THE EVERYDAY LIFE OF WOMEN AGES 85 AND OLDER LIVING ALONE IN

THEIR OWN RESIDENCES WHO RECEIVE HELP

A DISSERTATION

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DEGREE OF DOCTOR OF PHILOSOPHY

IN THE GRADUATE SCHOOL OF THE

TEXAS WOMAN'S UNIVERSITY

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BY

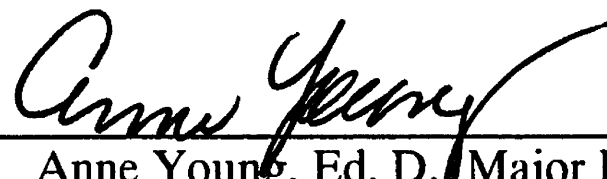KAREN HAHN, B.S.N., M.S.N.

DENTON, TEXAS

DECEMBER 2008

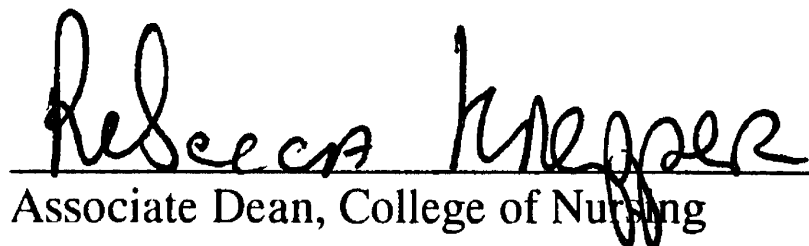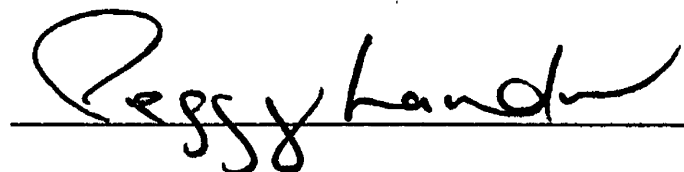TEXAS WOMAN'S UNIVERSITY
DENTON, TEXAS

July 29, 2008

To the Dean of the Graduate School:

I am submitting herewith a dissertation written by Karen Hahn entitled "The Everyday Life of Women Ages 85 and Older Living Alone in Their Own Residences Who Receive Help." I have examined this dissertation for form and content and recommend that it be accepted in partial fulfillment of the requirements for the degree of Doctor of Philosophy in the College of Nursing.
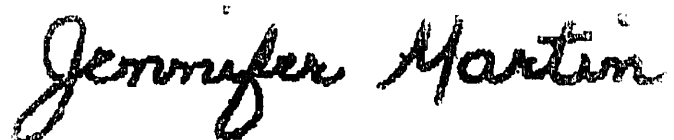
_____
Anne Young, Ed. D. Major Professor

We have read this dissertation and recommend its acceptance:

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Associate Dean, College of Nursing

Accepted:

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Dean of the Graduate School

DEDICATION

To the Crones and Matriarchs throughout the Ages, especially Amy, Mama Kelley, Mama
Rose, and Mama Moore.
Thank you for your legacies of wisdom experience, and love.

To the grandmothers, mothers, daughters, granddaughters of my bloodline and the
generations to come.
Thank you for your gifts of life and feminine knowing.

To Divine Wisdom.
Thank you for inspiration and guidance.

ACKNOWLEDGMENTS

ABSTRACT

KAREN HAHN

THE EVERYDAY LIFE OF WOMEN AGES 85 AND OLDER LIVING ALONE IN
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DECEMBER 2008

This ethnographic study explored the everyday life of women 85 and older living

alone in their own residences with physical limitations who receive help. Integrating the

perspectives of the women with those of interdisciplinary health professionals found a

picture of everyday life highlighting management, functional, and transcendent spiritual

dimensions rather than the frailty construct more commonly used by health professionals.

Four urban women ages 86-92 of African-American, Cuban-American, and

European-American ethnicity were visited in their own residences for five months. Two of

the respondents lived in homes they had owned for 30+ years and two in subsidized senior

housing apartments.

Participant observation and semi-structured interview sessions were conducted

during home visits and phone calls. Spradley's systematic method was used to gather and

analyze the data. The cultural theme which described their everyday life was *managing the*

business of daily living.

The theme "managing the business of" summarizes the everyday life experience of

these women, filled with the multiple responsibilities of caring for themselves, maintaining

a household, tending to important relationships, and preserving autonomy within the reality of physical vulnerability.

None of these women described themselves as frail. "Living alone" was used by these women in reference to the experience of inadequate support rather than a living arrangement. The autonomy of staying in one's own place was more important than living longer or staying in the family homestead. Help was described as a mutual exchange of services rather than receiving help.

The belief that "God takes care of me" supported them in caring for themselves and others. They were committed to doing what they saw as necessary to stay in their own place. Relationships with God and family were most important to them. Staying actively connected with family and friends, contributing to their communities, and leaving a legacy were also important. Respecting and receiving the wisdom of those who live long and well can help society plan for healthy aging for all.

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CHAPTER I

INTRODUCTION

Little is known about the everyday life of solitary living women ages eighty five

and older who receive help for daily living. Reports highlight the growing numbers of

the 85+ year-old elderly, the increasing trend to live alone with advancing age, the

increasing need for costly medical and support services as people age, and the

genderization of service challenges in this vulnerable population. Because of their need

for close monitoring and supportive social services, this age group has been named the

"frail" elderly.

According to *A Profile of Older Americans* (Administration on Aging, 2003),

people 65 and older comprised 12.4% of the population and those 85 and older made up

1.5% in 2000. By 2030, these percentages are projected to increase to 19.7% and 2.6%

respectively, with aging women comprising an ever growing percentage of the elderly

population with advanced age, poverty, solitary living, and disability (Administration on

Aging, 2005).

Increasing life expectancy contributes to the need for more services to meet

growing needs in those added years. Life expectancy for women is longer than men,

with average life expectancy at age 65 being 19.4 years for women and 16.4 years for

men (Administration on Aging, 2003) In 2001, life expectancy for women at age 85

was 7 years (Federal Interagency Forum on Aging Related Statistics, 2005). Elderly who

live alone do not have help as readily available as those who live with caregivers, yet both solitary living and the need for help with daily living increase with advanced age. In the Administration on Aging (AOA) *Aging into the 21st Century* report, the year 2005 will find that 12% of those 85 and older compared to 8% of seniors 65 and older live alone.

Limitations in activities of daily living (ADLs) and instrumental activities of daily living (IADLs) cause persons to need help. The Federal Interagency Forum on Aging Related Statistics' newly released *Older Americans 2004: Key Indicators of Well-Being* study found that one in five (20%) of Medicare enrollees 65 and older report limitations in one or more ADLs and IADLs (2005). At least one third of community-dwelling persons 70 years and older receive help with activities of daily living (ADLs) from a caregiver (Center for Disease Control, 2000). Illness and disability increase sharply among those 85 and older, with almost one fifth of these oldest old in nursing homes (Center for Disease Control).

The need for more help means the need for more resources. The Older Americans Act of 2000 allocated $155.2 million for caregiving support services in 2003 to augment the limited medical home health services covered by Medicare (International Conference on Family Care, 2002). However, most of the help with ADLs/IADLs is provided by informal and unpaid caregivers (Knickman, & Snell, 2002; Volbrecht, 2002).

Because these rising numbers have significant policy implications for allocation and structuring of resources, data on this increasing population is growing. This ethnographic study contributed to that needed body of knowledge.

Problem of Study

This study provides a beginning understanding of the everyday lives of the women aged 85 and older who live alone in their own residences and receive help with one or more ADL(s) or IADLs. Little is known about how these women manage despite disabilities and declining function.

This study provides a beginning understanding of their everyday lives. Understanding their cultural experience can help providers to more effectively identify their strengths and meet their needs, identify questions for research, and perhaps suggest anticipatory interventions for the younger old which could promote positive aging. This study also contributes to the limited body of nursing ethnographic research.

Rationale for the Study

Women who are hardy enough to live to age 85 do face the challenge of dwindling reserves and needing help as they continue to age. However, they also have the opportunity to embrace the opportunities of advancing age, fully experiencing the wholeness of life (Thomason, 2006). Physical limitations can be experienced as invitations to transcendence, contemplation, and letting go of separateness. In her book, *The Living Spirit of the Crone—Turning Aging Inside Out,* Sally Palmer Thomason challenges contemporary society to embrace a new vision of aging, one which embraces aging's opportunities for growth and benefits of wisdom.

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It is true that aging women who choose to live alone represent a growing population of elders who pose special challenges to society as their need for support increases. However, they also hold a repository of wisdom for society on ways to grow older. From the conventional cost analysis approach to aging, providing effective support to these women can not only facilitate a lifestyle choice preferred by most Americans, but can also prevent costly institutionalization (Knickman & Snell, 2002). From a wholistic perspective which also values the contribution these women can give to society, however, providing needed support to these women also strengthens all of society.

Women represent an increasing majority of the oldest old, those living alone, and the disabled. Most research and intervention in the oldest old population has focused on prediction and reduction of negative outcomes like disability, institutionalization, and death. Older women who live to be very old, however, often do not reduce risks in ways which have been recommended by care providers. Many of these same women surprise providers with their continued longevity and creative resourcefulness. Some of these women do not access formal services even with their increasing disability. Little is known about how these women manage their everyday lives.

Most research on the oldest old has been conducted from within the risk reduction and frail construct perspectives. This body of research has developed into large, epidemiological quantitative studies with important predictive contributions.

Contemporary models of frailty such as that used by The Interventions on Frailty Working Group (Ferrucci, Guralnik, Studenski, Fried, Cutler, & Walston, 2004), and

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others emphasize measures of and predictors of functional decline and disability (Brody, Johnson, Ried, Carder, & Perrin, 2002; Gill, Allore, & Guo, 2003 & 2005; Markle-Reid & Browne, 2003; Puts, Lips, & Deeg, 2005; Saliba, Elliott, Rubenstein, Solomon, Young, Kamberg, et al., 2001).

Although there is no consensus definition or model, the critical attributes across studies of frailty are physical or mental functional impairment requiring help, old age, limited physiological reserve, disability, poor physical health, and vulnerability. This study focused instead on women with physical frailty who need help.

Physical frailty, however, is only one factor within the lives of women who need help. Young (2003) described challenges and solutions of caring for the vulnerable and frail older adult. She called for more of a health promotion orientation in caring for this population. She suggested discovering and promoting positive ways for the older population to meaningfully contribute to society as well as improve their general health and well-being. As she says, this creative perspective requires more qualitative studies to help society learn from this population.

This ethnographic study of 85 and older women who live alone in their own settings, therefore, hopefully contributed critical information to better understand this complex and growing population of persons within the context of their everyday lives, environment, and culture. This method captured the perspective of the women themselves, women who have been hardy and resourceful enough to live to 85 and beyond. Surely those who have been hardy and resourceful enough to live to 85 and beyond have much to teach society about living long and living well.

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Since few studies describe the everyday lives of these oldest old elderly who live alone, this longitudinal study explored their everyday life within the culture of their environment and within the meaning context of their life stories, activities, self-concept, and norms. It was hoped that society could then learn from those living long and living well.

This qualitative study explored the world in which the women actually lived in as they themselves described that world. The description of their everyday living was therefore not limited by the risk reduction paradigm which dominates the health literature, but rather, was framed within the context of a wider range of their intentions and values.

To date, few studies have described the everyday lives of these oldest old elderly who live alone. This longitudinal study explored their everyday life within the culture of their environment and within the meaning context of their life stories, activities, self-concept, and norms. This study describes the knowledge gained from some of these long-lived women and integrates that perspective with those of caregivers and health providers.

Conceptual Orientation

This ethnographic study builds on Kaufman's anthropological landmark work on frailty in 1994 in which he described the social construction of frailty. In it he described frailty as diminished reserve capacity resulting in diminished ability to carry out important daily living activities due to a complex interaction of personal and environmental factors. In this study, rather than focusing on frailty itself, women's

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physical frailty will by only one inclusion criterion and therefore described within the wholistic context of everyday living in their home environment.

Ethnography is both a method and a product (Werner and Schopfle (1987). The product is a description of a group—*ethno* ("folk") and *graphy* ("description"), a localized group of people who share many cultural and social characteristics. The product reflects the philosophical lens of the investigation as well as the method.

Philosophical lenses include the classical, comprehensive and wholistic reformulations of the raw "facts," interpretive analyses inferring the meanings of observed social interactions, critical interpretations with more postmodern and feminist impressions, focused "rapid appraisals" for program development, hermeneutic ethnography with its thick description, and systematic ethnography with its structured and formalized methodology (Boyle, 1994).

This ethnographic study represents the systematic ethnographic perspective. The systematic perspective attempts to accurately represent the knowledge of the local people being studied through rigorous semantic analysis of folk taxonomies of words, naming units, and emergent themes. Spradley's *You Owe Yourself a Drunk: An Ethnography of Urban Nomads* (1970) is often cited as an excellent example of this type of ethnography.

Spradley's (1979) work, *The Ethnographic Interview* is used by health researchers with its systematic methodology. In it he states,

The essential core of ethnography is this concern with the meaning of actions and events to the people we seek to understand ... people make constant use of these

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complex meaning systems to organize their behavior, to understand themselves and others, and to make sense out of the world in which they live. These systems of meaning constitute their culture; ethnography always implies a theory of culture. (p.5)

Therefore, this interdisciplinary, longitudinal study applied ethnographic methods to discover and describe the everyday life of women ages 85 and older who live alone within their home environments and receive physical help over a five month time span.

Assumptions

This research design assumed that requiring assistance with instrumental activities of daily living is a critical component of frailty. This assumption is congruent with the operationalization of the concept of frail in the existing body of research as will be discussed in the literature review in the next chapter.

This study also assumed that the study time period of six months is of adequate length to capture the dynamic nature of frailty within the everyday life in this population. This time span was chosen based on the investigator's prior experience with this group of women as the time span most likely to include at least one episode of acute illness and the resulting challenges of convalescence and functional variations. This assumption was confirmed. All respondents experience at least one episode of acute illness during the course of the study.

Lastly, this study assumed that people living alone experience a unifying culture which justifies using this method. This study used a cross-sectional approach to

ethnography. The unit of study was elderly women living alone in their homes or apartments. Although these women did not interact with one another, this study design assumed that women of this population share an integrated culture because they share a similar lifestyle. This population is comparable to the population in Spradley's classic work (1979) in which he assumed that homeless persons similarly shared an integrated culture although they did not necessarily interact.

Research Question

The research question in this study was: What is the everyday life of women ages 85 and older who live alone in their own residences and receive assistance with one or more activities of daily living or physical instrumental activities of daily living? This question was explored from a multidimensional and multifactorial perspective.

Orientational Definitions

Terms used in this study which needed definition for clarity included: cognitively intact, physically frail, everyday life, living alone, caregiver, activities of daily living (ADLs), and instrumental activities of daily living (IADLs). These are defined in turn.

Cognitively intact was defined as alert to time, place, person, and situation. Intact cognition in this study was operationalized by the respondents' ability to accurately verbalize the role of the nurse researcher as distinct from a home health nurse or friendly visitor and the ability to verbalize comprehension regarding the study. Comprehension of the study included verbalizing the purpose of the study, expectations of respondents, and the respondents' right to not participate in any of all sessions.

Physically frail was defined as 85 or older and receiving assistance in one or more physical ADL or IADLs. The classic categories for gerontology identify the 85 and older as the old-old, and frequently label that age range as the "frail" elderly. Foundational scholars on frailty identified its critical attribute as dependence on social support for important activities such as ADLs/IADLs (Brown, Renwick, & Raphael, 1995), and all subsequent works include this component.

Everyday life was the day-to-day experience of living. This included ordinary daily activities which are typical of a day such as daily routines as well as the less common occurrences such as trips to the clinic, hospitalizations, and shopping.

Living alone was the state of residing in an apartment or house with no live-in caregiver, family member, roomer, or friend. For the purpose of this study, persons had to be living alone at the beginning of the study and not planning to move into assisted living, a long-term care facility, group home, or with a family member within the next 6 months.

Caregiver was a person who formally or informally assists with one or more ADLs or IADLs, whether identified by the respondent as a caregiver or not and not necessarily paid for such services. It is recognized that many elderly have several persons who provide such supportive services. For the purpose of this study, an attempt was as made to observe and interview caregivers identified as such by the respondents. Friends frequently provided the bulk of informal caregiving services and were not be identified by respondents as caregivers. In such cases, it was most appropriate for the

researcher to refer to the caregiver as the respondent's friend rather as a caregiver when speaking with the respondent.

Activities of daily living (ADLs) were the tasks of personal self-care. This study used the categories of the traditional Katz index of ADLs to label those tasks: bathing, dressing, toileting, transferring, managing continence, and feeding.

Instrumental activities of daily living (IADLs) were defined in this study to include physically essential and more complex tasks which support personal self-care functioning, such as shopping, community mobility, food preparation, housekeeping, laundry, managing medication, and telephone use. Managing finances was not included because it is a cognitive task.

Limitations

Study limitations included the limited generalizability of a qualitative, exploratory study. Findings cannot be generalized to all elderly women who live alone in their own residences and receive assistance with one or more IADLs. In particular, findings cannot be generalized to those who engage in moderate or vigorous exercise, or women who do not speak English. However, findings do suggest areas for further study and enrich the descriptive base of knowledge about this population.

Summary

In conclusion, this ethnographic study explored and described the everyday lives of women 85 and older who live alone in their own residences and who receive help with one or more physical activities of daily living. This study contributed to the understanding of this growing population of persons who receive an increasing amount

of supportive and healthcare services. Perhaps more importantly, this study contributed

knowledge about this population outside of the risk reduction and biomedical paradigms.

In addition, this study added to the limited nursing body of ethnographic research.

Findings helped provide direction for further study, contribute to a more wholistic

perspective on aging, suggested health promotion strategies for younger elderly, and

provided some guidelines for healthcare providers and the designing of support systems.

CHAPTER II

LITERATURE REVIEW

Little is known about the culture of the everyday life of women age 85 and older who live alone in their own homes and receive help. This chapter describes key works relevant to understanding this subculture. Culture embraces the named and unnamed norms, activities, and meanings within a group as well as that group within the larger society. The professional literature provides norms and meanings perceived by the health professions that contribute to the larger cultural context of this group.

This chapter presents literature related to each of the components of the research question: everyday lives, older women living alone, in their own homes, who are physically frail and who receive help. First, however, it presents the broader theoretical framework of the theories of aging used for this investigation. The question components will be explored in turn, including key works on frailty. This chapter will conclude with implications of research on this little understood subculture of older adults.

"Frail" and "oldest old" are the descriptors most commonly found in the health professional literature categorizing the age group of 85 and older. Ironically, women must be pretty hardy to live that long and live alone. Often these women are the same women who refuse services and become labeled "non-compliant" and "stubbornly independent." An ethnographic study can perhaps provide a clearer image of these women, one that might help to bring together the discrepant images into an accurate one.

An ethnographic study that combines the perspectives of the women and the health professionals studying them in their everyday lives helps synthesize the wisdom these women have to share about living long and living alone with the direct observation of them in their everyday environment and activities. This study integrated multiple perspectives—of the women themselves, caregivers, and a diverse research team. This chapter summarizes the published perspective which was also brought to this study.

Theories of Aging

The underlying frameworks for this study were those of gerotranscendence and the Environmental Theory of Aging (ETA). Gerotranscendence was described as the ninth developmental stage of aging for the very old by Tornstam (1994) and Joan Erikson in her extended version of her husband Erik Erikson's book (1998). With people living longer, gerotranscendence as both a life stage and construct has recently been revisited and is beginning to be tested (Adams, 2004; Brown, & Lowis, 2003; Levensen, Jennings, Aldwin, & Shiraishi, 2005). By contrast, the ETA, foundational to the field of environmental gerontology, has been tested and refined in many studies from many disciplines. Both of these theories are essential to this inquiry and will therefore be described in turn.

Adams (2004) summarized the life stage of gerotranscendence well:

Gerotranscendence involves a turning toward a more contemplative way of life, narrowing the social circle, giving up unrewarding social relationships to focus on a few close ones, and achieving more time for solitude. There is also a "cosmic dimension" in which the concept of time changes until the past feels very real and

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nearly like the present...The gerotranscendent older person feels free to select only those activities that are meaningful, and to break away from role expectations...and social conventions. (p. 93)

Tornstam's (1994) gerotranscendence includes two factors: cosmic transcendence and self-transcendence. Cosmic transcendence includes

an increasing feeling of cosmic communion with the spirit of the universe; a redefinition of the perception of time, space, and objects; a redefinition of the perception of life, death, and a decrease in the fear of death; and an increasing feeling of affinity with past and coming generations...[Ego transcendence involves] a decrease in the interest in superfluous social interaction; a decease in the interest in material things; a decrease in self-centeredness; and an increase in time spent in meditation. (pp. 208-209)

The ETA addresses more concrete tasks of aging. The ETA proposes that persons will successfully adapt to stressors to their competency, called environmental press (EP), when EP is within their adaptive range. Older persons adapt to increasingly more challenge as their competency increases or they settle into a comfort zone; or, as competency decreases, older persons reduce their EP. Persons faced with EP greater than their adaptive range will have negative effects or maladaptive behavior. Both boredom and high demands can be experienced as EP by persons. The adaptation level available in an expanding or contracting adaptive range includes both a comfort zone and challenge zone.

Nahemow (2000) detailed the contribution of the ETA, which she calls "Lawton's legacy," to the young field of environmental psychology. The ETA is a model also foundational to the emerging field of environmental gerontology (Wahl & Weisman, 2003). The ETA model has been used by different disciplines to study various person-environmental linkages in aging. Relevant works will be described in more detail below. Person-environmental linkages help describe the context of people living in their homes, such as Diehl's (1998) work on everyday competence.

Everyday Living

Literature about everyday living in old age includes important historical works which helped lay the foundation for contemporary approaches as well as the field of environmental gerontology. Therefore, this section will begin with pioneer Rubinstein's (1986) classic ethnography on the construction of a day in elderly widowers' lives using Spradley's method. Diehl's state of the science work on everyday competence in 1998 provided the historical background which has framed much of the functional emphasis in studies on the daily lives of older persons and will be summarized next. This section will then summarize studies measuring and describing change in activities within theoretical frameworks, comparing resources in everyday functioning and survival, and everyday problems and problem solving. This section on everyday living will conclude with an in depth presentation of two qualitative studies describing everyday lives.

Environmental gerontologist Rubinstein's classic ethnography of widowers will be summarized here and his pioneer work on the meaning of home will be described in a

later section. Rubinstein's (1986) ethnography of 25 widowers living alone described these men as organizing time around the notion of a "day."

Many of the widowers described themselves as living "day to day," with a "daily highlight," and structuring their "days" with work-like schedules. These men described and demonstrated various degrees of structural reorganization in their "days," with expanding chunks of time correlating with increasing adjustment to bereavement.

The widowers' average age was 78 years, about half from senior centers or residents of senior housing projects, most married once for an average of 40 years, with an average of 5 ½ years since the death of their wives.. The men were interviewed using Spradley's ethnographic method over 6 weeks for a total of 9 to 15 hours, usually in their homes. This was part of a larger study of men living alone in Philadelphia in 1981.

The guiding research question was: How are personal identity and meaning expressed through defining and choosing activities and using time? The biographical interviews included a standard set of general questions as well as open-ended questions and discussions about their daily activities, social relations, ideas about their lives, past life events, and the experience of loneliness.

Loss of wife had posed two adaptive tasks for the men—working through grief and establishing meaningful and satisfactory use of time. Eleven of the men had successfully reorganized their lives and 14 were unsuccessful. Those successful were able to experience time in units larger than a single day, as worthwhile, and with some structure. Men unsuccessful at reorganizing their days experienced time as aimless,

disjointed, dragging, passive, and painful. They lived "one day at a time" or "from day to day."

Rubinstein found that

Within the context of these men's current lives, it might be said that the goal of arranging activities is to live in a way that combines the regular schedule of some outside enterprise with significant room for the expression of more individual tastes and needs in a way that produced a minimum of stress and little conscious strain in the experiencing of time ....Structure frequently included a daily highlight, with an important focusing activity generally outside the home, usually vaguely social, with the men feeling they had "accomplished something" (pp. 163-164).

Diehl (1998) analyzed the status and future directions of the phenomenon of everyday competence in later life. Early environmental gerontologists paired "everyday" with "competence," an association which has framed subsequent research from a functional approach. He wrote,

The term "everyday competence" refers to a person's ability to perform, when necessary, a broad array of activities considered essential for independent living, even though in daily life the individual may not perform these tasks on a regular basis or may perform a subset of these activities . It involves multiple domains (physical, psychological, and social function) [and is a] result of the transactions

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between an active human individual and his physical and social environment. (p. 423)

In this 1998 publication, he concluded that a sound knowledge base had been established regarding antecedents and consequences of everyday competence, but its components and mechanisms needed more study. Some intraindividual components have subsequently received much study, especially those related to ADLs/IADLs in the research on frailty and functional limitations described below. However, important components still being neglected are those functional domains of spiritual/transcendent development in the ninth stage of gerotranscendence.

Building on earlier works in environmental gerontology, Lang, Rieckmann, and Baltes (2002) conducted a study on everyday functioning and resources in the Berlin Aging Study. They used Paul and Margret Baltes' Selection, Optimization, and Compensation (SOC) model to compare strategies and 4-year survival in resource-rich and resource-poor older adults. They also examined longitudinal data to compare cross-sectional indicators of adaptive everyday functioning among survivors and non-survivors across a 4-year time interval.

Their sample was 195 community-dwelling and institutionalized participants from the Berlin Aging Study out of the 485 who participated in the first measurement. They measured sensorimotor-cognitive and social-personality resources and used the well-tested Y1 instrument. The Y1 instrument developed by environmental gerontologists Moss and Lawton (1982) provides a minute-to-minute detailed self-reported reconstruction of activities of the preceding day to assess everyday function.

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Participants were categorized into high and low resource groups based on a median split at the first measurement of resources. The differential mean change of everyday functioning between the resource-rich and resource-poor groups was compared by analyses of variance. Resource-rich persons were more likely to have survived the 4 years than resource-poor. Non-survivors were more likely to have more sleep and more passive activities and less social activities than survivors. Resource-rich older people reported more social time with family members, less diversity of activities within their most prominent leisure domain, sleep more often and longer during the daytime, and more change in their activities after the 4 years.

The SOC model proposes that older adults adapt to everyday demands and functional decline in later life by selecting, optimizing, and compensating in everyday life. Selection is actively or passively reducing the number of activities and goals to focus on those most important in order to preserve diminishing resources for meaningful and obligatory activities. Compensation refers to regenerating with sleep or rest or through other means once losses have occurred. Optimization is making the most of resources in a selected domain of functioning where no direct or indirect aging losses have occurred.

Contextual components and their interaction with motivational mechanisms are in the early stages of exploration. The SOC theory proposes to address the formerly neglected area of compensatory efforts and motivational mechanisms. However, the tools being used to test it, such as those described earlier, have not included items which satisfactorily measure the spiritual/transcendent factors.

Note the functional emphasis and the absence of the spiritual/transcendent function as a domain of function. The absence of spiritual/transcendent domain in this framework leaves a significant hole in its foundation for understanding everyday competence in adults and gerotranscendence. It can be argued that if gerotranscendence is the outcome of successful aging, the spiritual /transcendent domain is at least as important of an area of function as physical, psychological, and social function in everyday competence.

Unidentified components and domains tend not to be seen and investigated and measurement tools are not sufficiently developed. For example, microbes could be inferred but could not be seen without microscopes. Similarly, the interior dimension of aging is currently unseen by researchers. Hence, it is critical to specifically ask older adults to help researchers to "see" this domain of their lives and to describe its relationship to their everyday lives.

Change in everyday activities was also studied by Adams (2004), who developed and tested a tool to measure change in activity and interest within the disengagement, socio-emotional selectivity theory, and gerotranscendence theories on aging. The tool, Change in Activity and Interest Index (CAII), is a 30 item self-report tool designed to compare present-day activities to those 10 years ago. Items include Active Instrumental (AI) activities, Social Intellectual (SI), Spiritual concerns (SC), and Transcendence (TR).

This exploratory study presented participants' self-reported changes in activities, data on CAII as an instrument, and comparisons of those principle component scores with client variables. The sample consisted of a total of 327 outpatients from a random sample

of 990 adults aged 65+ from the 5,000 non-institutionalized members of a regional HMO in Maryland.

Theories of disengagement, socio-emotional selectivity, and gerotranscendence were summarized and the tool presented. Respondents compared their interest in listed activities "nowadays" to 10 years ago as "more now," "less now," or "about the same amount." Disengagement was measured with dichotomous scoring of those items with less interest vs. same or more interest. Items related to socio-emotional selectivity and gerotranscendence include "social events with new people," "like getting together with old friends," "size of circle of friends," "spending time alone is more appealing," and "spiritual life or prayer." Questionnaires included the CAII, demographic information, and measures of health and functioning.

The change in interest, tool item correlations, and relationship between tool scores to each other and to other study variables were tested. T tests were performed between familiar to new activities to measure disengagement and selectivity. Alpha correlations were performed between principal component scores and total disengagement score. Disengagement/engagement items with less than.0.87 alpha reliability were omitted from the total disengagement score. Subscale scores of the CAII were correlated with the total disengagement score. CAII subscale scores were compared with demographic variables.

Using the CAII, Adams (2004) found a self-reported increase in socio-emotional interests and decrease in active instrumental pursuits with increased age. To test the disengagement theory, items were given one point for each answer in the "disengaged" direction and 0 points for each answer of *about the same* or *more* engaged. Zero-order

correlations of CAII scores with dichotomous recoding between socio-emotional concerns with the CAII total was 0.844 ($p < 0.001$) and active instrumental scores was 0.916 ($p < 0.01$). Coefficient alpha reliability for the 30 dichotomous items was 0.87.

The items related to Active Instrumental (AI) and Social Intellectual (SI) activities had acceptable alpha correlations between each other ($r = 0.66$) but the Transcendence (TR) and Spiritual Concerns (SC) did not ($r = 0.35$).

Items showing at least 30% decreased investment responses included Entertaining in my home, Concern with others' opinions, Shopping and buying things, and Attending social events with new people. She concluded that the socio-emotional and selectivity and gerotranscendence theories were supported with the increased investment in social intellectual and decreased investment in active instrumental pursuits associated with functional losses in advanced age.

The weaker alpha of 0.47 with Spiritual Concern factor and 0.56 for the Transcendence (TR) factor show that these two factors as measured in this exploratory study do not meet the usual standard for reliability as stand-alone variables. The weakness of these factors perhaps represents fewer and perhaps not as valid items, reflecting a weakness in the existing body of research and theories regarding the functions of spirituality dimension. For example, it can be argued that worry about friends and family and being a good neighbor are not valid indicators of spiritual concerns. Likewise, although the TR items are congruent with the theory of gerotranscendence, as interest in spending time alone and interest in current events can

also reflect introversion and extraversion as personality traits rather than development changes.

In summary, although the body of research on everyday competence and environmental gerontology provides a helpful framework for understanding the everyday lives of older persons, those frameworks have perhaps left out factors important to older persons themselves, such as spiritual and transcendental tasks. The ethnographic process will hopefully provide an opportunity to discover areas previously not recognized as important.

Older People Living Alone

Articulating assumptions such as those in the theories above helps to outline the framework of inquiry. This section summarizes works related to older women living alone, two within the context of Switzerland's (Petry, 2003) and the United States' (Luken & Vaughan, 2003) culture from a critical feminist perspective, a large epidemiological study describing characteristics of older women living alone (Gustavson, & Lee, 2004), three phenomenological studies describing their lived experience (Porter, 1994a, 1994b; Hink, 2004), and concludes with a study on resources identified by women as helping them live at home alone (Morrissey (1998). Although none of these studies specifically address the experience of women aged 85 and older in this stage of life, all of them have valuable information for understanding this unique subpopulation of older women.

Petry (2003) examined elderly women's experience of living alone in urban Switzerland. She used feminist and hermeneutic methodologies to critically explore how

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these women experienced aging and how these experiences, attitudes, and concerns were shaped by Switzerland's historical and sociocultural conditions. She intentionally searched for positive stories to counterbalance the negative images of older women in the Swiss society.

Petry recruited a purposive sample through a local agency providing senior services. Nine German-speaking Swiss women ages 73 to 89 participated. Petry conducted interviews and participant observation in home visits. Her procedure was to ask open-ended questions and then to probe for content related to power relations.

Five of the nine women had been single their entire lives, 3 widowed, and 1 divorced. Five had an 8th grade education and the other 4 had educations ranging from 10th grade to a graduate degree. Six felt they had more than adequate pension and savings and 3 had just enough to live. Most felt content, well, and had no major regrets.

Petry used constant comparative thematic analysis on transcripts of audiotaped interviews and field notes to identify the main themes in the women's stories. She concluded that the women's descriptions and perceptions were "shaped by previous gender and professional roles, social policies, the prosperity of the Swiss country and by common discourses of aging" (p. 66). A theme was, "aging happens," an unconscious process which the women were unaware of and accepted as an inevitable part of the life stream.

She found that these women, all describing themselves as healthy, exhibited Kaufman's "ageless self." They did not identify themselves with their age since age in Swiss culture is associated with decline and disease rather than wellness. However, all of

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the women found their increasing memory loss disturbing, associated it with aging, and were taking some action to exercise or increase their memory skills.

Another theme regarding culture was "If I had been a boy." Although the women originally did not acknowledge experiencing any disadvantages as women, they did reveal them when specifically asked, "How would your life have been if you had been born as a boy?" Disadvantages included being denied education, not having voting privileges until midlife, and being denied career pathways. All of these women had internalized and satisfactorily met societal expectations of being a good wife, mother, and a dutiful daughter, and if single, being a nurse or teacher.

"Independence" was a consistent and strong theme throughout the women's narratives. Petry described how the importance of independence to these women illustrates both compliance with social expectations as well as "resistance to societal perceptions of older women as weak, vulnerable and dependent" (p. 60). Independence meant the ability to continue living alone, make their own choices, doing what they have always done, and doing what they want to do. It also meant freedom from obligations and past worries, such as financial.

Petry identified another theme, "being vulnerable," which was most prominent in their concerns for personal safety, such as robbery, and physical integrity, like falls. She described how the women's fear for their safety is shaped by their being women, their age, shifts in neighborhood demographics, and power relationships in Swiss society.

Petry concluded that although power imbalances were evident in the women's stories, the women did not feel there was an imbalance because they had internalized

those societal norms. Their commitment to independence in their life styles offered the positive stories Petry had sought in order to counterbalance the negative images of older women in the Swiss society.

The other cultural approach was Luken and Vaughan's (2003) critical ethnography. Their study, "Living alone in old age: Institutionalized discourse and women's knowledge," analyzed both the narratives of elderly women and the written descriptions of the culture in the professional, popular, and academic discourses on older women and living alone. They attempted to show how existing practices make women's perspectives "invisible" in the housing industry, especially regarding maintaining independence.

Luken and Vaughan (2003) examined the social organization of living alone in popular and professional writings and audiotaped narratives of women. They analyzed transcripts of interviews of 5 women aged 60 and older who had lived alone in the Phoenix metropolitan area. They interviewed the women on their housing experiences throughout their lives.

The researchers contrasted the women's descriptions of living alone throughout their lives with the societal categories of living alone and independence as presented within the "capitalist housing market" perspective. They summarized how these women "pioneers" described living alone in terms of everyday activities and social relations. By contrast, the featured institutional discourses focused on marital status, gender, age, and risk of institutionalization.

The textual discourses (governmental publications, healthcare articles, popular writings) conceptualized living alone as one value of the variable "living arrangements" or household composition. Luken and Vaughn then showed how this variable is used as an indicator of someone "at risk" or in need of specific health or social services and a market for "alternative housing." They described how living alone seen as an economic unit becomes both a commodity (potential consumer) and criterion for support services, a "problem" of a "client" or "customer."

By contrast, women's use of the term "living alone" illustrates a dynamic relationship with other people and the environment. Women described "living alone" as a way of living in social relationships (help, companionship, everyday functioning, emotional work). The women's narratives included familial relations as options to living alone, such as remarrying or moving in with family.

Similarly, women's narratives did not equate independence with living alone as a living arrangement, but rather with taking care of themselves and with a personality trait. For the women, this meaning of "independence" was in contrast to their taking care of a spouse or dependent (physically or emotionally). For example, living independently was living without an overnight caregiver without being scolded by a son.

Luken and Vaughan's (2003) critical ethnography concluded that

Constructing older women living alone as a social problem reinforces ruling

relations and reorganizes the political bases by dissociating women from class and

gender relations organized extra-locally, and it ignores older women's everyday

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competence in living alone in society organized through class and patriarchal

gender relations. (p. 130)

Since care systems are embedded within the social structures of the mainstream culture,

an ethnography such as the one proposed by this author integrating the views of the

women with providers' views could perhaps provide a valuable perspective on the

phenomenon of living alone.

Some characteristics of older adults living alone were studied in a sample of 5,265

members from a social Health Maintenance Organization (HMO). Gustavson and Lee

(2004) found that elderly living alone were less depressed, more highly functional, and

more likely to be female, widowed, and European American than those living with

others.

They compared self-reports of depression, functioning, and demographics in

Nursing Home Certifiable (NHC) clients of the Senior Care Action Network in southern

California. "NHC criteria is a standardized measure for determining frailty among older

adults" used by Medicare, Healthcare Financing Administration (HCFA), and social

HMOs (p. 8). Almost half (43%; *n=2,279)* of the participants lived alone although all

were NHC. The mean age was 83, with ages ranging from 65 to 91+.

The researchers conducted secondary data analysis on cross-sectional survey data

from the SCAN Health Questionnaire which had been sent out to the 8,700 NHC clients

during the calendar year of 2000. They received a 61% response rate. This 42-question

survey includes global questions regarding depressive symptoms, access to a social

support network, specific questions on Katz's ADLs/IADLs, and demographic

characteristics. T-tests and chi square were used to compare the 2 groups. Four hypotheses were tested. Two hypotheses were supported and two not supported.

The two hypotheses which were supported were: those who were European-American, female, older, and single were more likely to live alone than those who lived with others and those living alone functioned at a higher level than those living with others. Twenty six percent ($n=593$) of those living alone reported a need for help with one or more ADLs compared to 40% ($n=2,988$) living with others *(t, df, and p not reported)*. Those living alone needed significantly less help with IADLs than those living with others *(t=-11.22, df not reported, p<0.0001)*.

Those living with others relied more on relatives (especially spouses) for help and those living alone relied more on children, agency personnel, and friends *(X²=912.38, p<0.0001)*. Those living with others also reported lower use of agency personnel than those living alone. Both those living alone and those living with others reported comparable amounts of help from children.

The two hypotheses not supported perhaps raise questions about societal perceptions about those living alone. Those two hypotheses were those regarding depression and social support. Those who lived alone reported less, not more, sadness than those who lived with others and there was no difference in social support between the two groups. It would have been helpful if the design had compared persons with same levels of IADL functioning in the two groups to control for loss due to declining function.

Noteworthy was that 15% ($n=819$) in both groups reported no social support system. The authors emphasized concern for these 15% ($n=819$) and the minority elderly

who were unrepresented in this study and therefore not receiving formal support and services which they qualified for in the current delivery system. They concluded with the statement that HCFA has not promoted growth of social HMO's although nearly half of these frail seniors lived alone.

Porter's (1994b) early investigation, "Older Widows' Experience of Living Alone at Home," along with her subsequent studies within this subculture provide rich descriptions of women ages 75-84 who live alone. Her studies feature women of this subculture in the life stage preceding the one in this study. Because it will be particularly interesting to be able to compare and contrast findings in these two life stages, Porter's studies will be described in depth.

In one early study, Porter (1994b) described older widows' experience of living alone. Using Husserl's phenomenological method, Porter interviewed seven healthy women ages 75 to 83. Her research question was "For older widows, what is the experience of living alone at home?" (p. 20). Porter said that she chose this question because when she had asked widows if there was "anything more important to them than being independent... they emphasized that continuing to live alone at home was more important than doing everything for themselves" (p. 19).

The widows were city women recruited through notices posted at senior citizens centers and in church newsletters, widowed at least one year, living alone in their own homes, had not relocated to a different community after their husbands' death, had one child living within a 30 mile radius, and described themselves as healthy.

Several interviews of about 2 hours long were conducted and audiotaped in the women's homes and combined with Porter's field notes as participant observer. The interview guide "was based on one opened ended question: 'As a person who lives alone, please describe how you do this.'" Relevant probes asked for descriptions like "Describe decisions that you make to solve your day-to-day problems" and "Explain how you invent new ways of doing something that has to be done" (p. 20).

Data analysis followed Husserl's phenomenological steps and transcripts and field notes were analyzed to identify the intention of an action. Porter grouped these intentions into a broader classification called component phenomenon and then explained some relationships between those component phenomenon. Reliability of the analysis was tested with a panel of eight judges by a presentation and discussion on the last interview.

Four intentions were identified: "making aloneness acceptable," "going my own way," "reducing my risks," and "sustaining myself." Each of these phenomena had components which further explained the overall intention. For example, three components of "making aloneness acceptable" were "counting on others to count them in," "redesigning companionship," "relishing the freedoms," and "getting out and coming home."

The intention "going my own way" had six component phenomena: "monitoring ... performances of the tasks and responsibilities required to live at home alone," "taking care of business," "asking those who know and care," "separating my life from their [children's] lives," and "proving that I am still capable."

The intention of "reducing my risks" had three components. Women reduced their risks in performing their daily tasks by "exercising caution," "negotiating reliance" with people and the structural features of their homes, and "bringing my world closer to home." The last component phenomenon, "sustaining myself," had four component phenomena. These women described sustaining themselves so they could continue living at home by "staying able" to take care of themselves, "savoring satisfactions," and "finding peace."

Porter found that all seven women emphasized that they intended to continue living at home "for as long as possible." Staying living at home rather than independent functioning was their primary goal. The emergent umbrella component of "negotiating reliance", then, encompassed both the bracketed concepts of help-seeking and acting independently, concepts which are generally polarities in the professional health literature.

In another publication, Porter (1994a) describes the component phenomenon of "reducing my risks." These 11 women identified risks to personal safety, such as "losing one's balance," "not being found," "doing too much," "you never know" (neighborhood crime), and interpersonal risks, such as worrying others and intruding on others.

The women described reducing their risks by "exercising caution" and also "sustaining themselves." "Exercising caution" included: doing some tasks less frequently, discontinuing other tasks if risks were too great, purposefully thinking about a movement while they were moving, planning series of movements, taking their time, scrutinizing their surroundings, and negotiating reliance.

"Negotiating reliance" included features of structure such as locking doors, and of people, which was an interactive and complex phenomenon. Particular activities to sustain themselves in order to reduce risks were staying able to take care of themselves, keeping active, and taking it easy.

Findings by Hinck (2004) in an older, rural sample of older adults living alone in their homes were congruent with Porter's. Hinck had also conducted a phenomenological investigation on the lived experience of older adults. Research questions were to find out how they perceived the experience of living alone, how they perceived their health, what adaptive strategies they used to continue living at home, what trade-offs they were willing to make in order to stay in their homes, and what social support or resources they saw as necessary for them to stay in living at home.

Hinck interviewed 19 white adults ages 85-98 in rural Missouri every 2 weeks for 12 weeks in their homes Eleven of these 13 women and 6 men received help with housekeeping or yard work; two (both 97) received help with bathing and dressing. Being at home was extremely important. A feature perhaps unique to the rural population is that they all treasured the solitude of living alone and did not feel isolated. In fact, privacy was so valued that they would choose to living in nursing homes rather than with family or have someone stay with them. An urban sample might have different values and experiences regarding living alone in the city, especially in high crime or non-accessible neighborhoods.

Most (17 of 19) described their health as excellent or good although all had at least one chronic health condition resulting in limited mobility, pain, weakness, or

impaired balance. Their ability to walk and do other activities needed for self-care were of primary importance. Activities to stay healthy involved activities they could do at home as part of everyday life and staying active. They defined health by their ability to function rather than by pain or disease, viewing disease processes as common and normal in old age.

They modified daily patterns of living to accommodate physical discomfort, restricted mobility, and varying energy resources and demands. They initially tended to conceal struggles and present themselves as self-sufficient. Then "stories unfolded of the tenuousness of living alone" (p. 787).

Adaptive strategies included: changing how they performed the task, paying more attention to the task, using adaptive equipment or technology, obtaining help from others, eliminating the task, and reframing self-expectations of what was acceptable. "Daily patterns of living could be disrupted by fatigue, pain, illness, or injury," (p. 788), with fatigue having the greatest impact. Fatigue changed what activities were important.

Regarding safety assessments and trade-offs, "participants did not mentally evaluate the danger in everyday practices and activities" (p. 788). Instead, risk was gradually recognized and changes in daily practices made later when the risk was great enough and a solution seemed possible. "Participants did not consider their ability to remain at home in the context of being safe from injury. The deciding factor of whether they could remain at home was whether they could still care for themselves day to day, for example, dress, bathe, and move about at home" (p. 788).

All of these rural adults had strong reciprocal support networks. None viewed themselves as socially isolated despite geographic distance. All took active roles initiating social contact and supporting others. They perceived few unmet needs except for transportation to social events and knowing that someone was available in an emergency. They all saw themselves as having the social support or resources they needed for them to stay at home.

An earlier study by Morrissey (1998) had also explored variables which influence older women's ability to remain living in their own homes. Morrissey followed 15 women age 76 to 92 in their homes who lived alone for 4 to 64 years in a Midwestern city of the United States. Ten were widowed, two divorced, and three single. Seven of the women had 8th grade educations or less, three with high school, one with nursing school and another with a post high school business course.

Morrisey (1998) analyzed audiotaped "conversations" and used Lawton and Brody's IADL scale and Circirelli's modified version of Rotter's internal-external locus of control scale. She categorized data chunks from the transcripts and validated her interpretations with participants. She found that independence was the most frequently recurring theme which was seen in the participants' determination to remain in their own homes. She found that

> Value systems evolved over the years and functioned as a "mediator" regarding
> "acceptance of assistance;" those who did not relinquish the value of
> "independence" and needed help moved into assisted living or nursing homes
> when they experienced mild functional decrements... An elderly woman's ability

to continue the lifestyle "living alone" is to some extent dependent on her ability to construct a lifestyle that is acceptable to her.(p. 420).

Morrissey also identified 15 categories which described characteristics of these women: self-description, kind of person I am, locus of control, personal loss, unresolved issues, value system, perception of my world, interpersonal relationships, health status, work history, organization of time. Self-descriptions of the women were mostly positive; "negative descriptors offered by all participants were related to losses often concomitant with aging" (p. 414). Locus of control scores were unrelated to any other factors. Ten of the 15 women described a sense of personal loss related to death of family or friends.

Reciprocity and directness characterized their relations with other people, except when "redeeming 'earned credits'" with children. Women's value systems "guided efforts to negotiate their world." Self-reported health was good or very good in 10 of the women, fair in 3, and poor in 2. Ten of the women reported stable health and 2 reported declining health. All had held a market job some time in their lives. All of the women had a framework for organizing their day, most of them performing necessary activities in the morning.

Resources described by the women as influencing their ability to remain living in their own homes were income adequacy, transportation, supports, and coping behaviors. Only one of these women considered her income to be inadequate. Transportation availability influenced the amount of social interaction. Social supports were primarily informal, with one child often the primary informal support; 4 of the women identified a supernatural being as a social support.

Coping behaviors were designed to: alter the situation, alter the meaning of the situation, or control stress; altering the meaning was the most frequent coping behavior. "Adaptive behaviors to cope with aging decrements" were usually directed toward problem-solving. Strategies to compensate for decreased functional competence were developed by most of the women, even the 10 women who were self-sufficient in the IADL scale.

This study, then, hopes to describe such strategies within the everyday context of living alone at home with physical disabilities. Independence as usually defined by providers, as not needing help, did not emerge as the primary intention of older women living alone. Rather, maintaining autonomy and staying in their own homes emerged as primary concerns.

Older women described a wide range of creative and adaptive strategies to reduce their risks, a key concern of health professionals and caregivers. Women's definition of risks, however, included the risk of being a burden and a worry. Striking was the reciprocal and interactive nature of giving as well as receiving care. The high percentage of those living alone without social support was worrisome. The service gap challenges existing systems to more intentionally address the needs of this population in order to help them to effectively stay in their own homes.

Frailty

Advanced age has been found to be one of the single most predictive characteristics of frailty. However, in their comprehensive concept analysis of frail, nurses Markle-Reid and Browne (2003) caution that the current association of aging with frailty "reinforces the assumption that ageing is synonymous with disease, disability, and decline," (p. 64) and therefore reinforces negative stereotypes rather than assets in aging.

In both studies describing older women's experiences of growing older and living alone, themes of "vulnerable" (Petry, 2003) and "risk" (Porter, 1994b) emerged in their self-descriptions of aging. "Frail" has been conceptualized and operationalized to categorize those most vulnerable, or at-risk.

This section summarizes key works on frailty, including large, epidemiological studies on the frailty syndrome (Ferrucci, Guralnik, Studenski, Fried, Cutler, & Walston, 2004; Mitnikski, Song, & Rockwood, 2004; Saliba, et al., 2001), a philosophical approach to the concept consistent with gerotranscendence (Gadow, 1983), a nursing concept analysis of frail (Markle-Reid & Browne, 2003), concluding with a qualitative description of women's experience of their disability within context of place (Grenier, 2005).

Mitnikski, Song, and Rockwood (2004) have conducted many studies on frailty and age in thousands of Medicare recipients through the Canadian Study on Aging. They have developed a frailty index constructed through mathematical models which apply formulas designed to represent the physiological complexity, allostatic load, and self-

report data of this dynamic construct. They summarized previous studies showing that self-reports were accurate predictors of negative outcomes.

Mitnikski, Song, and Rockwood (2004) reported that earlier studies found that a *proportion* of deficits rather than specific deficits were predictors of mortality. Therefore, they had constructed a frailty index as an average of the deficits within an individual. They have used a Cox regression model with both chronological and a biological age scores to compare variables in multiple studies. They summarized several studies using this frailty index. This section will describe their most recently published study.

Mitnitski et al. (2004) conducted a secondary analysis of data on 9,008 community-dwelling people to test the use of binary data in their frailty index. This was to expand on their 1999 study of 81,859 subjects which used nonbinary data in the index. The frailty index was calculated from self report variables, deficits, and outcomes. The 40-self report variables addressed symptoms, attitudes, illnesses, and function. Personal biological age was calculated for each person as the mean chronological age for the frailty index value.

Mathematical formulas were presented to show the construction of the mathematical model of frailty. Regression techniques were used to analyze the age trajectories of the average frailty index for all of the population and to compare men and women. Individual frailty was compared to the regression line for the entire population to assess individual frailty. Frailty indices were correlated with biological and chronological age using a gamma density function. Similar to their previous studies, they found that generally women accumulate more deficits than men of the same age, although their

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mortality risk is lower. This frailty index using binary variables successfully predicted not only the 6 year death rate, but also survival time and progression of frailty.

The frailty index showed an average exponential increase with age of 3% per year. The greatest difference between the calculated biological age and chronological age was observed in persons who died within one year. Personal biological age was more accurate in predicting negative outcomes than chronological age. The researchers concluded that the similarity of these results to those of earlier studies implies that dichotomizing the variables does not affect the major properties of the frailty index.

Researchers in the Interventions on Frailty Working Group and related colleagues have evaluated over 100 studies on frailty and published recommendations for intervention trials titled "Designing randomized, controlled trials (RCTs) aimed at preventing or delaying functional decline and disability in frail, older persons: a consensus report" (Ferrucci et al., 2004). The consensus report was published by the American Geriatrics Society, synthesized recommendations from conferences and meetings as well as the literature, and was conducted under the auspices of the Italian Geriatric Society. Most of the 70 cited studies were randomized control trials related to preventing progressive disability. They focused on methodology rather than interventions.

The Interventions on Frailty Working Group defined physical frailty as

The concept of physical frailty was used to create a working definition of the population at high risk for disability onset or progression. ... It is recommended that operational criteria to define physical frailty be based on impairment in the

physiological domains most frequently cited in the frailty literature. These include

mobility, balance, muscle strength, motor processing, cognition, nutrition (often

operationalized as nutritional status or weight change), endurance (including

feelings of fatigue and exhaustion), and physical activity. (p. 626)

They labeled the umbrella construct "frailty syndrome." They presented a table of 14

methodologically sound studies which displayed which studies addressed each of these

components.

Their analysis concluded with the following recommendations regarding

methodology: eligibility screening should be multistage to allow for changes in status and

exclude those too well or too sick; criteria should target those most likely to benefit and

have impact; disability outcome measures should include self-report, objective, and proxy

measures; designs should include strategies to improve retention and compliance and to

monitor for effectiveness; estimates of cost and sample size should plan for high dropout

rates and interference by competing outcomes.

A previous study also published by the American Geriatrics Society which had

received the 2000 Presidential Poster Award for Health Services Research had

summarized studies predicting physical frailty and tested the tool used in this study, the

Vulnerable Elderly Survey, VES-13 (Saliba et al., 2001). This tool was developed to

screen community dwelling older populations at risk for health deterioration. It was

tested on a nationally representative community-based survey of 6,205 Medicare

beneficiaries age 65 and older over 2 years.

The tool features 13 items using age, function, and self-reported diagnoses which are scored from 0-3 to predict functional decline and death. One third (32%) of those identified as vulnerable with this screen had 4.2 times the risk of functional decline or death over 2 years compared to the remaining 2/3 of this sample. The results of this study were consistent with other studies, with self-reports of IADL/ADL disability rather than self-reports of medical diagnoses being significant predictors of decline and death. The researchers concluded that the V-13 successfully identified the 1/4 to 1/3 vulnerable older adults most at risk for decline and death.

Markle-Reid and Browne (2003) acknowledge the value of these large, randomized controlled studies while calling for more studies which capture the contextual, individualized, multidimensional characteristics and address the 'fit' between the needs and resources of the person and the demands and resources of the environment" (p. 65). These Canadian nurses conducted a concept analysis based on their review of the literature.

Their 2003 state of the science article cited 77 articles which included most of the significant work on frailty, but only up to 1999. As can be seen from the preceding section, the concept has been significantly developed since then. However, their recommendation is still relevant. Contemporary work on frailty has successfully identified predictors and indicators of the construct. It is time to more closely explore some contextual and developmental factors which were identified in the foundational works on frailty two decades ago and to focus on the growing numbers of oldest old.

Only one author has described frailty consistent with the gerotranscendence developmental theory on aging for those in their ninth stage. More than 2 decades ago, Gadow (1983) challenged readers to consider frailty as an opportunity. She quoted Scott-Maxwell (1979):

It is a place of fierce energy.... It has to be accepted as passionate life, perhaps the life I never lived, never guessed I had it in me to live.... It is just life, the natural intensity of life, and when old we have it for our reward and undoing. (p. 33)

She concluded that when frailty and vitality become fused, the body becomes a beloved to be protected, and one's energy becomes completely expressed in taking simple steps rather than focused outwardly. Frailty is "essential to the making of a self and—far from being an indignity in aging—is a source of intensity and life without which no self is whole" (p. 146).

Grenier (2005) asked older women how they actually experienced their disability and physical decline within different physical locations, including their homes. She concluded that "frailty" was an experience within context. Women described their physical disability as created and defined by the experience of "getting round" within the context of available resources and relationships in a setting rather than defined by their bodies as disabled. Home was both a safe and restrictive space depending on available and accessible transportation. For example, the bus was ironically the transportation resource and the reminder of disability because of its inaccessibility.

She explored how older women "potentially classified as 'frail' understood the concept and lived out their daily experiences of disability and decline. She conducted in-

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depth unstructured interviews with 12 English-speaking older women ('in their 60's to 80's'"; p. 133) in Montreal from various social backgrounds and parts of the city. The women participated in one to three unstructured interviews lasting up to three hours. Sample demographics and selection were not described. Ten chose to be interviewed in their homes and two in their offices. The method of data analysis was not described.

Grenier concluded that women's experiences were more connected with the social locations and contexts of their disability rather than the functional limitations of their bodies. She also stated that the women described compensatory styles congruent with maintaining personal identity and harmony consistent with Baltes' (1997) selective optimization with compensation (SOC) strategies for life management.

Since Grenier's methodology was not explained, findings not systematically presented, and interpretation mixed with data throughout, it is not clear if her conclusions emerged from the respondents' narratives or whether the respondents' quotations were used to illustrate and support the researcher's perspective. However, the "mix" of negative as well as positive quotations about home as context was an interesting addition to the literature.

In summary, much substantive work has been done on frailty. Frailty is a complex, multidimensional construct with fairly well-established defining characteristics. Although frailty has a variable course, predictors of decline and death have been identified, with high VES-13 survey scores and slow gait speed independently reliable predictors. However, individual's experiences of that process have had comparatively little study, especially within the context of their homes. With frailty highly associated

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with advanced age, it is critical that providers better understand how physically disabled elders' actually manage within the context of their homes.

Home Environment

The daily activities and functional adaptation of these oldest old is clearly intertwined with their environments. The study of home environments is a research domain within the field of environmental gerontology, an interdisciplinary field that is experiencing a resurgence of study and is grounded in Lawton's ecological theory on aging (Wahl & Weisman, 2003).

This section summarizes studies within this framework on home environment and modifications by occupational therapist Gitlin (2000; 2002); Rubinstein's (1989) classic work on the meaning of home; nurse Swenson's (1998) classic Heidegerrian study on "attachment to place"; attachment to home and possessions (Shenk, Kuwahara, & Zablotsky, 2004); and caregiver's descriptions of home modifications (Messacar, Archbold, Stewart, & Kirschling, 2002).

Gitlin (2002) described the state of the research on home environments and posed three broad areas for inquiry: methodology, meaning, and interrelationships between environment, well-being, and functioning. She also urged contemporary researchers to base studies in theoretical frameworks, citing the frameworks of early environmental gerontologists like Lawton as examples.

Gitlin's earlier work (2000) reviewed person-environmental research in the area of home modifications under the umbrella of environmental gerontology and Lawton's model. She titled it *"Adjusting 'person-environment systems': helping older people live*

the 'good life' at home." In it she described broad sweeps across the studies and disciplines: intrapersonal considerations, such as the centrality of continuance of self and place, and objective environmental conditions.

Environmental gerontologist Rubinstein's (1989) classic work spawned a few explorations around the meaning and function of home in older persons. Rubinstein's work was an ethnographic study of seven informants aged 68-90 using Spradley's "ethnographic" and Levinson (1978) "biographical interview" techniques every week for 4 months. In it he described how older people endow home environments with meaning. The basic interpretative groupings he found in their statements were three classes of psychosocial processes which served as foci for environmental meaning: the sociocultural order, the person-centered life course, and the body-centered process.

He described the psychosocial processes linking person to home environment as representing channels describing the relationship between the self and the environment. These relationships reflected a person's cultural operational definition of self and environmental competence. In the sociocultural process, the ordering of the home environment was based on a person's rules for domestic order, such as public vs. private space.

The person-centered process concerned the expression of the life course in features of the home environment. The person-centered process included: accounting, knowledge of the totality of environmental features (such as what is where); personalization, endowing environmental features with meanings whose referents are distinctive properties or events of one's own life; extension, a more intense degree of

psychological involvement with an environmental feature; and embodiment, the subjective merging of the individual with the environmental feature.

The body-centered process is the ongoing relationship of the body to the environmental features that surround it: entexturing, the fine-tuning of the environment to sensory modalities in daily routines; and environmental centralization, the manipulation of the home environment to accommodate increasing physical limitations by centralizing living space.

Rubinstein concluded his analysis with research and practice implications of changing the home environment when the home environment is subjectively intertwined with meanings and aspects of personhood. His study, therefore, has provided an invaluable framework for investigating home modifications in the face of physical limitations. A few of these are described below.

Nurse Swenson (1998) studied "attachment to place" as described by environmental gerontologist Rowles (1983). She explored the meaning of home to women who were living in their own homes and who were competent, independent, and "in charge" of their home life.

She used Heideggerian phenomenology to explore the meaning of home in terms of attachment to place, phenomenological meaning, and autobiographical memory. Heidegger conceived of home as dwelling and a fundamental characteristic of the human condition. Swenson analyzed interviews along with photos of the homes of 5 widowed women aged 75-87 years who lived in their own rural homes for 30+ years and who then

lived alone. All of them were high school graduates, had been employed, and had been caregivers of their deceased husbands.

Swenson found that

The home provided the focus for the definition of self, a nurturing space for the woman and her family. It provided both a behavior setting for activities within and the starting point for activities outside. Homes for these five women reinforced their sense of self and self-identity, their sense of being needed and useful, and their sense of independence and autonomy in the world. (p. 384)

All of the women's homes contained Lawton's control center with its comfortable chair surrounded by items most commonly used, usually facing a surveillance zone, where women monitored the "outside" world.

Swenson (1998) wrote that the "construct 'home' combines meanings of the physical building, the family and affection, of dwellings in time and space, of ownership and responsibility" (p. 391). She concluded that her study highlighted "awareness of the meaning and symbolism of the home environment as a symbol of self, a symbol of personal aspirations, and a symbol of status transition" (p. 391).

Three constitutive patterns emerged which described the meaning of home to these women. These were home as center of self, home as center of caring, and home as center of reach ("home base"). Home as the center of self included the relationship between self and home as manifested in being "at home" and "in control" of one's house and revealed in the personalization of lived space inside and outside and revealed in stories.

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Home as the center of caring included caring for themselves, their families, and their homes. For these women, taking care of themselves partly meant they would not have to depend on their adult children. Taking care of their homes showed their families and neighbors they were competent and well-kempt. Home as the center of reach meant that home provided a "home base," a place of "rootedness" and ownership.

A more recent study explored older women's attachments to their home and possessions within the context of the gender role and expectations of their cohort of women (Shenk, Kuwahara, & Zablotsky, 2004). In-depth interviews with four older widows in North Carolina who still lived in the homes where they had lived with their deceased husbands were analyzed within the perspective of their life courses.

The cultural norms and expectations that formed the background of these women's lives were summarized and presented in relationship to home and possessions, especially their cohort roles as homemakers, mothers, and wives. With identities tied to home and family, possessions and homes were tied to family memories and their relationship to home was building a comfortable "nest" for their families. Home as a place of comfort and competence meant a place for their own personal rituals and routines.

Home modifications can significantly affect personal rituals and routines as well as components of meaning described earlier. The literature does not yet include studies on how home modifications affect personal rituals, routines, and meaning from the perspective of older adults themselves. However, nurses Messecar et al. (2002) have

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explored home environmental modification strategies used by family caregivers of elders from the perspective of the caregivers.

Messecar et al. (2002), classified home modifications as described in the literature in their helpful overview. These classifications were: type, cost, modification, target, purpose, and impairment. Their investigation combined open-ended, semi-structured interviews with Spradley's participant observation techniques to explore home environmental modification strategies used by 24 caregivers in a variety of community-dwelling settings. Families provided guided tours and allowed selected observation of some caregiving activities.

Through data reduction with Miles and Huberman's (1994) method, they identified 44 home environmental modification strategies and organized them according to seven purposes. These purposes were: organizing the home, supplementing the elder's function, structuring the elder's day, protecting the elder, working around limitations or deficits in the home environment, and enriching the home environment.

Receiving Help

Functional disability refers to the inability to perform ADLs or IADLs without help. Receiving help makes it possible for these older women to remain living alone in their own homes. This section summarizes large, epidemiological studies on the trajectories of ADL disability (Gill, Allore, Holford, & Guo, 2004; Li, 2005), a comprehensive study on the relationship between social support and mortality (Temkin-Greener et. al., 2004), a large study estimating total hours of paid and unpaid help (LaPlante, Harrington, & Kang, 2002), relationships between unpaid, nonprofessional,

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nonkin caregivers and frail community-dwelling older adults Barker (2002), descriptions of home care providers from the perspective of older women themselves (Porter, 2004), and elders' experience in receiving help from family (Crist, 2005).

Gill et al. (2004) have conducted several longitudinal studies on the development of disability in ADLs in community dwelling persons. They reported that previous studies found predictors of disability to be: slow gait speed, which is the single best predictor, prior episodes of disability, and hospitalization in the preceding year.

The purpose of their recent study (Gill et al., 2004) was to determine how often disability in ADLs develops insidiously and whether the likelihood of insidious disability differs based on physical frailty. They recruited 754 physically frail, community dwelling persons 70 years and older through a large health plan in a small city in Connecticut. Physical frailty was defined as taking longer than 10 seconds to walk back and forth quickly over a 3 meter course. This prospective study began with initial home-based assessments and continued with monthly phone calls for 3 years. Disability was classified as insidious if it developed in the absence of a precipitating event such as hospitalization, injury, or illness leading to restricted activity. Catastrophic disability was defined as a new disability in 3 or more ADLs.

Of several factors, such as age, gender, ethnicity, number of chronic conditions, education, cognitive impairment, and depression, only physical frailty was significantly associated with the development of insidious disability. Insidious disability developed in 203 or the 322 participants who were physically frail compared to only 26 of the 432 who

were not physically frail. The likelihood than an insidious episode of disability was progressive increased significantly with each additional disability.

Data gathered over 64 months from this prospective cohort group were also later analyzed to investigate transitions between states of disability and independence (Hardy Dubin, Holford, & Gill, 2004). Participants were assigned to one of four groups based on their initial home assessment: no disability, mild disability, severe disability, and death. For each person, the number of transitions a year, the number of disability episodes of year, and the percentage of time in each state was calculated for each participant.

This study extended the previous one in months and added the dimension of transitions. Of the participants, 268 (36%) stayed independent throughout the 64 months. Almost 20% of frail participants and almost half of nonfrail remained independent throughout the almost 6 year follow-up and therefore had no transitions. Among those with transitions, the median numbers of transitions were 6 for frail and 3 for nonfrail. The range in number of transitions was very large, showing much variability within as well as between groups. Nonfrail participants were more likely to stay independent than frail. Brief disability episodes represented the majority of episodes for both frail and nonfrail participants. These studies did not adjust analyses for age.

Li (2005) also examined trajectories of ADL disability among community-dwelling frail older persons. She studied how the pattern of change varied between those who subsequently died or were institutionalized and those who stayed living in the community. Using hierarchical linear modeling (HLM), she analyzed multiple sequences of data from 3,161 older adults in Michigan's Medicaid Waiver Program over a two year

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period. Older adults who died or were institutionalized had shown a steep increase in ADL disability the few months before the events. Those who continued to live in the community were fairly stable in ADL disability. Similar to the previous studies, older adults showed much individual variations in ADL disability trajectories within each group. As a group, frail participants showed more frequent and slightly longer disabled states.

Li concluded that acceleration of ADL disability among older adults with moderate levels of disability may result in nursing home placement and recommended intervening to prevent deteriorating functional ability. Instability of ADL disability, especially increasing ADL disability, appears to predict death and institutionalization. However, some frail older persons show stable ADL disability or even improve in function while others become more disabled. Understanding the process can help guide effective intervention.

Temkin-Greener, Bajorska, Peterson, Kunitz, Gross, Williams, et al. (2004) conducted a comprehensive study on the relationship between social support and mortality in 3,138 people enrolled in 28 Programs of All-Inclusive Care for the Elderly (PACE) who were nursing home certifiable. They summarized more than two dozen studies which found a protective effect of social support on mortality. They proposed that a unique contribution of their study was its focus on frail elders who shared access to a comprehensive range of formal social support services within a health plan which had variations across sites. Formal social support included help with meals, personal care, and

instrumental ADLs. They differentiated between 3 domains of social relationships – availability, source, and content/quantity.

Data were obtained from dataPACE, including self-report, social worker, intake workers, nurses, physician, and formal caregivers. The average PACE enrollee was 78.6, with 6.8 medical conditions, 4.0 ADL limitations, and a frequent diagnosis of dementia (51%; *n=1,600*). Seventy two percent (*n*=2,259) of participants had informal caregivers who were just as likely to live with as not live in the same household with participants. Informal caregivers were more often children or children-in-law (55.3%, (*n=1,735*) than spouse or other relatives, with non-relatives fewer than 10% (*n=not provided*). On the average, non-household caregivers reported devoting 8.5 hours weekly in instrumental supports.

Sociodemographic variables significantly predictive of mortality were older age and male gender. Predictive health need factors were: poor self-assessed health, need for help with toileting, difficulty walking, impaired cognition, oxygen dependence, and diagnoses of cancer, diabetes, or renal failure. PACE site differences were significant.

Ordinal data were transformed to dichotomous data and semi-parametric Cox proportional hazards models were constructed to assess the importance of individual risk factors, program effect, and social support variables. When all participant and caregiver variables were statistically controlled, participants with spouses as caregivers had a significantly lower risk of mortality (hazard ratio = 0.63) compared with those with non-spouse caregivers. Most significant was that caregivers' assistance with meals was

associated with significantly lower risk of morality (hazard ratio = 0.66) compared with no assistance with meals.

LaPlante, Harrington, and Kang (2002) analyzed data from the Disability Followback Survey of the National Health Interview Survey on Disability (NHIS-D) to estimate the total hours of paid and unpaid help for ADLs in persons living in their homes in the United States. The sample consisted of 8,471 home-residing adults ages 18 and older who received help for up to 5 ADLs and 10 IADLs from up to 4 helpers.

LaPlante et al. (2002) calculated that the market value of informal (paid and unpaid) personal attendant services of the 18.7 billion hours in their study valued at $9 an hour totaled $166 billion a year. They concluded that 13.2 million noninstitutionalized adults receive an average of 31.4 hours weekly of help in ADLs and IADLs. Of these, 3.2 million people receive an average of 17.6 hours of paid help compared to 11.7 million receiving an average of 30.7 hours of unpaid help. Only 16% ($n=$ 3 billion hours) of the total hours are paid. Younger people received more hours of help than older, probably due to more severe levels of disability.

Barker (2002) investigated relationships between unpaid, nonprofessional, nonkin caregivers and frail community-dwelling older adults. They conducted intensive, semistructured face-to-face interviews with a convenience sample of 114 caregivers and care recipients. Themes were identified from transcripts of the audiotaped interviews at the beginning and then again 12 months later. Duration of caregiving relationships varied from 6 months to 20 years. Major topics were the natural history of the relationships, the

kinds of activities and tasks performed, and the experience of the relationship from each participant's perspective.

Caregivers were mostly female with a wide ranges of ages and generally modest income, and uncommonly well educated, with 22% (*n=25*) having postgraduate degrees. Nonkin caregiving relationships showed wide variations in duration, tasks performed, and integration with family resources. An important mechanism for establishing these relationships were ordinary activities or chance encounters, such as exchanging greetings with neighbors.

Most (58%; *n=66*) of the nonkin relationships actually began through caregiving. Most relationships were of short to modest duration, with one quarter longer than 5 years and some longer than 50 years. Almost half of the caregivers were themselves aged 65 or older, with 12% (*n=14*) aged 80 or older. Almost one third (*n=35*) were age peers. In many cases, it was unclear who actually cared for whom, with help flowing back and forth depending on needs at the time. Almost one in five partnerships (17%; *n=19*) involved heavy physical or personal care for 4 to 6 ADLs, more often in relationships longer than 5 years.

Four styles of relationship were found: casual, bounded, committed, and incorporative. Casual relationships tended to be shorter, pleasant, fluid in content and regularity of task, including mainly socializing and minor instrumental task assistance. Caregivers were older and tended to live closer to their care recipients. Bounded relationships generally involved more extensive contacts, but still largely with help in impersonal and instrumental tasks and of shorter duration.

Committed relationships comprised about one fourth of partnerships and ranged from dyadic relationships to career caregivers, usually lasting longer and with more intimacy and a more complex mix of tasks in multiple domains, often including help with ADLs. Incorporative relationships composed one fifth of the partnerships. In addition to the multidimensional components in committed relationships, these have greater emotional intimacy and involvement in the life world of the care recipient. Distinct from other styles in three key ways, the incorporative relationships have the youngest caregivers, a significantly longer duration than casual or bounded styles, the greatest proportion of caregivers providing personal care, and either the caregiver or care recipient becoming centrally incorporated into the other's family nexus.

The three motivations most often mentioned by caregivers across ages and gender and duration and relationship style were fairly equally represented. These were: prior history of volunteering, especially of providing care, seeing an otherwise unfilled need, and religious belief. Top ranked concerns were getting too involved and not being able to set boundaries, getting too attached, and the dependent's being too demanding or unappreciative. Negative comments were one fifth as common as positive even with probes. Over one third (38%; $n=43$) of nonkin partners were the primary or sole caregiver of the dependent elder. Most (53%; $n=60$) nonkin caregivers provided essential supplementation to formal and family services. A strong affective bond sustained most of the relationships, with 10% ($n=11$) caregiving claiming they were family and more than half (56%; $n=64$) using kin terms to describe the quality of the relationship. Only 40%

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(*n=46*) had living kin, most with no children or with deceased children. Often (55%; *n=*; *63*) the caregiver's family also got involved in caregiving.

Barker (2002) concludes with a significant summary regarding frail elders receiving help and everyday life:

> The strength of these naturally occurring relationships seems to be their unscripted ordinariness, their everyday quality. These partnerships focus largely but not exclusively on the minor, mundane tasks of everyday life in a context of fluid, spontaneous, personal interactions and a variety of social structural opportunities. It is important to frail elderly people to have someone to chat with regularly, someone to do the small but important household and everyday jobs that paid services do not do or cannot do, someone willingly available to help at night or other times when formal services or family are unreachable. (p. S166).

Porter (2004) has also done work on classifying and describing home care providers, but from the perspective of older women themselves. Three interviews were conducted with 25 widows aged 80 to 94 years living alone in Missouri. A phenomenological approach was used to differentiate helper types on the basis of the nature of the help and to explore variations in compensation arrangements. All of the women's helpers were classified as "Stand-by's." This phenomenological analysis was part of a larger 3 year study, which will be described subsequently.

The women reported an average of eight helpers which ranged from 2 to 14. Helper's responsibilities did not fall into the most commonly used dichotomy of paid/unpaid or formal/informal and often had changed over time. Porter described policy

implications of using a dichotomy which did not reflect the value or nature of help from the women's perspectives.

The women described four types of helpers: the Regular Helper, the On-Call Helper, the Can-Will Doer, and the Mainstay. All of the women had at least one Regular Helper who came at a specific time to do a certain task or tasks only. Each woman also had at least one On-Call Helper to call upon for help with a new problem or provide transportation on an irregular basis. Most of the women (18 of 25) had a Can-Will Doer who could or would take responsibility for a task the woman could not do alone, such as managing money. Ten of the women described at least one or two helpers without whose help they felt they could not live alone at home. The help was not necessarily frequent, systematic, frequent, family, or paid. Mainstays were trusted, companions who were willing to help out indefinitely and willing to do more as needed.

The greatest range of variability in compensation was for Can-Will Doers and Mainstays, whom the women did not usually pay if they were kin, unless they were males doing repairs and mowing lawns. Paid helpers who were Regular Helpers sometimes functioned in other roles as well.

Porter's (2004) analysis of helpers had been conducted as part of the larger study exploring the experience of home care for older widows living alone in their own homes. The larger study (2005) investigated the overall experience and context of home care, with particular attention to the women's perceptions, actions, and intentions related to their helpers and to the help they received from them. Porter (2004) reported that the women were not passive recipients of home-care services, but actively negotiated

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reliance on their standby helpers in specific ways. An average of 7 interviews were conducted with urban and rural widows living alone over 3 years.

The common phenomena that described the women's experience of homecare were sorting out who can best do what needs to be done, protecting my standby, mobilizing my standby to help with this job too, and working together to get the job done. This involved sometimes providing respite to their standbys and receiving help on tasks not performed within the home. The women described home care services as those which allowed them to stay living in their own homes. Although assignment of tasks within the current home care system is structured downward from health professional to nonprofessional, the women themselves mobilize help from available standbys which frequently does not correlate with or coordinate with the formal system. Porter (2004) (2004) discussed policy implications of viewing home care from the perspective of women actively negotiating their reliance on help in order to remain in their homes.

Crist (2005) also explored elders' experience in receiving help, with a focus on family care, and reported that previous studies found that 70 to 80% of care is provided by family members. She also used hermeneutic interpretive phenomenology. Crist conducted 2 to 5 home-based interviews and participatory observation with a convenience sample of nine elders (5 women and 4 men) living in urban and rural areas in the Pacific northwest of the United States. Elders were asked to describe their day-to-day experiences of receiving family care. Common themes and paradigm cases were identified by the research team.

Findings were that elders viewed themselves as autonomous, comfortably incorporating family care in their lives. Elders reported receiving family care as an acceptable and positive experience which reflected positive relationships and the experience of reciprocity of care. The elders in this sample described a balance between accepting help and maintaining autonomy, accomplished through mutual caring and trust. Crist compared these findings with the Euro-American reported value of independence and elders' reported dread of receiving help.

Physical disability impacts the need for help. Large, epidemiological, and longitudinal studies found predictors of ADL disability to be slow gait speed (most predictive), prior episodes of disability, and hospitalization the previous year (Gill et al., 2004). Progression of disability showed wide variations, with the acceleration and instability of ADL disability predictive of institutionalization and death (Li, 2005).

Social support has consistently shown a protective effect on mortality (Temkin-Greener et al., 2004). Predictors of mortality in frail elders with access to a comprehensive range of formal social support services across 28 PACE sites were: older age, male gender, non-spouse caregivers, and those not receiving spouses' help with meals (Temkin-Greener et al.). Most care for disabled adults is unpaid (84%, *n= 7,116*), with informal (paid and unpaid) personal attendant services averaging 31.4 hours weekly and valued at $166 billion a year (LaPlante, Harrington, & Kang, 2002).

Qualitative studies, by contrast, did not find that the traditional dichotomies used in these studies regarding help with ADLs matched older women's descriptions of their experience of help/helpers. The conventional categories of formal/informal, paid/unpaid

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help, kin/nonkin, care receivers/care providers, care receivers/careproviders, dependence/independence did not capture the dynamic, reciprocal, and fluid relationships of older disabled women managing their everyday lives (Barker, 2002; Crist, 2005; Porter 2004, 2005).

Implications

Understanding contextual factors such as environment, culture, and everyday living patterns in this unique population could guide program and policy development to help to promote quality of life and healthy aging and reduce morbidity and mortality. Financing for more integrated and effective community-based delivery systems will be critical to meet the needs of this growing population (Knickman & Snell, 2002; Mollica, 2003). Systems will need to be culturally appropriate and responsive to be effective. A better understanding is needed about the everyday lives and values of this population in order to design and provide effective in-home prevention and support services.

For example, Stuck, Egger, Hammer, Minder, and Beck. (2002) recommended integrating chronic disease prevention programs into preventive home visitation programs in national and health maintenance programs. Their systematic review and meta-regression analysis of 18 controlled trials of preventive home visitation highlighted the critical role of comprehensive, multidimensional geriatric assessments and follow-up.

Understanding the culture of this group can help in developing proactive programs for younger persons as well as designing more effective long-term care alternatives. For example, better and innovative support services might include resilience-enhancing programs, volunteer caregiving networks, senior-friendly environments,

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neighborhood watch programs, social HMO's, personal care homes, senior volunteer programs, telephonic devices, assisted living facilities, and technological monitoring services. Elders need to co-design these systems and programs, if not directly, then through leaders who listen to what they want and need and with researchers who ask the questions which help guide system and policy development.

Summary

More women are living longer and living alone than previously. Understanding this subculture of elders can help us all become better prepared for this growing population. We must better prepare both our society and ourselves for healthier, longer lives. Theories of aging like gerotranscendence propose a developmental stage of transcendence for those added years, which could include transcending cultural norms and negative expectations of physical disability. Theories like the ETA propose functional and adaptive emphases for these late years, but omit the spiritual and transcendent function. Therefore, this study explored living longer as experienced in the everyday lives of the experts themselves—those 85 and older.

CHAPTER III

PROCEDURE FOR COLLECTION AND TREATMENT OF DATA

This exploration was an ethnographic study of the everyday life of women age 85 and older who live alone in their own home or apartments and receive assistance in one or more IADLs/ADLs. Ethnographic studies are conducted to explore phenomena within the context of culture in the natural setting. Spradley (1980) wrote that culture

> "refers to the *patterns* of behavior, artifacts, and knowledge that people have learned or created. Culture is an organization of things, the meaning given by people to objects, places, and activities. (p. 86)

Scholars studying this age group emphasize the multidimensional and dynamic nature of frailty, a term frequently used to describe those 85 and older. These researchers urge using methods appropriate to investigating a changing and contextual phenomenon. These methods include longitudinal studies, qualitative approaches, contextual and environmental assessments, and multidimensional and interdisciplinary approaches. Therefore, this interdisciplinary study applied ethnographic methods to the everyday life of these elderly women living alone within the home context over six months. This chapter discusses the setting, study sample, and human subject protection.

Setting

Respondents were selected from Houston, Texas. Houston is the fourth largest city in the United States with a population of 2,280,827 (U.S. Census, 2000). As a major

seaport rich in oil near the Gulf of Mexico, it is unique for its multiethnic diversity, international trade, the Texas Medical Center, and its petroleum industry (Houston, 2006). Its rapidly growing population is younger, more diverse in ethnicity, has more new immigrants, and has a higher per capita personal income than the national average. Compared to the nation's other largest metropolitan areas, Houston ranks fifth in Hispanic and tenth in Asian Pacific Islander population (Greater Houston Partnership, 2006). There is a dramatic generational difference in ethnic distributions, with 75% of those 60 and older being Anglo, which contrasts with about 75% of those 30 and younger being non-Anglo (Klineberg, 2005).

Houston's population comprises most of Harris County, which is the nation's third most populous county (Greater Houston Partnership, 2006). The county has a major regional Care for Elders (2004) initiative which includes planning, implementation, advocacy, and data (summarized below). County residents 65 years and older represent 7.4% of the county's population, with the majority being women (59%) and white (73%). Minority elders tend to be concentrated in certain zip codes; 1.7% of the county are African American seniors, 0.9% Hispanic, and 0.3% Asian. County residents 85 and older are 7.4% women; this population increased 52% in the last decade.

Household income of those 65 and older varies widely, with older householders having lower household incomes than younger counterparts, 12% with 1999 with income 100% below the federal poverty level, and poverty most prevalent in African American (24.2%) and disabled (16%) older adults.

Care for Elders (2004) also found that most of the county's vulnerable older adults rely on an informal network of family and friends for help (91%), even with approximately 3,000 programs for seniors. However, a significant percentage still said they had no one to call in an emergency (25% Hispanics and 15% of both white and African American respondents).

Those living alone in 1999 comprised 25% (64,063) of those 65 and older, with women living alone about 4 times more than men; one fifth of those living alone (20%) were living below the poverty level. Similar to the nation, elder care was primarily a family affair, but the pool of family caregivers was decreasing, and elders with the greatest need for help with ADLs were also least able to afford it. In 2002, most of Texas' Medicaid dollars went to nursing home care ($1.8 billion) rather than personal care ($318 million) or to home- and community-based waivers ($644 million; Care for Elders, 2004).

In 2000, almost half (43.5%) of those 65+ reported some type of disability; of those, one in three needed help with at least one ADL or IADL. Non-white vulnerable seniors reported more need for help with ADLs (33% African Americans, 22% Hispanic) than whites (14%) and also with IADLs (46% African Americans, 44% Hispanic). About one fourth of vulnerable elderly who needed help with at least one ADL (26%) and more than one third who needed help with at least one IADL reported not having enough help.

Care for Elders, therefore, targeted personal attendant services as a primary area for intervention. Area providers identified the need for cultural competency in providers as a priority need. This study therefore included women of different ethnicities and

personal care attendants as informants to contribute to the knowledge base regarding this subculture of vulnerable elders.

Sample

The study sample consisted of four elderly women, 85 years and older, living alone in their own homes or apartments who received help in one or more ADLs or physical IADLs. A purposive sample was selected from English-speaking, cognitively intact elders. They were referred to the primary investigator through community health colleagues who knew them well to ensure that the respondents were cognitively intact at the beginning of the study and they comprehended that the nurse investigator would not be providing nursing care.

In order to increase the likelihood of capturing the dynamic phenomenon of physical frailty, respondents were selected who met criteria of receiving assistance in one or more physical ADLs or IADLs. Persons who engaged in structured moderate exercise more than once a week were excluded because persons who exercised vigorously have been shown to be outliers in other studies.

The investigator recruited study participants until no new cultural themes emerged from the constant comparative analysis. Data saturation occurred with the fourth respondent.

Informants were kept in the study even when their living situation changed and included a temporary live-in caregiver or a change in living setting. This allowed the study to more fully describe the dynamic status of these women. Two of the respondents

did experience temporary live-in caregivers or temporary changes in residences during the six months of the study.

Protection of Human Subjects

The protocol for visits (Appendix A) approved by Texas Woman's University's Institutional Review Board was followed for all visits and visits made after IRB approval was obtained (Appendix B). Phone consent to make an initial home visit to describe the study was obtained. The informed consent process approved by the IRB was used on that first home visit and throughout the study. The process included a consent form for study participation. Caregiver(s) were asked to sign consent(s) for the ADL/IADL visit. If visitors arrived during a visit, the tape recorder was stopped and interviewing was continued after the visitor left or scheduled for the next visit

To ensure that participants had decisional capacity to give informed consent, only persons known to the nurse researcher or her colleagues as being cognitively intact were invited to participate. Only persons who could accurately verbalize the purpose of the visits and the role of the nurse were included in the study to make sure that participants comprehended that the nurse researcher would not be providing home nursing care.

In order to minimize a risk that persons might attempt to rely on the researcher(s) for healthcare instead of accessing appropriate care providers, the researcher emphasized that she would be functioning solely as a researcher and would refer study participants for needed healthcare and support services rather than provide the care.

Persons were assured that they could withdraw from the study at any time and could choose not to answer any questions, involve caregivers in the study, or be observed

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performing ADLs/IADLs during the study. The voluntary nature of consent for observation of ADLs/IADLs was reinforced by reassurance of continued inclusion in the study even if they chose not to be observed. This choice was respected, as evidenced by only 2 of the respondents agreeing to be observed by the occupational therapist and only one allowing her caregiver to participate.

The respondents were also assured that their participation and data would be confidential. When politically sensitive or highly confidential information was shared, such as identifying information related to political persecution or community leaders, the tape recorder was temporarily turned off to reassure the respondents and sometimes at their request. One respondent requested that taping be stopped after the fifth visit after her daughter had verbalized concern that the research might jeopardize her receiving provider services.

Instruments

Demographic information was collected on each participant (Appendix C). The 13-item Vulnerable Elders Survey (VES-13) (Appendix D) was completed in the initial interview (Saliba et al., 2001) to describe baseline physical frailty status. Ten to twelve semi-structured interviews (Appendix E) and participant observation periods were conducted during bi-monthly home visits around sequenced topics (Appendix F) to the participants over a six-month period. Three of the four of the respondents re-scheduled home visits or answered questions over the phone rather than allowing researcher home visits during periods of illness and convalescence.

Demographic Data

Basic demographic data were collected on all study participants. This included age, educational level, respondents' self-reported medical conditions, persons and agencies providing services, emergency contact number, and nearest relative and neighbor (Appendix C).

Vulnerable Elders Survey-13

The Vulnerable Elders Survey (VES-13) for identifying community-dwelling vulnerable older people who are at risk of functional decline or death was used to measure classic baseline characteristics of frailty in this sample (Appendix D). All persons 85 and older are automatically classified as vulnerable with this tool. This 13-item screening self-report survey was tested on 6,205 Medicare beneficiaries 65 years and older over a 2 year period (Saliba et al., 2001).

This five minute survey efficiently and accurately identified older people at risk of functional decline and death (Saliba et al., 2001). In this nationally representative sample, 32% had scores of >3 and were identified as vulnerable. Those thus identified as vulnerable had 4.2 times the risk of functional decline or death during the 2 year study as those with scores of <3.

Older adults are rated on age, self-reported health status, and difficulty with physical activities. A score of <3 in the study classified persons as vulnerable. Age of 85 and older is 3 points. Self-ratings of experiencing a lot of difficulty or inability to perform one or more of physical activities are given a score of 4 points. Self ratings of health of fair or poor are given a score of 1. Scores range from 0-10.

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The VES-13 physical abilities items ask about physical activities which had been found to predict functional decline: difficulty stooping, crouching or kneeling; lifting or carrying objects as heavy as 10 pounds, perceiving help walking across the room (use of cane or walker is not considered help); receiving help doing light housework (like washing dishes, straightening up, or light cleaning); receiving help with bathing or showering.

Although information on reliability was not reported, acceptability of validity was established the VES was found to compare satisfactorily to Medicare Current Beneficiary Survey (MCBS) in predicting negative outcomes of decline and death in Saliba, et al.'s large, epidemiological, longitudinal study (2001).

More recently, the VES has been used to predict functional decline and death in intervals shorter than 2 years and with higher scores of vulnerability (Min, Elliott, Wenger, & Saliba, 2006). Four hundred twenty community-dwelling older people from two managed care plans with baseline scores of 3 or more (moderate to high risk) were re-evaluated at a mean of 11 months.

Higher VES scores were significantly predictive of death and decline in both groups. The estimated combined risk of death and decline rose with each VES point, increasing from 23% in those with VES scores of 5-10 to 60% to those with scores of 10. In fact, each 1-point increase in VES-13 score increased odds of death by 1.18 (P = 0.008) and death by 1.50 (P < 0.001).

When death or decline was considered as a joint outcome, the odds of either negative outcome was multiplied by 1.25 for each 1-point increase in VES-13. When

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VES-13 score was controlled, neither gender nor comorbidity were significant predictors of death. Using the Cox proportional hazards model, the relative risk of death at any point in time was multiplied by 1.30 for each increase in VES score by 1 point.

Semi-Structured Interview Questions

The semi-structured questions and guiding probes were focused on sequential topic areas of the respondent's life story, usual day/unusual day, ADLs/IADLs, self concept, and meaning of living in own place, with approximately two visits devoted to each topic (Appendix F).

Validity and reliability are dependent on truthful and accurate disclosure and demonstration by study respondents and accurate observation and description by the co-researchers. Validity and reliability in qualitative research is generally referred to as trustworthiness.

Reliability

Reliability was strengthened by capturing the variability of functioning over time. It was expected and confirmed that biweekly interviews and observation within the home setting over 6 months would give accurate snapshots of everyday life in this population.

Emergent cultural themes on the ADL/IADL module were independently derived by the nurse and the occupational therapist researchers and compared by the co-investigators for the analysis. Discrepancies were discussed and categories representing investigator consensus were validated with the respondents.

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Validity

Validity refers to the credibility and accuracy of a description, explanation, and interpretation. To ensure valid findings, qualitative methods must build in ways to test their accuracy and to understand potential researcher influence on those findings (Maxwell, 1996). Tests of validity include checking for the researcher's bias or perspective and the effect of the researcher as participant observer. Checks on researcher accuracy include completeness of data, transcription of tapes, multiple researchers, trusting relationships with researchers, and respondent input on researcher interpretations. This study included all of these validity tests.

Completeness of data collected was facilitated by both written and audiotaped field notes and transcription of recorded field notes. Four interviewers conducted visits in order to facilitate observation and data collection from multiple perspectives. Researchers periodically presented their interpretations to respondents for feedback and correction during regular visits or phone calls.

The validity of the data is dependent on respondents truthfully and accurately describing and demonstrating their daily routines and ideas to the researcher(s). Participants were selected who had an intact cognitive status in order to improve the trustworthiness of respondent data. The sequence of visit topics was ordered in a manner which facilitated the natural development of a trusting, disclosing relationship. This involved exploring more intimate content and observation, such as help with ADL/IADLs, later in the visits.

Researchers of frail populations have consistently recommended the combined use of self-reports and observer ratings for accurate assessment of functional status and frailty characteristics (Markle-Reid, & Browne, 2003). Self-reports have consistently had the greatest predictive power of negative outcomes but would sometimes differ from provider ratings, be under-reported in depression, or vary due to changes in cognitive status (Ferrucci, Guralnik, Studenski, Fried, Cutler, & Walston, 2004).

Potentially fluctuating cognitive status throughout the day, during periods of illness, and over the length of the study might influence the validity of self-disclosed data. The investigator's years of experience with this population suggested that a trusting and disclosing relationship could be established over a period of 6 months even with persons who experience declining mental status. One of the respondents did exhibit a temporary mild decline in mental status during medication adjustments and a temporary stay in a convalescent center.

Input by care-providers and the investigator's biweekly informal assessment of cognitive status helped to identify the compounding variable of declining cognition. If cognitive status had deteriorated during the study period enough to impair validity of the data, additional respondents would have been added to the study as needed for data saturation. Data from this subset of visits during cognitive impairment would also have been treated separately if necessary. However, cognitive status remained intact during the course of the study for all four respondents, with only mild and temporary decline in one.

Participant observation by the research team helped to insure that discrepancies between self-reported data and actual performance could be identified. Respondents'

potential denial, cover-up, and lack of self-awareness of declining function and cognition were identified by the research team's routine assessments through close observation of the respondent and environment on visits.

The discrepancies between respondent report and researcher observations were significant data and were included in the field notes and noted in the data analysis. The discrepancies occurred in the area of physical limitations and environmental safety. These are described in the findings and the implications for interventions will be addressed in the discussion.

Trustworthiness

Trustworthiness, or reliability and validity, of qualitative data is dependent on both the individual and team observations and process. The overall research process was reviewed at each team meeting. This involved taking a cultural inventory of the emerging understanding and evaluating how the data from the latest visits contributed to that evolving picture.

Each research nurse summarized previous visits with her respondent and discussed the emerging understanding with that respondent to validate the researcher's individual and emergent team analyses and further refine them. These emerging themes and the summary analyses were validated with the study participants periodically during the study as well as on the final study visit to ensure that the research team was accurately representing and summarizing respondents' experiences.

The focused ethnographic interview and participant observation technique

developed by Spradley (1980) guided the both the observation and interview process for

data collection. Data collection and analysis were conducted by the research team, which

included: the primary investigator, a community health nurse with 30+ years of

gerontological experience; a research nurse with 35+ years of occupational health and

some home health experience; a registered nurse with faith community health and

gerontological nursing experience; and an occupational therapist for the ADL visits with

30+ years experience in home health, occupational health, and gerontology.

The data collection and analysis process were both on-going throughout the visits.

On-going analysis guided the participant observation and interviewing on subsequent

visits.

Data collection included interviews and transcripts of audiotaped field notes and

extensive field notes written by the inteviewers on all visits. Transcripts of narrated field

observations, detailed field notes, and interim analytic memos were continuously

reviewed and compared with each other by the research team using Spradley's (1980)

matrix and developmental research process.

Spradley's Grid of Categories

Spradley's (1980) ethnographic method was used for this investigation because

his methodology provides structure to understand the "meaning of actions and events to

the people we seek to understand" (p. 5). Spradley's grid of categories was used to

facilitate comprehensive data collection. This matrix crosses each category (space, object,

act, activity, event, time, actor, goal, and feeling) with itself and every other category to fully capture the multidimensional context of the focused topic. This method helped investigators to observe and describe the complexity of multifaceted and interactional components.

Visit Topics

Semi-structured interviews, participant observation periods, and phone calls were conducted two to four times a month over a five-month period. Two interdisciplinary observational periods were conducted between the nurse researcher and occupational therapist researcher for observation of the ADL/IADL session with the two respondents who consented to be observed. Four to six interview phone calls were provided during periods of illness, convalescence, or times very busy for the respondents.

Visits were focused around five general topics in the following sequence: two on life story and one each on usual day/unusual day, ADLs/IADLs, self description, and the meaning of aging in their own residences (Appendix E). These foci facilitated collaborative, systematic, and in-depth exploration with the respondents.

When possible, a semi-structured interview was used to guide the general direction of the dialogues. Attempts were made to also interview caregivers during one visit if caregivers were involved and both older persons and caregivers consented to their participation in the study. None of the women consented to observation with their caregivers, although one allowed interviewing her caregiver.

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Treatment of Data

The constant comparative and cultural thematic analysis of Spradley's (1980) focused ethnographic method were used for data collection as well as analysis. This section discusses the team process around treatment of data. The next chapter will describe the analytic process.

The research nurses all participated in all stages of Spradley's (1980) developmental research process throughout the course of data collection. These steps were: the participant observation, making ethnographic records, making descriptive and selective observations, analyzing the domains, making componential analyses, discovering cultural themes and taking the cultural inventory.

Team Process

Each research nurse was matched with a respondent of her same ethnicity: the African American research nurse with the African American respondent, the Hispanic nurse with the Cuban refugee, and the European American with the European American respondent. This facilitated rapport, disclosure, and mutual understanding.

The European American occupational therapist participated in two visits with the African American respondent and two visits with one of the European American respondent. The other two respondents chose not to have the occupational therapist visit them.

The research nurses met every other week for 2 to 4 hours to discuss their process and observations. Each research nurse took detailed field notes on observations and interviews. All three typed their own in-depth summaries and highlighted the key

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statements and themes after each visit. These detailed notes were read by all. They met as a team to process and analyze their visits within the same 2 week period. They tried to keep their interview schedules in line with each other as the respondents' stories of their lives unfolded. This facilitated focused discussion and systematic exploration.

The primary investigator listened to and took detailed notes on each tape, on the research nurses' typed notes, and the team's discussion on those notes. The primary investigator took notes on the team's analytic process and distributed them for team review. These team notes were then validated and further discussed by the research nurses.

The occupational therapist audiotaped and wrote her detailed field notes on the four ADL visits. She discussed her observations and analyses with each of the two research nurses who had conducted the home visit with her and also with the respondents on the second visit. She also discussed the observations and analysis with the primary investigator.

The primary investigator listened to and took notes on the audiotapes and validated the analysis with the occupational therapist and the research nurse. The occupational therapists notes were distributed to the research nurse team and discussed by the research nurses during the team meetings.

Conclusion

Spradley's focused participant interview and observation process was used for data collection. Data were collected using his matrix of elements to ensure a comprehensive approach. Semi-structured interviews were conducted according to topics

sequenced in a manner to facilitate rapport and disclosure. The research team met between visits to compare data and process. Data collection was a constant comparative process conducted along with data analysis. The on-going data analysis guided future data collection and was validated periodically with respondents.

CHAPTER IV

ANALYSIS OF DATA

Analytic Process

This chapter will describe the analytic process, the sample characteristics, and then the findings. Data analysis was a continuous and comparative process of identifying emerging themes in the transcripts and observational field notes which described the cultural context.

Ethnographies explore and describe the culture of a group of people. An ethnography describes the meaning, norms, and behaviors of people within the context of their environment and community. Ethnographic data analysis is conducted along with participant observation and interviewing.

The analytic process in this ethnography was continuous with data collection throughout this study and guided subsequent visits. Spradley's categories were used to identify the need for more data on subsequent visits. Emergent themes as well as the summary analysis were validated with respondents.

The analytic process followed Spradley's systematic analytic sequence. These steps began with the identification of key units. These were then grouped into significant domains using semantic analyses to identify the relationships between those units and key components. The overall cultural theme was identified and subsequently guided more focused inquiry.

Sample Characteristics

Demographics

The respondents were recruited through community health friends of the primary investigator. Four women ages 86-92 of African-American, Cuban-American, and European-American ethnicity agreed to participate. Two of the respondents lived in homes they had owned for 30+ years and two in subsidized senior housing apartments in different neighborhoods of the City of Houston.

All were widowed; two of these had divorced former husbands and remarried. All except one had been employed in younger years; all employment had been in domestic and childcare related work. Former occupations were: cook, grocery store, childcare worker, school bus driver, and kindergarten teacher. Two of these ad gone back to work for a few years after retiring—one as a childcare worker and the other as a school bus driver.

Physical Limitations and Help

The VES-13 scale was used to measure the degree of vulnerability as measured by age, physical limitations, need for help, and self-ratings of health. The VES-13 has 0-10 points, with an automatic 3 points for age 85 or older, a score of 10 for the greatest vulnerability and highest need for assistance.

The VES-13 scores of these respondents ranged from 5-10; the highest possible score was 10 and lowest possible score was 3. The youngest woman, the 86-year-old European American, had the lowest score (5). The 90-year-old African American woman

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had the highest score (10) and was the only one who rated her health as less than good (fair).

All four respondents had physical limitations that affected their mobility and required mobility devices. One also had upper extremity limitations. Two of the four respondents had surgery during the course of the study. One was 5 weeks post-op after gall bladder removal at the start of the study. All experienced an increase in physical limitations post-operatively.

All four of the women had extensive family networks. Only two of them felt they had family members they could actually rely on for help. Of these, the 91-year-old had a granddaughter who lived nearby as well as an elderly daughter who lived out-of-state who came and stayed if needed. The 86-year-old had a daughter with serious chronic health problems who was caring for a husband with early Alzheimer's; the daughter lived nearby and visited often. The day the respondent's phone stopped working, her daughter purchased and installed another one.

Of the two who did not feel they had someone they could count on, the 92-year-old respondent's only son had died three years prior. She had an unemployed grandson who visited once a week and tried to help. After her fractured ankle and subsequent surgery, her grandson took on more responsibilities but relied very heavily on neighbors to help her with personal cares and everyday needs.

The 90-year-old's helpful niece had died during the study. Although this respondent had not felt her children or other relatives were dependable, she was able to stay with her granddaughter after her colonoscopy. The week after she returned home,

her daughter, granddaughter, and 4 great grandchildren stayed with her for 4 days. She was grateful to regain her privacy when they left.

The 92-year-old respondent who had not worked and did not receive Medicaid paid both a companion and housekeeper out of her meager savings to each come one day a week to help clean and shop for her. The other three respondents had providers through Medicare, Medicaid, or a government program. Mrs. Fernandez said, "When you are old, you need to have some money. If you have some money, you can pay somebody [for care]."

The three women all had 3 hour/day providers on weekdays. One of these lost her post-operative weekday morning provider 5 weeks into the study. She subsequently experienced increasing challenges for the duration of the study. She struggled to keep up with her own housekeeping and health problems while dealing with family stressors to her main helping daughter. The respondent frequently said that she really needed a provider one day a week and could not understand why "my provider was taken away."

The other two participants had 3 hour/day providers as well as Meals on Wheels on weekdays. The respondent with the highest possible VES score of 10 and the only one who rated her health below good (fair) received home physical therapy and home physician visits even while she was medically stable.

The respondent with the most limited community mobility explained why she did not go places outside the apartment building when she was invited, even when people offered to bring her. She said she did not like for people to see her as frail and needing assistance. She also said she never walked outside her apartment without someone with

her. Having a provider made it possible for her to live alone and not "bother" her children.

Findings

Although these older women had distinct ethnic, socioeconomic, geographic and individual differences, they clearly shared a unifying culture around their everyday life while living alone in their own residences. That unifying culture can be summarized in the overall cultural theme which emerged from the ethnographic process.

The shared cultural theme that emerged from this ethnography was "Managing the business of daily living." The core values that shaped how these women managed their daily lives were values around family, God, friends, community, living in their own place, maintaining autonomy, caring for self, and caring for others.

All four of these women can be described as "living long and living well." They often verbalized gratitude and pride at having lived a "good life" despite times of suffering and loss. These women all had full lives and full schedules.

They actively maintained connections with family, friends, and neighbors as well as formal support systems and people. All of them participated in community life and were both social and sociable. They had faith in God, contributed to their communities, and wanted to leave a legacy.

Overall Cultural Theme

The cultural theme that best describes how these women lived their everyday life is "managing the business of daily living." This phrase describes both the position these women took and the dynamic of organizing their complex network of support to take care

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of the responsibilities of their everyday life. Their complex network of support included formal and informal individuals and systems. They saw their responsibilities as: caring for self, others, their dwellings, and their communities. Daily life included activities of daily living, usual days, unusual days, and periods of illness and convalescence.

The key domains of the overall cultural theme are "managing the business of" and "daily living." "Daily living" included significant components. These were: managing daily activities (routines, activities, schedules, special events, health challenges) , managing environment (control center, mobility aids, adaptive devices, and environmental modifications); managing health and illness, staying connected (relationships, phone calls, playing games, and social activities); managing vulnerability (burden, driving, falls, surgery, burns, and fire); managing change and the unexpected, and spirituality and transcendence (faith, God, church, community, legacy).

Some of these domains overlapped each other because components served multiple functions. For example, attending church served as a means of staying connected as well as expressing faith for one woman. Driving served as a means of purchasing needed items as well as a social outing for one. The selection and presentation of these significant domains below reflects the commonly shared experiences.

"Managing the Business Of"

The term "managing the business of" summarizes the leadership used to organize and meet multiple responsibilities of caring for themselves, maintaining a household, tending to important relationships, and preserving autonomy within the reality of physical vulnerability.

The term "daily living" includes two important components—"daily" and "living." "Daily" captures the living in today rather than the past or the future as well as being settled into or settling into ordinary and routine days. The word "living" evokes how these women choose to be—active and alive rather than passively allowing time to simply pass.

"Managing" is the word that best described the everyday reality for these women. Even when these women reclined for hours in their chairs, they were "managing." In those chairs, they were managing their schedules and health through numerous activities like: "resting," planning their activities, coordinating multiple support personnel schedules, skills, and service exchanges, "taking care of business" like paying bills, balancing out their emotions, selecting memories and thoughts to reflect on, maintaining relationships over the phone, watching television or the neighborhood, and praying to God.

The word "business" indicates the work involved in managing daily living. The intricate interconnections between necessary self-care tasks like bathing with other tasks like navigating in the environment, monitoring risks, and managing emotions require careful coordination with other scheduled activities and people. Tasks which supported self-care like shopping required very careful planning, focused effort, and "taking my time" to accomplish the many mini-steps in the process.

Managing help around activities was carefully planned and requests were budgeted. Some tasks were delegated with reluctance when the women could no longer manage them independently; others were delegated readily when help was available. God

and friends were identified as helping all of them manage their daily living; family and formal or informal providers were identified by most.

When these women suffered the loss of a person in their life, they worked at managing their emotions and memories around that loss as well as the loss of support. When they experienced the loss of a formal or informal provider, they "manage[d]" as "best [they] can" until they established a new usual day with a new routine.

They managed their self-expectations and adjusted priorities to match new realities in the face of changing resources and abilities. For example, they no longer expected to keep the rug vacuumed when it became hard. Instead, they tolerated crumbs and dustballs rather than vacuuming. This saved time and energy to visit with other people.

The women saw "business" as the responsibility of caring for self, others, and dwelling. The word "business" came up in phrases like "It's *my* business" and "taking care of business." "Business" for these women is associated with autonomy and privacy, like "my right" and "my business," as well as meeting their responsibilities, like "paying the bills" and "not running out of money." Congruent with the business of taking responsibility for selfcare, the women valued autonomy more than independence.

Taking care of themselves and taking care of their families were responsibilities they took seriously. Taking care of themselves involved doing all they could for ADLs/IADLs, exchanging services with friends and family when needing help, advocating for their needs with the healthcare system, seeking advice and information when needed, keeping up with medical appointments and recommendations, balancing

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needs for rest with required and discretionary activities, and managing networks of friends and support.

Taking care of their families included activities like remembering birthdays and special events with gifts, cards, and calls; giving counsel and support; lending and giving money; giving furniture and acquired belongings; avoiding behaviors not approved by them or worrisome to them; arranging their activities to participate in family gatherings in person or to receive the family visitors with hospitality and food; not burdening them with requests that friends or paid providers could take care of or requests that could wait; and withholding information that might worry them.

The word "business" should not be understood within the context of the marketplace type of business, but rather as responsibility. These women see self-care and caring for their homes as their responsibility. A particular task might be temporarily or permanently delegated or may require help, such as housekeeping and bathing, but the women still manage the tasks by coordinating the requests and timing with other activities. The women often see such help as similar to a business exchange ("She needs the money and I need the help;" "I cook for her and she shops for me.")

The term "business" is like "responsibility" for these women. Self-care is serious business to these women. Self-care includes attending to ADLs like bathing and eating, maintaining their health, balancing activity and rest, meeting their obligations, and scheduling activities to leave room for meaningful social activities. The women often combine their need for help with taking care of the person who is helping them. For example, they make shopping requests which fit with the shopper's schedule, the

shopper's ability to carry things, the shopper's own shopping, and the shoppers need for extra cash.

Like businesses, these women's schedules showed regular hours, with times open and closed to visitors and phone calls. Their homes also showed a fair amount of people traffic in an out. When possible, the women tried to schedule various support people so that they were not alone at times they felt unusually vulnerable, such as taking a shower. Their schedules were fairly full with usual daily routines, scheduled activities, provider visits, rest periods, appointments, and special events and maintenance tasks.

The women worked hard to maintain the building they live in and the equipment they need—complying with apartment requests for inspections, supervising or doing the cleaning themselves, seeing to trash disposal, and locating and coordinating people and systems to do repairs and routine maintenance. They controlled placement of furniture and necessary items to maximize convenience, comfort, and safety for themselves, family, and visitors.

"Daily Living"

Daily living included components of daily activities, managing the environment, managing health and illness, staying connected, managing vulnerability, managing change and the unexpected, spirituality and transcendence. These domains will be described in further detail.

Daily activities: Routines, activities, schedules, providers, appointments, events.

Daily activities included components consistent with the semi-structured, scheduled visits. They described ADLs/IADLs within the context of their routines and

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schedules and in ways they spent their usual and unusual days. Other categories also emerged as significant components of their everyday life. These emergent categories were: routines, schedules, providers, appointments, health challenges, and events.

Daily activities were carefully planned and followed routines when possible. Usual and unusual days framed activities in their everyday lives. Usual days were characterized by full schedules. These schedules did not necessarily include regular sleep and waking times, but usually included waking and sleeping rituals and naptimes, often in their recliners. Personal care routines were highly structured and carefully planned to "make it through" the shower or bath safely.

When possible, high risk activities were performed when someone else was within calling distance, such as when the provider was in the next room or available to do the task or to accompany the respondent. Activities like shopping and cleaning were delegated to providers, friends, or family when deemed too difficult and not too burdensome.

Doing laundry was challenging and very carefully planned and or delegated to a provider by all four women. Maintaining balance posed safety challenges while carrying clothes, reaching hangers, opening doors, and lifting clothes in and out of machines. Food preparation and meals were enjoyed by only two of the four. These two planned and structured social activities around feeding themselves and others. Ironically, these two women also received Meals on Wheels.

Unusual days were days characterized by the unexpected, health event, and special events. The unexpected included unplanned visits or phone calls, changes in

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health or energy, family crises or surprises, and environmental challenges such as equipment breakdown. Special events were usually planned and spent with family, friends, church, or apartment members. Outings were usually to special events, most often with family and church or to the doctor, lab, or diagnostic facility. Outings for all women decreased as their energy and overall health diminished.

Unusual days with health challenges included short "not so good" days due to allergies or arthritis, episodes with cold and flu, planned diagnostic preps and follow-up, labwork, falls, surgery, and convalescence. On these days, the health challenge raised concerns about an uncertain future and worries about being able to care for themselves. All four women worked hard to maintain a positive but realistic attitude about their ability to care for themselves. The focus, then, was on self-care rather than the actual health or medical challenge.

All of these women had full schedules, days structured by regularly scheduled provider/other visits, apartment or community activities, and fairly regular personal routines. Their usual days were carefully planned to meet needs for rest and activity, balancing their energy, and taking care of themselves and their responsibilities.

All had discretionary time of various amounts depending on their current health status. This discretionary time was sometimes experienced as empty time for which they had to find "something to do" as well as scheduled activities like watching TV game shows or participating in apartment or other community events. Using the phone was the discretionary activity used most often and by all of the respondents.

Visitors included in-person and phone visits, most of them in their residences. One of the women had regular but scheduled visitors. The other three also had regular "drop-in" visitors of families, neighbors, and friends. All four of the respondents had people they called or who called them at least once a day "to visit."

Managing environment: Control center, mobility aids, devices, and modifications. Like staying connected, managing their environment was critical to their everyday life. However, all of them suffered from unnecessary fear, fatigue, and risk due to inadequately managed environmental challenges. These undue challenges were caused by the gap between needed and available devices and services. This gap reflected many factors. Contributing factors included: system failures, policy gaps, fluctuating functional status, maintenance problems, lack of awareness, and respondent decisions.

System failures and policy gaps reflected dominance of the biomedical model, which focused on coverage for medical treatments rather than supportive aids and services. Fluctuating functional status introduced intermittent and new challenges, only some of which were predictable. Lack of awareness in both the providers and respondents resulted in less than optimal safety and energy. Less than optimal respondent decisions reflected multidimensional factors.

Significant environmental components included the: control center, mobility aids, adaptive devices, and environmental modifications. All of the respondents had a control center surrounding a recliner chair where they spent most of their waking time. Without exception, the most important objects in their waking environment were their recliners, phones, and mobility aids.

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All respondents had to regularly use adaptive devices, mobility aids, and environmental modifications to compensate for physical and energy limitations. They were all creative in how they managed everyday tasks, energy, and their mobility. However, all of them still needed more devices, teaching, equipment, and modifications for safer functioning in managing their environment and daily activities.

All four women used a combination of adaptive devices, mobility aids, and environmental modifications to manage their physical limitations. Mobility devices included: a motorized chair, various kinds of walkers, and canes. Two of them faced safety difficulties with those mobility devices during the study, such as a malfunctioning lock on the rolling walker and improper tips on another rolling walker.

One of them received physical therapy during the study, and one who needed it had refused it. The one who was receiving physical therapy did not have a necessary elevated toilet seat or handheld shower because they were not covered by Medicaid or Medicare. The one who refused physical therapy had received an elevated toilet seat and physical therapy after a prior surgery. She said she had subsequently fallen because the elevated toilet seat had not fit properly and could not get up from the floor even though she had received therapy.

Use of adaptive devices varied, with a range of skill and comfort level. Two of the women needed teaching and practice on devices they had but did not use, such as a reacher and sock puller. All of them adapted available objects to meet special needs, like hanging an oven mitt from the motorized chair for the portable phone and using a rolling

kitchen cart with pots, plates, and silverware to serve as both a walker and serving tray in a narrow kitchen.

The key environmental modifications were those around the control center for all of the women. Each control center had a recliner chair facing a window to see the neighborhood, a drinking glass, and a portable phone, writing materials, address book, and letters.

The women varied in their adaptations to accommodate limited reach and balance. The apartments had built-in lazy susans in the cabinets. The homeowners needed help re-organizing items in cabinets and refrigerators to keep them within safe reach. One of the homeowners needed a handheld shower. Both homeowners needed bathtub non-skid strips. One homeowner needed grab bars but had no one to install them.

The two homeowners needed ramps; one of those two had a ramp which did not have adequate access or railings and the other had a ramp at the front door but needed one off the kitchen back door for emergency exit. No systems were in place at the start of the study to install a ramp for the respondent who badly needed one. By the end of the study, a new partnership had been established to build ramps for persons who were disabled or elderly and could not afford them.

Environmental modifications included those built into the senior apartments, such as emergency call lights and grab bars, and others not provided but critically needed for safety. One woman who lived in the senior apartment complex reported falling from the toilet on an improperly seated elevated toilet seat prior to the study. One who lived in her

home and received home visits from both a physical therapist and a physician did not have an elevated toilet seat which she needed and requested for safe toileting.

Other adaptive aids and equipment they needed but did not have included: an ironing pad, fitted shoes, an emergency call bracelet/necklace, a smoke detector battery, a lifter recliner chair, a mail drop box, and portable talking phones. Use of existing aids was less than optimal due to lack of awareness, education, maintenance, and practice. These included the smoke detector, the sock aid, the reacher, the location and locking of the rolling walker, and the placement of kitchen items within reach.

Although all exhibited safety needs and would have benefited from the occupational therapist's participant observation, only two agreed. The two who agreed to the occupational therapist visit verbalized much gratitude for the corrective demonstrations on safety which the occupational therapist provided afterward. One did not have energy for a new assessment because she was recovering from surgery. The other refused because she did not want to "worry" her daughter, who was anxious about the research compromising her eligibility for a provider.

Managing health and illness. Like the environment, managing their health was seen as serious business. This included an array of activities which required decisions and daily actions. None of the women abdicated self-responsibility for health to the physician or their families. All advocated for self and appropriately refused or delayed some recommended procedures to minimize their risks.

Refusals reflected rational responses to routine orders which were not appropriate for their advanced age, did not provide adequate in-home support, or did not fit with their

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personal goals. All of them experienced system failures and unsafe orders which required self-advocacy.

Managing health and illness took much time and effort on a daily basis. This included balancing activity and rest, staying active, making and keeping doctor's appointments, keeping up with lab tests and diagnostic procedures, evaluating their care, selecting and changing physicians, scheduling office visits and procedures when they could get necessary help if needed, speaking up for themselves, asking or allowing family to speak up for them, taking and monitoring medication, managing dietary intake, exercising, applying first aid, calling the doctor, asking questions, using home remedies, monitoring their healing and recovery, picking up their own X-rays, and purchasing and using over-the-counter medications.

Three of the four verbalized much frustration with the health and social systems. Areas of dissatisfaction for more than one respondent included: the inequity of provider services ("Why should she get a provider five days a week when she doesn't even need a cane to get around and I don't get one at all?"), governmental insensitivity to the needs of seniors ("The government does not pay attention to the seniors"), inadequate medical care ("I don't know why he missed that problem all those years"), inadequate staffing ("I was crying and I received no help"), inappropriate procedures ("Why should I have surgery when all I need is a Life Alert necklace?"), inadequate government assistance for seniors ("Government assistance for seniors is not right"), need to advocate for self ("You learn not to put up with it"), inattention in nursing homes ("They do not attend them. They ring and ring for help and nobody comes. They don't come.").

uncompassionate care ("You have to watch out for yourself here"), for-profit emphasis of the healthcare system ("it is money, money, money. If you don't have the money they say, 'No we cannot help you.'"), dissatisfaction with hospitalization ("I told my doctor don't ever leave me in that place again"), and lack of access to their own medical information ("I went and got those X-rays so I could see for myself and they did not even charge me like that doctor said they would).

One of the respondents said, "You have to be a strong willed woman [to live long]". That statement puts a different perspective on conventional words like "non-compliance." These women saw advocating for self in the healthcare system as an important factor in living long. As one woman said, "You have to stand up for yourself" to get needs met. Rather than resisting and criticizing such self-agency in these determined women, providers should perhaps honor its value and strength.

Perhaps "non-compliance" in this population serves a valuable self-protective function. For example, Mrs. Bell's physicians had ordered a colonoscopy "because she said I'd never had one" and did not alert Mrs. Bell to potentially serious effects of diarrhea and the need to have someone stay with her. Because of the safety considerations, the research nurse counseled Mrs. Bell to have her granddaughter spend the night for the prep. Mrs. Bell did not know enough about what to expect to know how to reduce her risks.

The procedure was so depleting that Mrs. Bell needed to stay with her granddaughter for over a week to recover. The purpose of the colonoscopy was unclear since Mrs. Bell said she had told her doctor, "I'm not going to do anything at my age if

they find cancer" The special needs and preferences of this population need special consideration. Their refusals of standard orders may be in their best interests.

Staying connected: Relationships, phone calls, playing games, and social activities. Staying connected was vitally important to all of these women. Staying connected required managing relationships, phone calls, and social activities. Maintaining social connections facilitated a network of support, on-going mutual exchange of services, meaningful daily structure, cognitive and social stimulation and monitoring, sense of identity, and making social contributions.

Key relationships for all of the women were family, God, friends, neighbors (in the building or in the surrounding neighborhood), and self. For most, relationships with church, providers, public support staff (postal persons or apartment staff), and healthcare providers were also significant.

Neighbors and friends were very important. They provided monitoring and extra unpaid services on almost a daily basis for all and several times daily for others. Living in the apartment buildings was much like living in a dorm with full executive suites for each resident. Residents had routines of gathering informally for games in the lobby or socially at the end of the day by the elevator.

All of the women regularly used phone calls to stay connected. They called old and new friends, family, providers, and vendors. Phone calls became lifelines when their community mobility became restricted. They carried portable phones from room to room and even outdoors. Most made and/or received regular, scheduled phone calls from family or friends.

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A good example of an activity which helped the apartment-dwelling women stay connected was playing games. Although usually considered a social activity, playing games served multiple functions. Playing games was experienced by the women as caring for self and others as well as staying connected. It facilitated a mutual exchange of services, meaningful daily structure, cognitive and social stimulation, monitoring of self and others, a sense of identity and helping others.

Mrs. Fernandez called the bingo numbers in Spanish. This gave her an opportunity to contribute, a specific role in the apartment building, and the opportunity to use her needed expertise. Mrs. Aye shopped for new games and adaptive equipment like card holders and shufflers not only for her apartment building, but also for her daughter's apartment building.

The scheduled game times helped to provide structure to their days. The available game table in the lobby gave a place and activity for spontaneous socialization, visitors, and diversion. For example, Mrs. Aye occupied her friend's great grandson by playing table games with him when her friend fell and needed medical attention.

They both said that playing games "helps keep me going" and "keeps my mind active." The game tables were important places to "keep up with everybody." When a regular player did not arrive, someone would call to check on that person. The game times were used as a way to help each other keep mentally and socially fit and to communicate acceptable and unacceptable social behaviors as well as to monitor one's own behavior and other's.

Managing vulnerability: Burden, driving, falls, surgery, burns, and fire.
Managing vulnerability was an integral part of these women's lives. In their daily lives, they experienced vulnerability to many risks. They lived with daily awareness of that vulnerability. Daily risks included: being a burden, driving accidents, falls, surgery, burns, and fire. How they lived with this vulnerability reflected their lifelong values.

These women can be described as courageous women who took risks to live according to their most important values. Therefore, managing their risks of car accidents, break-ins, surgery, being a burden, and falls needs to understand within the context of the high value they place on autonomy, privacy, "being who I am," and caring for self and others.

Although all of them took care to manage their vulnerability, all of them could have improved their safety in areas of their everyday life if safety had been their highest value. Throughout their lives, however, personal safety had been secondary to other values or for the purpose of higher values—a means to an end rather than the end goal.

For example, the two who said family was most important to them had made decisions to leave their husbands in order to protect their children from living in situations not congruent with their values. Mrs. Aye divorced her first husband because a home where the man "drinks and womanizes is no kind of home to raise children in." Mrs. Fernandez took her children out of a Communist country hoping her husband could join her later because she did not want the Communist government to take her children and did not want to raise her children in a Communist regime.

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Reducing burden and worry on family and friends was an important part of managing their vulnerability because it served their values of caring for self as well as caring for others and maintained their sense of identity. Reducing burden and worry served to preserve critical social networks and as well as roles in relationships.

For example, Mrs. Aye gave her car to her oldest daughter, "who needed it more than I did," to appease her youngest daughter's "worry about driving at my age even though I've only had two tickets in my life." She preserved her autonomy and sense of identity by driving herself and her friends around in her friend's car instead. As she said about her daughter's preferences regarding various activities, which included driving, "I have to pay attention to them [daughters]. I depend on them." However, Mrs. Aye found creative ways to still maintain her sense of self. She, who had become a school bus driver after she had retired, became the apartment building chauffeur for friends who needed rides.

Driving is seen by society as one of the greatest risks in this population. However, three of the four women were driving at the start of the study. The one who had stopped driving years ago stopped after an accident in the rain. Of the three drivers, one drove a friend's car and two drove their own. One of those three was unable to drive near the close of the study due to an ankle fracture.

Mrs. Aye, the youngest of the respondents, took much pride in chauffeuring her friends in the friend's car, saying, "We take care of each other. We're all good friends here [in the apartment building]." Another of the three was careful never to drive alone. Only the youngest driver drove unfamiliar places or distances outside of the immediate

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neighborhood. This respondent took pride in "knowing how to get places" and driving safely. Knowing how to get places was seen as managing risks related to driving.

Make of car and choice of driver were other factors important to managing risks related to driving. When Mrs. Aye's friend bought a car to replace the car she also had given to her daughter, her friend bought one of the same make and model as before and the same make and model as Mrs. Aye's former car. Mrs. Aye said she would not ride in her friend's car when her friend was driving because her friend's driving "scares me." Instead, Mrs. Aye would drive when they rode together in her friend's car. Mrs. Aye would drive her friend to her friend's appointments and they would go on outings together to shop and eat. Mrs. Aye also had a set of keys to her friend's car so she could use the car for her own errands.

Managing risk of falls and fear of falls was an underlying reality for all of the women. They all knew that a fall could end their preferred lifestyle. Managing the fear and very real vulnerability was critical to their daily life. However, managing the risk and fear was complicated. Managing risks and fear required a delicate weighing of values regarding privacy, connectedness, caring for self, reducing burden, and staying safe. Falls of themselves, neighbors, or friends were followed by in-depth reflection and re-evaluation of risks and benefits.

Two of the women had falls during the course of the study, one of them requiring surgery and temporary institutionalization. That respondent, Mrs. Smith, had purchased a rising recliner chair during the course of the study to facilitate her in-home mobility and reduce her risk of falls. Her fall occurred due to a spontaneous fracture of her

osteoporotic ankle while she was simply standing in her kitchen. That fall was followed by surgery, a temporary stay in a convalescent center, and need for daily help with ADLs when she returned home.

Mrs. Smith's delicate balancing act was not successful in preventing this fall. She was clear that even though she had been realistic and proactive about exercising to maintain her strength and balance and modifying her environment and activities to accommodate diminishing strength, that she was "getting older" and there were "just things you have no control over. You just have to trust God. There is a reason for everything."

The other respondent who had a fall during the study, Mrs. Aye, described having six falls in her seven years of living in the senior apartment complex. She managed her apartment mobility out of a motorized chair and rolling walker and her community mobility out of a car, rolling walker, and motorized store carts. She managed falls by virtually living out of her motorized chair in the apartment and even riding it to the other apartment buildings. She managed her fear of falls by describing herself as being able to "do everything with my chair."

Mrs. Aye had structured her activities and expectations around what she could or could not do out of her motorized chair, her car, store motorized carts, and 10 foot walks with a folding, rolling walker. Her big fear was of falling. The fall on her daughter's lawn during the study was followed the next week with a burn on her hand while cooking from her motorized chair. She worked hard to shore up her self-confidence and mood after these events. She managed these risks with the decision to be more careful.

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Mrs. Aye had structured apartment and community mobility around her fear of falls and her desire to stay comfortable and safe in her chair. She minimized her risk for falls by "doing everything in my chair." This gave her a false sense of safety and strength but managed her fear. Her dynamic balance, both standing and sitting, were not adequate. She chose not to address her precarious balance getting to a standing position or reaching for things from her chair. She did everything possible from her motorized or recliner chair and walked only to get to her chair or the walker. She had refused physical therapy, saying, "I don't need it" and expressed concern that the therapist would push her too hard.

For Mrs. Fernandez, managing fear of falls was also important, but especially around falling alone. She weighed this fear against burdening others, modesty, and a fear of surgery. She was very afraid of falls, especially at night when there was no one to call for help, so she minimized walking at night. She never walked outside of the apartment alone. She chose to bath herself without help because she highly valued modesty. However, she always bathed herself while the provider was within calling distance.

She said her physician had told her she would have to have surgery for kidney stones to make sure she did not have an attack when no one was around. She refused, saying she did not want to undergo general anesthesia for preventive surgery when what she needed was a life alert necklace. She felt the risk of surgery was greater than the risk of an unattended fall due to a kidney stone attack.

Mrs. Fernandez had found out that she was just over the eligibility for a life alert necklace and did not feel right burdening her children with money to pay for one. She

said, "It is not right that my husband and I worked hard, paid taxes, and now I am not able to get government's help." She subsequently had an attack which required surgery and her daughter's live-in care toward the end of the study.

Managing past, present, and future surgery was critical for these women. Surgery posed serious risks. Surgery caused physical limitations, required caregivers, changed how they lived their lives, and affected decisions for their future.

Two of the respondents had surgery during the five months of the study. One other woman was 4 weeks post-gall bladder removal at the start of the study. Past surgeries accounted for mobility limitations in two of the women. Mrs. Aye had been in a motorized chair since surgical removal of a cyst in her leg seven years ago. Mrs. Bell had quit working at the daycare during her retirement years when she fell and broke her ankle.

During the study, Mrs. Fernandez decided after day surgery for her kidney stones that she would not undergo another surgery even though she still had stones which the surgeon said needed another treatment. Her daughter had to stay with her to care for her for two weeks. Mrs. Fernandez said her doctor "wanted to put me in surgery on Thursday, but I said, 'No, no. I will not have this surgery until my daughter can be here to stay with me.'"

Mrs. Smith did not have anyone who could stay with her after her surgery for repair of fractured ankle, so she required a temporary stay in the convalescent center. She described her post-operative experience in a way which summarizes all four women's responses to health challenges:

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You can't imagine what it is like to have to learn to walk again.... This is the hardest thing I have ever done.... You never know how it is going to turn out. Of course I am not going to get all better, but this time I came out of it all right and I am going to be able to cope with it. Next time you never know, but this time I am going to be able to go home and I am going to be able to manage.

Managing risks due to burns and fire was a theme in the study although one not addressed by any of the respondents until accidents occurred. This was a risk area identified by the research nurses but did not seem of much import to the respondents. Even after the burn and fire accidents, the respondents seemed less concerned than the research nurses.

Two of the respondents had burns during the course of the study. These occurred during ironing and cooking. One of these was due to a hot iron left face down on an ironing board during the ADL demonstration. Mrs. Smith did not smell the burning fabric from the next room and the smoke detector did not go off because the battery had been removed by her male neighbor when it had gone off a couple months earlier. Both senior apartments had regular fire drills and one had evacuation during the night during the study.

Mrs. Aye burned her hand while cooking from her motorized chair in the kitchen. She briefly described putting ice on it and her plans to purchase burn cream to treat it when asked, but her concern was having to miss playing cards because it had to be covered and did not look good. She also had an old iron burn on her rug under the ironing

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board. She proudly described how she had shopped for and found a lighter, economical iron to replace the iron which had fallen.

Managing change: Unexpected, planned change, and living arrangements. Managing change, either unexpected or planned, posed significant challenges with limited physical abilities and energy. No change was small when connected to many other carefully balanced factors.

Most changes required dozens of steps as well as different systems and other people to accomplish them. To manage more momentous changes, like when they could no longer manage living alone during illness and convalescence, they had to manage their daily living amidst the change in setting, culture, relationships, and privacy.

When the unexpected happened, these women had to manage the change in carefully balanced plans and routines. These had usually been carefully designed and developed over time to maximize energy and to compensate for variable or diminished ability. The most common tasks involved in managing change were: making and answering phone calls, changing waking or nap times, re-scheduling other activities, contacting other people, revising the menu, asking for help, and moving things.

Not surprisingly, change in living situation was the biggest change for these women. Three of the four women experienced temporary changes in setting or living arrangement after a surgical or diagnostic procedure. These changes were: hospitalization and convalescent center stay, living with a granddaughter at her house, and having a daughter stay with her for help with personal cares and 24-hour monitoring.

In all three cases, these changes in living arrangements actively opened discussions with family members about future plans and internal decisions about how they wanted to spend their "remaining" time. All four voiced the desire "not to linger" and "not to be a burden." None of the four wanted to live with family if they needed 24 hour care. As one of them said, "Then I can't do what I want when I want." Preserving personal routine, autonomy, and privacy was most important.

Managing even desired and planned changes involved much work. For example, an important and often recommended environmental modification became a major, extended activity—changing the recliner. The recliner chair was a key environmental feature for all of these women. Its height, location, angle, ease, and size greatly influenced comfort, safety, and mobility.

Mrs. Smith's chair was too low, wobbly, and unsafe. She wanted and needed a new one. However, getting a better recliner chair required obtaining and coordinating help from many different people and systems. Each stage of the process involved 10 or more big steps, each of which included several mini-steps. The stages included: selection of, delivery of, adjusting to, and paying for the chair.

Key steps involved in selecting the chair were: obtaining a prescription from a physician so the chair is covered by Medicare and can be afforded; submitting the prescription to a medical supply company; talking the company into waiving remaining charges; grieving the loss of a chair steeped in years of memories; and selecting the size, shape, color, and type of recliner by catalogue or delegating that decision.

Next she had to manage the activities around delivery of the chair. These included: coordinating the delivery with a helper to move out the old one; being able to answer the door or making arrangements to leave the door open for the delivery person(s); arranging for satisfactory disposal or gifting of the old one; vacuuming the rug while the space is empty; rearranging the table/control center to match height and reach from the new chair.

Then Mrs. Smith had to manage activities around adjusting to the chair: select appropriate pillows for the new fit; learn and remember how to recline the chair; get used to the look and feel of the new chair; learn how to manage balance and gait when rising from and sitting in the chair; figure out placement of the walker by the chair; and coordinate room features like decorations, colors, furniture placement, and mobility devices with the new chair.

Each of these stages related to changing the recliner chair was again a series of more mini-steps, like dealing with billing for the recliner. These activities describe for the recliner billing related to most medical bills as well. Although all of the women took pride in "paying my bills myself" and carefully guarded that "right", most of them required help with the confusing flood of medical bills following a health event.

Bill-related steps to only one health-related activity, Mrs. Smith's recliner, included: following up with the physician's office for submission of the completed paperwork, receiving the bill in the mail after sorting the mail, checking the bill, noting that the bill was incorrect, calling to have the bill corrected, writing the check, addressing

the envelope, applying the stamp, and watching for the postal person to give the envelope to him to mail it for her.

Managing unexpected health events predictably created challenges in managing paying bills. After Mrs. Smith's fall and temporary institutionalization, she reluctantly relinquished paying medical bills to her grandson. He put them on a computer spreadsheet to keep up with them. She continued to pay her routine bills such as utility. She still sorted the mail and bills and selected the bills for his attention. All four women took great pride in paying their own bills, "taking care of business," although none could sort through the medical bills without help.

Spirituality and transcendence: Faith, God, church, community, and legacy. All four women said that God and/or religion made it possible for them to get through the everyday and hard times. Two of them identified God as the center of their lives; two others identified family as the center. Religious and spiritual practices were key activities in three of their lives. The actual practices and role of faith communities differed widely between the women although they were central in the everyday life of three of the women.

A religious practice and belief which were similar across the women were prayer and faith. They all described praying throughout the day and times of prayer. They all believed that God had taken care of them throughout their lives, was taking care of them, and could be trusted to take care of them in their uncertain futures. Common statements were: "I have faith in God," "I depend on God," and "He looks after me."

Mrs. Bell summarized statements made by all respondents well:

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I prays all the time. It means a whole lot to me. Without prayer I don't think I could make it because I can ask God. He don't leave his children.... He knows your address. He don't have to write it down. He be with you at all times.... You can feel it. He ain't never left me yet. In the night, he wakes me up to go to the potty. When I get up, he gives me strength to get up and get around.... Sometimes I be lookin' for things, and I come in the room and there it is.... Without God I wouldn't have no other soul buddy. Sometimes I can't hardly turn over in the morning and he gives me the strength.

The experience of faith community differed widely, with two of them describing their churches and God as the center of their lives. The religious affiliations were of different Christian faiths: Missionary Baptist Church, unaffiliated, United Methodist Church, and Roman Catholic.

The unaffiliated woman occasionally attended the Sunday evening prayer service in the apartment building. The United Methodist Church member had been a leader in the United Methodist Women's group of her church of 25+ years. Her best friend was still active in that group and those women visited her every Sunday after church to pray with her and bring her news. The Roman Catholic woman watched Mass on Spanish TV for major religious holidays like the feast of Our Lady of Guadalupe. She frequently watched church TV and looked forward to receiving Eucharist which was delivered to her weekly in her apartment.

The two who described church and God as the center of their lives were Mrs. Bell and Mrs. Smith. Mrs. Bell was the matriarch of the Missionary Baptist Church which she helped to found 61 years ago. Church members were her main friends. Her church sent people to check on her if she missed a service or event. She said: "Church to me is my heart. It means a lot to me. I was raised up in church all my life. If I miss that, I don't have a good feeling. I can't do that much now, but I can still be there to feel that joy." Mrs. Bell also said,

Church is not a partnership. It's me, my soul...I can go to any church. I love all of them.... We associate with other churches. We learn a lot from that.... It's teaching you how to live. And teaching you how to forgive.

Mrs. Smith also helped found her church, the United Methodist Church in her neighborhood. She so identified with her church that she described herself in terms of her aging church. She often said, "You have to be realistic about it. We are both getting older and we will not live forever." Her church congregation was steadily aging and getting smaller as members passed away.

Death was usually discussed within the context of God, religion, church, or the afterlife. All four freely talked about death and had made arrangements for their burial, caskets, and in two cases, their clothes and funeral services. Two experienced deaths of close family members during the study; one of them had to make many of the arrangements for the funeral even though it was out-of-state. Most compared their longevity to members of their family ("My great grandmother ran her onion farm when she was 101 years old and I guess I am like her"). The respondent who outlived her only

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child frequently said things like, "I don't know why I am living this long. I guess God has a reason. God has a reason for everything."

The reported activities of these respondents did seem to show an increased interest and time in spiritual and transcendent activities as physical limitations and vulnerability increased. They also clearly pulled in their social circle with temporary challenges to health during the study and have done so increasingly over the last decade. They all spoke of relying on God during those and other challenges. The women who described lives of greatest challenges spoke more frequently and passionately about the importance of their faith, church, and God in their life over the years.

Making contributions to society, their families, and their communities were important to all of the respondents. They all wanted to leave a legacy. The legacies included: stories, tradition, jewelry, photos, inheritance, family traditions and values. Social contributions included giving counsel, "helping out when I can," keeping track of the church history, participating in this study, and actually starting new social ministry programs.

Mrs. Smith, for example, actually started a clothing ministry in her church when she found out that children in her neighborhood could not go to church because they did not have dress clothes and shoes. She got on the phone and called her pastor to reserve a room, called a friend to organize the distribution, and called church members to encourage donations. She also crocheted lap robes for people in nursing homes when she found out that her church had bags of unused yarn in that storage room. She said she did not like to crochet but did "like helping people" and saw "no reason to waste the yarn."

Later, when she was in the convalescent center and received an Easter gift basket from a neighborhood coalition, she said,

> This is what I want to be doing. I want a group of ladies to meet at my home and we do this. I should be able to do that [sew the lining]. I have never known how to get that started, but I want to do that…. [tearfully] There has just been an emptiness since I have not been able to be active in church activities [repeated].

Summary

In summary, four urban women aged 86 and older with physical limitations, who lived alone in their own places consented to participate in this ethnography. Participant observation and semi-structured interview sessions were conducted during home visits and phone calls over five months. Their everyday life emphasized functional and transcendent rather than risk reduction or frailty characteristics. The cultural theme which described this everyday life was *managing the business of daily living.* The theme "managing the business of" summarizes the everyday life experience of these women. Their everyday life was filled with the multiple responsibilities of caring for themselves, maintaining a household, tending to important relationships, and preserving autonomy within the reality of physical vulnerability.

CHAPTER V

SUMMARY

This ethnographic study explored the everyday life of women 85 and older living alone in their own residences with physical limitations who receive help. Most health studies investigate this population from a risk reduction perspective within the construct of frailty. However, in integrating the perspectives of the women with those of interdisciplinary health professionals, this study found a broader picture emphasizing the functional and the transcendent spiritual dimensions.

This chapter will begin with a summary of the study. The findings will be systematically compared with the literature presented earlier. Implications for practice, education, and research will then be discussed. This chapter will conclude with counsel from the women on living long and living well.

Study Summary

Four urban women ages 86-92 of African-American, Cuban-American, and European-American ethnicity were visited for five months. Two of the respondents lived in homes they had owned for 30+ years and two in subsidized senior housing apartments. Participant observation and semi-structured interview sessions were conducted on five sequenced topics: life story, usual day, unusual day, ADLs/IADLs, and aging self. These sessions were done on home visits, during one temporary institutionalization, and by

phone calls two to four times a month. Two of the respondents agreed to interdisciplinary ADL/IADL participant observation visits with an occupational therapist.

Spradley's systematic method was used to gather and analyze the data, conduct the componential, taxonomic, and domain analyses, and to identify the cultural theme. The cultural theme which described their everyday life was *managing the business of daily living.*

The theme "managing the business of" summarizes the everyday life experience of these women. Their everyday life was filled with the multiple responsibilities of caring for themselves, maintaining a household, tending to important relationships, and preserving autonomy within the reality of physical vulnerability.

The term "daily living" includes two important components—"daily" and "living." "Daily" captures the living in today rather than the past or the future as well as being settled into or settling into ordinary and routine days. The word "living" evokes how these women choose to be—active and alive rather than passively allowing time to simply pass.

The belief that "God takes care of me" supported them in caring for themselves and others. They were committed to doing what was necessary so they could stay in their own place. Relationships with God and family were most important to them. Staying actively connected with family and friends, contributing to their communities, and leaving a legacy were also important.

None of these women described themselves as frail. Managing their lives did include the conventional risk reduction strategies. However, reducing burden on family

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and friends was also a necessary risk reduction strategy because it helped to preserve a critical social support network as well as lifelong roles.

The descriptor "living alone" was used by the women in reference to the experience of inadequate support rather than as a living arrangement. The autonomy of staying in one's own place was more important than living longer or staying in the family homestead. Help was described as a mutual exchange of services rather than receiving help.

These findings support existing conceptual models for aging: gerotranscendance, Ecological Theory of Aging (ETA), and Selection, Optimization, and Compensation (SOC). More research needs to explore the transcendent and spiritual as well as the management dimensions in this population. How these models fit together needs further exploration.

Approaching these women within a framework emphasizing their management skills acknowledges the complex coordination, work, and responsibility required to stay in their own place. Implications for health promotion strategies include building on management strengths. Respecting and receiving the wisdom of those who live long and well can help society plan for healthy aging for all.

Comparison with the Literature

Overall, the findings were similar to much of the literature in many areas. The importance of spirituality and transcendence as well as the functional dimensions was highlighted in this study. This perspective is different, although not incongruent with the studies described from the biomedical, frail, risk reduction frameworks.

Although congruent with the previously described qualitative studies, the emphasis on "management" and "staying connected" were new and significant findings in this ethnography. Also, the women's active avoidance of words like "helpers" and "caregivers" was unique to this sample.

The similarities of these multiethnic women to the younger and rural samples in previous studies suggest that the subpopulation of women who continue to live alone even when they need help and grow older do share a common lifestyle. They will do what it takes to stay living in their own places as long as they can.

The findings of this study were similar to the literature in demographics, physical limitations and help, selected aging frameworks, living alone, staying in their own place, and housing. Therefore, significant discoveries in this study were themes of "management" and "staying connected" and the importance of spirituality and transcendence.

Demographics

This sample reflected the current city's demographic and geographic aging profile of women 85 and older in ethnicity and socioeconomic status except that it did not include any English-speaking Asian women or affluent women. Many of the more English-fluent Asian seniors had been displaced and were staying with relatives because of a senior apartment building fire in the city's Asian district.

This sample reflected the regional levels of formal provider usage except for the unusually high usage of formal provider visits for one community-mobile senior during her 3 months after surgery. Also, these physician home visits that one respondent

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received were available only to those in specialty geriatric/affluent clinics or in those in the very impoverished neighborhood near the County hospital.

Theories on Aging

These women's lives did demonstrate congruence with the gerotranscendance, Ecological Theory of Aging (ETA), and the Selection, Optimization, and Compensation (SOC) models of aging. Decreasing community mobility and challenges to health were associated with more time in prayer and reflection. All of them showed generativity and concern for leaving a legacy. When faced with acute and chronic increasing limitations, they compensated by adjusting self-expectations and selecting activities which optimized their energy and rest for meaningful relationships and activities.

Consistent with increased longevity in resource-rich seniors found in Moss and Lawson's (1982) early work on the ETA, all four of these women can be categorized as resource-rich. They show intentional daytime sleep and rest, selective and meaningful social engagement, and a change in activities in the last few years to compensate for increased physical limitations. The women framed increasing sleep within a health promotion context.

Spiritual and Transcendent Dimension

The findings supported the importance of the spiritual and transcendent dimension of gerotranscendence in advanced age. Clearly, this developmental stage needs more attention and exploration. This dimension needs to be treated as a concept and domain of its own rather than subsumed under other domains like adaptive/coping strategies, social support, and significant relationships.

We must better prepare both our society and ourselves for healthier, longer lives. Theories of aging like gerotranscendence propose a developmental stage in advanced age of transcending cultural norms, spirituality and interiority, wisdom and cosmic attention, and concern for preceding and subsequent generations. Other theories like ETA and SOC emphasize the functional, selectively adaptive, and compensatory tasks of these later years.

Resources and Independence

The findings are somewhat consistent with the critical feminist studies by Petry (2003) and Luken and Vaughan (2003). Like Petry's (2003) women in Switzerland, these women did not see aging as an experience separate from all of life but part of life's stream—"aging happens." Unlike the women in Switzerland, however, the women in this study did not verbalize limited life options because of their gender. Rather, they verbalized much satisfaction with their domestic occupations and lives.

Independence for these American women was similar to the Swiss women. Independence meant living alone, making their own choices, doing what they have always done, and doing what they want to do. Like Petry's women, these women described themselves as physically vulnerable, especially in regards to falls, although they did not use the word vulnerable.

Living Alone

Similar to Luken and Vaughan's (2003) study of older women living alone, these women experienced "living alone" in terms of everyday activities and social relations rather than the conventional use of the term "living arrangement." This was true for both

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those living in the senior apartments and those in their own homes. "Living alone" was experienced as "alone" and in the negative sense when support services were perceived as inadequate.

Those in the staffed senior apartment building had a full range of support services, especially during business hours. For example, the apartment-living women in this study described a lifestyle almost like a huge lodge with private, locked rooming suites and regular communal gatherings. When asked about living alone, one respondent described how her neighbor friend who lived below her heard her fall and sent her son upstairs to lift her off the floor. The other apartment-dwelling woman said she felt herself alone at night after the apartment staff went home. That same woman's daughter came to stay with her and care for her for 2 weeks after her surgery.

Both of the apartment-dwelling women participated regularly and eagerly in the structured and unstructured social events available in the apartment complex. Unstructured activities included games in the lobby area for one and nightly social gatherings by the elevator for the other.

The two respondents who lived in their own homesteads had a different experience of living alone. One of the two women who lived in her own home can be described as the matriarch of the neighborhood, feeding and counseling drop-in visitors at least once a day. Again, social activity mediated the potentially negative experience of living alone. The other woman in her own home did experience herself as living alone once her needs for help exceeded the neighbors' reliability and availability. Inadequate

support services in those living alone should tag persons at highest risk of morbidity, mortality, and institutionalization.

Staying in Their Own Place

The importance of staying in their own place for these women was very similar to those in the three phenomenological studies of younger or rural women described earlier (Porter, 1994a, 1994b; Hink, 2004). These studies were the two by Porter on receiving help and the one by Hink of rural women living alone. Porter's study differed in that her sample was slightly younger (75-84) and those respondents used "helpers" to describe those who provided supportive services. The descriptions of Hink's sample of 85 and older rural women highlighted cultural themes almost identical to this study's urban women.

Therefore, the unified culture of this population of women seems to be around managing the business of living alone in their own places. Staying in their own place was the main goal of the women in all four studies despite differences. These differences included: location (urban and rural), setting (senior apartments and homesteads), ethnicity (Hispanic, African American, Western European), experience of receiving help (helpers and providers), or degree of advanced age (old-old and oldest old).

However, all were willing to do what they saw as necessary to stay in their own place "as long as possible." For one, the matriarch of the neighborhood, the neighborhood was part of her homestead. When asked if she would be willing to leave her neighborhood if she had to, she said, "I've lived here all my life. I wouldn't be happy living anywhere else. Everyone knows me here and I know everyone." For the other

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three, the physical place and location were not critical aspects of their "own place," but rather the privacy and autonomy.

Receiving Help

Receiving help was necessary for these women to live alone their own place as long as possible. However, provider language around support services does not match the values and folk language important to these women. Similar to the other qualitative studies on older women receiving help, these women's descriptions did not match any of the traditional dichotomies, like dependence/independence, formal/informal, paid/unpaid help, kin/nonkin, and care receivers/care providers.

None of the conventional categories capture the fluid, reciprocal, and dynamic relationships of older women managing their everyday lives found in this and the studies described earlier (Barker, 2002; Crist, 2005; Porter 2004; and Porter 2005). Barker's (2002) succinct summary accurately emphasizes the "ordinariness...their everyday quality" of these "minor, mundane tasks" and of the helpers and help which are socially embedded.

These women resembled Gustavson and Lee's (2004) large, epidemiological study which found that those living alone were less depressed and more highly functioning than those living with relatives and spouses. Like in that major study, three of these women usually relied more on formal providers, children, and friends than on other relatives for help. They relied on grandchildren when children were not available. This study did not include any childless women. Not having reliable and living children was a

significant factor for these women and placed grandchildren and informal providers in positions of greater than usual responsibility.

For example, Mrs. Smith's son had died three years prior and she did not receive formal provider services because she did not meet income eligibility and homebound requirements. After her surgery, she struggled with sadness and the constant challenge of scheduling and juggling adequate paid and volunteer help from neighbors. Two months after the study ended she died at home. Perhaps not having a supportive, living child or formal provider are major risk factors for mortality in this population.

Porter's descriptive studies (1994a, 1994b) on older women's paid and unpaid helpers closely match these women's relationships with the people who help them and other features of living alone. Although Porter's (1994a, 1994b) methodology differed and her sample was of younger women ages 75-84, the similarities were striking. The similarities suggest that maybe these features describe a lifestyle and culture of older women who live alone and stay in their own places.

There was one significant difference between Porter's samples and this one. The women of Porter's (1994a, 1994b) study used the word "helper" but these women did not. The respondents in this study used "provider" or the name or relationship of the person, like "daughter" or "friend" or "neighbor" when referring to people who provided support. This could reflect a regional language difference or maybe the preference for this older sample to emphasize the exchange of services rather than receiving help. This is consistent with Morrissey's (1998) group of 76-92 women summarized earlier who described help as reciprocal and interactive.

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Choice of language when referring to support people was a sensitive issue with the women in this study. All of them showed discomfort with the word "caregiver." This has important implications for agencies which often find their services refused by this population. Support services need to be framed and offered in a manner respecting the women's dignity and autonomy. Avoiding terms like "caregiver" and using words related to "taking care of business" emphasizes management strengths rather than receiving care.

Several of the exact phrases made by the women in this study about their intentions in receiving help were also themes in Porter's and Morrissey's (1998) samples. This suggests that a unifying cultural theme in these women is *they accept help and reduce risks in order to stay in their own places as long as possible.*

Although this study was conducted with an urban sample, the findings are very similar to Hinck's (2004) rural older adults who lived alone in their homes. Those rural oldest old were similar to this urban sample in all aspects: they valued the privacy of living alone, stayed actively connected, had strong social supports, were not isolated or lonely, described their health as good because they were functional despite physical limitations, described fatigue as the factor with greatest impact which caused them to modify activities, and de-emphasized how tenuous their adaptive strategies might be.

Most significantly, the women in this study, like those in Hinck's, did not structure their lives to stay safe, but rather to care for themselves so they could remain at home alone. Presenting risk reduction strategies as ways these women can better care for themselves so they can stay at home rather than emphasizing preventing falls can engage women's strengths rather than fears in making safety modifications.

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Providers need to speak to this population from a "managing everyday business" rather than "reducing risk" framework. Providers need to understand that this population sees "being a burden" and "worrying my family" as significant risks which must be factored into any calculation of risk. When their living style is dependent on social support, factors which jeopardize possible support are very real risks.

Housing Choices

These women made housing choices which supported their preference for social engagement, safety, personal autonomy, and privacy. These choices were consistent with those found in Morrisey's study (1998), in which women with more resources of social support and higher function chose to live alone.

Two of the respondents in this study chose senior apartment living to preserve their autonomy and privacy when physical limitations made living in their own homes too hard. Their plans to live in assisted living rather than with family should they need more help is consistent with these values.

The other two respondents, however, could not afford assisted living if needed, were still living in their own homes, did not have existing formal or informal support structures for intense and extended help in their own homes, and had lost their primary caregiver/closest family member to death in the last few years.

One of these two respondents said she did not think God would let her "linger," so was not worried if she could no longer manage at home. The other respondent died in her sleep a couple months after the study ended. She had been unsuccessfully juggling paid and unpaid help from neighbors and giving away treasured heirlooms a few weeks before

she died. Perhaps mortality is associated with being unable to manage a lifestyle which is acceptable. Social support has consistently shown a protective effect on mortality (Temkin-Greener et al., 2004).

Conclusion

These findings, then, were congruent with the literature but did show new findings. For example, the emphasis on management as a frame for everyday life is significant. Significant conclusions of this study were:

1. "Managing the business of daily living" described the everyday life of these women of advanced age with physical disabilities who lived alone in their own places. Managing their everyday life was a full-time and surprisingly complex job.

2. Staying connected helped them manage the business of everyday living as well as to live according to what was most important to them--family and God.

3. Taking care of themselves and others were life themes that continued into their advanced years.

4. The spiritual and transcendent and functional dimension more accurately described their everyday life than the predominant health professional frailty and risk reduction frameworks.

Implications

Further implications for practice, education, and research are presented below. Practices recommended by the findings are primarily activities to promote healthy aging.

Recommended practice strategies can be promoted for individuals as well as systems. Some require policy changes so they can be routinely structured into health and social service plans. These health promotion activities include spiritual and psychosocial, physical and environmental, and systems interventions.

Spiritual and psychosocial interventions recommended by the findings of this study are those which would enhance the strengths of wisdom and life experience and helping them stay connected. The physical and environmental recommendations would maximize safety, energy, and monitoring resources. The systems interventions would increase housing options and long term care supports.

Implications for education include content and experiences related to healthy and aging for all ages, and in particular, for those in health and social service professions. Health professional education should incorporate interdisciplinary experiences. Nursing education needs more attention to the environmental, spiritual, and transcendent dimensions.

Research strategies implicated by this study are methodological considerations regarding this population and multicultural research. Some questions for further inquiry will be presented.

Practice

Description of implications for practice follow.

Spiritual and Psychosocial Strategies

Recommended spiritual and psychosocial strategies reinforced the developmental tasks of gerotranscendance.

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Structured activities for reminiscence and life review. Offering structured activities for reminiscence and life review support healthy aging in the psychosocial and spiritual dimensions. All four women said they valued the visits because they enjoyed telling their stories and reflecting on their lives. Neither of the apartment buildings nor faith communities of these women offered life review or reminiscence groups.

Reminiscence and life review groups used to be offered at most senior centers and by some seniors groups of faith congregations. Although such groups fell out of fashion with the advent of computer classes, they could be given a new design to become fashionable again. For example, centers could provide "scrapbooking" and "treasure-trove" gatherings. Youth groups could be invited to help the seniors and hear their stories.

Leaving a legacy. Older adults need ways to continue contributing meaningfully to society. Providing ways for women to contribute can include things they can do from their recliners, such as sending greeting cards, participating in an intercessory prayer chain, making phone calls, reading or tutoring children, and bringing small meetings and outreach craft projects to their homes.

Three of the seniors in this study sought opportunities to serve not only through their existing social network and also through non-profits they became aware of during the study. The physical limitations imposed by the limited energy of one and limited communitywide contacts of the other had isolated them from previous levels of community contacts and involvement.

Providing mechanisms for leaving a legacy for their families and communities can promote healthy aging for individuals as well as families and communities. The

importance of leaving a legacy was another motivation for these women to participate in this study. They not only wanted their story told. They also wanted to hear someone else tell it. They wanted to leave a legacy.

Structuring activities around leaving legacies can establish richer traditions in families and communities. These traditions can help faith communities, seniors groups, senior housing units, and families tune into wisdom, chronicle family and community history, and highlight contributions of their elders.

For example, birthdays were keystone events in these women's lives. Since birthday celebrations are fairly common in different groups, using birthdays as times to showcase memories, accomplishments, and contributions in addition to recognizing age might be a good way to enhance current traditions. Forming group scrapbooks of favorite recipes and having recipe potluck gatherings can enrich sharing and pass on traditions which are especially needed for the fast-food, microwave generation.

Intergenerational activities. Intergenerational activities need to be encouraged in group and family settings. Two of the four women "loved children." All 3 research nurses benefited and learned from the woman they interviewed and made significant decisions based on their experience.

All 4 women looked forward to the visits. With more age-segregated housing and age-separated programming in group settings, intergenerational programming must be intentional to give the young and the old time to enjoy each other and learn from each other. Too often educational and faith organizations send youth groups to nursing homes

but do not give their youth opportunities to experience healthy older adults in the community.

The old and the young need each other, just as they each need their separate places. A church youth group in Mrs. Bell's neighborhood installs and checks smoke detectors in the homes with adult supervision. This brings three generations together in seniors' homes. This service learning activity can facilitate dialogue about growing older and give service experiences outside of nursing homes. It also meets critical safety needs and reinforces the importance of having working smoke detectors in all households.

Financial and long-term planning. Community centers, faith congregations, and apartment buildings should regularly offer speakers and consultants on financial planning, long term care options, and advance directives. Older adults often find themselves managing money and assets without adequate understanding. They need to know financial and legal strategies to maximize their housing and long-term care options. Explanations about such important matters should not be left for times of health crisis when decision-making can be impaired. Financial planning and health status are critically important to quality of life.

Unlike severely impoverished seniors, all four of these respondents had adequate money and benefits for basic needs and healthcare. However, only 2 of them could have afforded assisted living. One needed assisted living after her fall but could not afford it. However, she could have afforded it had she known how to move and protect her assets when she was younger. One respondent was confused about the difference between durable medical and financial powers of attorney. Her apartment complex offered many

valuable educational programs, but none on financial planning, long-term care options, or advance directives.

Physical and Environmental Strategies

Physical and environmental considerations were critical. Not having needed items or having unsafe items like elevated toilet seats and ramps posed real dangers for these women. Assessment of these features cannot be left to physical therapists and occupational therapists. Nurses must become competent and proactive in this. Nurses must know when to make referrals and provide follow-up support and monitoring.

The most important objects for all 4 women were the phone, mobility aids, and the recliner chair. Phones need closer assessment and intervention. The appropriateness and safety of mobility aids needs on-going nursing evaluation with the fluctuating status of this population. Financial coverage for critical equipment like recliners and grab bars needs to be provided and seniors need physical help to make installation possible.

Safety and communication aids. The centrality of phone as an instrument of connectedness, safety, and monitoring needs attention. With the capability of telemonitoring technology and transmission of visual images, the "virtual" community, tele-health, social support, and tele-communication could become fairly comprehensive delivery systems and specialty practice.

Recommending portable and volume-enhanced talking phones as part of annual health visits needs to be part of the annual health check-up. Assessing the need for these should be as standard as the annual cardiopulmonary assessment. Asking older persons if they have portable phones, how many, whether they have speaker phone capability, caller

ID, and volume enhancement, and giving information on where to obtain them and for how much or even having them for sale or giveaway at physician offices could help keep older adults connected and safer.

Most older adults do not know the capability of current technology and may have no idea how having a speaker phone and caller ID could eliminate rushing to the phone for telemarketing and could help them know when family and friends have called. A grandchild or neighbor could install the phone and program in the emergency numbers. The senior needs practice and tutoring in using the phone features.

Persons with physical limitations should have three phones, with stations next to the recliner, the bed, and the toilet. Two of the four of the respondents had falls in the bathroom and had to crawl to the bedroom to reach a phone. A fourth phone would be even better, because the smaller phones make it possible to carry them in pockets and in bags on walkers and wheelchairs.

An emergency call system should be available and affordable for all older adults willing to wear one. Some prefer to wear them as armbands and some prefer necklaces. No older adult should be fearful of falling and not getting help simply because they cannot afford a call system. Mrs. Fernandez had searched for one she could afford without success. Her surgeon even recommended "proactive" surgery so she would not have a kidney stone attack at night when she could not reach anyone.

Emergency call cords in apartments help but do not meet that need. For example, Mrs. Aye could not reach her cord when she fell in her living room. Her neighbor below

her heard her hit the floor. Perhaps future technological research can design wireless emergency call systems for homes and apartments which even can be worn as rings.

Systems Changes

Implications for systems strategies are focused around building community structures and networks of support, both formal and informal, and routinely providing supportive services and equipment.

Criteria and services for in-home support. Our society needs to examine how to best provide extra support needed when not available in the community or family system. Currently, those who do not have skilled nursing needs and do not meet poverty guidelines do not qualify for even limited provider services. The current income and eligibility criteria need to be weighed against the cost of institutionalization. Quality of life, morbidity, and mortality of healthcare plans with and without home support systems need to be compared and more equitable and appropriate guidelines developed.

Requiring homebound status to qualify for provider services is short-sighted. Temporary formal provider services should be available to the oldest old after periods of illness, surgery, extensive diagnostic work-ups, and falls. On-going formal provider services should be available to the oldest old with physical limitations. Provider services should be included in benefit packages, Medicare, and Medicaid.

Medicare and Medicaid need to cover the provision and installation of essential safety equipment. Systems need to be put in place to safely install necessary safety equipment like grab bars and ramps and elevated toilet seats. Mrs. Aye fell in her bathroom from an unsafely installed elevated toilet seat. Mrs. Bell was receiving home

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physical therapy but did not have the necessary elevated toilet seat. Grab bars and ramps are similarly dangerous when absent or improperly installed.

Home OT consultation should be ordered as part of the standard package of preventive procedures at ages 80, 85, 90, and 95 and one month post-operative to any surgical procedure. Physical limitations increase with age and often post-operatively. Proactive management strategies can maximize functioning and safety.

Care managers. The current care systems need to structure in roles and functions for care managers in all geriatric teams. Management skills were necessary for these women to stay at home in their own places. Policy makers need to explore the cost of providing care managers as a part of geriatric care, persons who can step in to coordinate and authorize needed services when older adults cannot do this for themselves or do not have someone who can do it for them. These women were still able to manage the array of people and services they needed. Two of them did not have someone they felt could and would manage their care if they could not.

Summary of Implications for Practice

This study suggests a framework for working with this age group which differs from the more conventional frailty and risk reduction paradigms. An emphasis on managing, emphasizing strengths rather than deficits, can shift how providers approach these women. Meeting women in their strengths aligns providers as allies rather than as caregivers.

Working with the women rather than taking care of them acknowledges their self-responsibility and life experience. The proper posture for providers might be respecting

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and receiving their life wisdom in exchange for the opportunity to support them. These women do meet criteria for frailty, but they continue to maximize and manage their resources within their own value systems.

Education

Implications for education include integrating experiences and content related to healthy aging and health promotion into all types of curricula for all ages. In particular, health and social service providers need to be provided clinical practica and stronger theoretical content regarding healthy aging. This study found the interdisciplinary perspective invaluable. Nurses, physical therapists, and occupational therapists should experience interdisciplinary home visits during their educational process in order to better understand each others' expertise. Nurses need more in-depth content and experience in client functional and environmental assessment within the home setting.

Research

This study suggested both methodological approaches as well as topics of inquiry for future studies. The research process emphasized the importance of cultural considerations. and the possible use of phone calls to reach older women less able or willing to have home visits. The findings suggested questions for further study, especially in the area of spirituality and transcendence.

Methodological Implications

The experience of conducting ethnography on this population suggests methodological approaches for future explorations, which include phone interviews and multicultural considerations.

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Phone interviews. Using phone for data collection in this growing population could be very productive from both the research and clinical perspectives. Both short and more lengthy phone calls and interviews were highly informative and also enjoyed by the women. Phone calls were also the preferred mode of contact during times of fatigue, illness, disorganization, and high stress.

The home visits were very rich in content and helpful. They were essential to including the environmental context in this study and to understanding the values and choices of the respondents around reducing risk. However, home visits were time intensive for both researchers and clients. Also, the intimacy and time required excluded introverts, persons not wanting others in their home, and persons "too busy" for visitors. Although not stated, the risk of strangers in the home was probably a key factor in so many family members not allowing women to participate.

Conducting one or two home visits could have provided most of the essential environmental data with the other "visits" conducted over the phone. All of the respondents used phones heavily and communicated effectively by phone. Shorter, more frequent calls were more effective and representative "snapshots" of everyday life for one respondent than the scheduled home visits. Participant recruitment probably would have been easier if only phone contacts were required. Phone interviews might work best for large, epidemiological surveys which require large and representative sampling.

Multicultural research. More multicultural research is needed on this population. Phenomena need to be understood within and across cultures. The multi-ethnic dimension

of this study was a strength. It is not clear how the description might have looked if only one person of one ethnicity had interviewed and visited all of the women.

The primary investigator learned new approaches, language, and cultural characteristics while listening to almost every tape. The team discussed ethnic considerations at most team meetings as well. Because of the multiethnic process in this study, the team was confident in concluding that there is in fact a unifying culture in this population of women.

Matching ethnicity of the researcher with the ethnicity of the women definitely facilitated rapport, disclosure, and mutual understanding. For example, the Cuban woman was very fluent in English. However, when she was expressing deep emotion, especially when she was upset, she spoke in Spanish. The Spanish-speaking researcher said that all of the Spanish had equivalent or nearly equivalent words and phrases in English, but that the respondent was obviously more comfortable speaking in Spanish when upset.

Similarly, the African American researcher was intimately familiar with the church customs in the African American culture. She understood their meaning, how the church rituals and worship had changed over time, the neighborhood culture, and some of the neighborhood people. The Anglo and Hispanic research nurses found her in-depth explanation of the cultural context invaluable when discussing field notes.

Similarly, the Caucasian, western European researcher knew the culture, general neighborhood, pastor, and people of the Caucasian older woman's church. This common knowledge made it easier for her to understand this respondent than the other Caucasian respondent.

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The other Caucasian respondent and her neighborhood were new to the investigator. Knowing one respondent's context and not the other respondent's helped the Caucasian primary investigator to compare and contrast the two living settings and how knowing and not knowing influenced the data collection and analysis process.

All three research nurses agreed that the quality of the data, disclosure, and rapport was richer when they shared similar backgrounds with the respondents. Communicating their observations in the team meetings and "interpreting" cultural norms and values unique to that ethnicity or religion helped all of the researchers become aware of the ethnic and religious perspectives of both respondents and interviewers.

This process was especially helpful in describing and discussing the differences in the role of church in African American Missionary Baptist culture and in the Cuban refugee's Roman Catholic culture. The religions themselves had strong cultural features rooted in the roles of church in their faith traditions as well as their personal experience.

For example, the Cuban refugee did not feel disconnected to her "church" because she did not attend "Mass." Her denominational experience was more an individual style of worship and one centered around the sacrament of "communion." Receiving the "communion" which was brought to her each week "filled" her. She would watch big religious ceremonies on TV, like Mexico City's televised Mass on the feast day of Our Lady of Guadalupe. She felt connected to the worldwide Catholic community through prayer, TV, and communion.

By contrast, the African American woman who helped found the Missionary Baptist Church in her neighborhood did not feel complete without physical contact

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through attending church or being visited by members of her church. Pastoral visitation was part of her church's tradition. Her church functioned like a community center, with frequent gatherings and events in addition to worship services. "Fellowship" was central to her church experience and her church members functioned as extended family.

The team spent an entire meeting describing aspects of their individual and respondent's ethnic and religious cultures to one another to better understand the context and respondents' language around this phenomenon of importance to the respondents. Research studies around "church" and faith and the divine should be sensitive to the cultural differences and similarities of different religions and not assume that key words like "church" and "God" and "religion" have the same meaning to people even within the same community.

Further Inquiry

Recommendations for future studies, therefore, included some methodological considerations as well as topics and questions for further inquiry. Based on study findings the following research studies are recommended:

1. The value and meaning of staying in one's own place in different settings needs further exploration. Identifying factors which preserve the desired features within varied congregant living settings.

2. Best practices around desired housing features need in-depth study. Findings can guide new program and community development. Valued housing features were: privacy, autonomy, available help, friends, and socialization, and for one woman in particular, the neighborhood itself.

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3. The kind of help that is most cost-effective and most acceptable for this growing population needs examination. These women wanted paid providers when they felt their needs would be a burden or impossible for family and friends. They preferred relationships where services and kindnesses were exchanged.

4. More health studies need to explore the support which communities can provide and how to strengthen those support networks. These networks and the surrounding communities were critical to supporting the women's desire to stay in their own places.

5. The congruence of these findings with the everyday lives of those who are isolated, depressed, and disengaged needs to be explored using methodologies more appropriate for those who do not want visitors or interviewing. Perhaps brief phone surveys on specific topics could reach this population.

6. The management as well as the risk reduction paradigm must be used to frame inquiry in order to predict positive outcomes and promote healthier aging. Perhaps designing support systems from a framework which strengthens the ability of seniors to help each other and themselves manage their own lives can help society better understand how to promote healthy aging for all.

7. Elders whose lives exemplify higher developmental stages should be invited to help design a theory of aging which synthesizes both the functional and the transcendental dimensions. Both dimensions are important to people who live long and live well.

8. The transcendent and spiritual dimension of aging needs much more exploration. These long-lived women showed everyday lives which not only integrated both the transcendent as well as functional dimensions, but also placed high value on the spiritual dimension.

9. Some questions for future research include: What are healthy developmental stages related to diminishing physical abilities and how can those be supported? What does the developmental stage of gerotranscendence look like and how can it be tested? What are the similarities and differences of everyday lives of older women and men? What are the differences between women who live into their eighties and above and those who do not?

In conclusion, older women who manage to live alone in their own places provide hope for all. They manage the business of daily living with its challenges and opportunities, its complexities and its ordinariness. They have a legacy to leave and wisdom to share. Their counsel about living long and living well can be summarized as: "Take care of your self, your family, and others as best as you can. Love and forgive. Thank God for taking care of all. Then you can look on your life and say it is a good one."

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APPENDIX A

Protocol for Semi-Structured Interviews During Home Visits

Protocol for Semi-Structured Interviews During Home Visits

Informed Consent

Mental capacity for informed consent will be verified over the phone and again on the initial visit by the older person's demonstrated ability to accurately describe the purpose of the research, the nature of the visits, and the role of the research nurse. The primary investigator will summarize the study and emphasize these points and then will ask the potential respondent to answer questions which will provide an opportunity to demonstrate accurate understanding.

If the person cannot accurately describe these points on the telephone, then a visit will not be scheduled. If the person cannot accurately summarize these points or accurately answer the questions on the initial visit, the primary investigator will diplomatically explain that the person does not meet the criteria for the study. In order to do this with sensitivity, the primary investigator will preface the invitation to participate with a statement emphasizing that meeting the criteria will be required.

Demographic Information & VES-13

The researcher will attempt to gather as much demographic information as possible on the first visit. However, completion may take two or three visits. The investigator will complete the VES-13 survey on the first visit by asking the respondent the survey questions.

Institutionalizations/Convalescence Away from Home

If the regularly scheduled visit should occur during a period of hospitalization, nursing home stay, assisted living, other institutionalization, or convalescence at

someone's home, the interviewer will attempt to see if there is any change in the person's previous statements about the meaning of aging and living in her own residence and her plans regarding discharge, what it is like to need help with ADLs, and self concept.

The Interviews

Interviews will address five sequenced topics: life story, usual day/unusual day, ADLs/IADLs, self description, and the meaning of aging in their own places of residence. The interview questions will be threaded throughout all visits, although the investigator will attempt to have each visit focus in-depth on each topic consecutively by introducing the topic of the visit with the opening question and directing conversation when possible.

Caregivers and Visitors

Caregivers will be asked if they are willing to be observed by the researcher and the occupational therapist during the two ADL/IADL visits while they are providing assistance to the older persons. If they agree, they will be asked to sign consent forms. If they refuse, their refusal will not interfere with the older persons' continued participation in the study.

Unscheduled family or other visitors during a visit may require rescheduling the visit through mutual agreement with the respondent in order to continue the interview. If family members come in during the interview, taping will be discontinued while they are present. and the investigator will attempt to re-schedule the visit.

Respondents will be informed of their right to tell family members and caregivers about their participation in the study. They will be told that they can ask those persons to call the nurse researcher to discuss the study and the nurse researcher will answer

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questions about the study but cannot disclose their participation in the study or what actually happens during the visits without their permission. The nurse researcher will inform the respondent of phone calls received from caregivers or family members.

ADL/IADL Observation Visit

The primary investigator may ask the participant to demonstrate various ADLs for the occupational therapist and her. A visit may be deliberately scheduled for observation during the participant's "bath day" or other time of special challenge or when receiving caregiver assistance. The occupational therapist will clearly state that her role is observational only.

Scheduling of Visits

Visits will be scheduled at times mutually agreeable and at times to best observe respondents at different times during different activities during the day. Visits will be scheduled for every two weeks regardless of respondents' place of living or convalescence during the time of the study.

APPENDIX B

TWU IRB Approval Letter

TWU

EXAS WOMAN'S UNIVERSITY

DENTON   DALLAS   HOUSTON

Office of Research
6700 Fannin Street
Houston, TX 77030-2343
713-794-2480   Fax 713-794-2488

December 19, 2007

Ms. Karen Hahn
6700 Fannin St
Houston, TX 77030

Dear Ms. Hahn:

Re: *The everyday life of women ages 85 and older living alone in their residences who receive help*

Your application to the IRB has been reviewed and approved.

This approval lasts for one (1) year. The study may not continue after the approval period without additional IRB review and approval for continuation. It is your responsibility to assure that this study is not conducted beyond the expiration date.

Any changes in the study or informed consent procedure must receive review and approval prior to implementation unless the change is necessary for the safety of subjects. In addition, you must inform the IRB of adverse events encountered during the study or of any new and significant information that may impact a research participant's safety or willingness to continue in your study.

Remember to provide copies of the signed informed consent to the Office of Research, IHS 10110 when the study has been completed. Include a letter providing the name(s) of the researcher(s), the faculty advisor, and the title of the study. Graduation may be blocked unless consents are returned.

Sincerely,

Dr. Gayle Hersch, Co-Chair

Institutional Review Board - Houston

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Appendix C

Demographic Information

Demographic Information

CODE #: _____

Age: _____

Address: _____

_____

Phone Number: _____

Marital Status: _____

Living Situation: _____

Highest Educational Level: _____

Former Occupation: _____

Closest Relative: Name: _____

Relationship: _____

Phone numbers Home: _____

Work: _____

Neighbor: Name: _____

Address: _____

Support Agencies/Services: _____

_____

_____

Major Medical Conditions: _____

_____

_____

_____

_____

_____

_____

APPENDIX D

Vulnerable Elders Survey (VES-13)

1.   Age_____   **SCORE: 1 POINT FOR AGE 75-84**
                        3 POINTS FOR AGE 85 OR OLDER

2.   In general, compared to other people your age, would you say that your
      health is:
      ____ Poor, * **(1 POINT)**
      ____ Fair,* **(1 POINT)**
      ____ Good,
      ____ Very good, or
      ____ Excellent.

3.   How difficult, <u>on average,</u> do you have with the following physical
      activities: **SCORE: <u>4 POINTS</u> FOR ONE OR MORE ***
                   RESPONSES IN Q3a THROUGH Q3c

	No Difficulty	A little Difficulty	Some Difficulty	A lot of Difficulty	Unable to do
a. stooping, crouching or kneeling	____	____	____	____ *	____ *

             No___
             Don't do___ → Is that because of your health? Yes___ * No___

| b. lifting, or carrying objects as heavy as 10 pounds | ____ | ____ | ____ | ____ * | ____ * |

             No___
             Don't do___ → Is that because of your health? Yes___ * No___

c. walking across the room? USE OF CANE OR WALKER IS OK.

| | ____ | ____ | ____ | ____ * | ____ * |

             No___
             Don't do___ → Is that because of your health? Yes___ * No___

d. doing light housework (like washing dishes, straightening up, or light cleaning)?

| | ____ | ____ | ____ | ____ * | ____ * |

             No___
             Don't do___ → Is that because of your health? Yes___ * No___

e. bathing or showering?

| | ____ | ____ | ____ | ____ * | ____ * |

             No___
             Don't do___ → Is that because of your health? Yes___ * No___

APPENDIX E

Semi-Structured Interview Questions

Semi-Structured Interview Questions

The semi-structured questions and guiding probes will be focused on sequential topic areas of the respondent's life story, usual day/unusual day, ADLs/IADLs, self concept, and meaning of living in own place, with approximately two visits devoted to each topic.

The proposed key questions and probes are presented in the following interview schedule. The general opening question will be: **I am interested in learning about what it is like to grow to be eighty/ninety …. years old. I wonder if you would tell me what it is like for you to be eighty/ninety … years old.**

Life Story—Today I wonder if you would tell me about your life. When you remember your life, what are some of the memories that stand out for you?

- What things were important to you when you were younger?

- What kinds of things are important to you now?

- What are your greatest joys?

- How do you cope with the losses in your life?

- What gives you comfort when you are sad (or lonely, whatever emotions were mentioned)?

Usual Day/Unusual Day—Today I wonder if you would tell me about what your days are like—your everyday life.

- Can you tell me what your usual day is like? Tell me how your day begins. And then what? (Through the 24 hours.)

- Do you take any medications? If so, would you please show them to me? How often do you take them? Do you ever skip any of them? How do you keep track of what to take and when? How do you manage refilling your prescriptions?

- Can you give me an example of what an *unusual* day is like? Can you give me another example?

- Please tell me what it is like when you go out of the house (apartment).

- Tell me about going to the doctor/visiting a family member...

ADLs/IADLs—Today I would like you to tell me about the things you do to take care of yourself and the things other people help you with.

- How would you describe your overall energy level?

- What kinds of things do you like to do by yourself?

- Do you have people who help you with different things, like transportation, doctor's visits, cleaning, shopping? Can you tell me about that? What about... (cover all ADLs and ADLs)

- Tell me what you would like to do that you cannot do anymore.

- What is it like to need help to do some of the things you could do by yourself when you were younger?

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- What would you tell me about what to expect about taking care of myself when I grow older?

Self Concept—Today I wonder if you can tell me what it is like to grow older.

- How is your overall health?

- Tell me what you like about growing older.

- Can you tell me what you don't like about growing older?

- How would you describe yourself when you were younger?

- How would you describe yourself now?

- What would you tell a young person about what it is like to grow old?

- What advice would you give me about planning for my older years?

- How do you think others describe you now?

- How would you like people to remember you?

Meaning of Living in Own Place—Tell me what it is like to stay living in your own place.

- What makes you happiest about living in your own place?

- What makes you saddest about living in your own place?

- Have you thought of living somewhere other than your own place? Where? Why? What do you think that might be like?

- What is it like for you to live here instead?

What advice would you give me about choosing a place to live when I grow older?

APPENDIX F

Visit Contents and Schedule

Visit	Contents and Schedule	
VISIT **First**	**TOPIC** *Life Story*	**Verify that inclusion criteria are met** **Ask older person to sign consent form** **Complete VES-13** **Gather Demographic Data** **Begin Life Story interview**
Second	*Life Story (cont.)*	**Continue Life Story interview**
Third	*Usual/Unusual Day*	**Usual/Unusual Day interview**
Fourth	*Usual/Unusual Day*	**Usual/Unusual Day interview** **Request respondent's permission to talk with caregiver about participating in ADL/IADL visit**
Fifth	*ADLs/IADLs*	**Introduce occupational therapist** **Ask caregiver to sign consent form** **Begin ADL/IADL observation**
Sixth	*ADLs/IADLs*	**Continue ADL/IADL observation**
Seventh	*Self Concept*	**Begin Self Concept interview**
Eight	*Self Concept*	**Continue Self Concept interview**
Ninth	*Meaning of Living in Own Place*	**Begin Living in Own Place interview**
Tenth	*Meaning of Living in Own Place*	**Continue Living in Own Place interview** **Introduce upcoming visit closure**
Eleventh	*Validate Analysis*	**Validate analysis** **Begin visit closure process**
Twelfth	*Concluding Visit*	**Re-validate analysis** **Conclude research visits**