do, you leave it till tomorrow....(here) you have to do more like what you are told to do, or what you know is their way of doing things. You have to do somebody else's way.... You know, you have to follow the rules wherever you are." [i1*9].

Arthur implies that needing to obey rules limits his feelings of independence, but also hints that he is selective in which ones he obeys.

Arthur - "I do have to let them know where I'm going. When I first came here I didn't - well, I have to sort of obey the rules". [a1*9].

Harry explains the relationship between independence and living in a nursing home as follows.

Harry - "Well, there's a certain amount of it (independence) that is lost.

Yes, because they have to have their rules and regulations, and there are certain things you can do and can't do, that they have to do for you." [h1*5].

Frank made reference to an aspect of rules and policy that involved rights of the resident, then added

Frank - "if the aides are too insistent in taking away your rights, you have recourse. And it's very good. (The channels are) first the nurse, you appeal to the nurse. Then you go to the (pause) uh, I'm not sure just where it goes. But you have recourse" [f3*7].

Katie, when asked specifically about rules shifted the focus to resident rights.

Katie - "Well, we have resident rights. I mean, they went over those with us, what our right is." However when asked what those rights included she responded with "well, I think they are fairly lenient." [k1*16]. However, she could or would not expand on the comment.

The theme of CHOICES makes up the second theme within the dimension of INTERACTING WITH THE SOCIAL ENVIRONMENT. Each resident identified at least one example that fit into the theme of CHOICES as an aspect of independence in the nursing home. The references to rules and policies, choices, and managing affairs overlapped considerably within the statements. Such overlap is not surprising given the pervasive nature of rules and policies in guiding much of the standard daily operations of any institution. Perhaps the rules become problematic for the resident, and therefore equated with "not independent" when the rules prohibit some desired activity or limit the range of choices which one is offered. Examples of topics within the theme of CHOICES

are grouped by topic rather than by individual quotes.

Choices in selection of food type and/or seasoning were mentioned by five residents with each finding the restrictions in this area to carry connotations of limits to independence. [e1*8,13 & e2*3, f3*6, h1*26,28, i2*13, k1*4].

Comments about the presence of choices with respect to participation in recreational activities were also made by five of the residents as examples of independence. [b2*22-23, c1*17, f2*28, g1*6,9, h1*17-18]. However, Bertha differed in that she recognized that choices exist, but wished for more variety in the available options. Selection of clothing to wear provided another way in which choice was linked to feeling independent [d1*16, h1*14-15, j1*15].

Related to the theme of CHOICES was a collection of comments that went beyond choices between or among options to choices affecting aspects of residents' personal care. Arthur, when asked for an example of feeling not independent, identified the limits in selection of a physician as being problematic [a2*10]. Frank wished for choices as to which aides provided his care [f2*34]. Harry identified as an example of independence his ability to say "no" and have that preference honored by the staff [h1*8]. Katie, though not admitting that this provided any feelings of independence did mention that her preference to eat in her room rather than in the noisy dining room is honored because she retains the ability to feed herself and to eat rapidly. In this comment, Katie links physical ability to the condition of having her preferences honored [k1*2].

A third theme within the dimension of INTERACTING WITH THE SOCIAL ENVIRONMENT was that of SCHEDULES. SCHEDULES refers to topics that have to do with the usual daily routines within the nursing home. The

existence of schedules set by others had the connotation of serving as a limit to independence. However, the extent to which this was viewed a problematic varied. References to scheduled activities closely paralleled the themes expressed in the references to rules and policies. However, these are different in that they are more specific to the daily pattern of life and predictable activities within the nursing home.

For Clara, the schedule in which activities take place is not viewed as problematic.

Clara - "because mealtimes and bedtimes and those things are about the way I like. I didn't eat my lunch at 11:30. I usually ate it at 12. But here it is at 11:30. But that's not bad." [c2*23].

Irene, in reference to getting needed help with care seemed to accept scheduled events as welcome expressions of caring in the following comment.

Irene - "Now like - they will tell you when your bath time - when it's time for your bath. You get a bath twice a week. They will tell you when that is. And if you need soap, well, they will get it for you. If you need powder and things like that." [i2*31].

Specific barriers (restraints in form of side rails) can serve as symbols for the schedule that is set by the caregivers - as illustrated by Joanna when she was asked whether she could get up at a time different from the schedule she had just described.

Joanna - "You can't do it! They got a rail there (pointing to the side rail on the bed). You have to ring for the nurses, you see, the one that's on duty. And they come and take you. But I very seldom ever have to go (to the bathroom at night) - never have, so they put me on that (the side rail)" [j1*11].

Elsie implies a reference to schedule in her response to a question about how she could feel more independent, yet followed the implied complaint with a recognition of the helpfulness of the services provided within the context of that schedule.

Elsie - "Well, I like to do for myself if I can. But I have to listen to the other person. You got to get up early... They get me up about 6:00, that's the time I get up. They get up and put my hose on. That's one of the biggest help there ever was. I can't hardly get them on." [e1*9].

Harry, when asked for an example of feeling not independent mentioned the schedule in the first comment. However, a few minutes later in the same interview when redirected to the topic of the schedule as related specifically to his bedtime, Harry implies that the ability of the person influences that schedule.

Harry - "you have to - they have certain things scheduled that they have for you to do, different patients to do. You can't do just anything you want to whenever you want to. You have to go according to their schedule." [h1*16].

Harry - "Oh, anytime I want to (go to bed) before 9:00 or 9:30. I usually try to get ready to go earlier than that. I tell them when I'm ready. I'll punch the bell and call them, and say I'm ready to go to bed. Now, you have a certain amount of independence along those lines. That is if you're able. If you're able, you can go to bed whenever you feel like it." [h1*32].

Arthur links the theme of rules with that of schedules but in doing so also hints that because of his specific physical condition and his higher level of cognitive functioning he is an exception.

Arthur - "Oh yes. They get these people up, some as early as 6:00 in the morning. You have to take a shower, or bathe. You have to wash your hair. I don't do that because of my condition... But all these others, every single one of them ... they take them out and give them a shower, then they dress you - you have to get dressed. I'm the only one who doesn't get dressed. I'm up all night so I sleep half of the day - in here [his room]. They have to get dressed, they have to sit out in the hall or go up to the front end of the lounge or wherever they can keep an eye on them. Everything is done by the clock. You just can't get up and do what you feel like. If you want to go downtown, they can arrange to take you downtown at some weird hour or whatever, but it's usually by their rules. You don't live by your own rules." [a3*7].

Dora and Frank, the two persons in the sample with the greatest limitations in physical mobility, placed their comments about schedule within the context of choices and preferences. Both residents implied that the activities associated with meeting the physical care needs are the ones in which choices are limited.

Dora commented "I can decide what I want to do during the day. If I want to play games, or go to anything that is going on. I can decide that. But I can't decide about what kind of a bath - whether I have a tub bath or just a bath in bed. I can't decide that. They have that all scheduled up." [d1*18].

For Dora, the fact that she emphatically stated that she does not enjoy the tub baths serves to compound the lack of choice she feels in this matter. Frank, when asked for his suggestions about making changes in how a nursing home operates, implies that staff control of the schedule for care interferes with delivery of care in a manner that respects the wishes of the resident.

Frank - "I would okay three-fourths of it (the way the home is administered), but I would make it a little more personal - with the aides. They would have to - They will say to me 'now Frank, we can't give you any special privileges or you know you (inaudible words)'. You can't go

to bed until a certain time, and that clashes with your wishes." [f1*19].

LIVING SPACE is the fourth theme within the dimension of INTERACTING WITH THE SOCIAL ENVIRONMENT. Aspects of life in the nursing home that impact one's preferences include a variety of topics coded into the theme of Living Space. Simply being present in a nursing home was equated with "not independent". Once the person is in the nursing home, some options exist for adjusting this living space to more nearly approximate one's preferences. However, there are limiting factors to this individualization that overlap the themes of Choices, and Rules & Policies. Further overlap occurs when the resident needs help from someone (family or staff) in order to implement those preferences. Examples of aspects of life in the nursing home that impact one's preferences are varied. Comments from Arthur, Elsie, Irene, and Grace reflect some of this variety.

Arthur, (at the outset of the member check interview) in response to the question "what does independence mean in a nursing home?" responds - Arthur - "I tried to answer that the last time. The fact that you're in a nursing home, you automatically lose independence (a3*2).

Elsie, in reference to circumstances in which her father needed care but would not go to a nursing home clarifies her statements as follows: "no, he didn't want (to go) - he said he wanted his independence... He didn't like the nursing home, I don't know why. He wanted to be independent there at home." (e2*2).

Irene clearly articulates this theme in her comment "Well, you don't always feel exactly like you are at home." (i1*8). This theme was echoed by Grace.

Grace - "(the nursing home) isn't quite like home". (g3*16).



Specific characteristics within that LIVING SPACE that both function as reminders that one is not at home, and that in various ways are not in accord with one's preferences help illustrate the link between the theme of LIVING SPACE and the broad strand of "HAVING PREFERENCES HONORED". Noise made by staff as well as by other residents (d2*5, i1*19, i2*24), objectionable odors from a roommate (i2*28), windows that cannot be opened (j1*18), limited space in which to place possessions (a1*11), staff invasion of one's living space and moving possessions (j2*15) all must be "endured" (Irene's term). Sharing the room with another person is an added characteristic of that LIVING SPACE that is a constant reminder that one is not at home. Frank's comment suggests an underlying reality inherent in the LIVING SPACE theme.

Frank - "Well, it is a little hard to occupy a section like we have here (motions toward the other bed in the room). Two people - it's pretty hard to get two that suit together. That's an extreme piece of being very diversified (here in the nursing home)" (f2*29).

Once the person is in the nursing home, some options do exist for adjusting this Living Space to more nearly approximate one's preferences. However, there are limiting factors to this individualization that overlap several themes within the dimension of HAVING RESOURCES. For example, if one has the financial resources, a room with more privacy can be obtained (e2*28), as illustrated by Elsie's "modified private" room.

Further overlap occurs between the LIVING SPACE theme and that of functional ability as addressed in the dimension of MOVING ABOUT THE

ENVIRONMENT. Joanna and Katie each provide examples of this overlap, an issue that is addressed in more detail in a later section.

Joanna is permitted to individualize her room with bulletin board displays and pictures, but at present does not have these items displayed because she needs assistance for this specific activity.

Joanna - "This window is mine. I can close my curtains at night, you see. And I'm allowed to put pictures up. But I've never been able to get them all up yet. Never have since I've been here. I can't do it and others can't come in always to do it." (j2*21).

Katie enjoys watching the birds at her bird feeder, conveniently located outside her window, but must rely on another person to provide the steady supply of food that attracts those birds (k2*18). Katie also is permitted to eat in her room rather than in the noisy dining room because she retains the ability to feed herself without problems. This permission further illustrates the link to functional ability inherent in independence within the nursing home.

SELF-IMPOSED BEHAVIORAL EXPECTATIONS is the final theme within the dimension of INTERACTING WITH THE SOCIAL ENVIRONMENT. The label (Self-Imposed Behavioral Expectations) for the theme is selected to capture the variety of unique ways in which each individual resident seems to interact with the social environment of the nursing home. This theme represents efforts or activities in which the resident makes a conscious effort to exercise self-control of emotions, thoughts and/or actions. Included within this theme are comments about voluntary adherence to the formal and informal agency rules, norms, and

implied social expectations. To a limited extent, the residents' statements give clues to their perceptions of this nursing home setting.

Within the theme SELF-IMPOSED BEHAVIORAL EXPECTATIONS, an attempt is made to relay a sense of how each resident views himself or herself within the context of this environment. Triangulation of data from chart sources and from researcher observation was used in conjunction with the statements from interviews to construct the following brief description of each resident's style of interacting with the nursing home environment.

Katie reflects her views about INTERACTING WITH THE SOCIAL ENVIRONMENT in a sequence of comments in which she draws on her past observations of behaviors of other nursing home residents.

Katie - "Well, I knew pretty well what to expect. That when you're helpless, you have to be at the mercy of others." (k2*19).

Katie considers this state of "helplessness" a situation that is to be accepted.

Katie - "You have to learn to accept it" (k2*31) to avoid what she considers to be undesirable actions, alluded to in her comment about how she manages to accept it. "Oh, without the Lord, I'm sure you'd get impatient and probably irritable. But He gives grace." (k2*32).

Additional data obtained from notes written by staff on Katie's chart indicate that the "acceptance" may be a goal that she has not yet attained.

Joanna's SELF-IMPOSED BEHAVIORAL EXPECTATIONS include self-imposed responsibilities for her roommate that may at times function to shape how INTERACTING WITH THE SOCIAL ENVIRONMENT is operationalized for her. In reference to independence within the nursing home and associated

adjustments that a resident must make, Joanna makes the following comments.

Joanna - "Well, I couldn't leave her (bedfast roommate) just all alone all day long. I don't think I could do that. But I come back and forth with her. I go out and do different things, and they (staff) come in. I just turn it over to them, and they do (take care of her)." (j2*16).

However, when it comes to letting her personal preferences be known and to correcting unacceptable situations, Joanna seems to also have a set of behavioral expectations that specifies that the resident is to let it be known what they want and need. This response is illustrated by the quotes from Joanna describing the situations involving her "everyday hose" and missing magazines in which Joanna "reported it to front office" and wrote notes to correct situations that she deemed unacceptable. The detailed quotes are included in the section of MANAGING OWN AFFAIRS within the dimension of BEING ONESELF. Irene's SELF-IMPOSED BEHAVIORAL EXPECTATIONS call for her to be a "good patient", who is thankful for everything the staff members do for her, who gives the nurses a pat on the back, praises and loves them, and avoids making demands of the staff who are overworked caring for all the "sick patients". However, in discussing one particular activity for which she desired more assistance than she received, she also commented that "I might be better off if I did a little bit of demanding". (i1*14).

In general Irene believes that "a patient shouldn't be fussy... they shouldn't be too demanding" (i2*41), should ask questions (permission) before taking the initiative to do something new, and should follow instructions of nurse and physician if given for her good. The appropriate responses to situations which one does not like include to "grin and bear it, keep a smile", "take it on the chin",

and display endurance.

Irene - "Some of these things you have to endure, cause you can't, you just can't do nothing about it". (i2*28), and above all, don't tattle about less than desirable conditions because "If you are a tattler, you get yourself in trouble". (i3*28).

Irene implies some relaxation in her behavioral expectations for those residents who are sick.

Irene - "(they) can't do anything else. They are sick people... like this Alzheimer's disease - see. They will holler, they will yell, they just - I don't think they know what life is all about. I think their life is in the past." (i1*23).

Harry's behavioral expectations seem to require using "common sense". He also expects that persons of like abilities are to be treated alike. Harry's view specifies that he is to be responsible to notify the staff of his needs, and to have enough sense not to ask to go to activities to which he has not been invited, or for persons other than the ones "put in that class" (h1*9). In response to a question about how he gets the staff to do the things he wishes them to do, Harry responded as follows.

Harry - "Oh, you ask for it. You ask for it. And they either say 'Well, that's against the rules' or they say 'Oh, I'll have to see about it' or something like that. They give you some kind of answer, but you have to ask for it. Anything that you want that's not in their routine, you have to ask for it... if it's something that they think might be objectionable to them, they say 'We'll have to find out and let you know'. if they don't (get back to you with an answer), well, you get after them and if it's important enough, you follow through on it." (h2*5).

Chart data suggest that the manner Harry uses to "get after them" may

border on unacceptable to the staff. Besides letting staff know his desires, Harry has additional comments about his SELF-IMPOSED BEHAVIORAL EXPECTATIONS.

Harry - "you just limit yourself, that's all. You either limit yourself, you might as well limit yourself, if you are thoughtful enough you just don't try to do it. Don't try to do something that you can't do." (h2*7). And if you wish to go somewhere, just "make sure it's all right with headquarters" (h2*12)

Overall, Harry continues - "I've never been bothered about it (violating the rules) you know. I've never been questioned, I've never been called down, I've never been reprimanded or anything like that. You just use common sense, that's all." (h2*35). and "just learn as much as you can about the rules and regulations and try to get along with the nurses and everything. It's not difficult." (h2*37).

Grace responds to the environment of the nursing home simply by trying to do as expected. Later she hints that her informal rules for behavior from the past continue to apply in the nursing home environment.

Grace - "I feel pretty independent here for myself. I don't care about running out and doing this and doing that, and going. I can do it if I have permission, I just don't bother about those things." (g1*5). I'm supposed to tell them if I go away". (g1*10).

Grace - "...here I try to do like I think they want me to do. And that's the way I did at home. (g2*9).

Frank, in response to a general comment about issues of independence in nursing homes, gives indications of the belief system that structures his view of the informal rules by which he now lives, in effect his SELF-IMPOSED BEHAVIORAL EXPECTATIONS.

Frank - "I think we are in a different world entirely. I would advise anyone that is coming in that door to just - don't forget everything that is in the past, but to recognize that we are a different fraternity.... I think you just adjust yourself, to make the best of the situation. That's the main

thing I would suggest. Find out, I mean get yourself (involved) - enjoy your life the best you can." (f2*40,41).

Within this different world, added themes include the following comments. Elsewhere Frank clarifies the next comment to include individualization of wishes within limits.

Frank - "I think you just adjust yourself to what the rules and regulations are for the most of the people. Regardless of whether you like it or not, you have to give in to it" (f3*21). "I would advise them to try to take their part in the group that helps bring happiness to others. In other words, try to look on the bright side." (f2*17). and

Frank - "anything that makes for happiness as long as it doesn't interfere with the happiness of others... cause if you get special privilege and it interferes with others, then it's wrong. That's the way I see it." (f1*27).

The strong message Frank relays throughout his comments is that of "adjusting yourself" perhaps most strikingly presented as he attempts to describe feeling independent.

Frank - "but you clash with your - your service here and everything else. But it is just a matter of adjusting yourself. You are helpless and you can't do anything about it." (f1*9).

However, Frank does use a variety of formal channels within the institution in attempts to address his needs. Calling his physician, talking to the Director Of Nursing about staffing, having his daughter straighten out the problems with his menu, and coming to an understanding with certain aides about his preferred care routines illustrate his views about interacting with this social environment.

Elsie views "the rules" within the nursing home as ones that must be obeyed, even if this is contrary to her wishes.

Elsie - "But you got to build yourself up to just take it... They do want you to be clean here. The dress I have on today I have to take off and put another outfit on (tomorrow). (e1*5). and "well, I like to do for myself if I can. But I have to listen to the other person. You got to get up early." (e1*9).

Elsie's behavioral expectations are implied in her response to a question about freedoms in the nursing home as well as her advice to a hypothetical new resident.

Elsie - "That's a question, now, I tell you!. You have to obey - be under the rules." (e2*24) "You can't tell them nothing. But always obey the person. I always obey the rules. One thing is certain, obey the rules" (e2*26). and -

Elsie - "Be nice to everybody - and do everything what they say you ought to do.... Just take everything off of them, what they say - And be good to them, and don't ask no questions or nothing." (e2*19,20).

Dora seems to be living by behavioral expectations that also say she is to be nice to the staff and control her actions. While she is able to exercise this self-control in some of her actions, she cannot control the situations or frequency with which she begins crying while talking about her experiences in the nursing home "I'm so emotional, I just cry at every little thing", (d1*15). Somewhat with satisfaction in her ability to exercise restraint, Dora cites an example in which a staff member was trimming her painful ingrown toenail but called in an assistant to help hold Dora's foot stationary.

Dora - "And then one of the other girls came and sat on my knee and held

me down so that I wouldn't move around when it hurt. I had a notion to punch her, but I didn't" (d1*19).

When asked what advise she would have for someone just entering the nursing home, Dora gives a clear indication of the informal rules by which she operates.

Dora - "Tell them to try to be good to the nurses - because you are at their mercy. [begins to cry]. You have to be good to them - Is this recorded?" (d2*12).

The conversation, which continued without the recorder, contained themes of recognition that the staff also have troubles at home, a desire to be nice to staff by sharing her candy with them, and clarification that most of them are good, with only a few that are not good. It is almost as if Dora's SELF-IMPOSED BEHAVIORAL EXPECTATIONS call for her to be nice to the staff so that they do not handle her roughly during frequent and potentially painful activities involving turning and cleaning her to prevent skin breakdown. (d2*16, 18, 19).

Clara's behavioral expectations for interacting with the social environment of the nursing home came into play years before her admission. She placed her name "on the waiting list" many years prior to needing the type of care provided in this home, because she believed that this home provided the quality of care that she considered important. Now that she is residing in this home, her view about her role within the institution seems to be that the routines of group living are both understandable and acceptable.

Clara - "Well, there are not many things that I have to have done my way. I let them do it their way, unless, what would it be, - well, they don't - don't abuse you or anything like that." (c1*16). "I do it (walk) whenever

they come and want me to, but they don't come offer to help me every day." (c1*3).

Beyond those examples, Clara talks of the need to accept the situation, a theme that is also evident as she talks about changes in her physical body.

Clara - "Well, you just have to get used to and accept the way things are here. You can't live like you did when you were in your own home."(c2*21). and -

Clara - "So I have to adjust to how my body is and what it takes. Just have to - accept it (by) you just have to admit that that's a fact and live by it." (c2*27).

Bertha's SELF-IMPOSED BEHAVIORAL EXPECTATIONS seem to call for her to be nice to the nurses by sharing her candy with them and to try to mostly abide by the formal rules. She cites examples of curtailing her trips up and down stairs on the advise of the nurse who was concerned for her safety (b1*7), yet on another occasion climbed the steps unassisted because she did not want to wait for the alternate transport to a far distant, alternate elevator.

Bertha - "And I could go anywhere that I wanted to go. Well, the steps, I wasn't supposed to go on the steps, but I even did that one time. The elevator was out of commission and I wanted to get upstairs to my room, second floor to my room. There wasn't any way to get there except the steps. So I just took the steps and took the walker and walked up the steps, holding on to the banister. They said 'don't ever do that again'. Well, I didn't do it again, but whenever the elevator stopped, I was planning to again - because I wanted to get upstairs" (b1*15)..

In describing the seating arrangements for the dining room, Bertha implies compliance with the formal rules as she understands them.

Bertha - "Well, we are supposed to sit where we want to, but most of us have our regular place that we go to. If someone gets in our regular place, we get upset" and have the staff make them move (b1*2).

Arthur's Self-Imposed Behavioral Expectations seem centered around his view of himself as intellectually and physically so superior to "these other people" that he is "not one of them" but is part of staff. He relays a theme of selective compliance with the formal rules, almost as if he considers most of those formal rules within the nursing home to apply to the other residents who lack his cognitive abilities and mobility skills.

Arthur - "Well, they let me do anything I feel like. As long as I tell them where I'm going" (a1*6). Later, while talking about feeling independent, he responded "Well, I have to sort of obey the rules. I would like to put some more boards up, some more pictures on the walls. But there's a limit to that" (a1*9).

On another occasion, Arthur seemed willing to accept limits on the number of extension cords used for his many electrical items because one of the top administrative persons in this home also had to "give up" his extension cords in the interest of fire safety. The theme of selective compliance with rules was evident later in response to a question about losing independence in a nursing home where Arthur mentioned medications.

Arthur - "Well, you have to do what they tell you to do. You can't take the medicines that you - If I wanted to take some ExLax, for instance, I can't do that (because) they can only give you what the doctor tells them. I would have to call the doctor - matter of fact, you're supposed to see them and they call the doctor." (a2*27).

In summary, the dimension of INTERACTING WITH THE SOCIAL ENVIRONMENT addresses the fact that the resident must now attempt to "DO

THINGS" within the constraints of the nursing home rules, policies, schedules, choices, and living space. However, these constraints imply limits on independence, particularly in the "HAVING PREFERENCES HONORED" or self-determination aspect of the meanings. The task of the resident is that of BEING ONESELF now in this "different world" where INTERACTING WITH THE SOCIAL ENVIRONMENT may require the use of a variety of methods for interacting. The residents' Self-Imposed Behavioral Expectations represent an important theme that affects how those interactions take place as they attempt to interact with this social environment.

Summary for Research Question One

To summarize the meanings of independence as articulated by these residents, it is helpful to return to the analogy of the piece of fiber art. Just as the fiber art piece can have an endless combination of ingredients, so can each individual have an endless combination of meanings of independence. This unique mix of meanings of independence developed over years of life experiences.

Various changes in circumstances and conditions that the individual experiences can alter the integrity of the art piece. The integrity and characteristics can be altered by erosion of the base fabric, unequal stretching or shrinking of the different types of yarn, and alterations in the color or texture of the components of the art piece.

The fiber art work is unique to the individual, but common to all such works are threats to the integrity of the piece. Likewise, meanings of

independence are unique to the individual. Those meanings will be affected in individualized ways by the variety of circumstances the person encounters in a new environment such as a nursing home.

Within the nursing home context, there are two symbolic threats to independence that are common among all the residents in this study. The symbolic threats to independence within the nursing home are "NEEDING HELP" and "WAITING". The next section deals with these symbolic threats to independence as a consequence of changes in the functional ability of the individual.

Chapter Five Results

Interpretation of Meanings

Introduction

Functional ability is at the heart of the issue of independence within the context of the nursing home. The resident would not be living in that setting if there were not some problem with functional ability of sufficient magnitude to result in the nursing home placement. Quotes from several residents highlight this obvious connection as they talk about independence in the nursing home.

Arthur neatly sums up the issue in his comment about autonomy and independence within a nursing home. "There are so many things that you can't do for yourself any longer. That's the whole problem. That's the reason you are in a nursing home. You have lost your independence. You can't do these things." (a2*22).

Dora concisely articulates this interaction in her statement about her lack of independence in the nursing home - "it's not the home's fault, it's because I'm ill" (d1*2).

Clara, when asked whether it was harder to adjust to the changes in her physical condition or to the change in location, thoughtfully responds "Oh - well - I think they pretty much pull together. Because the body condition is what causes - causes the other change (moving to the nursing home)." (c2*27).

While the connection between functional ability and independence may seem obvious, only the "DOING THINGS" strand of the meanings is represented in these quotes. The "HAVING PREFERENCES HONORED" strand of the collected meanings is omitted in these comments, yet is closely intertwined with the overall meanings of independence as articulated by these residents.

Research Question Two

This chapter addresses Research Question TWO and deals with the interaction of functional ability on independence within the nursing home using the themes, dimensions and strands described in the previous chapter. Research Question Two as formally stated is:

What do these meanings (of independence) reveal about the influence of functional ability on independence within the context of a nursing home?

The previous chapter contains the description of meanings of independence as articulated by the participants in this study. In that chapter, five dimensions of independence were identified, with each dimension containing several themes. (see Figure 1 on page 77) These dimensions and themes of independence are supported by and interwoven with a general view of independence as comprised of two strands; "DOING THINGS" and "HAVING PREFERENCES HONORED".

With respect to the general meanings as "DOING THINGS" and "HAVING PREFERENCES HONORED", independence carries meanings much like those held within society at large. However, for these nursing home residents, the term independence, while reflecting these same two strands, must be examined within the context of residents' abilities in "DOING THINGS", essentially a discussion of functional ability. Changes in or problems with functional ability set the stage for a tension between ability "DOING THINGS" and the extent to which "HAVING PREFERENCES HONORED" is possible. Writings addressing autonomy from the perspective of an ethicist (Collopy, 1988)

provide a useful parallel by which to answer this second research question.

Decisional versus Executional Autonomy

Collopy (1988) discusses six different polarities inherent in the concept of autonomy as applied to the long-term care setting. The polarity particularly salient to this discussion is that of "decisional autonomy" versus "executional autonomy". Collopy distinguishes these as follows:

"Decisional autonomy, as the name implies, consists in the ability and freedom to make decisions without external coercion or restraint. Autonomy of execution consists in the ability and freedom to act on this decisional autonomy, that is, to carry out and implement personal choices." (p. 11).

Collopy makes the point that the frail elderly person is at risk of being viewed as lacking in autonomy if one considers only "executional autonomy" as the measure by which autonomy is evaluated. He further suggests that care providers need to be increasingly protective of the "decisional autonomy" of the individual who is experiencing limits in "executional autonomy".

In essence, the two strands of meaning as articulated by the residents in this study are analogous to Collopy's polarity in the following manner. The strand labeled "DOING THINGS" is parallel to "executional autonomy" in that capacity to function for the purpose of accomplishing activities is a condition essential to the process of "DOING THINGS". The strand labeled "HAVING PREFERENCES HONORED" contains themes dealing with personal wishes, choices, preferences, and behavioral expectations that are generally parallel to the "decisional autonomy" described by Collopy.

It is within the above understanding of this polarity that description of the meanings of independence as influenced by functional ability will be presented. In this chapter, the labels "NEEDING HELP" and "WAITING" are used as symbols for threats to independence in the nursing home. "NEEDING HELP" symbolizes limits in executional autonomy, a threat to the "DOING THINGS" strand within the general meanings of independence. "WAITING" symbolizes a threat to the "HAVING PREFERENCES HONORED" strand within the general meanings of independence, and parallels restrictions in decisional autonomy.

"NEEDING HELP" as Vehicle For The Move Into The Nursing Home

Functional ability is related to independence through a process, or chain of interacting events. The person experiences changes and/or problems with functional ability of sufficient magnitude to warrant nursing home care. The person seeks that care because of the condition of needing help. The help is received within a setting typically associated with limits on the decisional autonomy of the individual. Within the nursing home context then, "NEEDING HELP" becomes symbolic for whatever problems with functional ability the individual experiences that limit his or her ability to be independent by actively "DOING THINGS". In effect, "NEEDING HELP" is the antithesis to the strand of "DOING THINGS" within the meanings of independence. The condition of "NEEDING HELP" is analogous to experiencing restrictions in executional autonomy.

Individuals differ in the type and extent of those functional ability problems for which they seek assistance. They differ in the degree to which their

executorial autonomy is restricted. However, they are alike in that all have the condition of "NEEDING HELP". Because of the condition of "NEEDING HELP", they are now living in a social setting commonly associated with restrictions in decisional autonomy. Just as the residents differed with respect to specific functional abilities, so also they differ with respect to their views about and skills for interacting with the new social environment. One factor associated with these differences in how they interact is the set of SELF-IMPOSED BEHAVIORAL EXPECTATIONS the resident brings to this environment. In spite of the differences in SELF-IMPOSED BEHAVIORAL EXPECTATIONS, the residents are alike in that waiting was associated with the condition of "NEEDING HELP".

Once again, it may be useful to return to the analogy of independence as a piece of fiber art. The problems with functional ability that were responsible for the move to the nursing home can be viewed as a threat to the person's meanings of independence. "NEEDING HELP" becomes like some sort of noxious liquid which is "spilled" onto the fiber art work. That liquid potentially affects all ingredients that make up the work, but may exert different effects on the various parts, depending on both the character of the fibers, and the nature of the liquid "spill". The nursing home context functions as the environment to which the fiber art piece is taken for care and recovery.

Functional ability is linked to independence via the condition of needing help and a process of taking action to secure that help. "NEEDING HELP" become a vehicle for placement of the person in a nursing home. In effect, the limits in "executorial autonomy" set in motion a chain of events which result in admission to an institution typically believed to present threats to "decisional

autonomy".

For the residents in this sample, the move to the nursing home was viewed as a chain of events rather than as a sudden and/or singular event. Clara, Arthur, Dora and Harry described the move to the nursing home within a context of a series of health problems, each problem in some way limiting their ability to care for the physical body. However, with respect to the setting in which they would receive the care needed to compensate for their limits in executional autonomy, the residents in this study exercised a certain amount of decisional autonomy in that they selected Maplewood over other options. The decisional autonomy was evident not only in their selection of Maplewood, but also in pre-planning for such care.

Two residents (Elsie and Clara) made specific reference to having placed their names "on the waiting list" as long as 10 or 15 years prior to their move to Maplewood. Another six residents mentioned specifically moving to this retirement community so as to automatically be "on the list" for Maplewood if and when they needed this type of setting for assistance. In effect, they recognized the likelihood of decline in functional ability and corresponding loss of autonomy of execution. They anticipated that they might need help. Part of their preparation included autonomously making the decision to receive care in an institution about which they had knowledge. Clara illustrates this pre-planning in her explanation of how her name came to be "on the list".

Clara - "I had put my - I had given my name to (name of the nursing home that preceded this new one) and they had called in different times - a couple of times and said that my name had come up. But of course, I didn't need to come in. I just, I put it there so that if I got helpless and

needed it I could be there." (c1*5).

Although residents are living in an institutional setting commonly associated with limits in decisional autonomy, it was the limits in executional autonomy that were responsible for the move. "NEEDING HELP" is therefore a vehicle by which persons encounter the restrictions in decisional autonomy. One aspect of those restrictions in "HAVING PREFERENCES HONORED" is symbolized by "WAITING" for assistance. For each resident, the waiting began even before they arrived in the setting where they would encounter the constant symbolic limit to independence in the form of "WAITING" for specific types of assistance with daily care.

Functional ability and the residents' SELF-IMPOSED BEHAVIORAL EXPECTATIONS interact to shape that experience of waiting. The following section describes some of the differences in physical condition present among the residents in this study. It is followed by an example of the variety within the theme of SELF-IMPOSED BEHAVIORAL EXPECTATIONS.

Description of Functional Ability of Sample

The nursing home residents interviewed for this study all experienced some type of change in and/or problem with their functional ability that was of sufficient magnitude to precipitate the move to the nursing home. They all were experiencing the condition of "NEEDING HELP". Within Collopy's (1988) view of autonomy, these residents demonstrated some degree of restriction in "executional autonomy". In effect, the residents experienced a variety of changes in functional ability (i.e. the type of liquid "spill" varied), but for each of them, the

"spill" in some way had an impact on the integrity of their "fiber art". The paragraphs that follow provide a description of this sample with respect to the variations in functional ability.

Sampling decisions shaped the mix of types of abilities with which residents were experiencing problems. However, the sample generally represented persons from along the continuum of physical problems typically found within the intermediate care level of a nursing home setting.

All 11 participants received at least some assistance with bathing, in traveling away from campus, and with managing physical conditions. Sampling decisions made following the interview with the third participant shaped the sample so that nine (9) of the 11 participants received assistance with getting out of bed and/or with walking. Additional sampling criteria of "having at least occasional problems with urinary incontinence" further shaped the sample to include at least six (6) residents who received assistance with toileting during the daytime hours. Of the six (6) persons receiving daytime assistance with toileting, three (3) mentioned this need as an example of feeling "not independent".

Within each of three dimensions closely related to physical ability, there was a continuum of abilities represented in the sample. The range in abilities of these residents with respect to three dimensions of independence is described below.

Ability to function with respect to MOVING ABOUT THE ENVIRONMENT ranged from Arthur who received assistance only in travel away from campus to Frank who could move his arms only enough to activate the controls on devices such as the call bell and on his electric wheelchair.

Ability to function with respect to CARING FOR THE BODY ranged from Bertha who reluctantly admitted that she probably could even wash her own back "in a pinch" (b1*6) to Frank who needed assistance from staff for all hygiene and grooming, as well as feeding activities. Without his adaptive equipment (the electric wheelchair) Frank was totally lacking in executional autonomy.

Functional ability of these residents included cognitive and sensory abilities that were necessary for communication with persons in the nursing home environment. The specific themes of VISION AND HEARING and ABILITY TO THINK AND TALK were placed into the dimension of HAVING RESOURCES because they facilitate the communication activities mentioned as important to independence. Additionally, in some circumstances, problems in these areas can be improved by the use of material resources to purchase adaptive equipment (eyeglasses, hearing aides) or professional services to compensate for the problem. Description of the sample with respect to these communication resources follows.

At least five (5) persons (including Irene, Clara, Dora) had problems with vision severe enough to interfere with desired activities; two of these (Arthur and Elsie) being classified as "legally blind". For these five persons, the visual problems contributed to their limits in executional autonomy. They could not see well enough to engage in activities they considered important. They were "NEEDING HELP" for specific aspects of "DOING THINGS" but these limits in function also restricted the ways in which they could HAVE PREFERENCES HONORED.

A second physical ability in the dimension of HAVING RESOURCES for

which residents experienced limits was the sense of hearing. Selection criteria eliminated from the sample those persons so severely impaired in hearing that normal conversation could not be understood. However, several residents implied problems with hearing severe enough to interfere with interactions with other persons, a component of activities they considered important to their independence. For example, Irene, for whom one aspect of independence was visiting with others, commented directly about the way in which her hearing deficit greatly inhibits her ability to converse with other residents, particularly those who do not have strong voices. (i1*26). Joanna referred to her hearing aides within a context that implies that inserting them was part of getting dressed for the day's multitude of activities. (j2*6).

Cognitive ability, represented in the theme ABILITY TO THINK AND TALK, is an essential part of independence as conceptualized by several residents. However, the sample did not include persons representing the continuum of cognitive function typically found among nursing home residents. Excluded from the list of possible participants were all residents of the unit designated for treatment of persons with Alzheimer's Disease. Also excluded was anyone on the other three nursing units who could not recall and verbally state why they were living in this setting. In effect, the sampling method shaped the interviews so that, with respect to cognitive function, opinions were obtained primarily from "the elite" among nursing home residents. At least seven (7) participants had this distinction. Three of the seven residents specifically mentioned that they had been either interviewed or observed by some other researcher recently, though each had difficulty recalling the focus of those interviews.

The continuum with respect to cognitive ability ranged from Arthur and Bertha who recalled details from previous interviews, to Grace who was somewhat vague about her reason for living in this setting. Grace also varied in her ability to "place" where the researcher "belonged" within a specific family system, a behavior that was judged by the researcher to be an indicator of her highest cognitive function.

Description of the functional ability continuum for the residents in this sample is not complete without also relaying a sense of another continuum evident in the data. The SELF-IMPOSED BEHAVIORAL EXPECTATIONS that residents bring with them to the setting also seemed to shape their meanings of independence. These expectations form a continuum much less tangible than the one for functional ability.

Just as the ability of the resident to function with respect to physical abilities influences their "independence" within the nursing home, so also the self-imposed behavioral expectations of each resident seem to influence their "independence". This was particularly evident in statements about interactions with other persons within the nursing home context. In effect, there were some constraints on "decisional autonomy" or the extent to which they succeeded in "HAVING PREFERENCES HONORED" that were characteristic of the individual rather than solely that of the institutional environment. An example of one range of responses is presented below.

Irene and Harry provide an illustration of differences in expectations. They lived not only on the same unit, but also on the same wing of that unit. Their expectations for their own behavioral responses as well as views about

"WAITING" for assistance represented end points along a continuum. Irene expected the staff to automatically know what she needed and desired. She also tried to "be a good patient", and to quietly wait her turn for assistance. Irene interpreted any waiting as indicative of her low ranking in importance to staff. Her response contrasts with that shown by Harry, who expected that he would need to inform staff of his desires. Harry simply "got after them (staff)" if he was made to wait too long for assistance. It was as if Harry expected that the staff might sometimes forget what he needed, so it was his responsibility to monitor the care he received and take action if some aspect of that care was omitted.

Within the Collopy (1988) distinction, not only did the residents in this study vary with respect to the degree to which they were compromised in their "executorial autonomy", there is some indication that they also varied with respect to constraints on their "decisional autonomy". This variation was particularly evident within the theme of SELF-IMPOSED BEHAVIORAL EXPECTATIONS.

Collopy (1988) implies that "decisional autonomy" is constrained by external forces. However, omitted from that discussion is a view of the person as having an internal set of beliefs, values, and views by which they interpret the external world. So, while these persons were all living within the same nursing home, they demonstrated unique views of the extent to which they had "decisional autonomy" within this home. Residents also varied with respect to the personal and social skills they used while interacting with the social environment for the purpose of "HAVING PREFERENCES HONORED".

In summary, each resident experienced some problem with functional ability that was of sufficient magnitude to warrant the move to this nursing home setting. The residents are alike in that all are in this setting because of "NEEDING HELP". They are also alike in that "WAITING" was something they encountered in the setting. However, in addition to their varied functional abilities, each resident brought to this setting a unique mix of personal characteristics that likely influenced how they experienced independence within this setting, specifically with respect to "WAITING" for help.

Nursing Home As A Different Social Environment

In response to the "NEEDING HELP" that residents experienced, they took specific actions that ended up in the move to Maplewood. Although the residents selected, even waited for space in, Maplewood, the move was one which involved entering a different environment with a unique set of social rules. That environment is so different that it is viewed by Frank as a "different world".

Frank - "But this is a different world - entirely. It's hard to accept that to start with. But I have pretty well adjusted. You have to recognize that you are near the end of life anyway. (f2*8).

Inherent in such a move is the new (different) social environment with which the person must learn to interact. Harry comments about how to get along in this new world.

Harry - "Well, just learn as much as you can about the rules and regulations and try to get along with the nurses and everything. It's not difficult." (h2*37).

Among those factors present in the new environment are the institutional

rules, policies, and schedules as well as tangible elements of the living space; all factors typically associated with limits in "decisional autonomy". Joanna comments about a specific limit in her decisional autonomy in this response to a direct question about limits to her wishes.

Joanna - "Well, let's see. I can't open my windows - that's one thing I can't do. You are not allowed to open a window." (j1*18).

A number of themes within the dimension of INTERACTING WITH THE SOCIAL ENVIRONMENT are similar to those identified by other researchers as linked to limits in autonomy for older adults. Chapter Six (Discussion and Implications) addresses the parallels between these themes and the topics addressed by other researchers. For the most part, comments by participants in this study implied an acceptance of some limits to their preferences because they were "part of the package" that came with obtaining the type of assistance they needed (i.e because of their condition of limited "executorial autonomy"). Frank explains his view.

Frank - "I think you just adjust yourself to what the rules and regulations are for the most of the people ... Regardless of whether you like it or not, you have to give in to it (the rules, because) ... They take care of everybody's needs - that's how it is." (f3*21,22).

Clara relays somewhat the same message in her comment about adjustment in the nursing home.

Clara - "Well, you just have to get used to and accept the way things are here. You can't live like you did when you were in your own home." (c2*22).

So in a sense, because the person needed specific types of assistance that could be secured within this setting, that person made the decision to enter Maplewood. It is as if they knowingly exchanged some decisional autonomy for the assistance needed with the physical ability problems that were compromising their autonomy of execution. However, the possibly unexpected or at least undesirable "part of the package" was that of needing to wait for assistance. Since the activities for which one needs assistance include those occurring daily in the routine life of the resident, the functional ability limits continue to serve daily as a vehicle for interacting with staff.

In effect, the condition of "NEEDING HELP" is potentially a constant reminder of compromised "executorial autonomy" or the "DOING THINGS" strand of independence. "WAITING" becomes a symbol for "not independent" in the "HAVING PREFERENCES HONORED" strand of the meanings, essentially one form of limit to "decisional autonomy".

"NEEDING HELP" As Vehicle For Daily "Waiting"

The condition of "NEEDING HELP" that serves as vehicle for the move to the nursing home setting also continues as vehicle for interactions with the social environment on a daily basis in the context of obtaining assistance. Since "NEEDING HELP" is something with which the resident must contend on a daily basis, there are frequent reminders of the lack of ability to DO THINGS. "NEEDING HELP" continues as the constant "vehicle" by which interactions with the staff occur on a daily basis. "WAITING" for that help serves as an equally constant reminder that one is also limited in the extent to which

"HAVING PREFERENCES HONORED" is possible in this setting. Frank provides a clear example of the recurrent nature of both symbols in his comment about being "stuck here" and unable to move.

Frank - "Well, for instance, if I wanted to move around, I would have to wait. For instance, sometimes you can't get anyone for 1/2 hour. And that's not generally - they answer the call very readily. But you get the feeling you are helpless when you can't move and are stuck here." (f2*22)

Waiting permeates life in the nursing home. A theme of "WAITING" ran through many of the statements that were coded as examples of independence. Essentially, if the resident needed help with any part of an activity, there was some degree of waiting involved. The condition of "NEEDING HELP" with any aspect of "DOING THINGS" involves "WAITING" and thereby places limits on "HAVING PREFERENCES HONORED". Elsie's comment illustrates the problem.

Elsie - "And here I got to wait on everything!... Have to wait, yes, to get everything done. It's very different. It's a lot of difference in a nursing home than to be at home." (e2*4).

Katie relays a similar theme in her response to the researcher's observation that "it sounds like you wait to call until you know they (nurses) are not as busy".

Katie - "I try to. (pause). But we do have to do an awful lot of waiting. Sitting in the hall or wherever we are put. You just have to learn to be patient and wait. Because there is nothing else to do but wait." (k3*25).

The theme of "WAITING" for assistance was evident in multiple examples within each of the five dimensions of independence. The examples of

"WAITING" ranged along a continuum with respect to degree of urgency and predictability of the need for which the assistance was required. At times, a related theme was also evident that linked staffing levels to "WAITING" for assistance.

Although "WAITING" themes run throughout all five dimensions of meanings of independence, each theme in some way overlaps with the INTERACTING WITH THE SOCIAL ENVIRONMENT dimension. Additionally, the physical condition of the resident was linked to that resident's response to "WAITING". On occasion, rather than wait for some scheduled assistance, the resident sort of "took matters into my own hands" and did not wait for the usually received or expected help. Examples come from the two most mobile participants, Bertha and Arthur, as well as from Irene whom staff believed to have confined herself to the wheelchair.

Bertha "was kind of pig headed ... and wouldn't do what they wanted me to do" (b1*15) and climbed the steps unassisted in a situation where she did not want to wait for alternate transport when her preferred elevator was not working. Likewise, Arthur's ability to walk allows him the option of getting his medication on his own schedule. He describes the situation as follows:

Arthur - "I don't wait for the girl (nurse) to bring it (the medication) to me. I could do that, but you, you know sometimes they allow a half hour one way or the other, half hour early, half hour late unless it's some really weird drug. I go get them (his medications). I don't have to do that. It's because I, you know, I like to be my own man." (a3*11).

Irene improvised with her adaptive equipment (her cane) to reach and position objects rather than rely on (and wait for) the staff to honor her preferences. In this example, Irene provides yet another link between physical

ability and the degree to which one might need to wait for assistance.

The pervasive nature of "WAITING" is evident in each theme within each dimension of meanings of independence. The pervasiveness is particularly evident the INTERACTING WITH THE SOCIAL ENVIRONMENT dimension and overlaps the dimensions of MOVING ABOUT THE ENVIRONMENT, CARING FOR THE BODY, HAVING RESOURCES, and BEING ONESELF. Examples of "WAITING" are presented to illustrate the extent to which this theme permeates the daily life of residents.

Within the dimension of MOVING ABOUT THE ENVIRONMENT, a theme of "WAITING" was reflected in comments about needing assistance with moving into a different position for pain relief. Themes of POSITIONING AND TURNING as part of pain relief illustrate the overlap between the dimensions. The positioning is needed as a form of MANAGING PHYSICAL CONDITIONS, a theme within the CARING FOR THE BODY dimension. "WAITING" for this type of assistance is an implied threat to "HAVING PREFERENCES HONORED".

Less problematic was the waiting for transport to an appointment off campus. Additional "WAITING" occurred when the resident needed help getting up, out of bed in the morning, or needed help getting into bed for a nap. However, the more striking examples of "WAITING" were evident within the overlapping dimension of CARING FOR THE BODY.

"WAITING" was present throughout the CARING FOR THE BODY dimension of independence. Themes of "WAITING" for scheduled activities such as serving of meals, and assistance with bathing and grooming were common, but were mentioned almost as an accepted part of life within this environment.

Waiting for staff to bring the pain medication that one would have self-administered at home presents an additional example in which "WAITING" is symbolic of restrictions in decisional autonomy now that the resident has limits in their executional autonomy.

Among the most striking examples of feeling "not independent" were the three in which the resident needed help with toileting and was required to wait for that assistance. "WAITING" for help with unscheduled activities such as assistance in toileting may be more symbolic of "NEEDING HELP" and therefore "not independent" because of the association of this need with a much earlier stage in life. This link is addressed in a subsequent section.

The examples within the HAVING RESOURCES dimension are less directly related to "WAITING", but do contain an implied theme of "WAITING" for some type of assistance with a specific resource. Joanna talked about waiting to learn the scheduled date of her new appointment with the eye doctor, a visit that she hoped would result in new glasses and improved vision. Joanna also waited for staff to help her insert her hearing aids every morning, thereby enabling her to use adaptive equipment to compensate for the loss of her ability in hearing that allowed her to engage in her many social activities. Frank waited for the repair and return of his electric wheelchair, the one piece of adaptive equipment that allowed him to feel even a little bit independent.

"WAITING" further limits independence when it interferes with BEING ONESELF. The theme of "WAITING" within this dimension of independence was evident primarily in comments about needing help with some aspect of social or recreational activity. Examples of such activities included; waiting for staff to

obtain pen and paper from across the room so Clara could write letters, and waiting for transport to the Activities Department so that Grace could participate in scheduled events that she enjoyed. Dora waited for visitors to come, all the while hoping that she would not be simply resting in bed with her eyes closed and have the visitors leave because they assumed that she was asleep. Arthur, who equated money with independence, required assistance of a woman from outside the nursing home to manage his monetary affairs, needed to wait for her scheduled weekly visits if he wished to re-calculate his current net worth.

The themes of "WAITING" within the dimension of INTERACTING WITH THE SOCIAL ENVIRONMENT were multiple and varied. Several residents mentioned the need to wait to enter and or to leave this setting. Eight residents mentioned needing to wait for a bed in this home, in effect, "WAITING" to enter an environment in which they would then need to wait for daily assistance in aspects of care. Frank mentioned that he was "WAITING" to die, thereby leaving this environment. After telling about a recent dream, Frank continues with the following comment.

Frank - "I had a vision of the next life. In other words, I'm 93 years old, and I can't be here long - maybe a few months or maybe a year. Not long. So I more or less look forward to heaven when I pass on. Now a lot of my friends - I pick the paper up each morning and have a look at the obituaries to see if any of my friends have passed on. Most all of my friends have died. I don't have many left." (f2*25).

Frank repeats this theme of waiting to die in another interview in which he was talking about adjustments in the nursing home. He comments "I'll just as well pass on and see what's going on in the next life - my wife and friends - hundreds of friends that have gone on have adjusted themselves to eternal happiness." (f1*30).

The majority of themes about "WAITING" within the dimension INTERACTING WITH THE SOCIAL ENVIRONMENT were related to waiting for staff assistance. Although there were choices of activities, and specific encouragement for the residents to express their individuality and preferences, "WAITING" for assistance placed restrictions on the degree of independence associated with engaging in the needed activities. In order to individualize the room with wall hangings, as permitted within the rules, Joanna needed to wait for assistance from staff and/or family. In order to attend the activities chosen as important to their experience on a given day Irene, Grace, Dora, and Harry waited for the assistance of staff or volunteers to transport them to the location in which those activities were taking place.

One method by which residents communicated to staff that they needed assistance was by use of the bedside call bell. Assuming that the call bell was within reach of the resident, "WAITING" was experienced during the time that it took the nurses' aides to respond to the bell. On one occasion, the researcher observed that it took staff 5 to 10 minutes to answer some call bells. The researcher also observed at least three occasions in which the call bell was placed out of reach for the resident who was sitting in a chair near the bed. The symbolic nature of this type of waiting is discussed in Chapter Six.

Several residents made reference to staffing issues within the context of talking about "WAITING". Irene links predictability of the breakfast schedule to the number of staff present in the following comment.

Irene - "Sometimes they bring my breakfast no telling what time. See,

sometimes they bring it one time and sometimes another. I think it all depends on how much help they have." (i1*18).

Irene also specifically links waiting for assistance with pain control to staffing but then provides an explanation for the delay and takes the side of the staff in a later comment.

Irene - "And it takes a long time sometimes before you get someone to bring you a dose of medicine. Of course, the nurses are busy, but it's shortage of help. And that's one thing they can't help and I can't help. ... Have to wait and wait you know, you're suffering and can't do a thing about it." (i3*6).

Irene - "See now, a lot of times, the nurses, they'll be giving baths or with another patient or something and can't come to you right away. But they're good when they do come. Good when you get them. (i3*12).

Grace also links waiting and staffing in the following comment in response to a direct question about waiting.

Grace - "Well, I think that would be the comment of some here, thinking they have to wait. Sometimes I wonder if our help is a little bit scarce, it seems to me like maybe it is. But I'm not sure of that, and I've never asked anybody. But it seems to me that maybe we could just use another nurse or two. Especially certain times of the day." (g3*15).

Clara comments on her need for assistance with toileting as a reminder that she is not independent, then also links the delays to staffing issues.

Clara - "Sometimes they are just awful busy. They say they are short of help nearly always on weekends. And I think there have been times that the bell was cut off without being answered. I've been told that that's happened. And it seemed like it. ... Anyway, sometimes they just can't seem to come and help you." (c1*12).

Katie places her comments about staffing and waiting within the context of limits in her choices.

Katie - "Well I don't have many choices. Now this morning I wanted to get up - but the night nurse didn't have time, and the day girls, after I was out on the commode, I was put back to bed and had breakfast in bed (rather than in her preferred chair)". (k2*3).

Although the comments from the four residents just cited imply that an inadequate level of staffing was a factor contributing to their waiting, Frank suggests that having too many nurses' aides present may also compromise the quality of care delivered.

Frank - "It's ideal here (when) we have four aides for 29 of us on this floor, I mean, this section. And we have four is about ideal, three is bad. Now six or seven is bad because they argue among themselves - some discussion about why (inaudible). Now two, that's too short. I did ask, I guess they have about four this evening - I hope it's four. ... four is ideal, yes." (f2*26).

"WAITING" as Symbol

The theme of "WAITING" for assistance is so closely associated with the condition of "NEEDING HELP" that it cannot be separated from functional ability. Functional ability affects the meanings of independence because limits in those abilities constitute "NEEDING HELP", the antithesis of ability with "DOING THINGS". The condition of "NEEDING HELP" was the vehicle by which the person came to be living in the nursing home. It continues as a daily vehicle for interactions with the staff in the nursing home environment. "WAITING" is one reality associated with the process of obtaining help and

thereby represents one symbolic threat to "HAVING PREFERENCES HONORED". Multiple individualized meanings can be present because of the symbolic nature of both the "NEEDING HELP" and the "WAITING" threats to independence within the nursing home context. Statements from the residents suggest that needing help with and waiting for assistance with toileting and with pain relief may be particularly problematic for residents. The symbolic nature of specific types of assistance can be linked to the metaphor of the fiber art as well as to a theoretical discussion of "independence" as a form of the human development concept of autonomy.

The metaphor of the piece of fiber art is again useful, this time in summarizing how functional ability influences the meanings of independence within the nursing home context. It is as if, depending on the characteristics of the "yarn" representing the SELF-IMPOSED BEHAVIORAL EXPECTATIONS dimension of independence, some threats have a worse impact than do others. The person and the opinions, life experiences, and the meanings of independence that he or she holds are analogous to the piece of fiber art. The functional ability changes are a symbolic "threat" to independence much as a noxious liquid spill would be to art work. The noxious liquid can be any one or more of a wide variety of types - some stain fabric, others bleach it, still others erode, stretch, and/or shrink fibers. The characteristics of the fiber determine the response to the specific threat(s). So too, the nursing home resident will display a variety of types of functional ability problems, some symbolically more problematic than others. As unique individuals, they will also possess an unending variety of beliefs, values, views and SELF IMPOSED BEHAVIORAL EXPECTATIONS for how to interact in this social

environment.

The nursing home context is the environment to which the fiber art piece is taken following the "spill". There can be many factors in that environment, analogous to time, temperature, light, friction, even other liquids that can be used following the "spill". Some of the factors can help correct the damage or minimize the evidence of the problem. Other factors within that environment can compound the damage to the fiber. It is as if the different "treatments" affect individual fibers differently and affect the damage from the various types of "spills" differently.

There are common general types of conditions (treatments) that are somewhat similar within any nursing home, though not all nursing homes will possess all the possible "treatments". Likewise, there are common general types of threats or "spills" that require "treatment". However, greatly compounding the challenge is the fact that each work of art can contain a large variety of fibers, and there are many such works within the environment.

"WAITING" for assistance is analogous to timing as part of a treatment for damage to fibers. The time dimension is also important to the impact of the liquid "spill" on the integrity of the art work. The timing of the application of the "treatment" can influence the outcome of the damage caused by the liquid "spill". The damaging effect of waiting will vary depending on the characteristics of the individual fibers within the work and on the nature of the spilled liquid. Likewise the time dimension (waiting for assistance) in the nursing home is important to the feelings of independence for the individual resident and may vary with different types of conditions for which one needs assistance.

The nursing home environment presents an endless combination of possible treatments for the conditions that created the "NEEDING HELP" threat to independence (the fiber art) for each person. Essential to effective application of a treatment is good understanding of the ingredients of the art work, as well as knowledge of the history of other influences on the fabric. Some treatments and some liquids differentially affect the base fabric, causing the wool to shrink or the elastic to stretch.

Summary for Research Question Two

The meanings of independence articulated by these residents and as interpreted by this researcher are both highly individualized and quite varied. The meanings, though varied in specifics, relay an underlying view of independence that connotes physical ability to "DO THINGS" within circumstances that allow for "HAVING PREFERENCES HONORED". The ability to "DO THINGS" requires that an individual possess a variety of functional abilities. Within the nursing home context, functional ability influences the meanings of independence when problems develop that are of sufficient magnitude to warrant nursing home care. These limits in functional ability, conceptualized as "NEEDING HELP", are the antithesis of "DOING THINGS" and are symbolic threats to independence.

The required assistance with "DOING THINGS" is obtained within an institutional setting of group living. The resident experiences "WAITING" as one aspect of interacting with the staff within this "different world" of the nursing home. "WAITING" for assistance is the symbolic antithesis of "HAVING PREFERENCES HONORED".

The types of assistance for which the resident experiences waiting may carry additional symbolic meanings that are unique to the individual. Among the residents in this study, waiting for assistance with toileting and waiting for pain relief were the most vivid examples of feeling "not independent". These needs are theoretically linked to the Erikson concepts of autonomy and trust.

Research Question Two interpreted the meanings of independence within the realities of functional ability of residents to be associated with the symbolic threats of "NEEDING HELP" and "WAITING". The following section (Chapter Six) is presented to answer Research Question Three and represents a theoretical interpretation of the meanings of independence now that the resident is living within the nursing home context.

Chapter Six - Discussion

Introduction

"WAITING" permeates life in the nursing home, just as does the condition of "NEEDING HELP" with physical care. Both symbols are part of the reality from which residents attempted to talk about the meanings of independence in the nursing home. Research Question Three provides the focus for the discussion of the results of this study and relates the findings from the two previous chapters to the Erikson developmental framework. Data available in the interviews allow discussion of the theory only from the perspective of Erikson's first two stages, trust and autonomy, with some reference to the eighth stage, wisdom. Researcher thoughts are used as an added data source in this discussion.

Research Question Three

The third and final research question guiding this inquiry is: Can those meanings (of independence) be analyzed productively from the perspective of Erikson's developmental theory?

Erikson's developmental theory is useful in several ways to the analysis of the meanings of independence as expressed by the Maplewood residents. It provides theoretical support for: 1) use of the dual strands of DOING THINGS and HAVING PREFERENCES HONORED as foundational to the discussion of themes of independence; 2) the importance of the theme "Self-Imposed Behavioral Expectations" as a crucial part of the dimension of INTERACTING WITH THE SOCIAL ENVIRONMENT; and 3) the premise that "NEEDING HELP" and "WAITING" are symbolic threats to independence within the nursing

home context. Additionally, specific comments from residents participating in this study provide data to support the Erikson premise that some reworking of life stages occurs in old age.

Erikson on Advanced Old Age

The initial Erikson theory (Erikson, 1963, 1968, 1982) did not specifically address issues of advanced old age except with reference to persons age 60 and above as one group. The implied view was of one developmental stage covering the span from age 60 to 100 plus years. The Eriksons' expanded work in 1986 represents an attempt to rectify that omission by focusing specifically on that last stage of life (Erikson, Erikson, & Kivnick, 1986).

The 1986 work describes findings from a follow-up study growing out of Erikson's earlier work. Three researchers conducted interviews with available older (75-95 years) adult parents (n=29) from the original longitudinal study in which the Erikson child development theory was generated. The researchers focused on "vital involvement" in old age, specifically looking for ways in which the strengths from each of the eight stages continue to function as the person, now in old age, interacts with the social environment (Erikson, Erikson, & Kivnick, 1986).

The examination of ways in which persons express those strengths in old age expands on a theme within the Erikson theory. The theme suggests that at each new developmental stage, persons need to reformulate their previously mastered or attained strengths in a manner also acceptable for the new life situation. The cumulative effect of successful struggle at each stage is

development of the adaptive strength of wisdom as the person moves toward old age.

The Erikson theory as expanded in the 1986 work suggests that in advanced old age, persons rework all previous developmental stages whenever life circumstances change in a significant manner. Issues that were unresolved, or for which the individual did not develop the expected strength, can resurface during the process of re-examination. Implied within that statement is the view that persons bring unique life histories and experiences to the re-examination process.

Limitations in physical ability are among those circumstances that can lead to reworking of developmental stages. Physical changes in particular can reactivate the struggle to maintain control over the body as well as over behavior and total life. Erikson explains the interaction as follows:

"As the body changes and develops throughout the life cycle, capacities for autonomous behavior also develop and change, expanding and contracting with the overall waxing and waning of physical prowess. Along with actual behavioral capacities, individual feelings of self-determination and of helplessness remain connected with the body, and they resurface throughout life - at times, for example, of bodily damage from illness or injury, of the bodily changes of puberty, and of the deteriorations of old age" (Erikson, Erikson, & Kivnick, 1986, p. 188-189).

The expanded theory provides a framework from which to present a theoretical discussion of the meanings of independence for these Maplewood residents. Responses during the interviews support the Erikson premise that some sort of reworking of life stages takes place in advanced old age. Furthermore, the manner in which several residents participated in the interview process suggests that this was the first occasion in which they had given conscious thought to the

meanings of independence within the realities of their current life in the nursing home. The following paragraphs illustrate these statements.

Reconceptualizing Independence

For the residents in this study, the meanings of independence, in a general sense, are those held by persons in society at large. However, personalized meanings of independence are called into question as a result of the combined effects of having some problem with functional ability and that of needing to live within a nursing home. "NEEDING HELP" becomes the impetus for re-conceptualizing the personal meanings of independence.

Current meanings of independence are less clear to these residents than some view that applied to their lives prior to living in the nursing home. In a sense, the process of participating in this research may have provided a stimulus for the residents' re-conceptualizing of independence. It seemed that they had not actually given conscious thought to independence within the nursing home context before these interviews.

A puzzled curiosity about the topic was evident as Arthur and Irene gave their thoughtful responses and expressed an eagerness to hear the researcher's findings from other residents. Clara, Dora, and Frank (the residents in the sample requiring the most assistance with physical care) also were reflective, though more puzzled by the notion that independence might be a concept relevant to nursing home life. Each of these five residents seemed to be in some way working to re-conceptualize "independence" within the realities of "NEEDING HELP" and "WAITING".

Theoretical Support for Dual Strands of Meanings

The Erikson framework provides a perspective from which to examine the dual strands of meanings of independence, labeled in this research as "DOING THINGS" and "HAVING PREFERENCES HONORED". The topical focus for the interviews centered around meanings of the term "independence", as a way of exploring meanings within the broader concept of "autonomy". In Chapter Four, Description of Meanings, two interwoven general meanings of independence are identified as "DOING THINGS" and "HAVING PREFERENCES HONORED". These two strands of general meanings both support and permeate each of the identified themes of independence.

Although the term "independence" is used throughout this research, the meanings as viewed by these residents carry connotations strongly resembling the concept of "autonomy" within the Erikson developmental theory. "DOING THINGS" represents the physical ability component of the Erikson concept of autonomy, and is much like the polarity labeled "executorial autonomy" in the writings by Collopy (1988). "HAVING PREFERENCES HONORED" represents the self-determination component of the Erikson concept of autonomy, and is much like the "decisional autonomy" within the Collopy discussion.

These two inseparable strands permeate each of the themes identified as making up the meanings of independence for these residents. The parallel with the concept of autonomy was useful in the final grouping of themes. The recognition that each theme contained elements of both self-determination and of

ability to take action in behalf of those wishes was useful in bringing closure to the prolonged stage of data analysis.

Theoretical Support for "Self-Imposed Behavioral Expectations" as Important to Interactions.

The Erikson framework provides a theoretical explanation for the influence of the theme "Self-Imposed Behavioral Expectations" as a crucial part of the dimension of INTERACTING WITH THE SOCIAL ENVIRONMENT. Erikson views human development as taking place within a social context, a concept particularly important as the person addresses issues associated with the stage of autonomy (Erikson, Erikson, & Kivnick, 1986). Theoretically then, part of reworking the stages in advanced old age would include recognition of the existence of the new social context in which that person is now situated.

Although the persons in this study did experience changes in their functional ability, it was the move to the nursing home that brought into focus the limits to independence. This study did not examine ways in which the residents responded to those functional ability changes or losses. However, those changes in ability were instrumental in the chain of events that resulted in the change of residence. Frank's use of the phrase "its a different world" implies that the nursing home is a unique social environment in which there are some new social norms. The ways in which these residents responded to that new environment were multiple and unique to the individual.

Not only do residents bring to that new social environment a lifetime of experiences that likely shape their perspectives about life in the nursing home, the

persons also bring widely divergent sets of skills for interacting with the people and structures present within that environment. This research suggests that one factor of crucial importance in the issue of independence (or autonomy) for nursing home residents is this set of unique individualized characteristics that are part of the person who is experiencing the limits in functional ability that were primarily responsible for their placement in this setting.

The meanings of independence that were grouped within the dimension of INTERACTING WITH THE SOCIAL ENVIRONMENT include themes that have parallels in the gerontology literature focused on autonomy in long-term care. Resident comments coded within the themes of choices, schedules, and living space, as well as institutional rules and policies, serve to illustrate the changes inherent in this new environment. These themes represent crucial factors affecting life for the resident. Now that the person, with specific functional ability problems, is in the nursing home, the social environment of that setting becomes a mediating factor in the extent to which "HAVING PREFERENCES HONORED" gets operationalized.

Although the physical abilities of the person have changed, residents do retain individuality that they bring to the new setting. Past life history and individual skills for dealing with new situations are assumed to be used as the person begins to learn new rules or norms for interacting within that "different world". One important finding of this research is the theme of "Self-Imposed Behavioral Expectations" representing the unique individual factors that residents seemed to use as they interacted with this different environment.

A variety of conceptually related topics have been the focus of investigation by researchers. Topics such as choices, policies, and schedules are among those addressed within the gerontology literature, and cited in the literature review for this study. Less well represented in the literature are references to phenomenon resembling the "Self-Imposed Behavioral Expectations" that residents bring to the nursing home living situation. This study suggests that more attention needs to be paid to this aspect of life within the nursing home as it relates to issues of autonomy.

Another important and unique finding of this study is contained within the theme of "Self-Imposed Behavioral Expectations". The theme seemed to play a crucial role in the ways in which residents talked about independence within the nursing home context. During the data coding and analysis phase of this research, themes originally coded as "self-control" and "complying with expectations" were associated with comments about the meanings of independence. The two categories were eventually combined because together, they seemed to represent something unique about the individual that was important to that person's view of independence within the nursing home context. Such uniqueness has been neither clearly identified nor adequately explained in the studies focused on variables such as perceived control, and/or choice, nor in research focused more broadly on autonomy. One exception is evident in the work of Agich (1990) in writing about autonomy in long-term care.

Agich (1990) argues that with respect to frail elderly persons living in nursing homes, the discussions about autonomy need to go beyond that of providing choices. He broadens the discussion of autonomy to include respect for

persons, a distinction that implies the need to learn about the specific individual. An expanded view of autonomy is needed that includes awareness of, respect for, and support of the individuality of specific persons. It becomes important to focus on actions needed to support “the individual’s own sense of self-worth and identity” (p. 15). Attention to the ways in which individuals have habitually acted is suggested by Agich as more important than a focus on specific choices that can be offered within the long-term care setting.

Porter and Clinton (1992) suggest that residents bring to the nursing home setting their unique perceptions about the requirements of life in that environment. Their work supports the finding of this research that some expectations about nursing home life accompany the resident to the setting. Further research is needed that explores the role of individual beliefs about nursing home life as one possible component within the discussion of issues of autonomy in long-term care.

A recent focus within the nursing gerontology literature has included studies addressing a variety of issues from the perspective of the residents, exploring the topics using qualitative research methods. Although the topical focus has not been that of autonomy, the findings do contain themes supportive of the finding that residents may have a variety of meanings attached to their experience in the nursing home. One such study resulted in suggestions by Porter in her critique of the “ADL Research Tradition” from the perspective of phenomenological research.

Porter (1995) found that for older women living alone, the extent to which they performed specific tasks without assistance was not necessarily indicative of

the extent to which they viewed themselves as independent. Ability to remain in their homes was conceptualized as being independent. Porter's finding suggests that within the nursing home, independence must be conceptualized more broadly than simply the ability to engage in specific tasks associated with daily living. Although her sample was comprised of elderly women living at home alone, those women included in their concept of independence, such elements as "creating their own schedules, (and) deciding how tasks would be done even when someone else did the tasks"(1995, p. 39). Within the nursing home setting many tasks are performed for residents by staff who quite likely are working under a wide variety of scheduling pressures. The potential impact of those work conditions on the extent to which residents feel independent is an area for further research. There may be something within the caregiving relationship that holds a key to the extent to which residents feel independent, (or autonomous) even though they are in need of assistance from others.

Russell (1996) addressed the issue of the care seeking process in her work with non-institutionalized elderly women. As part of the "initiating stage" of the "care eliciting phase" of the process, she found that the preferences and beliefs of the elder with respect to their dependence on others were important factors in determining when and how the person sought help from a caregiver. Her findings support the view that older adults have complex views regarding dependence and independence. Russell's findings support one recommendation from this research; that more attention needs to be paid to the unique views that elderly residents have regarding their care.

"NEEDING HELP" and "WAITING" as Symbolic Threats

The Erikson framework provides theoretical support for the premise that "NEEDING HELP" and "WAITING" are symbolic threats to independence within the nursing home context. As viewed from the perspective of human development theory, Erikson linked the concept of autonomy with physical growth and development of ability to control the body and use muscles in a purposive way to express "the will" or self-determination. Development of mobility skills and use of muscles to propel the body within the environment are characteristics of the stage of autonomy for the child. Restrictions to mobility imposed by circumstances within the environment typically are followed by protest from the child. Societal pressures help shape the range of acceptable expressions this protest can take.

The early childhood stage of autonomy is one in which the person also develops control of smaller muscles, such as the sphincters, so that one "fits into" the social environment - essentially a process of learning what constitutes acceptable behavior. The development of a sense of shame and doubt is linked to this aspect of physical development, and in particular is associated with ability to exert control over bowel and bladder functions. As persons develop beyond this early childhood stage, it is assumed that they retain this ability to control the body within parameters defined as acceptable behavior in society.

The elder differs from the child in several pertinent ways. Typically the older adult has mastered the expected skills from the autonomy stage as well as from subsequent ones. In addition to specific skills from each stage, the adult brings multiple life experiences and theoretically also brings the strength of

wisdom. However, as a result of injury or illness, the elder may be experiencing problems with mobility. The muscles may not be functioning adequately enough to allow expression of "the will" to move about the environment without assistance from others. That assistance may be sought within the context of a nursing home. A relevant issue likely becomes that of learning how best to maintain control over the body now that the resident must rely on other persons for assistance in mobility. Part of that learning process may include learning how to effectively request and obtain assistance from staff in a timely manner.

Theoretically, the need for help raises not only issues of autonomy, but also those of the ability to trust caregivers to respond in a timely manner to requests for assistance. In effect, the circumstance of needing help can remind the elder of his or her limits in ability to move about freely. Waiting for the arrival of the needed assistance has the potential for compounding the problem. The resident is reminded of how dependent he or she is upon the actions of others. The dependency extends even into actions directed toward the basic self-determination to remain comfortable and behave in a socially acceptable manner. One area for future inquiry is that of the relationships between and/or among variables such as waiting for assistance, trust of caregiving staff, and any number of desirable health outcomes relevant to nursing home residents. Physical care problems associated with mobility limits, urinary incontinence, falls, and even behavior problems may be associated with the issue of waiting for assistance. These problems may represent tangible examples of attempts by residents to deal with dependency in situations where they cannot trust the staff to respond in a timely manner.

To extend the theoretical discussion, it seems plausible that there might be some rank ordering to the problems for which the resident experiences the waiting for assistance. Waiting for assistance with some needs may be symbolically more problematic than the wait for other types of assistance. While there might be some similarities among residents in their rankings, it is also quite possible that unique individual differences would exist in such rankings. Comments by residents in this study support the existence of some such hierarchy in their references to needing help with toileting as one of the most difficult examples of feeling not independent. Added support for the premise that such hierarchy might exist is illustrated by a case commentary involving ethical dilemmas within the daily routines of caring for nursing home residents.

Fry (1990) provides commentary on ethical issues present in a situation about a nursing home resident who has accidentally wet the bed on occasions when there was delay in answering her call for assistance to the bathroom. The resident considered such calls to qualify as having higher priority than requests for many other types of assistance, because she was horrified at the prospect of again wetting the bed. The aide cheerfully attempted to reassure the resident that changing the bed was no problem, apparently totally oblivious to the meaning "the accident" held for the resident. Not only does this example suggest some hierarchical ranking to/for types of assistance, it also illustrates a difference between the significance staff and residents may assign to a given situation.

Toileting and Independence

In this study, residents cited as important examples of feeling “not independent”, times in which they needed assistance with toileting. A theoretical explanation of the significance of help of this type is provided by an understanding of the stage of autonomy in development of the person.

In certain circumstances of illness or injury among older adults, there is a decrease in ability of the muscles to move the body at the will of the person. Part of moving at will is for the purpose of fitting into society and continuing to function in ways expected of the adult. So when the elder needs the help of another person for the process of moving, simply needing that help may emphasize their limits in ability to function independently. However, waiting for that help to arrive can also function as a reminder of the limits to “the will” or self-determination of the person. The meanings attached to this waiting are likely highly individualized.

Needing help with toileting may evoke memories of early childhood vulnerability. The person risks embarrassment and shaming by others if an “accident” occurs. Although typical standards for care providers advocate avoiding “shaming” the person, meeting those practice expectations does not remove the internal sense of embarrassment and feelings of doubt the elder may feel about their own ability to meet normal adult expectations for themselves. Ideally caregivers try to avoid responding in ways that make persons feel worse about the situation. However, even when the caregiver tries to help the person “not feel bad”, the resident may still experience the situation as one reminding

them of lack of autonomy. Just such a situation is illustrated by the example of “everyday ethical dilemmas” upon which Fry (1990) comments.

An issue such as the above can undermine the sense of dignity for the nursing home resident. If that dignity is one of the few remaining characteristics of adult function for this individual, then autonomy even in the Agich (1990) sense of the term is compromised. The dignity to which Agich refers is perhaps further eroded in symbolic ways such as having staff ignore or delay in answering the call bell indicator for assistance.

Pain Control and Independence

In a similar manner, the issue of pain control may threaten feelings of independence. The threat may occur directly through the limits placed on the access to pain medications the resident might have used at home. To a certain extent, the rules and policies of the setting that control a resident’s ability to administer his or her medications place limits on the independence of the individual. However, limits in functional ability can compound the issue. If the person retains some abilities, such as ones needed to go to the telephone, call the physician, and have that physician call the staff to change the medication orders, then, even though the person is in a setting that limits an aspect of independence, that person can exercise his or her self-determination through other routes, but requires functional ability to do so.

Indirectly, through trust issues, the sense of autonomy or independence that a person feels may also be limited in situations involving pain control. The extent to which the resident can trust staff to “fill the gap” between their own ability and the actions needed to be comfortable may be an important aspect of how autonomous the person feels within the nursing home setting. At issue may be a question of whether the staff will deal with the pain relief issue in a timely manner. Waiting in such a situation theoretically would impact not only the sense of autonomy, but also the sense of trust.

An added source of potential difficulty in the situation of pain relief is that of differing views as to the effectiveness of whatever treatment is prescribed. Not only can there be difference of opinion about the cause or source of the pain, and its intensity, but also there may be different opinions as to appropriate types of treatments. Important to the situation would be the extent to which the care provider is able to recognize (and “buy into”) the world view or sense of reality from the resident’s perspective.

The Call Bell and Independence

Several residents in this study mentioned as problematic having the call bell be either out of reach or having it be ignored when they needed assistance, although they did not specifically link the reference to independence.

Theoretically, this can be interpreted as one form of staff control over the requests that residents make. There are control issues in the waiting - including the call bell placement, the time it takes for staff to respond to that call bell when used, and the time it takes staff to honor that request after it is relayed. At issue also is the degree to which that action is carried out in the way the resident wishes - i.e. to what extent is the “will” or preference of the resident honored in the manner in which their care is delivered?

Because each resident is a different person and comes in with a different history, life experience, etc. i.e. different self-imposed behavioral expectations, there is/may be a need for much more individualized work in orienting the new resident to the setting - and to follow-up reorientation at times during the early weeks.

Summary for Research Question Three

In this section, the meanings of independence for these nursing home residents were examined from the perspective of Erikson’s developmental theory. Although the meanings of independence as articulated by these participants were found to be similar to those used by society at large, those meanings carry an added layer of meaning because of the types of problems they have experienced that resulted in the nursing home placement. Among those additional meanings,

the issue of needing help with toileting was particularly linked to feelings of lack of independence on the part of several residents. The older adult brings to the nursing home experience a lifetime of experiences, a collection of values (including Self-imposed Behavioral Expectations for how they should interact), and also, theoretically the strength of wisdom. They also likely have very specific and unique meanings that they assign to situations encountered within the nursing home.

Using the Erikson developmental framework as basis for examination of meanings of independence within the nursing home context raises to awareness several important issues. The nursing home residents come to this social situation with unique histories as well as individualized needs. They are now living within a different environment, one to which they may bring any variety of views about issues of independence. Particularly problematic were the areas of needing to wait for assistance with toileting and with pain control. A related issue included implied complaints about delays in responding to the call bell when it was used to summon assistance. From the perspective of Erikson's developmental theory these issues may be linked to issues of trust, autonomy, and wisdom.

The degree to which staff meet these needs in a timely fashion might be associated with the degree of trust that residents have for the staff. Additionally, the resident might be using wisdom of age to quietly comply with what they view

as the staff expectations for how they should behave in this situation. It seems particularly important to give attention to the need for assistance with toileting because of the ways in which that issue is linked to early childhood issues of toileting as part of fitting into societal expectations. Because these adults are experiencing problems with their ability to move about freely, they may have some unique aspects of their care on which they place priority. Respect for the dignity of the individual demands that these unique views be explored with each resident. Chapter Seven outlines research and practice implications raised by these findings.

Chapter Seven - Implications and Recommendations

Introduction

Presentation of the implications of this research is framed within the context of a discussion about the morality of the mundane (Caplan, 1990). In that work, Caplan asserts that even seemingly small and supposedly insignificant events within the daily routines of life in a nursing home merit exploration as ethical issues affecting residents. Caplan states "...ethics concerns not only questions of life and death but how one ought to live with and interact with others on a daily basis. The ethics of the ordinary is just as much a part of health care ethics as the ethics of the extraordinary (p. 38). Among the eighteen case studies that are presented in remaining chapters of the book (Kane & Caplan, 1990) are ones dealing with issues that parallel those identified by the residents of Maplewood. Problems associated with assignment of roommates, the environment in which one is placed for meals, and promptness with which the call button is answered are subjected to ethical case analysis from the perspective of autonomy within the nursing home. Such issues were also identified as problematic by Maplewood residents. The importance to residents of these mundane aspects of life should not be overlooked in our efforts to address the quality of care within nursing home settings. Likewise, the findings of this

research study may seem mundane, but are highly important from the perspective of the residents experiencing those situations.

Major Findings

Two major findings of this study that differ from those addressed within the gerontology literature are the symbolic nature of WAITING and the role that Self-imposed Behavioral Expectations for interacting with the environment seemed to play for these residents. Waiting for help can be symbolic of feeling “not independent” for nursing home residents. Likewise, the self-imposed behavioral expectations that the resident brings to the setting may play a significant role in how that resident responds to any waiting that is encountered within the nursing home setting, thereby also affecting their feelings of “independence”.

As researchers and as clinicians, we must resist the temptation to discount the significance of these findings. When reflecting on life in a nursing home, the themes of NEEDING HELP and WAITING seem so obvious that one is tempted to ask why all the effort of dissertation research was devoted to it. “Conventional wisdom” tells us such issues would be problematic within long-term care settings. However, there is a sense of the profound in the simplicity of these findings.

A key assumption within the methods used for this research was that the views of the participants represent a reality that is important to them. Each

participant needed some form of help. Each also experienced waiting within the context of receiving that help. The symbolism expressed in the themes of NEEDING HELP and WAITING as threats to independence is grounded not only in the experience and words of the Maplewood residents; it is also supported theoretically. The experience of waiting within the nursing home setting has not yet been adequately addressed by nurse researchers but seems to be a potentially fruitful avenue for exploration.

The presentation of implications of this research is organized around three major findings. An additional area for which research is indicated is presented because it seems theoretically compatible with these findings. Listing of each of these findings will be followed by preliminary recommendations for practice as well as specific recommendations for additional research.

Implications Related to Waiting

Waiting for help can be symbolic of lack of independence, particularly if that wait involves assistance with toileting. More careful attention must be directed toward strategies for decreasing the amount of time that residents need to wait for specific types of assistance. Further research is needed about the phenomenon of waiting within the nursing home. Perhaps in light of so many losses and limits in ability to function that are experienced by nursing home

residents, the symbolic meanings of waiting may take on added significance. This merits further investigation.

Additionally, we need to explore further the meanings of waiting for specific types of assistance. Is there some sort of hierarchy of severity of waiting? If so, how does this differ between various residents, and between staff and residents? What interventions can be utilized at the staff level to improve the situation of waiting within the nursing home? From a practice perspective, the impact of cost containment efforts may aggravate the problems with waiting, particularly if those cost concerns have resulted in less than favorable staffing ratios.

Implications Related to Self-imposed Behavioral Expectations

Self-imposed Behavioral Expectations about nursing home life are unique to individual residents and likely affect how that person interacts with the nursing home environment. From a practice perspective, this finding adds support to the conventional wisdom advocating that nurses assess the uniqueness of each individual assigned to their care. Nurses would be wise to heed the suggestion of Agich (1990). Agich suggests that attention be paid to the habitual actions of the residents, and that this may be more important to their sense of autonomy than the provision of specific choices.

The theme of self-imposed behavioral expectations seems to be an important factor in how the resident interacts with the social environment now that he or she is in the nursing home. This finding is compatible with the Erikson concept of wisdom that develops as a strength in old age. Perhaps nursing home residents are displaying wisdom in their apparent efforts to abide by Self-imposed Behavioral Expectations. They may be employing a strategy for dealing with a new and untested environment. If this is the case, then one fruitful topic to explore could be the extent to which specific nursing strategies are effective in helping the resident change those expectations that interfere with their ability to have their care individualized within a specific nursing home. In light of this finding, one such strategy may involve education of the client. A relevant question might be: What teaching can be implemented (with the resident and/or the family) to help each resident know not only what resources are available for individualizing their care, but also how to get their needs addressed in a timely manner. Implications for additional research related to the role of Self-imposed Behavioral Expectations are multiple. One specific practice implication is that nurses need to pay more attention to is the careful individualization of strategies for working with persons newly admitted to the nursing home.

Re-conceptualizing Independence

Residents likely need to re-conceptualize “independence” as part of their process of adjusting to changes that resulted in their placement within the nursing home environment. Now that they are in need of the type of assistance that is available within the nursing home setting, they may need time and specifically targeted strategies to help them with this process of re-conceptualization. Further research is needed to identify such strategies.

Trust as supportive of independence

Although not grounded in the responses obtained from the eleven participants in this study, from a theoretical perspective, the issues of trust of the staff may be related to feelings of independence that residents experience within the nursing home context. The purposive sampling used for this research affected availability of data to pursue this issue for these residents. However, from a theoretical perspective, these issues are connected. Relevant questions include: To what extent can residents feel independent in situations or settings in which the staff cannot be trusted to respond to their needs in a timely fashion? and To what extent can residents feel independent in situations or settings in which the staff cannot be trusted to protect the resident and their property? Theoretically, trust is

fundamental to the issue of autonomy within the nursing home but this has not been addressed by other researchers.

Limitations to Application

This research was designed to explore and describe a situation about which little was known. The small sample size ($n=11$) and the purposive selection of the participants limit the generalizability of these findings. Of even greater importance however, is the purposive selection of the site for conducting this research as a limit in applying these findings to other settings. It was by intent that a nursing home with a long-standing, regional reputation for providing excellent quality of care was selected as the site in which to explore the meanings of independence for nursing home residents. However, that limit also serves as a strength for a study of this nature. Waiting for assistance was found to be symbolic of limits in independence. Since this finding was obtained even in a clinical setting with a reputation for excellent care, it is one that certainly should be explored further using different types of nursing home settings.

Conclusion - Summary of major findings

The meanings of independence are multiple and represent a wide variety of topics. Those meanings are quite like ones pertinent to life outside of the

nursing home setting. However, because of the conditions of the residents, and the fact that they are in need of help with specific aspects of care, the daily reminders of needing help and then waiting for that help create the feeling of being not independent.

Two major findings of this study that differ from those addressed within the gerontology literature are the symbolic nature of waiting and the role that Self-Imposed Behavioral Expectations for interacting with the environment seemed to play for these residents. The findings from this research serve to highlight the existence of problems associated with life in nursing homes. Many researchers have addressed a variety of concepts related in various ways to the quality of life experienced by nursing home residents. One theme unique to this study that has not previously been identified in the research literature is that in which residents linked needing assistance with toileting with lack of independence. This issue should be pursued with additional research. The concepts of autonomy and trust may be related to the waiting experienced by residents within nursing homes.

Chapter Eight - Epilogue

“Just Do It” - Interdependence while Exploring Independence.

At a key point near the end of this research project, a dissertation committee member inquired about the number of participants who died while the data collection for this study was in process. On the surface, such a question seems both fairly innocuous and highly germane to the academic aspects involved with field research. The inquiry about death of participants, a highly relevant one for a study involving sequential interviews with elderly nursing home residents, also provided impetus for intentional reflection on the effects of this research project on the researcher as a person.

It is nearly impossible to separate the personal and professional aspects of the above question. Equally important and perhaps even more striking was my response. That response addressed the recognition that, yes, several of the participants died by the time I had completed the data collection, but that more relevant to the research, I had experienced the deaths of several persons important to my life as a person outside of the research setting. The writing of an epilogue was agreed upon as a format for articulation of several factors that likely have shaped my thinking about meanings of independence and to bring closure to the reporting of this research.

This epilogue is written for several purposes. The task of writing coherent narrative comments requires review of, reflection upon, and summarization of multiple and diverse experiences that were associated with the planning and completion of this dissertation. The intended outcome is to bring closure to this phase of my professional life, a needed step in preparation for moving on into that world of “life after the dissertation”. Additionally, this epilogue serves to express thanks to the many persons whose interdependence was essential for me to complete this project.

In writing about applications of qualitative research Glesne and Peshkin(1992) distinguish between use of research findings and use of the knowledge that comes from engagement in the research process. They also recommend that the researcher reflect on the reasons why a particular topic was selected. The previous chapters have focused on the findings from this research study. This chapter focuses on what I have learned as a result of the process of completing this study.

I brought to this research effort a mix of experiences that affected not only my interest in the concept, but likely also the ways in which I conducted the data collection and analysis aspects of the process. As a person, I brought to this experience a rich background of contact with older adults, mostly relatives and/or members of the community of my childhood. In retrospect, I have become aware

of numerous influences that these persons have had on my views of aging.

Stories from and about my grandparents and their siblings shaped my views about ways in which “retired” persons experience life.

Vivid among those stories are the ones of a great uncle (well into his 80’s) with his one suitcase and many bus tickets, traveling across his church network advocating active involvement of youth in peace concerns. Another memory is of a great aunt, at summertime family reunions, intentionally inquiring about the lives of each of a large number of us, her much younger great-nieces. Later this same aunt, as a very active and healthy 86 year old, described for me the ways in which she helped the less fortunate “old people” who were unable to drive their cars. Also present as influences are my memories of the struggles faced by three of my grandparents as they each encountered circumstances that in a variety of ways, impacted their abilities to “be independent” as they aged.

In addition to the personal life experiences, I also brought to this research effort my experience as a nurse clinician and educator. My clinical experience has been primarily with hospitalized adults. My educator role exposed me to the challenges faced by older adults within the health care system. My nurse educator role includes supervision of nursing students during clinical work with persons living in long-term care settings. A known “bias” that I brought to this research project is my long-standing “pet peeve” about aspects of the care

provided in long-term care settings - specifically resident call lights and bells that seemingly go unanswered for long periods of time. It is impossible to determine the degree to which this reality influenced my recognition of the theme of waiting that was expressed by the participants in my study. However, the member check process as well as numerous incidental conversations with persons acquainted with nursing home life verified for me that the theme of waiting is grounded in the reality of the residents. The findings of Brubaker (1996) support the existence of waiting as problematic for nursing home residents.

In addition to the above ways in which I may have unknowingly shaped the study, there are multiple effects the process had on me. The activities associated with the completion of this research project spanned quite a few years and fell into two fairly discrete groupings. Phase One, data collection and early data analysis, occurred while I was living in a setting that was literally a return to the geographical location of my childhood roots. Phase Two was inter-twined with a return to my place of current residence and to my work responsibilities as a long-time member of the nursing department in a church related, four year, liberal arts college located in the Midwest. Each phase carried its own set of challenges.

Phase One of this research was conducted in fairly close proximity to the university in which I was enrolled as a doctoral student. The close proximity to and contact with other researchers, including my dissertation committee members

and fellow classmates, were essential in helping me stay focused on the specific tasks needed in order to conduct the research. The support of those colleagues as well as specific discussions with my peer debriefer provided adequate channels for processing issues such as the fact that several potential participants died before I had a chance to interview them. Likewise, support was present when I realized that I would be unable to complete all of the “modified member check” interviews because of the death of two participants and the significant decline in health status of another three participants. As a researcher who is also an experienced nurse clinician, I expected that such events were within the realities that “came free with the territory” whenever one is working with persons who are living in a nursing home. The resulting sense of loss and sadness represented feelings associated with my fondness for these persons and was grounded in the short term relationships that we had developed. Naturally, I could not help wondering what else I might have learned if I had been able to adhere to my original schedule for data collection, and thereby would have been able to conduct those missed interviews. However, the events that were responsible for the delays in my research schedule were also ones from my personal life that provided fodder for reflections on the meanings of independence.

During the data collection and early data analysis phase of the research project, I was living in a house once owned by my paternal grandmother. The

house was located not only in the community in which I grew up, but also “within a stone’s throw” of the house in which I spent most of my pre-college years. My sunny dissertation office was located in a room that provided an inspiring view of a familiar mountain range as well as a view of the physical facilities and equipment associated with the long-standing family business, initiated, owned and operated by my father. Pleasant memories of my younger days in which I was an active participant within this setting provided both inspiration for and distraction from the research endeavors. The work of exploring research concepts such as autonomy and independence within that setting admittedly likely went beyond the expected academic and theoretical examination of those meanings for the nursing home residents who were the easily identified participants in my study.

The context for Phase One also brought me into contact with many older persons who, in my youth I viewed as simply the parents of my peers and/or the influential adults within my extended family system and community. These persons now seemed old. They were not as greatly incapacitated as the nursing home residents who were the recognized participants in my study. However, they were obviously experiencing changes in physical health that could be considered precursors to the problems being experienced by the nursing home participants. Observing these persons as they lived with a variety of physical changes highlighted the fact that the topic of my research was not simply a theoretical one.

To explore the meanings of independence in a nursing home demanded that I recognize that real persons were confronting this topic perhaps on a daily basis, and that could include my parents. One troubling change that I could not ignore was the fact that my parents, though only in their 70's and generally "independent", were experiencing health conditions that affected aspects of that independence. Somehow the term "interdependence" seemed to be evolving as a more relevant one with implications for their quality of life. Such interdependence is illustrated by their preparation for a camping trip.

The typical division of labor for my parents on such occasions meant that Mother would prepare the food and housekeeping related items while Dad would prepare the mechanical and safety features of the camper. From my dissertation office, I observed one such safety check that called for the addition of air to the sets of double tires on the rear wheels of the camper. Dad was experiencing problems with mobility and flexibility that made it nearly impossible for him to connect the air hose to the tire stems for the inner tires. This activity was a small but essential step in the preparation for safe driving of that camper. A few minutes later as Dad thanked me for my assistance with the task, I was impressed with the irony of the situation. In order for Mom and Dad to "independently" go camping, there was a very small, but highly important step for which reliance on another person was needed. Did such reliance constitute "dependence", and if so

did that mean they were not “independent”? Or was the term “interdependence” a more relevant one in this situation? The memory of that tire episode resurfaced numerous times as I later attempted to make sense of the data provided by the participants in my study.

My awareness of complexities within my topic of “independence” grew over the months of data collection and early data analysis as a result of events within my personal life. I needed to become involved with family members as we all adjusted to some major changes within our family system. Dad rather suddenly developed impaired vision, severe enough to interfere with his ability to drive the car safely and to manage the family finances in accord with his standards. The term “interdependence” again seemed the salient one as I watched Mom and Dad adjust to Mother’s style of driving and of managing the checkbook.

Shortly thereafter, following Dad’s somewhat unexpected death, the complexities of the term “independent” again surfaced. My siblings and I became involved in the normal tasks of helping Mother adjust to her role as a new widow. However, that adjustment included managing several fairly complex financial and legal issues, ones that were fundamental to her ability to manage her life “independently” as a new widow. Her issues became more complex when she also needed to face the loss of her income producing property because of a highway project. For me, a persistent question seemed to be - If someone else

must provide assistance in order for a specific individual to “be independent”, are we not somehow using an irrelevant term?

Parallels between Mother’s situation and the life situations of the nursing home residents whom I was interviewing became apparent and likely influenced my thinking in ways that I cannot identify. I am thankful that I was able to be present and involved with my siblings and with Mother through those transitions. I am certain that these experiences influenced my thinking as I attempted to collect and analyze data for this research project. I am equally certain that those influences cannot be completely captured in words. The personal life influences continued throughout a large portion of the data analysis and early writing phases of this research project.

Phase Two, the data analysis and writing activities, was characterized by attempts to combine the dissertation with the expectations of full time employment within an academic role. Each of these activities carried different challenges, all affecting the ‘human instrument’. I was attempting to make sense of voluminous data as well as to condense it into a tangible entity that qualifies as an academically respectable dissertation. The work was completed by devoting multiple vacations and summers to the process of data analysis and writing. I found it necessary to return to the geographical area in which I lived while

collecting the data in order to meaningfully write about the process and the findings of the study.

Each time that I returned to the project and attempted to once again “gear up” for writing I needed to reacquaint myself with the data. However, of paramount importance for interpretation of meanings was my re-reading of the volumes of data that I had collected. The inefficiency of that process is obvious. Equally important, and as an added means to become reacquainted with the participants as unique individuals, I reviewed the detailed descriptions of the residents that I had compiled as part of the field notes. This review was supplemented at times by again listening to the audiotapes of the interviews as a strategy for placing myself at least symbolically within the context of the residents whose views I was attempting to describe. The value of those field notes as well as the inefficiencies inherent in the spacing of this work will remain indelibly etched in my mind and will shape advice that I have for other students and researchers.

Throughout Phase Two, I became aware of the value of other persons as essential for the challenge of staying inspired to complete the research project. The phrase “Just Do It” became a theme that characterized the focus of interactions that I had with many persons during the writing stage of this work.

The words “Just Do It” were actually neatly printed on a prescription pad and handed to me accompanied by the verbal and non-verbal messages that commonly accompany the dispensing of a prescription for pharmaceuticals. Additionally, those words were ones that I clipped from a magazine advertisement for a well known brand of athletic shoe and placed on the glass door of my kitchen cupboard, a family heirloom from my paternal grandmother. The irony as well as the intended inspiration included memories of this grandmother as one very influential person in my life, and one who demonstrated the type of self-discipline needed to “just do it” and get the final writing completed.

“Just Do It” became a recurrent phrase used by a number of my academic colleagues during the writing phase of this project. I am reasonably certain that each member of my dissertation committee thought the phrase numerous times. At least two of them even included it in specific verbal and/or written communications. The support of many friends and family members was also essential for me to “Just Do It”. Social communications from several of my former classmates, now with dissertations behind them, included the “Just Do It” theme as encouragement. Thank you Sonda, Kathy, and Marylou for the supportive nudges.

Additionally, my thanks also goes to Janet, my long-time friend and professional colleague, who showed me that it is possible to complete a

dissertation using qualitative research methods, encouraged me to enroll in doctoral study, and kept in touch throughout the process. She helped inspire me to continue the efforts to complete the data analysis even though we both knew that her encounter with cancer meant that she would not live to see my project completed. The academic cap from her own graduation, a gift to me shortly before her death, became Janet's continuing message to "Just Do It". Thanks Janet for the inspiration and thanks to my remaining friends and professional colleagues who continue to provide the interdependent relationships necessary to inspire intellectual creativity within an academic setting. Additional inspiration came in other forms and from a variety of persons.

One such inspiration came from my youngest niece in the form of two seemingly unrelated actions. Joelle, who has not know me except when I have in some way been living within the context of a dissertation in process, innocently asked "What do you do when you are not working on it - that thing?" The second inspiration from Joelle came in the form of a message written to her brother who was away at college and was long overdue with letter writing. That message included recognition of writing delays and omissions as a deficiency that can be overcome with support from others and with self-discipline. The message then moved to specific advice. Her composition "How to Write a Letter: A Guide to Writing" outlined specific steps needed to achieve the desired finished product, in

that case a letter from her brother. In effect, the message became for me another variant on the theme of “Just Do It”. That message was and is remarkably relevant for writing of the final chapters of a dissertation. So a thank you Joelle, as representative of my nieces and nephew who in a variety of small but important- ways also helped me bring this project to completion. The interdependence inherent in those interactions represents a link to the future, and to the next steps for this research, exploration of the issues that were raised by the nursing home residents who participated in this process.

My thanks also go each member of my family for their many and varied contributions and support along the way. Those contributions include a comment from my father, who at a very early point in my efforts to refine my dissertation topic around the general concept of “independence” commented that one must be careful to not become too independent. He expanded on his meaning of the term in his comment that linked independence to a self-absorption that excluded attention to the needs and desires of persons with whom one is associated. The theme was one of interdependence, much like that expressed by at least one of the participants in my study.

I learned much in the process of conducting this research. Within the cognitive domain, I have gained theoretical knowledge of multiple issues facing older adults. I am continually challenged by the complexities of efforts to apply

that theoretical knowledge within the current realities of practice settings that are increasingly concerned with control of financial costs. I have been and will continue to use that knowledge as I teach gerontological nursing to successive classes of undergraduate nursing students.

Within the psychomotor domain, I have gained skill in interviewing, typing of those interviews, and coaxing the computer to perform a variety of tasks. In retrospect, one skill that would have been useful is that of the use of some specific software package to facilitate the labor intensive aspects of the data analysis process.

Within the affective domain, my learning has been simultaneously more complex, and more difficult to articulate. I am aware of competing expectations. Writing in traditional academic style demands a degree of logical organization, clarity in use of words, and precision in word choice. However, processing of the topic of how this research process affected me requires reflection and implies attention to feelings. For me, attention to feelings evokes visual images for which words are limited. Perhaps the metaphor of fiber art, used in earlier chapters to explain the meanings of independence, can be expanded to also visually portray the affective learning that I take from this research project. For the present, recognition of such a possibility is all that time will allow, but the prospect of actually designing some art piece is intriguing.

I have developed an appreciation for the complexities of research within the constructivist paradigm. I have also developed a profound awareness of the importance of other persons in providing support so that individuals can engage in “independent” activities. An additional aspect of affective learning associated with this project is the glimmer of hope and sense of relief that is dawning now that this project is almost completed.

This project is not complete without expression of thanks to specific persons who were with me during this research process. I am using this format to publicly thank each member of my dissertation committee - Drs. Carol Gleit, Richard Steeves, and Bob Covert for their assistance, availability, and support during the endeavor. I also thank Dr. Judy Ozbolt, my committee chair, for her patience with my delays, helpful guidance when I got stuck, and tactful nudging at crucial points along the way.

The writing of this epilogue represents a retrospective effort at introspection. Both processes are associated with subjectivity and imply changing interpretations as new life experiences shape the meanings assigned at any given point in time. The topic of independence is complex and contains many interconnected concepts and issues. The research process has been equally complex. If I were to repeat the data analysis from the perspective of a different set of concurrent life experiences, it is quite possible that I would assign different

labels to the themes I found in my data. However, I am confident that the uniting themes would remain the same. My next steps are to move beyond the findings from this research into the exploration of some more tangible aspects of the issues associated with the NEEDING HELP and WAITING that are experienced by nursing home residents.

Today, as I complete the writing for this specific document, I continue to believe that the issue of independence for residents of nursing homes is one that is highly relevant to quality of life for persons within that setting. I conclude by expressing my thanks to those eleven residents of Maplewood who were the obvious participants in this study. Their candid expressions and thoughtful discussion of independence provided not only the raw data for this study, but also the inspiration to finally bring this project to completion.

References

- Agar, M. H. (1986). Speaking of Ethnography. Sage University Paper series on Qualitative Research Methods (Vol. 2). Beverly Hill, CA: Sage.
- Agich, G. J. (1990). Reassessing autonomy in long-term care. Hastings Center Report, 20 (6), 12-17.
- Alt-White, A. D. (1995). Obtaining "Informed" consent from the elderly. Western Journal of Nursing Research, 17 (6), 700-705.
- Arling, G., Harkins, E. B., & Capitman, J. A. (1986). Institutionalization and personal control: A panel study of impaired older people. Research on Aging, 8 (1), 38-56.
- Baltes, M. M. (1982). Environmental factors in dependency among nursing home residents: A social ecology analysis. In T. A. Wills (Ed.), Basic processes in helping relationships (pp. 405-425). New York: Academic Press.
- Baltes, M., Honn, S., Barton, E., Orzech, M. J., & Lago, D. (1983). On the social ecology of dependence and independence in elderly nursing home residents: A replication and extension. Journal of Gerontology, 38 (5), 556-564.
- Banzinger, G., & Roush, S. (1983). Nursing homes for the birds: A control-relevant intervention with bird feeders. The Gerontologist, 23 (5), 527-531.
- Barton, E. M., Baltes, M. M., & Orzech, M. J. (1980). Etiology of dependence in older nursing home residents during morning care: The role of staff behavior. Journal of Personality and Social Psychology, 38 (3), 423-431.

- Beck, P. (1982). Two successful interventions in nursing homes: The therapeutic effects of cognitive activity. The Gerontologist, 22 (4), 378-383.
- Bennett, R. (1963). The meaning of institutional life. The Gerontologist, 3 (3 Part I), 117-125.
- Brink, P. J. (1989). Issues in reliability and validity. In J. M. Morse (Ed.), Qualitative nursing research: A contemporary dialogue (pp. 151-168). Rockville, MD: Aspen Publishers.
- Brooke, V. M. (1987). Adjusting to living in a nursing home: Toward a nursing intervention model. (Doctoral dissertation, The University of Utah). Dissertation Abstracts International, 48, 2259B.
- Brubaker, B. H. (1996, July). Self-Care in Nursing Home Residents. Journal of Gerontological Nursing, 22 (7), 22-30.
- Burns, N. & Grove, S. K. (1993). The practice of nursing research: Conduct, critique and utilization, 2nd. ed. Philadelphia: W. B. Saunders, Company.
- Byrd, M. (1983). Letting the inmates run the asylum: The effects of control and choice on the institutional lives of older adults. Activities, Adaptation & Aging, 3 (3), 3-11.
- Caplan, A. L. (1990) The Morality of the Mundane: Ethical issues arising in the daily lives of nursing home residents. In R. S. Kane and A. L. Caplan (Eds.), Everyday Ethics: Resolving dilemmas in nursing home life. (pp. 37-50). New York: Springer Publishing.

- Chang, B. L. (1977). The relationship of locus on control, trust, and situational control of daily activities to morale of the institutionalized aged. (Doctoral dissertation, University of California, San Francisco, 1977). Dissertation Abstracts International, 38, 2613-2614B.
- Chang, B. L. (1978a). Generalized expectancy, situational perception, and morale among institutionalized aged. Nursing Research, 27 (5), 316-324.
- Chang, B. L. (1978b). Perceived situational control of daily activities: A new tool. Research in Nursing and Health, 1 (4), 181-188.
- Chang, B. L. (1979). Locus of control, trust, situational control and morale of the elderly. International Journal of Nursing Studies, 16 (2), 169-181.
- Collopy, B. J. (1988). Autonomy in long term care: some crucial distinctions. The Gerontologist, 28 (Suppl. June), 10-17.
- Covert, R. W. (1977). Content analysis: Analysis of work samples and other written documents. Unpublished manuscript, Evaluation Training Consortium, Evaluation Research Center, University of Virginia, Charlottesville.
- Curley, J. (1983). Letting the inmates run the asylum: Another point of view. Activities, Adaptation & Aging, 3 (3), 13-16.
- Driver, E. J. (1986). The birds of America: A study of independence for five elderly persons. Unpublished manuscript.
- Erikson, E. H. (1963). Childhood and society (2nd ed.). New York: W. W. Norton and Company, Inc.
- Erikson, E. H. (1968). Identity, Youth and Crisis. New York: W. W. Norton and Company, Inc.

- Erikson, E. H. (1982). The life cycle completed: A review. New York: W. W. Norton and Company, Inc.
- Erikson, E. H., Erikson, J. M., & Kivnick, H. Q. (1986). Vital involvement in old age. New York: W. W. Norton and Company, Inc.
- Erikson, J. M. (1988). Wisdom and the senses: The way of creativity. New York: W. W. Norton and Company.
- Felton, B., & Kahana, E. (1974). Adjustment and situationally bound locus of control among institutionalized aged. Journal of Gerontology, 29 (3), 295-301.
- Ford, S. (1989). Home care client's meanings of home. (Doctoral dissertation, The University of Virginia). Dissertation Abstracts International, 50, 4452-4453B.
- Fry, S. T. (1990). Caring on Demand: How responsive is responsive enough? Case Commentary. In R. S. Kane, and A. L. Caplan (Eds.), Everyday Ethics: Resolving dilemmas in nursing home life (pp. 190-198). New York: Springer Publishing.
- Glesne, C., & Peshkin, A. (1992). Becoming Qualitative Researchers: An Introduction. White Plains, N. Y.: Longman.
- Goffman, E. (1961). Asylums: Essays on the social situation of mental patients and other inmates. Garden City, NY: Anchor Books, Doubleday and Company.
- Grundner, T. M. (1986). Informed consent: A tutorial. Owings Mills, MD: National Health Publishing.

- Guba, E. G. & Lincoln, Y. S. (1994). Competing paradigms in qualitative research. In N. K. Denzin and Y. S. Lincoln (Eds.), Handbook of Qualitative Research (pp. 105-117) Thousand Oaks, CA: Sage Publications.
- Gubrium, J. F. (1993). Speaking of Life: Horizons of meaning for nursing home residents. New York: Aldine DeGruyter.
- Gubrium, J. F. (1975). Living and dying at Murray Manor. New York: St. Martin's Press.
- Hashtroudi, S., Johnson, M. K., & Chrosniak, L. D. (1990). Aging and qualitative characteristics of memories for perceived and imagined complex events. Psychology and aging, 5 (1), 119-126.
- Hoffart, N. B. (1989). Organizational sense-making by nursing joint appointees. (Doctoral dissertation, The University of Virginia). Dissertation Abstracts International, 50, 4453B.
- Hofland, B. F. (1988a). Autonomy in long term care: Background issues and a programmatic response. The Gerontologist, 28 (Suppl. June), 3-9.
- Hofland, B. F. (Ed.). (1988b). Autonomy and long term care. The Gerontologist, 28 (Suppl. June), 1-96.
- Horner, J. (1982). That time of year: A chronicle of life in a nursing home. Amherst MA: The University of Massachusetts Press.
- Huberman, A. M. & Miles, M. B. (1994). Data management and analysis methods. In N. K. Denzin and Y. S. Lincoln (Eds.), Handbook of Qualitative Research (pp. 428-444) Thousand Oaks, CA: Sage Publications.

- Hulicka, I. M., Morganti, A. I., & Cataldo, J. (1975). Perceived latitude of choice of institutionalized and non-institutionalized elderly women. Experimental aging research, 1 (1), 27-39.
- Hutchinson, S. A., Wilson, M. F., & Wilson, H. S. (1994). Benefits of participating in research interviews. Image, 26 (2), 161-164.
- Jameton, A. (1988). In the borderlands of autonomy: Responsibility in long term care facilities. The Gerontologist, 28 (Suppl. June), 18-23.
- Institute of Medicine Committee on an Aging Society, and National Research Council. (1985). America's aging: Health in an older society. Washington DC: National Academy Press.
- Institute of Medicine Committee on Nursing Home Regulation. (1986). Improving the quality of care in nursing homes. Washington DC: National Academy Press.
- Johnson, C. L., & Grant, L. A. (1985). The nursing home in American society. Baltimore: The Johns Hopkins University Press.
- Kane, R. A., & Caplan, A. L. (1990). Everyday ethics: Resolving dilemmas in nursing home life. New York: Springer Publishing Company.
- Kane, R. A., & Kane R. L. (1987). Long term care: Principles, programs, practices. New York: Springer Publishing Company.
- Kayser-Jones, J. S. (1981). Old, alone, and neglected: Care of the aged in Scotland and the United States. Berkeley: University of California Press.
- Lachman, M. E. (1986). Locus of control in aging research: A case for multidimensional and domain-specific assessment. Psychology and aging, 1 (1), 34-40.

- Lamb, G. S., & Huttlinger, K. (1989). Reflexivity in nursing research. Western Journal of Nursing Research, 11 (6), 765-772.
- Langer, E. J., & Rodin, J. (1976). The effects of choice and enhanced personal responsibility for the aged: A field experiment in an institutional setting. Journal of Personality and Social Psychology, 34 (2), 191-198.
- Lester, P., & Baltes, M. (1978). Functional interdependence of the social environment and the behavior of the institutionalized aged. Journal of Gerontological Nursing, 4 (2), 23-27.
- Lincoln, Y. S. (1992). Sympathetic connections between qualitative methods and health research. Qualitative Health Research, 2 (4), 375-391.
- Lincoln, Y. S., & Guba, E. G. (1985). Naturalistic inquiry. Beverly Hills: Sage Publications.
- May, K. A. (1989). Interview techniques in qualitative research: Concerns and challenges. In J. M. Morse (Ed.), Qualitative nursing research: A contemporary dialogue (pp. 171-182). Rockville, MD: Aspen Publishers.
- Mendelson, M. A. (1974). Tender loving greed. New York: Alfred A. Knopf.
- Miles, M. B. & Huberman, A. M. (1994). Qualitative Data Analysis: An expanded sourcebook. 2nd. ed. Thousand Oaks, CA: Sage Publications, Inc.
- Morse, J. M. (1989a). Qualitative nursing research: A free-for-all? In J. M. Morse (Ed.), Qualitative nursing research: A contemporary dialogue (pp. 3-10). Rockville, MD: Aspen Publishers.

- Morse, J. M. (1989b). Strategies for sampling. In J. M. Morse (Ed.), Qualitative nursing research: A contemporary dialogue (pp. 117-131). Rockville, MD: Aspen Publishers.
- Moss, F. E., & Halamandaris, V. J. (1977). Too old, too sick, too bad: Nursing homes in America. Germantown, MD: Aspen Systems Corporation.
- Mullins, L. C. (1985). An examination of the locus of desired control among young-old and old-old nursing home patients. Sociological Spectrum, 5 (1-2), 107-117.
- National Center for Health Statistics. (1989). The national nursing home survey: 1985 summary for the United States vital and health statistics, (Series 13, No. 97. DHHS Publication No. [PHS] 89-1758 Public Health Service). Washington: U.S. Government Printing Office.
- National Citizens' Coalition for Nursing Home Reform. (1985). A consumer perspective on quality care: The residents' point of view. Washington: National Citizens' Coalition for Nursing Home Reform.
- O'Brien, M. E. (1989). Anatomy of a nursing home: A new view of resident life. Owings Mills, MD: National Health Publishing.
- Pohl, J. M., & Fuller, S. S. (1980). Perceived choice, social interaction, and dimensions of morale fo residents in a home for the aged. Research in Nursing and Health, 3 (4), 147-157.
- Porter, E. J. (1995). A Phenomenological alternative to the "ADL Research Tradition". Journal of Aging and Health, 7 (1), 24- 45.
- Porter, E. J. and Clinton, J. C. (1992). Adjusting to the nursing home. Western Journal of Nursing Research, 14 (4), 464-481.

- Ramos, M. C. (1989). Some ethical implications of qualitative research. Research in Nursing and Health, 12 (1), 57-63.
- Reich, J. W., & Zautra, A. J. (1989). A perceived control intervention for at-risk older adults. Psychology and aging, 4 (4), 415-424.
- Reid, D. W., Haas, G., & Hawkings, D. (1977). Locus of desired control and positive self-concept of the elderly. Journal of Gerontology, 32 (4), 441-450.
- Rodin, J., Bohm, L. C., & Wack, J. T. (1982). Control, coping and aging: Models for research and intervention. Applied social psychology annual, 3, 153-180.
- Rodin, J., & Langer, E. (1977). Long term effects of a control relevant intervention with the institutionalized aged. Journal of Personality and Social Psychology, 35 (12), 897-902.
- Russell, C. K. (1996). Elder care recipients' care-seeking process. Western Journal of Nursing Research, 18 (1), 43-62.
- Ryden, M. B. (1982). Perception of situational control, climate for autonomy, and morale in institutionalized elderly. (Doctoral dissertation, University of Minnesota). Dissertation Abstracts International, 43, 3776-3777B.
- Ryden, M. B. (1984). Morale and perceived control in institutionalized elderly. Nursing Research, 33 (3), 130-136.
- Sandelowski, M. (1986). The problem of rigor in qualitative research. Advances in nursing science, 8 (3), 27-37.

- Sandelowski, M., Davis, D. H., & Harris, B. G. (1989). Artful design: Writing the proposal for research in the naturalist paradigm. Research in Nursing and Health, 12 (2), 77-84.
- Savishinsky, J. S. (1991). The Ends of time: Life and Work in a Nursing Home. New York: Bergin & Garvey.
- Schulz, R. (1976). The effects of control and predictability on the physical and psychological well-being of the institutionalized aged. Journal of Personality and Social Psychology, 33 (5), 563-573.
- Schulz, R., & Hanusa, B. H. (1978). Long-term effects of control and predictability-enhancing interventions: Findings and ethical issues. Journal of Personality and Social Psychology, 36 (11), 1194-1201.
- Shewchuck, R. M., Foelker, G. A., & Niederehe, G. (1990). Measuring locus of control in elderly persons. International Journal of Aging and Human Development, 30 (3), 213-224.
- Spence, D. A., & Wiener, J. M. (1990). Nursing home length of stay patterns: Results from the 1985 national nursing home survey. The Gerontologist, 30 (1), 16-20.
- Steeves, R. H. (1992). Technical notes: A typology of data collected in naturalistic interviews. Western Journal of Nursing Research, 14 (4), 532-536.
- Tisdale, S. (1987). Harvest moon: Portrait of a nursing home. New York: Henry Holt and Company.
- Townsend, C. (1971). The Nader report - Old age: The last segregation. New York: Grossman Publishers.

- U. S. Bureau of the Census. (1989). Statistical abstract of the United States: 1989 (109th edition). Washington: U.S. Government Printing Office.
- Vladeck, B. C. (1980). Unloving care: The nursing home tragedy. New York: Basic Books, Inc.
- Wolk, S. (1976). Situational constraint as a moderator of the locus of control-adjustment relationship. Journal of Consulting and Clinical Psychology, 44 (3), 420-427.
- Wolk, S., & Telleen, S. (1976). Psychological and social correlates of life satisfaction as a function of resident constraint. Journal of Gerontology, 31 (1), 89-98.
- Wright, J. E., Jr. (1982). Erikson: Identity and Religion. New York: The Seabury Press.

APPENDIX

Codes for Categories

DIMENSIONS and Themes

1. MOVING ABOUT - those activities/tasks that the resident engages in on a daily basis that facilitate the movement of the body in space.

HR = Handling things and Reaching - the ability to use the hands and arms to manipulate and obtain objects within arms reach of the person.

PT = Positioning and Turning - purposefully moving the body in bed or in a chair into desired positions

U = Getting Up - the ability to move the self from the bed or chair, and to transfer to a wheelchair or other chair by supporting one's body weight.

W = Walking - the ability to move about the room and within the nursing home by using muscle strength of the feet and legs, and including the use of assistive devices such as a walker or cane.

Tr = Traveling - the ability to move about outside of the nursing home, including around the campus, into other buildings, and travel off the campus.

2. CARING FOR THE BODY - those activities/tasks that the resident performs (or needs help with) on a daily (or regular basis) in order to preserve the physical integrity of the body.

B = Bathing - activities associated with the daily hygienic functions of "washing up", at bedside or in the bathroom. (Not including the twice weekly whirlpool tub bath because all needed assistance with that activity).

G = Grooming and Dressing - activities associated with getting dressed and undressed and daily care of the hair and teeth. (Not including nail care, haircuts, perms, and laundry because all participants needed assistance with these activities).

E = Eating - the activity of consuming meals at the scheduled times.

T = Toileting (bowel and bladder)- activities related to the handling of bowel and bladder functions, including any cleaning that is needed.

MPC= "Managing Physical Conditions". Category created from "Sym" and "Phys" original categories.

Smy=Symptom management - activities focused around the control of symptoms of disease and the prevention of additional injury.

Phys=Physical problem - references to specific medical diagnoses or disabilities when used in the context of talking about abilities or preferences.

3. HAVING RESOURCES - tangible or personal ability resources available to residents to facilitate their involvement in desired activities.

VH = Vision and Hearing Ability - comments about these senses when used within the context of talking about any activity the resident considered important to their life.

TT = Think and Talk - cognitive competence and memory sufficient to form thoughts and relay those thoughts verbally to other persons.

Res = Having Resources - references to the importance material resources, such as money, to the feelings of independence. Renamed to Material Resources.

AdEq = Adaptive Equipment - comments referring to the use of equipment to facilitate the ability to function in a specific aspect of daily life. (Included in this category are references to hearing aides, glasses, canes.).

4. BEING ONESELF - those activities in which the person engages that reflect their preferences, and efforts to express their uniqueness and individuality.

WPA = Having Wishes and Preferences - having preferences and wishes about aspects of daily life that affect this resident's life within the nursing home, including acting on those preferences. This includes general comments about "going places" and "doing things" of a recreational nature.

SC = Staying Connected - Maintaining contacts with other persons, engaging in activities that involve interaction with other persons, and/or that link the resident to past and future ties with persons.

OC = Staying Occupied - engaging in diversional activities and hobbies that do not necessarily involve interaction with other residents or persons.

MAf = Managing Affairs - those activities that involve handling resources, shopping, record keeping, making appointments, and notifying persons of one's wishes, including references to having control of one's life.

5. INTERACTING WITH THE ENVIRONMENT - comments about ways in which the resident communicates with and/or is influenced by persons, policies, and organizational structure.

RS = Rules and Schedules - the existence of specific rules, regulations, policies and schedules that are present within the nursing home. Renamed “Rules and Policies”, separate category created for “Schedules”.

Ch = Choices - the presence of choices and options for resident decision making and control within the nursing home.

Sch= Schedules - category created from RS above. Refers to comments about the daily routines within the nursing home.

LS = Living Space - control of the living space, such as using items, equipment, and the self to adjust the living space and its contents to one's liking and comfort. Included are references to not being in a nursing home.

SIBE= Self-Imposed Behavioral Expectations. Category composed of “Self” and “CE” original categories.

Self=Self-control - efforts or activities in which the person makes a conscious effort to exercise self-control of emotions, thoughts and/or actions and/or to influence the actions of others.

CE = Complying with Expectations - adherence to the formal and informal agency rules, norms, and implied social expectations, including having or securing permission.

Broad Themes (from coding that overlapped the above themes). Discussed under labels of “DOING THINGS”, “HAVING PREFERENCES”, “NEEDING HELP”, and “waiting”.

GH = Getting Help - the securing of assistance from staff and other paid helpers, family, friends, and volunteers, and comments about the quality of the help or helpers.

Wait =Waiting - time required for requests to be granted, assistance to be received, or preferences to be honored, including general references to waiting.

DT = Doing Things - general comments about ability to take care of the physical body and do things for or helping oneself, that are not specific to any other category.

HPH =Having preferences Honored - experiences of having staff and others respond to the expressed preferences of the resident. This includes respect for saying "no" and requests for "getting things".